

40TH PARLIAMENT



Report 1

MY LIFE, MY CHOICE

*The Report of the Joint Select Committee on
End of Life Choices*

Presented by
Ms A. Sanderson, MLA & Hon C.J. Holt, MLC
August 2018

Committee Members

Chair	Ms A. Sanderson MLA Member for Morley
Deputy Chair	Hon C.J. Holt, MLC Member for South West Region
Members	Hon R.H. Chapple, MLC Member for Mining and Pastoral Region
	Hon N.P. Goiran, MLC Member for South Metropolitan Region
	Hon Dr S.E. Talbot, MLC Member for South West Region
	Mr R.R. Whitby, MLA Member for Baldivis
	Mr J.E. McGrath, MLA Member for South Perth
	Mr S.A. Millman, MLA Member for Mount Lawley

Committee Staff

Principal Research Officer(s)	Mr Mathew Bates (from May 2018) Dr Jeannine Purdy (until May 2018)
Research Officer(s)	Ms Marion Huntly (from November 2017) Ms Michele Chiasson (from October 2017) Ms Catherine Parsons (until October 2017)
Administrative Support	Ms Pamela Clarke

Legislative Assembly
Parliament House
4 Harvest Terrace
WEST PERTH WA 6005

Tel: (08) 9222 7494

Email: eolcc@parliament.wa.gov.au
Website: www.parliament.wa.gov.au

**Published by the Parliament of Western Australia, Perth.
August 2018.**

ISBN: 978-1-925724-20-2

(Series: Western Australia. Parliament. Legislative Assembly. Committees.

Joint Select Committee on End of Life Choices Report 1)

Joint Select Committee on End of Life Choices

My Life, My Choice

The Report of the Joint Select Committee on End of Life Choices

Report No. 1

Presented by

Ms A. Sanderson, MLA and Mr C.J Holt, MLC

Laid on the Table of the Legislative Assembly and Legislative Council
on 23 August 2018

Chair's Foreword

Overwhelmingly, people want to live. For those left behind, the protracted death of a loved one from a terminal or chronic illness can be devastating.

These were just two of the clear messages the committee received from the many hundreds of people who shared their accounts of grief and loss with us. While this report outlines many of these accounts, it has not been possible to include them all.

The Committee received hundreds of submissions from people who watched on – powerless – while a family member or friend experienced a protracted and painful death.

One particular account, about a woman named Melanie, continues to haunt me. Some of Melanie's story is contained at page 117 of the report. She suffered with advanced motor neurone disease and could not find relief from her terrible symptoms. In the end, she chose to starve herself to death.

In this report, we have aimed to tell these real stories of human suffering rather than simply relay the clinical scenarios.

On behalf of the Committee, I want to sincerely thank the many people who took the time to make submissions and those who gave evidence at hearings – often recalling the painful and distressing experiences of their loved ones.

How we die has changed over the last 60 years. Medicine and the law have not kept pace with this change, nor with changes in community expectations.

Many of us are familiar with the deaths of grandparents and other elderly relatives who passed away peacefully in their sleep, often at home. This is not, now, the common experience. Modern medicine has given us greater longevity; but it has also delivered longer periods of dying. People now survive a lot longer than they did, but often with debilitating symptoms. The prevalence of chronic disease means that many of us may face a protracted death at an advanced age.

Over the course of this inquiry, the Committee found that too many Western Australians are experiencing profound suffering as they die. This is, in part, due to inequitable access to palliative care. Palliative care aims to provide treatment to alleviate symptoms from diseases and illnesses that cannot be cured. However, it is clear from the evidence that even with access to the best quality palliative care, not

all suffering can be alleviated. Palliative care physicians themselves acknowledge this.

There are many life-limiting conditions that cause profound suffering that cannot be completely palliated. The committee heard from individuals and health professionals about the terrible effects of some of those illnesses, such as motor neurone disease, Huntington's disease, Dementia, Parkinson's and some cancers. The report explores what it is like to die from these illnesses. It makes for difficult reading.

According to national coronial data about suicide, around 10 per cent of suicides in Western Australia are by people with a terminal or debilitating illness. This figure is similar to estimates for other jurisdictions, including the United Kingdom and the United States. These people die lonely and often violent deaths; including through plastic bag and helium asphyxia, carbon monoxide poisoning, self-inflicted gunshot wounds and by hanging.

The committee concludes that the current lawful options available to people experiencing grievous and irremediable suffering at end of life are inadequate, and can be exceptionally difficult for the dying person and for their family and friends.

A competent individual's absolute right to refuse food and water, and to refuse medical treatment is clear in law. At the end of life, those refusals are not suicide. Health professionals providing palliation for those who choose this difficult path are not aiding a suicide – they are providing good palliative care. There is, however, uncertainty among some health professionals about both these absolute rights for individuals and the protections afforded to health professionals under the law.

The report also notes that there has been a cultural shift across the community away from 'Doctor knows best' to individuals wanting more say over their medical treatments. The principle of patient autonomy emerged during the 1970s and is now a critical feature of modern medical ethics. This principle means that competent patients are free to make their own medical treatment decisions.

The earliest expression of medical ethics in the western world is contained in the ancient Hippocratic oath from around 470BCE. Many aspects of it survive today; however, other aspects have no application to modern medicine. The contemporary Declaration of Geneva builds on some of the principles of the Hippocratic Oath and has been adopted by the Australian Medical Association.

The current Geneva declaration provides for a 'Physician's Pledge' that: "I will respect the autonomy and dignity of my patient."

Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee’s recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.

The committee recommends that the Bill is drafted in consultation with a panel of experts including health and legal professionals and health consumers. The panel will provide a means for Government to undertake careful consultation with key stakeholders for the development of the Bill.

The report sets out a recommended framework for a Voluntary Assisted Dying Bill. The framework builds in safeguards and rigorous processes that are critically important to the safe functioning of any scheme. Establishing eligibility by ensuring individual decision-making capacity and the absence of coercion, together with non-discrimination, are critical elements of the framework to be considered by government. Participants must be 18 years or over and ordinarily reside in Western Australia.

In the course of the inquiry, the Committee found that a predicted timeframe until death as an eligibility criteria can result in some individuals being unfairly excluded, and may not be clinically justified. People with progressive chronic or neurodegenerative disease may experience intractable suffering for months or years before they die. The committee has chosen not to ignore the suffering of these individuals.

The committee has recommended that those who are eligible for voluntary assisted dying must be experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to that person, where death is a reasonably foreseeable outcome of the condition.

A person’s decision to end their own life in the face of terminal illness that is causing grievous and irremediable suffering is a rational choice for some. It is not necessarily a medical decision, but in some circumstances it may require the assistance of a medical professional.

Assisting someone facing hopeless circumstances to die peacefully with friends and family, in a setting of their choosing is a humane and compassionate act – fully in keeping with modern medical ethics and community expectations.

The committee acknowledges that some health professionals will not want to be involved in the process and, accordingly, recommends that there should be no compulsion for individual health professionals to participate.

The Committee also reviewed international jurisdictions that have legislated for some form of voluntary assisted dying. There are volumes of peer reviewed research and data on the various models, some of which have been operating for more than 20 years.

Given the ease with which video conferencing could be used to facilitate formal evidence gathering from overseas, the committee did not travel internationally. This approach will have many benefits for the public debate that is certain to follow the publication of this report. Evidence gathered from international travel is not easily shared with the wider community, whereas our video conferences have been fully transcribed and are available on the committee's website for anyone with an interest to review them.

We heard from those opposed to voluntary assisted dying about the dangers of a 'slippery slope'. Proponents of this argument contend that once you introduce a scheme it will inevitably lead to expansion to include vulnerable groups such as children and those with mental illness.

They assert that a particular course of action will inevitably lead to another action, with unintended consequences. In other words, it implies something out of control or unmanageable.

The Committee finds no evidence to suggest this has occurred in the jurisdictions that have legislated for voluntary assisted dying. Each jurisdiction has its own unique legal framework resulting from considered legislative processes and court rulings in those countries. The Oregon legislation for example has never been amended in its 20 years of operation.

I caution against drawing the wrong conclusions and lessons from international experiences.

There are aspects of these overseas models which the Committee has rejected. The model which our Parliament is asked to consider should be in line with the expectations of our community and reflect the values and safeguards we deem appropriate.

Palliative care was the single largest issue examined during the inquiry, and it became clear that much work is needed to ensure that palliative care services are able to keep pace with growing demand and growing community expectations.

Western Australia has the lowest number of publicly funded in-patient beds per capita and access to specialist palliative care is limited across the state. Access is even further limited in rural areas and almost non-existent in remote regions. In an extraordinary admission, the WA Country Health Service told us 'there is limited oversight, coordination and governance of medical palliative care services across WA Country Health Services'. This, together with the barriers to access across the state generally, must be urgently addressed by the State Government.

Over the course of the inquiry we met with many dedicated professionals involved in palliative care and we were consistently impressed with their commitment and dedication to their patients. The home and community palliative care model, currently delivered by Silver Chain in the metropolitan area, provides a valuable service and is recognised across Australia. It should be expanded.

Multiple health conditions and co-morbidities mean individuals may have more treating specialists and less overarching coordination of care and advocacy. This results in gaps in care, particularly when patients move from different palliative care settings such as in the community to hospital. The need for better coordination and integration of palliative care services was raised by many witnesses.

As already mentioned, dementia is now one of the most common terminal illnesses in Australia and the number of people affected is rapidly increasing. Around half a million people have been diagnosed and are living with dementia. This is a challenge of monumental proportions for policy makers and governments and is reflected by demands from individuals that their health care wishes be honoured once they have lost capacity. This was a strong theme amongst submitters.

This report does not purport to have the answers to this complex area but it does direct the government to carefully examine the question of dementia and advance planning.

As Chair of this Joint Select Committee I wish to thank those who shared their stories with us. This Inquiry was an enormous undertaking, receiving around 700 submissions and holding 81 public hearings. I thank the Secretariat Marion Huntly, Michele Chiasson, Mathew Bates and Dr Jeannine Purdy – without whom we would not have had such quality evidence to draw from.

Those who fundamentally oppose the introduction of Voluntary Assisted Dying lack rigorous evidence to back up their claims. They will inevitably criticise this process. I am proud to have led this Inquiry and stand by the many hundreds of people and experts who have participated, I stand by my fellow Committee members from across the political divide and I stand by the conclusions reached in this report.

In the words of submitter Mr James Hindle 'the ultimate act of compassion is surely to allow someone to choose to end their suffering, even when we want them to stay with us.'

A handwritten signature in blue ink that reads "Ms A. Sanderson". The signature is written in a cursive, flowing style with a period at the end.

MS A. SANDERSON, MLA
CHAIR

Contents

Executive Summary	xxi
Ministerial Response	xxix
Findings and Recommendations	xxxix
1 Introduction	1
<hr/>	
Profound suffering characterises too many Western Australian deaths	1
There have been numerous attempts at reform to end of life options	2
Modern experiences of death and dying	4
This Inquiry	6
Formation of the committee and Terms of Reference	6
Submissions and other evidence	6
Analysis of submissions	7
Thematic issues contained in submissions	10
Public hearings	12
Other evidence gathering	13
Consideration of jurisdictions with legalised assisted dying	14
A note about the Australian Medical Association	14
The AMAWA's evidence	15
This Report	16
Chapter outline	16
Terminology	17
2 Advance Health Care Planning	25
<hr/>	
Planning ahead	25
Box 1.1: the concept of 'capacity' – an overview	26
Priority of treatment decisions	28
First person responsible	28
What happens when a person loses decision-making capacity?	29

Advance care plans	33
Advance Health Directives	34
Common Law AHDs	35
Statutory AHDs	36
The Role of the State Administrative Tribunal	37
Enduring powers of guardianship	38
Being clear about health care preferences is important	39
Lack of understanding by health professionals and the wider community	39
The uptake rate is low	41
Preference for non-binding advance care plans	41
Failure to honour advance health directives	43
Statutory Template	47
Electronic Register	48
Increased education, promotion and use of advance care planning instruments	51
The question of dementia	52
3 Palliative Care	55
<hr/>	
Definitions	58
The changing nature of illness and death means more demand for palliative care	58
The process of dying differs from person to person	58
The symptoms experienced at end of life	60
Box 3.1 Palliative Care Outcomes Collaboration (PCOC)	61
Specialist palliative care	62
Palliative care is more than care during the terminal phase of an illness	62
Where do people receive palliative care treatment?	64
Palliative care in Metropolitan Perth	66
Inpatient	66
Community Care – Silver Chain Hospice Care	67
Community Care – Metropolitan Palliative Care Consultancy Service	68
Community Care – Residential aged-care	68
Palliative care in Rural and Regional WA	69

Access to palliative care is not equal across regional areas	71
Great Southern – Brief summary of visit	71
Kimberley – Brief summary of visit	72
In-home care is not always preferred	73
Limitations of community palliative care	73
Barriers to effective end of life care	74
We should all talk about death	75
More patients could benefit from referral to palliative care	75
Case study 3.1	77
Health Promotion – a necessity	78
Poor coordination and communication – impacting continuity of care	79
Access to effective Palliative Care in Western Australia	80
Socioeconomic Status a determining factor	81
Regional access to palliative care	82
Palliative care for Aboriginal people	84
Kimberley Renal Service (KRS)	85
The palliative care workforce	85
Patient coding	87
Palliative care funding	88
WA Health is aware of the shortcomings	88
Palliative care remains critically important to providing good deaths	90
Limitations of palliative care	91
Motor neurone disease	95
Huntington’s disease	97
Parkinson’s disease	98
Dementia	99
Stages of dementia	100
Suffering at end of life is not confined to pain	103
Existential suffering	105
Suffering is subjective and context dependent	106

4	Lawful options at end of life	109
<hr/>		
	Refusal of medical treatment	110
	What is the law on refusal of medical treatment?	110
	Refusal of medical treatment is not suicide	111
	Do health professionals understand the law on refusal of medical treatment?	111
	Refusal of food and fluids	114
	Is there a duty to provide the necessaries of life?	114
	A deliberate choice, or simply too tired to eat?	114
	What is the law in relation to voluntary palliated starvation?	116
	Futility	119
	How do health professionals decide futility?	120
	Is the discussion about futility avoided?	122
	Terminal sedation	123
	What is terminal sedation?	123
	Terminal Sedation: Lack of consistent language and definition	124
	When is terminal sedation an appropriate treatment?	124
	Terminal sedation is not a universally available treatment	125
	Case Study 4.1	127
	Terminal sedation in Western Australia	128
	Doctrine of Double Effect	130
	Where does it come from?	131
	How is it relevant to health care?	132
	The scope of double effect	132
	Intention versus foresight	133
	When do doctors rely on the doctrine of double effect?	133
	Some uncertainty regarding the doctrine	135
	Section 259 WA Criminal Code	135
	Possible reform?	137
	Suicide	138
	The incidence of suicide in Western Australia	138
	Development of the law	139

Current law in Western Australia	139
The evidence from the Western Australia Coroner	139
Do people deliberately end their lives because of terminal or debilitating illness?	140
Are people deliberately ending their lives early?	144
What is the impact on families, loved ones and first responders?	145
Unlawful practices	146
The Committee's view on the options at end of life	147
5 International experience with assisted dying	151
<hr/>	
Introduction	151
A note on terminology	151
The Netherlands	152
Legislative background	152
The Dutch model	152
Most recent statistics on deaths under the Dutch law	153
Belgium	154
Legislative background	154
The Belgian model	155
Most recent statistics on deaths under the Belgian law	156
Luxembourg	156
Legislative background	156
The Luxembourgish model	156
Most recent statistics on deaths under the Luxembourgish law	157
Switzerland	157
Switzerland operates under a unique model	157
Oregon	158
Legislative background	158
The Oregon model	159
Most recent statistics on deaths under the Oregon law	160
Washington	161

Legislative background	161
The Washington model	161
Most recent statistics on deaths under the Washington law	162
Vermont	162
Legislative background	162
The Vermont model	162
Most recent statistics on deaths under the Vermont law	162
California	163
Legislative background	163
The California model	163
Most recent statistics on deaths under the California law	164
Canada	165
Legislative background	165
The Canadian model	167
Most recent statistics on deaths under the Canadian law	168
What does the international experience tell us?	168
Concerns about international experiences raised in the submissions	169
Slippery slope	169
Expansion to include psychiatric illnesses	169
Expansion to include minors	171
The safeguards will not work	173
Abuse of the vulnerable	175
What the evidence says	176
Impact on suicide prevention	177
Distinguishing between suicide and assisted dying	177
Suggestions of suicide contagion are not supported in the evidence	179
Legislative frameworks determine how assisted dying is implemented	181
6 Legislation in other Australian jurisdictions	183
<hr/>	
End of life laws have long been debated in Australia	183
The Australian experience – failed attempts at reform	184

The Northern Territory	184
Legislative Background	184
The Territory's model	185
Doctor may refuse to provide assistance	186
Evidence regarding the Northern Territory's legislation	186
Victoria	188
Legislative background	188
Eligibility and the operation of the law	188
Doctor may refuse to provide assistance	190
Appeal mechanisms	190
Voluntary Assisted Dying Review Board	191
Evidence regarding Victoria's legislation	191
New South Wales	193
Legislative Background	193
Eligibility and the operation of the law	193
Doctor may refuse to provide assistance	194
Appeal mechanisms	194
Voluntary Assisted Death Review Board	195
Evidence regarding New South Wales' legislation	195
Tasmania	195
Legislative background	195
Eligibility and the operation of the law	196
Doctor may refuse to provide assistance	196
Registrar to review all deaths under the legislation	197
Lessons from legislative developments in Australia	197
Private members' bills seldom pass the parliament	197
Expected time until death	199
Initiating discussions with patients	199
Assessment by psychiatrist	200
Protecting the right of health professionals to <i>not</i> participate	200
Final approval from senior bureaucrats	201

7	Voluntary assisted dying	203
<hr/>		
	Introduction	203
	Autonomy and self-determination	204
	Western Australia should legislate for voluntary assisted dying	206
	Models for voluntary assisted dying	206
	Rights based change	207
	Criminal law defence of necessity	207
	Prosecution guidelines	208
	Legislative change	208
	Eligibility	209
	Nature of the condition	210
	Expected time to death	212
	Suffering	214
	Age	215
	Capacity and capacity assessment	215
	Residency	217
	Assessment	217
	Assessing doctors	217
	Eligibility criteria	218
	When is specialist referral required?	218
	Procedure	218
	Reflection period	219
	Personal objection	220
	Non-discrimination	221
	People with disabilities must have the same rights as others	221
	People with mental illness have the same legal rights as others	222
	Medication	223
	Death certification	223
	Oversight of voluntary assisted dying	224
	Reportable deaths	224
	VOLUNTARY ASSISTED DYING LEGISLATION FRAMEWORK	225

Appendices	231
<hr/>	
1 Inquiry Terms of Reference	231
2 Committee's functions and powers	233
3 Submissions received	235
4 Public hearings	257
Organisations	257
Individuals	262
5 Advance directives across Australia	263
6 Legislative reform attempts in Australia	267
7 Summary of other models	271
8 Bibliography	275
9 Statement of committee expenditure	283
10 Acronym List	285
Minority Report	287
<hr/>	
The Hon N.P. Goiran, MLC	287

Executive Summary

Chapter 1 notes that the nature of death and dying in Australia has changed over the course of the twentieth century and into the twenty-first. The chapter considers the change over time in community sentiment in relation to assisted dying, and outlines mortality trends including age at death, cause of death and the various attempts at legislative reform.

Parliament established the committee on 23 August 2017 and requested that it report by 23 August 2018.

In September 2017, the committee issued a public call for submissions and subsequently received more than 730 submissions and supplementary submissions.

The committee held 81 hearings and took evidence from more than 130 witnesses. The committee visited metropolitan palliative care providers and travelled to the Great Southern region and the Kimberley to visit health providers, hold hearings and meet with local communities.

A glossary of terms used in the report has been included in chapter 1.

Chapter 2 provides an overview of advance health care planning, beginning with the concept of capacity and including a summary of what happens when a person lacks capacity and there is a need for a treatment decision.

The chapter considers all forms of advance health care planning including informal advance care plans, advance health directives (both common law and statutory) and enduring powers of guardianship. It also looks at the 'Goals of Patient Care' – a document in the medical record completed by health professionals (after talking with the patient) to guide the health professional in the provision of care.

There is a discussion on the hierarchy of decision-makers and how to determine the lawful substitute decision-maker, when there is not a valid advance health directive.

The chapter includes evidence that valid advance health directives are sometimes ignored by some health professionals, with some indicating to the committee a clear preference for non-binding advance care plans over legally binding advance health directives, whilst others recognised the importance of the legally binding instrument.

Many individuals expressed concerns about the difficulty of completing an advance health directive due to the lack of guidance on the statutory template. Several health professionals also expressed concern regarding their uncertainty about how to interpret advance health directives and about the relevant law, especially in relation to whether or not an advance health directive applied in specific circumstances.

The committee received evidence that indicated uptake of advance health directives is low across Australia and even lower in Western Australia. A number of factors explain this low uptake, including the natural reluctance to discuss death from both health professionals and patients.

Many witnesses gave evidence that in Western Australia the lack of an electronic register accessible to health professionals 24 hours a day means there is currently no way of ensuring that health professionals are aware if a patient has an advance health directive.

The chapter also considers the increasing number of people diagnosed with dementia – it is now the second leading cause of death in Australia. The report acknowledges that it is important for those with dementia to have their health care wishes acknowledged and implemented once they have lost capacity. The report recommends that an expert panel be appointed to advise government how best to deal with this important issue.

The chapter concludes with recommendations on reform of and education about advance health directives.

Chapter 3 explores palliative care.

Palliative care is provided to Western Australians as either consultancy, inpatient or community services.

Evidence from palliative care specialists traversed the trajectories of different illnesses at the end of life, the stages of disease and the benchmarking of care undertaken by the Palliative Care Outcomes Collaboration (**PCOC**) at the University of Wollongong.

Specialists and individuals highlighted the common symptoms experienced at end of life and that the provision of palliative care is mostly, but not in all circumstances effective. Palliative care specialists consistently informed the committee that people should be referred early in the trajectory of a disease and that there is a need for education of both the public and health professionals about the benefits of palliative care.

Whilst Australia is regarded as having one of the best palliative care systems in the world, the committee heard evidence of barriers to effective end of life care including a general unwillingness to discuss death, uncertainty about what palliative care could offer and the difficulties in accessing and navigating palliative care services.

Coordination of palliative care in Western Australia is also problematic, particularly when patients move between community care and inpatient care in hospitals.

The committee heard evidence of challenges facing the delivery of palliative care for some Aboriginal people in Western Australia, including distance and isolation. This means access to specialist palliative care is difficult and services sometimes conflict with cultural practices and beliefs concerning death. Unsurprisingly, witnesses confirmed that

Aboriginal people want choice about where they will die, including the preference of some to die on country.

Specialist palliative care is only one part of the broader care landscape and palliative care needs to be integrated with other medical services.

The committee found it difficult to ascertain exact public expenditure on palliative care in Western Australia. The report recommends the appointment of an independent auditor to assess actual palliative care activity and precise expenditure in consultancy, inpatient and community services across Western Australia.

The chapter outlines the limitations of palliative care – this reality became clearer as more witnesses gave evidence of their experience of the death of those close to them. Some gave confronting evidence about the suffering of their loved ones, despite receiving the best palliative care available. Witnesses also told of the prolonged suffering associated with particular diseases. Motor neurone disease, Huntington’s disease, Parkinson’s disease and dementia can involve suffering over many months and sometimes years prior to death.

The report notes that suffering is not just about pain and it is both subjective and context dependent. The committee accepts there are profound philosophical differences on the meaning and value of suffering. The report acknowledges different positions can and should be respected following any decision to legislate for assisted dying.

The report makes a number of recommendations on improving understanding of and access to palliative care.

Chapter 4 addresses the lawful options currently available to those with grievous and irremediable suffering.

It became apparent that health professionals would benefit from increased education on the right of a competent patient to refuse medical treatment and the right to refuse food and water. Some health professionals appeared ambivalent about whether these rights were absolute or conditional. However, the law is clear that a competent individual has an absolute right to refuse medical treatment or refuse food and water, regardless of how unreasonable it may seem to others.

The report recommends further training for health professionals in these areas of law.

Another decision taken at end of life is when treatment is determined to be futile. Doctors are not obliged to administer futile treatment and can unilaterally decide – in the exercise of good clinical judgment – to withdraw or withhold treatment. Witnesses described how these decisions are difficult for both health professionals and for their patients.

The committee also heard evidence in relation to the practice of terminal sedation, sometimes referred to as palliative sedation. When a patient is dying, and severe adverse symptoms are unable to be relieved by other treatments, doctors will sometimes provide a patient with sedation until death. Hydration and nutrition is also withdrawn and the patient enters a coma state prior to dying.

Terminal sedation is not a universal practice and some doctors do not consider it an appropriate or even lawful treatment at end of life. However, WA Health, UWA medical school, the AMA (WA Branch) and a number of academic witnesses and health professionals all gave evidence that it is a lawful treatment offered right at the end of life for some patients with refractory symptoms.

The report notes the confusion amongst the health profession and recommends that WA Health provide clear guidelines about terminal sedation. The report also recommends that the practice be formally noted in the patient's medical record.

Chapter 4 also deals with the ethical doctrine known as double effect and concludes that section 259 of the WA Criminal Code operates as a defence to prosecution for doctors treating patients at end of life, providing they do so in good faith and with reasonable care and skill (by reference to the patient and the surrounding circumstances).

The report looks in detail at coronial data of suicides where the person was diagnosed with a terminal or debilitating illness.

The report acknowledges that the causes of suicide are multifactorial but it is clear that some people take their lives due to grievous and irremediable suffering. The committee was provided with data from the State Coroner that demonstrates as many as 10 per cent of suicides each year in Western Australia are carried out by people suffering with terminal, chronic or neurological conditions. In addition, the committee heard direct personal and tragic evidence about people who attempted or completed suicide due to a terminal or debilitating condition – often using violent means.

Fear of losing physical or mental capacity at some later stage leads some individuals to suicide before that loss occurs, cutting short their lives.

Chapter 4 also considers unlawful practices at end of life that currently occur. One survey of Australian doctors revealed that as many as 35 per cent of doctors had, at the request of their patient, administered medication to bring on death.

The chapter concludes that the lawful options at end of life are not adequate. Individuals continue to suffer needlessly. Many people would value the opportunity to put their affairs in order and spend valuable time with loved ones, knowing they had some control over the manner and timing of their death.

Chapter 5 examines the international experience with assisted dying and provides an overview of the legislation, the models of assisted dying and recent statistics in nine overseas jurisdictions.

Examination of the international experience of legislating for voluntary assisted dying tells us that:

- gaining legislative support has been a difficult and lengthy process;
- access to assisted dying cannot be gained without satisfying rigorous prerequisites;
- more than one doctor must assess the person to confirm eligibility criteria are satisfied;
- cancer is by far the most common illness driving requests for assisted dying;
- the ‘slippery slope’ is not a valid argument against assisted dying;
- the introduction of a legal framework for regulating end of life decision making reduces the level of unlawful activity;
- there is no evidence that vulnerable groups, including people with disabilities, are at heightened risk of assisted dying; and
- reports of suicide contagion are not supported in the evidence.

Chapter 6 reviews legislative reform and attempts for reform in other Australian jurisdictions. Between June 1993 and April 2016, 51 bills dealing with assisted dying were introduced into the various Australian parliaments at Federal, State and Territory level. Since then a further three bills have been introduced in New South Wales, Victoria and Tasmania.

In 1995, the Northern Territory became the first jurisdiction in the world to legislate for assisted dying. Four people accessed assisted dying under the *Rights of the Terminally Ill Act 1995* before the legislation was overturned by the Commonwealth Parliament in 1997.

In November 2017, the Victorian Parliament passed the *Voluntary Assisted Dying Act 2017*, which will come into effect in June 2019. Similar to the North American jurisdictions, the Act requires the person requesting assisted dying to meet stringent eligibility criteria. This includes that the request must be voluntary and repeated, and a person must have a prognosis of 6 months until death, unless suffering with a neurological condition, in which case it is 12 months until death.

In their evidence to the committee, assisted dying proponents were overwhelmingly positive about the Victorian government's achievement in establishing a legislative framework. However, the same witnesses sounded a warning about the limitations of the legislation. The legislature's concern to build as many safeguards into the law as possible created a model that was in the view of the witnesses, overly restrictive and in the end, may not help people who need it most.

It was also clear to the committee that private members bills are rarely successful. The committee found that any bill seeking to introduce a legislative framework for assisted dying in Western Australia will require government support, and should be developed with the expertise and resources of government.

Chapter 6 examines five key elements of the Victorian Act – expected time until death, initiating discussions with patients, capacity assessment, personal objections of health professionals and bureaucratic approvals.

These elements are considered further in **Chapter 7**.

In light of the evidence contained in the previous chapters, it is appropriate to make provisions for Western Australians to have the option of voluntary assisted dying. This is consistent with community expectations and will give effect to patient autonomy. Equally, it will assist people who experience grievous and irremediable suffering at end of life.

The chapter explores the various models for reform – rights based change (as per the Canadian legislation); reform to the Criminal Code (as per the Benelux countries); prosecution guidelines (as occurs in the UK) and the preferred approach of legislative reform (as per the North American jurisdictions and Victoria).

Legislative reform offers an approach that removes assisted dying from the realm of the criminal law. It also provides certainty for patients and their doctors.

The chapter explores eligibility and concludes that the legislation should provide for specific criteria before a person is able to access an assisted dying service.

The committee recommends death must be a reasonably foreseeable outcome of the condition and the condition must be advanced and progressive. Expected time until death should not be a feature of the Western Australian legislation unless it is clinically indicated.

The chapter concludes with a framework outlining elements to be considered for assisted dying legislation.

The report recommends that the Minister for Health establish an expert panel to consult with significant stakeholders and provide advice to the Western Australian Government

for the development of legislation in accordance with the recommended framework. See page 225 for the committee's recommended framework.

Ministerial Response

In accordance with Standing Order 277(1) of the Standing Orders of the Legislative Assembly, the Joint Select Committee on End of Life Choices directs that the Premier, Minister for Health and the Attorney General report to the Assembly as to the action, if any, proposed to be taken by the Government with respect to the recommendations of the Committee.

Findings and Recommendations

Finding 1

Page 46

There is a very low uptake of advance health care planning instruments in Western Australia. This is due, at least in part, to poor understanding amongst health professionals and the general community.

Finding 2

Page 46

There are many reasons why there is low uptake of advance care planning instruments, not least of which is the natural reluctance to contemplate our own frailty and mortality. In addition, advance care planning can be a lengthy process and health professionals may be unprepared to talk about death and dying with their patients.

Finding 3

Page 47

There is widespread evidence that the community and health professionals do not *understand* advance care planning, particularly legally binding instruments.

Finding 4

Page 47

Advance care plans and Goals of Patient Care are valuable tools to assist individuals to plan for future care, and they might be evidence of a verbal common law advance health directive, but they are not legally binding and do not ensure a person's preferences can be honoured during any period of temporary or permanent impaired decision-making capacity.

Finding 5

Page 47

Some health providers are promoting non-binding 'advance care plans' over legally binding advance health directives, and others are, for various reasons, failing to honour express health care preferences contained in valid AHDs.

Finding 6

Page 48

The current template for statutory advance health directives and supporting information is difficult for individuals to complete and can be difficult for health professionals to interpret.

Finding 7

Page 48

The current template suffers from a lack of guidance for people completing it. In other jurisdictions, examples are provided. Some of these medical conditions and treatments include but are not limited to:

- dialysis, antibiotics to treat infections (such as pneumonia and UTIs); blood transfusions; chemotherapy; radiation therapy; intensive care; intubation; invasive

and non-invasive ventilator support; the activation (and de-activation) of electronic device implantation for heart failure; transplantation; nasogastric or PEG feeding; CPR and lifesaving surgery; receiving pain relieving medication which may also have significant sedating effects and receiving only comfort care.

Finding 8

Page 51

Lawful advance health directives are not stored centrally and are not readily accessible to health professionals when required.

Recommendation 1

Page 52

The Attorney General, in consultation with the Minister for Health, appoint an expert panel to review the relevant law and health policy and practice – and provide recommendations in relation to the following matters:

- the establishment of a purpose-built central electronic register for advance health directives that is accessible by health professionals 24 hours per day and a mechanism for reporting to Parliament annually the number of advance health directives in Western Australia.
- a requirement that health professionals must search the register for a patient's advance health directives, except in cases of emergency where it is not practicable to do so.
- amendments to the current Western Australian template for advance health directives in order to match, as a minimum, the leading example across Australia, taking into account Finding 7 (see page 48).
- consider how the increasing numbers of people diagnosed with dementia can have their health care wishes, end of life planning decisions and advance health directives acknowledged and implemented once they have lost capacity.

Recommendation 2

Page 53

The Attorney General, in consultation with WA Health, and relevant health professional bodies, undertake an immediate and extensive program to educate health professionals about:

- the nature, purpose and effect of advance health directives and enduring powers of guardianship;
- how to identify a valid advance health directive; and
- how to identify the lawful substitute treatment decision-maker.

Recommendation 3	Page 53
<p>The Attorney General, in consultation with WA Health, provide greater education for the wider community about:</p> <ul style="list-style-type: none"> • advance health directives; • enduring guardians; and • the hierarchy of medical treatment decision-makers. 	
Recommendation 4	Page 53
<p>WA Health immediately develop a strategy to ensure that when an AHD is provided by a patient to a hospital, it is easily accessible and stored prominently on the medical record – until there is a central database.</p>	
Recommendation 5	Page 54
<p>The Minister for Health recommends to the Council of Australian Governments an amendment to the Medicare rebate schedule to include preparation of advance health directives with general practitioners.</p>	
Recommendation 6	Page 54
<p>The Minister for Health report to Parliament annually on the number of advance health directives held on hospital medical records in Western Australia.</p>	
Finding 9	Page 67
<p>Access to inpatient specialist palliative care in Perth is limited.</p>	
Finding 10	Page 67
<p>Apart from a small number of private beds at Glenngary Hospital, there is no inpatient specialist palliative care hospice in the northern suburbs of Perth.</p>	
Recommendation 7	Page 67
<p>The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.</p>	
Finding 11	Page 68
<p>Silver Chain is providing community palliative care to more patients than for which it is funded.</p>	
Recommendation 8	Page 68
<p>The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.</p>	

Recommendation 9**Page 74**

WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care (see Finding 18).

Finding 12**Page 75**

Access to specialist palliative care in the early stages of a diagnosis might improve remaining quality of life, mood, resilience, symptom management and allow for death in the patient's preferred location. These benefits would be more readily available to patients if difficult discussions about death and dying took place earlier.

Finding 13**Page 76**

More can be done to promote understanding of palliative care in the community and with health professionals to ensure that more non-cancer patients who could benefit from palliative care are receiving it.

Finding 14**Page 77**

There is inconsistency in the data regarding the number of patients with conditions amenable to receiving palliative care. This is perhaps reflective of the uncertainty regarding which diseases or conditions are appropriate for palliative care.

Recommendation 10**Page 78**

WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services with the aim of making those services available to more Western Australians.

Recommendation 11**Page 79**

To improve understanding of palliative care in Western Australia, WA Health should:

- establish a consistent definition of palliative care to be adopted by all health professionals;
- provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community;
- encourage knowledge sharing by palliative care specialists with their generalist colleagues; and
- establish a palliative care information and community hotline.

Finding 15	Page 80
<p>In giving priority to Goals of Patient Care, WA Health is elevating these documents as a form of advanced care planning. This is inconsistent with respect for patient autonomy. Whilst Goals of Patient Care are a valuable tool for clinicians, advance health directives are the legal standard for recognising patient preferences when patients cannot speak for themselves.</p>	
Finding 16	Page 81
<p>Access to hands-on specialist palliative care is limited for metropolitan and non-metropolitan patients.</p>	
Finding 17	Page 81
<p>Western Australia has the lowest number of publicly funded inpatient palliative care beds per head of population.</p>	
Finding 18	Page 81
<p>There is a gap in care for people who are seriously unwell but not close enough to death to be admitted for inpatient hospice care.</p>	
Finding 19	Page 83
<p>There is limited access to palliative care medical specialists in regional Western Australia.</p>	
Finding 20	Page 83
<p>There is limited medical oversight, coordination or governance of medical palliative care services across WA Country Health Services.</p>	
Recommendation 12	Page 83
<p>The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.</p>	
Recommendation 13	Page 83
<p>The Minister for Health should ensure regional palliative care be adequately funded to meet demand.</p>	
Finding 21	Page 87
<p>There are insufficient numbers of primary care workers providing palliative care in Western Australia.</p>	
Finding 22	Page 91
<p>Palliative care activity in Western Australia's hospitals is not being accurately recorded. It is important that the extent and cost of palliative care service delivery is clarified.</p>	

Recommendation 14**Page 91**

Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit:

- The level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity.
- The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.

Finding 23**Page 107**

Too many Western Australians experience profound suffering as they die, in part due to inequitable access to palliative care; however, in the committee's view, even with access to the best quality palliative care, not all suffering can be palliated.

Finding 24**Page 113**

There is uncertainty among some health professionals regarding the nature of the absolute right of a competent patient to refuse or consent to medical treatment.

Recommendation 15**Page 113**

WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.

Finding 25**Page 119**

A competent person's absolute right to refuse to eat and drink is clear at law, but not well understood by some health professionals.

Finding 26**Page 119**

In the case of a refusal of food and water by a competent person at end of life, there is clinical and legal support for the position that it is similar to the refusal of medical treatment and therefore is not suicide.

Accordingly, in circumstances where a competent patient at end of life has elected to refuse food and water, it is appropriate that the person be provided with palliative care.

Recommendation 16**Page 119**

WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. Training should also include those working in aged care.

Finding 27**Page 122**

Decision-making in the area of futility of treatment is fraught for patients, families and health professionals.

Recommendation 17**Page 122**

WA Health should provide ongoing professional development – beyond undergraduate training – for health professionals about the transition from curative to non-curative end of life care and effective discussions with patients and families about futile treatments

WA Health should consider how it might effectively educate the community about end of life decision-making, and implement appropriate health promotion in this area.

Finding 28**Page 130**

The committee received evidence from government agencies, medical professional bodies and medical educators providing a consistent explanation of terminal sedation and its use as an appropriate and lawful treatment option for patients suffering refractory symptoms at end of life.

There remains some confusion amongst health professionals as to the legal status and reasonableness of the clinical practice of terminal sedation and this confusion is likely to result in the denial of adequate symptom relief to some patients at end of life.

Recommendation 18**Page 130**

WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life. These guidelines should include an agreed name and definition of the treatment.

As per any other medical treatment, the requirement for informed consent must be clear.

The treatment must be specifically noted in the medical record as ‘terminal sedation’.

Finding 29**Page 138**

There was no overwhelming call from the medical profession or the wider community for amendment to section 259 of the WA Criminal Code.

Finding 30**Page 138**

The doctrine of double effect is an ethical doctrine relied on by some doctors when providing palliative care at end of life. Although it has not yet been fully determined, it is likely enshrined as a defence under section 259 of the WA Criminal Code.

Finding 31**Page 138**

There is a fine balance in providing protection for both vulnerable patients and the health professionals who care for them at end of life. Section 259 of the WA Criminal Code gives appropriate weight to both parties so that all relevant matters can be assessed on a case-by-case basis.

Finding 32**Page 144**

Approximately 10 per cent of all suicides in Western Australia in any year are carried out by individuals suffering from a terminal or debilitating chronic illness.

Finding 33**Page 146**

The prohibition of a peaceful, assisted death has driven some terminally or chronically ill individuals to suicide using violent means.

Finding 34**Page 146**

Some individuals who suicide under these circumstances are driven to take their lives early. All deaths under these circumstances are tragic and very often traumatic and distressing to family, friends and first-responders.

Finding 35**Page 146**

It is impossible to quantify the number of people who attempt suicide and fail. However, there is evidence that many do and are left further debilitated.

Finding 36**Page 148**

Western Australians want to be able to exercise choice in dying. If there is a choice between a death accompanied by prolonged suffering and a death that is without such suffering, most Western Australians would choose the latter.

Many people would value the opportunity to put their affairs in order and spend valuable time at the end of their lives with the people they love, knowing they had some control over the manner and timing of their death.

Finding 37**Page 171**

It is incorrect to describe the availability of euthanasia for mentally unwell persons in the Netherlands and Belgium as eventuating as a type of slippery slope through which an initially conservative approach to euthanasia was eroded over time. Since the practice

was legislated for in both countries, eligibility for assisted dying has included persons suffering from mental illness.

Finding 38

Page 173

Although Belgium expanded its law to make euthanasia available to legally competent minors in 2014, this should not be seen as supporting the slippery slope argument that further expansion of the assisted dying laws is somehow an inevitability. The experience in Oregon, where the law has undergone no change or expansion since its introduction in 1997, demonstrates the invalidity of any attempt to apply a universal slippery slope argument.

Finding 39

Page 174

The published evidence does not support claims that legalisation of assisted dying results in an inevitable move toward the erosion of safeguards and an increase of non-voluntary euthanasia. Indeed, the evidence supports the opposite conclusion – introducing a legal framework for assisted dying reduces the incidence of unlawful activity, including non-voluntary euthanasia.

Finding 40

Page 179

It is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one's life in the face of unbearable suffering. Given this distinction, there is no inconsistency in ongoing suicide prevention campaigns and a decision to legislate for the introduction of a targeted assisted dying framework.

Finding 41

Page 180

The evidence supporting claims that suicide rates have increased in United States jurisdictions following the legalisation of voluntary assisted dying is disputed in academic literature.

Finding 42

Page 181

Having weighed the evidence, the committee concurs with findings by similar parliamentary inquiries in Victoria and Canada that risks can be guarded against and vulnerable people can be protected.

Finding 43

Page 198

With the exception of the Northern Territory, where the bill was introduced by the Chief Minister, private members' bills seeking reform to end of life laws have failed to pass any Australian parliament.

Finding 44**Page 199**

Any bill seeking to introduce a legislative framework for assisted dying in Western Australia would require government support along with the expertise and resources of government.

Recommendation 19**Page 199**

The Minister for Health should ensure that any bill to introduce a legislative framework for voluntary assisted dying is introduced by the government.

Finding 45**Page 199**

With regard to timeframes, whatever model of assisted dying is enacted in Western Australia should reflect the best possible clinical practice.

Finding 46**Page 200**

In other jurisdictions, health professionals are afforded the opportunity to not participate in voluntary assisted dying services.

Recommendation 20**Page 201**

The Minister for Health should ensure that health professionals are not compelled to participate if any voluntary assisted dying framework is developed for Western Australia.

Finding 47**Page 206**

An expert panel including health and legal practitioners and health consumers would assist in the development, consultation and implementation of legislative reform to allow for voluntary assisted dying.

Finding 48**Page 206**

An expert panel would be assisted in its considerations by a framework that canvasses the issues considered by this committee

Recommendation 21**Page 206**

The Minister for Health establish an expert panel including health and legal practitioners and health consumers to undertake consultation and develop legislation for voluntary assisted dying in Western Australia, and that this report, together with the Framework contained at the end of Chapter 7, be considered by that Panel.

Finding 49**Page 209**

The best model for reform in Western Australia is a discrete legislative framework that is contained in a stand-alone Act making voluntary assisted dying legal.

Finding 50**Page 214**

A criterion of advanced and progressive terminal or chronic or neurodegenerative illness, that is causing grievous and irremediable suffering for the person, would be sufficient without a prescribed timeline until death.

Recommendation 22**Page 214**

The Minister for Health should ensure that legislation require that death be *reasonably foreseeable* as a consequence of the condition.

Recommendation 23**Page 214**

That the Minister for Health ensure the eligibility requirement in the legislation include that the person is experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person.

Finding 51**Page 217**

An individual must have decision-making capacity at the time of their request in order to be eligible for voluntary assisted dying.

Finding 52**Page 217**

Individuals wishing to access voluntary assisted dying in Western Australia must be either a citizen or permanent resident of Australia ordinarily resident in Western Australia, as defined by the expert panel.

Recommendation 24**Page 225**

The Western Australian Government develop and introduce legislation for voluntary assisted dying having regard to the recommended framework and following consultation with the Panel established under Recommendation 21.

Chapter 1

Introduction

Profound suffering characterises too many Western Australian deaths

- 1.1 Every Western Australian alive today will die, and around 90 per cent of us will live beyond 65 years of age.¹ Death and ageing are therefore an inevitability, as much a part of our lives as breathing or thought.
- 1.2 Dying and aging are a shared human experience, but they will occur differently for everyone. For some, death will be gentle, surrounded by family and friends. For others, death will be accompanied by suffering after a long struggle with illness that will have extracted a heavy toll – on not only the deceased, but also the ones they love.
- 1.3 In other words, some of us will have a good death while others will not.
- 1.4 This report, which is the culmination of 12-months of work by a cross-party committee, has been focused on good deaths – and how to make them more common – whilst hearing many distressing and very personal stories from members of the community as they recounted the deaths of their loved ones, both good and bad.
- 1.5 The report reflects community sentiment that people should have a greater range of options at end of life. Indeed, Australians have long accepted that people should be free to chart their own course, and make their own decisions, such that they can lead a good life, and one of their own making. Significant numbers of Australians have adopted similar attitudes regarding death and dying.
- 1.6 Lawmakers around Australia – and in this parliament – have been less willing to follow their constituents when it comes to allowing people to make their own choices to seek a good death. It is the lawmakers to whom this report is directed; it is they who must ultimately make the decision to change the law in Western Australia.
- 1.7 The report is not about death, but it is about the process and experience of dying for people while they are still living. Very few people want to die, and it is easy to find stories of people who overcome incredible odds to remain alive. It is also true that a desire for death, in the face of a terminal prognosis and irremediable suffering, can be a rational choice. It is a choice already exercised by many Western Australians. People with

1 The Actuaries Institute, *Actuaries Institute disappointed that Super Guarantee increase frozen*, available at:
<https://www.actuaries.asn.au/Library/MediaRelease/2014/140903RetirementPolicyPosition.pdf>

Chapter 1

terminal or other life limiting illnesses who choose to end their lives often do so alone and in secret, sometimes violently. For those who no longer have the physical capability to take their own lives, they can choose to withdraw from medical treatment and they can choose to forgo food and water. These deaths, typically in a hospital, and involving the administration of high doses of medication, can be drawn out, interspersed with bouts of delirium and, in many cases, consumed by suffering that is unresponsive to clinical intervention.

- 1.8 It became clear during the course of the inquiry that profound suffering continues to characterise too many deaths in Western Australia. It is time that our laws provided a humane choice for those who do not wish their final weeks and months to be consumed by such suffering.

There have been numerous attempts at reform to end of life options

- 1.9 There have been six attempts at passing legislation through the Western Australian parliament to allow for some type of assisted dying.² All have been private members' bills, meaning that the proposed legislation was not developed with the backing of the government and its vast resources. The earliest attempt in Western Australia was made in 1997 and the most recent in 2010. None of these bills were introduced by a member from a major political party – it has been the Australian Democrats and the Greens (WA) that have introduced bills into the Western Australian Parliament.
- 1.10 The earliest evidence in Western Australia's parliamentary record of community lobbying for changes to the law can be found in the Hansard for 1 April 1981. The Hon. WM Piesse, a National Country Party member, explains that she had received correspondence from the Western Australian Voluntary Euthanasia Society:

The plea of the society, with some justification as they see it, is that people should be allowed to exit from this world without the stigma at law of having committed suicide, or they should be helped out by somebody, and it should not be called – "murder" or "manslaughter".³

- 1.11 It is perhaps not surprising that community action in support of assisted dying began to formalise in the early 1980s. This period coincided with the end of what is known as the golden era of antibiotics, a period in which rapid developments in antimicrobial medicine brought to an end the rampancy of infectious disease.⁴ With control over infectious disease, the nature of death and dying changed.

2 See Appendix Six.

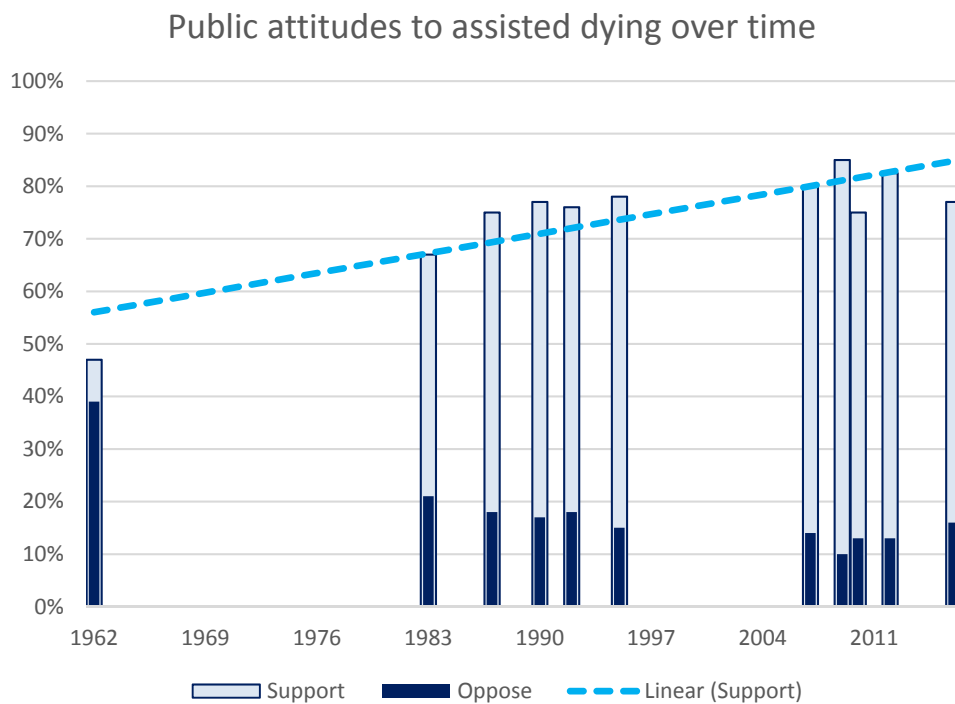
3 Hon WM Piesse, Member for Lower Central, Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 1 April 1981, p. 375.

4 W.A. Adedeji, 'The Treasure Called Antibiotics', *Annals of Ibadan Postgraduate Medicine*, vol. 14, no. 2, 2016, p.56.

1.12 The nature of patient relationships with doctors and other health professionals has also changed. By the 1960s, patient attitudes underwent a significant shift away from paternalistic notions of medical beneficence towards respecting patient autonomy and choice.⁵ The demand for choice in the face of terminal illness and irremediable suffering is a reflection of the continued shift toward respecting patient autonomy in medical decision making.

1.13 Polling suggests there is widespread community support for changing the law to allow for assisted dying, and political debate to legislate for such change has become more common since the mid-90s.⁶ The increase in public support for assisted dying as captured in polling (refer to **Figure 1.1**) also seems to have coincided with the change in the nature of death that took place during the second half of the twentieth century.

Figure 1.1: Polling summary from Dying for Choice demonstrates the consistently high levels of support for assisted dying in Australia over many decades.⁷



5 Edmund D. Pellegrino, Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship, *Journal of Contemporary Health Law and Policy*, vol. 10, no. 1, 1994, p. 47.

6 See Appendix Six.

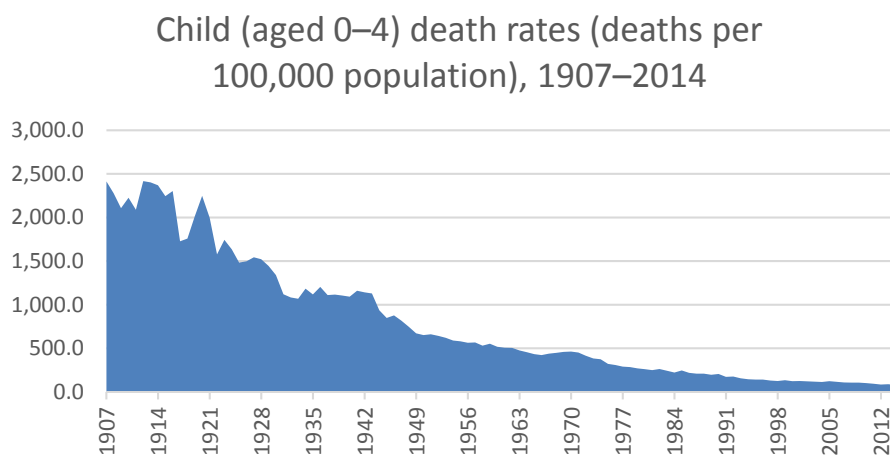
7 Adapted with permission from the presentation made by Mr Neil Francis, Dying for Choice, during a public hearing with the committee, 9 April 2018.

Chapter 1

Modern experiences of death and dying

- 1.14 Since the beginning of the 20th century, death has become less arbitrary and more predictable. In Australia in the early 1900s, 25 per cent of the population died before their fifth birthday and only five per cent lived beyond 85 years. By 2011, only one per cent of the population died before the age of five and around 40 per cent died after age 85.⁸ This remarkable turnaround has had a profound effect on how people die.
- 1.15 In the United States, for example, the leading cause of death has shifted from infectious disease to cardiovascular disease, cancer and stroke.⁹ The same is true in Australia, where most people can expect to die because of some type of chronic disease or illness.¹⁰
- 1.16 As a result, for most people in Australia, the process of dying is longer than ever before and involves an 'extended deteriorative decline'.¹¹ The fact that modern deaths are materially different to those in the past is a relevant consideration for any debate about introducing assisted dying. The charts below have been adapted from data from the Australian Institute for Health and Welfare and illustrate key statistical information about modern deaths in Australia.
- 1.17 In **figure 1.2**, the rapid and sustained decline in the rate of child deaths in Australia during the course of the 20th century is clear.

Figure 1.2: Child death rates have fallen dramatically in Australia over the previous 100 years



- 1.18 **Figure 1.3** shows that, in 74 per cent of all deaths in Australia were people aged over 70.

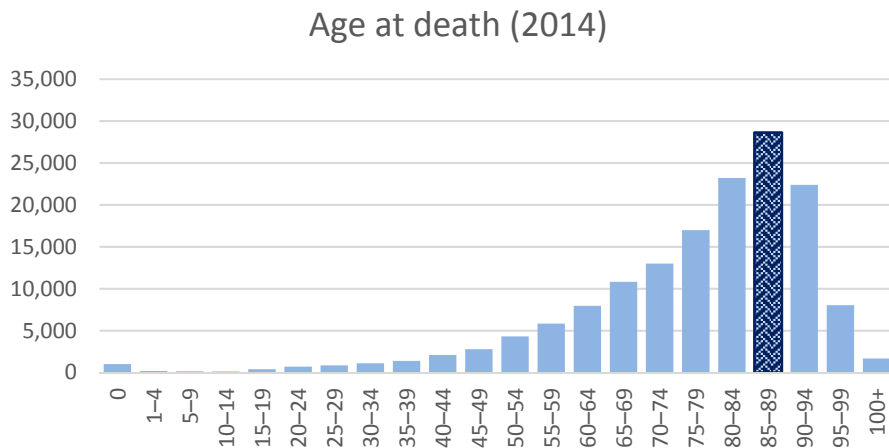
8 Grattan Institute, *Dying Well*, Melbourne, September 2014, p. 5.

9 W.A. Adedeji, 'The Treasure Called Antibiotics', *Annals of Ibadan Postgraduate Medicine*, vol. 14, no. 2, 2016, p. 56.

10 Grattan Institute, *Dying Well*, Melbourne, September 2014, p. 5.

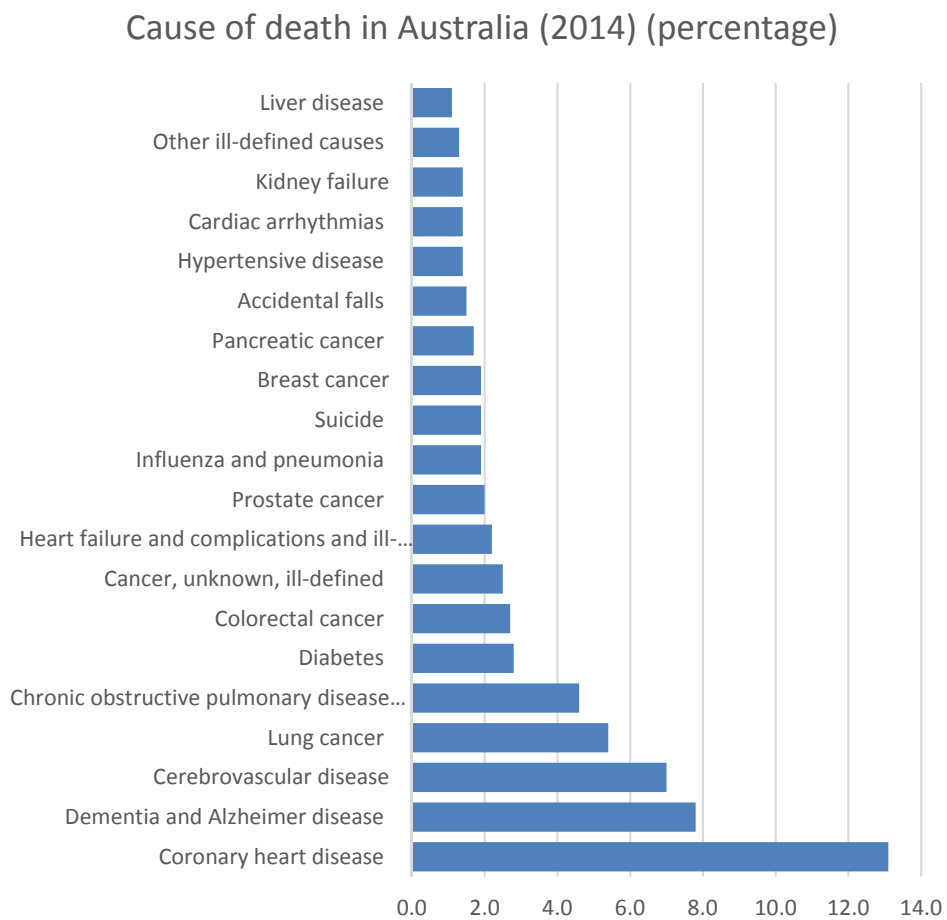
11 Penney Lewis, *Assisted Dying and Legal Change*, Oxford University Press, London, 2007, p. 3.

Figure 1.3: 25 per cent of Australians are under the age of 70 at the time of death



1.19 In **figure 1.4**, it is clear that chronic illness is the leading cause of death amongst Australians.

Figure 1.4: Chronic illnesses are the most common cause of death in Australia



Chapter 1

This Inquiry

Formation of the committee and Terms of Reference

1.20 This committee is a joint House committee consisting of members from both the Legislative Assembly and the Legislative Council. Its eight members – four from each House – were appointed by the parliament. The committee was established on 23 August 2017, following agreement from both Houses.

1.21 The committee's Terms of Reference (see Appendix 1) were debated in both the Legislative Assembly and the Legislative Council. The committee has been asked to inquire into the 'need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices'. In doing so, the parliament asked the committee to pay particular attention to:

- current medical practices for those at the end of life, including palliative care;
- international and interstate experiences and recent reforms;
- possible legislative changes; and
- the role of advance health directives and enduring powers of guardianship and attorney.

The parliament asked the committee to report by 23 August 2018.

Submissions and other evidence

1.22 The committee held its first meeting on 4 September 2017, at which the committee resolved to advertise a public call for submissions. At a subsequent meeting, the committee identified a comprehensive list of stakeholders associated with end of life care and asked for their input into the inquiry. The committee is grateful to each organisation and individual that assisted the inquiry by making a submission, appearing at a hearing to give evidence, or providing expert information via the committee secretariat.

1.23 During the 12-month period in which the committee has operated, 796 items of correspondence were accepted as evidence to the inquiry. This includes:

- 685 submissions;
- 47 supplementary submissions; and
- 64 answers to questions on notice or clarifications from hearings.

1.24 The sheer volume of evidence presented some challenges to the committee and its staff, but the high quality input of experts and the broader community added immeasurably

to the committee’s report. To the greatest extent possible, the committee has made all evidence it received publicly available via the inquiry’s website. In a small number of cases, the committee chose not to release evidence – most often at the request of the person providing the evidence.

1.25 The committee has drawn upon the evidence received during the course of the inquiry extensively throughout this report. Even if not specifically referenced in the pages that follow, submitters should know that their evidence was considered closely and helped to inform the committee’s deliberations and its findings and recommendations.

1.26 In addition to the information made available in submissions, the committee also made use of the vast and comprehensive academic literature regarding end of life care. A full bibliography of the sources relied upon by the committee can be found at Appendix 8.

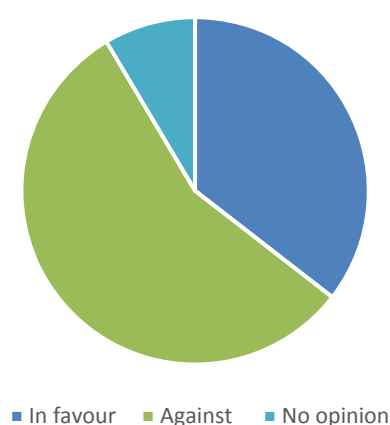
Analysis of submissions

1.27 Given the volume of submissions received, the committee has undertaken to provide a quantitative overview in order to provide some insight into the nature of the information before the committee as it deliberated on the report and its findings and recommendations.

1.28 As figure 1.5 demonstrates, 56 per cent of the submissions were opposed to introducing voluntary assisted dying legislation. 35.5 per cent were supportive of legislative change, and 8.5 per cent expressed no view on the issue.

Figure 1.5

Positions expressed on assisted dying in submissions

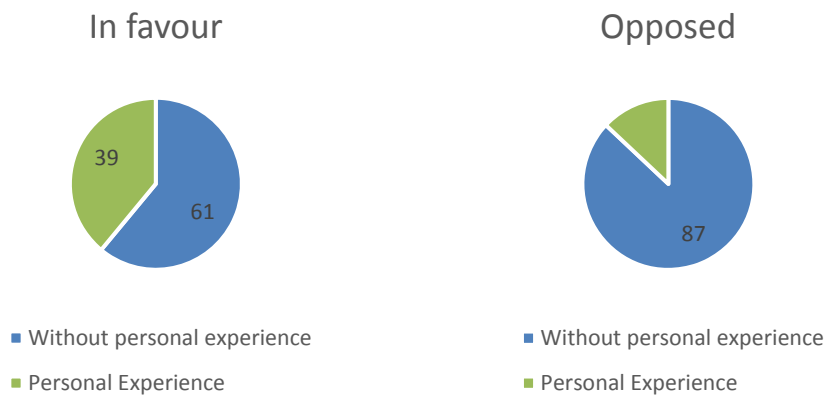


1.29 Some of the most powerful evidence received by the inquiry came from people who chose to share the personal experiences of a loved one as they died from a terminal or

Chapter 1

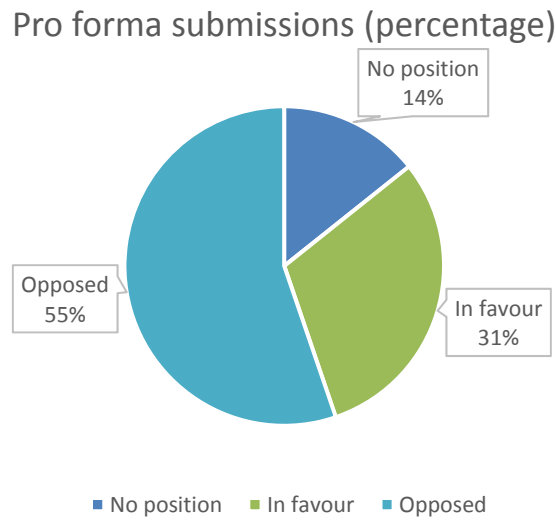
life limiting illness. The committee also heard from people who themselves were facing death as a result of illness. These personal stories were significant; they helped the committee translate clinical descriptions into real stories expressed by people facing incredibly difficult circumstances. As **figure 1.6** shows, those in favour of assisted dying reform were significantly more likely to include details of a personal experience with death or terminal illness in their submissions than those who were opposed to change. Indeed, 39 per cent of those in favour of assisted dying reform in Western Australia shared their stories with the committee, whereas 13 per cent opposing reform provided similar detail in their submissions.

Figure 1.6



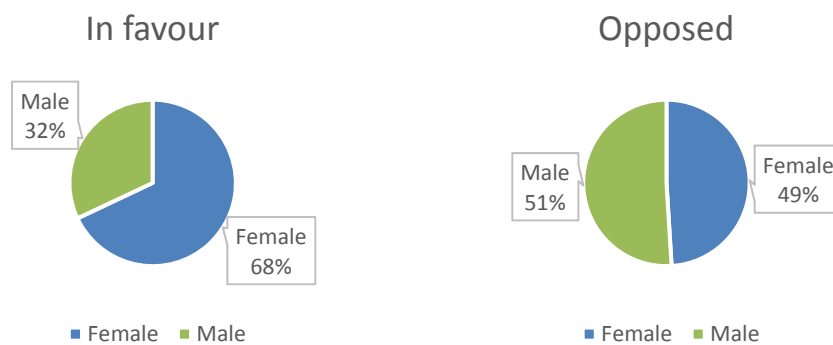
- 1.30 The committee also received a large number of pro forma submissions from both opponents and supporters of assisted dying law reform. The committee identified 12 distinct types of pro forma submission. In total, 210 pro forma submissions were accepted by the committee – 56 per cent of these were opposed to reform; 30 per cent were in favour; and 14 per cent expressed no view (see figure 1.7).

Figure 1.7



- 1.31 Not all submitters expressed a view either in favour or in opposition to assisted dying, and some submissions were made on behalf of organisations that maintained a neutral stance on the question of change to the law. In those submissions where an opinion was expressed by individuals, women were more likely than men to support assisted dying. The reverse was true for opponents to changing the law, with men more likely to oppose change.
- 1.32 Sixty-eight per cent of all submissions from individuals expressing support to change the law came from women. For those opposing change, it was a much closer split: 49 per cent of submissions came from women.

Figure 1.8



- 1.33 While few submitters chose to provide their age with their submission, the average age of submitters in favour of assisted dying (amongst those who chose to provide the information) was much higher than those opposing change.

Chapter 1

Average age of submitters in favour of assisted dying

Average age of submitters opposing assisted dying

78

53

Thematic issues contained in submissions

1.34 As noted above, the large number of submissions received during the inquiry means that it has not been possible to directly quote every person or organisation that has provided evidence. However, the committee has prepared a thematic summary of the issues most commonly highlighted in submissions as they relate to the inquiry's Terms of Reference. That summary is provided over the following pages.

Western Australia's current laws	
Adequate	Inadequate
<ul style="list-style-type: none"> •Current laws are adequate for WA citizens to make end of life decisions. •There is no need to change the laws, as terminal sedation is already available for those at the end of life with extreme suffering. •There is discretion to prosecute so the current system works. 	<ul style="list-style-type: none"> •Doctors are hamstrung by the existing laws. •The current laws are inhumane and cruel. •The law does not keep up with medical advances. •Laws around murder, manslaughter and assisting suicide need to be modified to allow for VAD. •Eighty per cent or more of Australians have consistently expressed support for laws permitting assisted dying. •WA needs a third party statutory authority/end of life service to provide training, guidance and direction. •If euthanasia is permitted the laws must be drafted broadly enough to provide for people with MND, MS and other progressive degenerative conditions.
Advance Health Directives (AHDs) and Enduring Powers of Guardianship (EPG)	
Adequate	Inadequate
<ul style="list-style-type: none"> •The laws on AHDs and EPG make sufficient provision for citizens. 	<ul style="list-style-type: none"> •Static instruments are available but more flexible and supportive decision making forms are required. •There are increasing numbers of patients with complexities and comorbidities who have reduced capacity to plan their end of life process. •WA needs more education and community discussion about planning for end of life.

	<ul style="list-style-type: none"> •Generally, there is very poor communication between medical staff and families when someone is dying. •Doctors should be bound by AHDs & EPGs.
Palliative care	
Adequate	Inadequate
<ul style="list-style-type: none"> •High quality palliative care is available to terminally ill people – people never die in agony. •Palliative care has significantly improved over time. •Modern medicine means that palliative care can minimise the discomfort and suffering of the dying. •Euthanasia should not be a substitute for palliative care – funding and research should continue. 	<ul style="list-style-type: none"> •The government needs to increase palliative care funding in WA. •People have suffered terribly right at the end of life and palliative care was not of assistance in reducing the suffering. •The availability of palliative care options is limited by socio-economic status or residential location. •Palliative care services are very limited.
Voluntary assisted dying	
For	Against
<ul style="list-style-type: none"> •People have experience of family members who have attempted, or succeeded in, suicide through terrible means because they were not offered lawful assisted dying. •Stop the horror of people dying with uncontrollable pain. •Why should people with serious illnesses or disease be condemned to years of misery? •People can take days and even weeks to die after nutrition and hydration is withdrawn. •Terrible deaths leave terrible suffering for those left behind. •No period of intolerable suffering is acceptably short. •People want reliable and peaceful means to end their life. •We treat our pets more humanely. •Mandatory psychiatric assessments of VAD patients are unnecessary. •There should be real choice at end of life for terminally ill people. •People want the right to decide when and how their life will end. •People should be able to choose how they end their life – it is a personal decision and it is not right for some to dictate how others will die. •Intense pain should not be the only criteria for assisted dying – people who lack 	<ul style="list-style-type: none"> •Even with terrible suffering lives are worth living. •Suffering is part of life and there are real benefits. •People have peaceful deaths under the current laws with palliative care services. •Legalising euthanasia would encourage increasing numbers of suicides. •We shouldn't be considering euthanasia until we have developed adequate palliative care services. •People facing difficult circumstances may want to end their life but change their mind when circumstances improve. •People with temporary depression should be encouraged to become well and not offered assisted dying. •Assisted dying can never be safe and voluntary. •Safeguards are not safe. It is not possible to draft all necessary safeguards into the legislation. •There is a slippery slope – if euthanasia is brought in there will be an increase over time in the categories of people to whom it will be applied. •There have been significant changes to euthanasia laws in overseas jurisdictions since the passing, and subsequent repeal,

Chapter 1

<p>autonomy, are completely dependent and who no longer wish to live should be given the option to end their life.</p> <ul style="list-style-type: none"> • Many of the older generation want legal, reliable and peaceful means to end their life. • Individuals should have the right to choose. • Patients have to be lucky to find a doctor who will provide terminal sedation. • Money should not be wasted on keeping alive people who are ready to die. • Expenditure during the final 6 months of life is exponentially greater than throughout the rest of a person's life. • Slippery slope does not exist – in other jurisdictions deaths from euthanasia have remained around 4 per cent. • Disability or mental illness should not automatically exclude individuals from assisted dying. • Doctors are already making the choice to stop nutrition and hydration – those choices should not be in their hands. • Doctors are constrained and unable to help due to the current law. • Medical profession needs greater support and clarity. • Medical practitioners should have the right to opt out if laws permitting euthanasia are enacted in WA. 	<p>of the Rights of the Terminally Ill Act 1995 NT.</p> <ul style="list-style-type: none"> • In overseas jurisdictions many people are involuntarily euthanased. • Particular groups in the community need referral to palliative care services. • People who can't speak for themselves need better palliative care. • Sick and elderly will be coerced into dying. • Vulnerable groups such as the disabled, mentally ill, aged and frail will be at risk if the laws are changed. • If euthanasia is allowed the elderly will see themselves as a burden. • People don't understand that disabled people value their lives, and have a quality of life they enjoy. • Every life has intrinsic value – every life is sanctified. It is for God to decide when we die and not for us to play God. • There need to be more conversations and consultation before deciding on euthanasia laws. • Doctors are bound by the Hippocratic oath to heal and not harm.
--	---

Public hearings

1.35 Commencing in December 2017, the committee conducted an extensive round of public hearings in Perth and the Great Southern.¹² In total, the committee held 81 hearings and took evidence from 146 witnesses. In total, the committee spent over 80 hours hearing directly from witnesses as they provided evidence to the inquiry. As with the documentary evidence received, transcripts and video recordings of the hearings are available on the inquiry's website. In a small number of cases, witnesses were permitted to give evidence confidentially, usually in order to protect their privacy as they provided highly personal stories of the deaths of loved ones. Broadly speaking, the witnesses belonged to one or more of the following categories:

- Public health officials representing WA Health across a range of health service delivery areas.
- Advocates, both for and against, voluntary assisted dying.

¹² Public hearings were planned for the Kimberley region; however, no witnesses came forward.

- Individuals telling their stories, some in favour of assisted dying and others opposed.
- Palliative care specialists.
- Medical professional bodies, for example the Australian Medical Association (WA).
- Academics in public health or health law.

1.36 To the greatest extent possible, the committee provided witnesses with questions in advance of their appearance. This was intended to assist witnesses prepare responses and ensure that the evidence gathered was of a high quality.

1.37 The committee extends its thanks to all who made the time to contribute via the hearings process. The high quality of the evidence received as a result has helped to both shape this report, and to refine members' thinking on the issues.

Other evidence gathering

1.38 An important element of the evidence gathering process took place during site visits to a number of health care settings in Perth, the Great Southern, and the Kimberley.

1.39 In Perth, the committee:

- visited Silver Chain's Service Centre, each member then accompanied a Silver Chain nurse on a community patient visit;
- toured the Brightwater high-care facility that provides residential care for people with advanced Huntington's disease;
- met with the palliative specialist team and the clinical team who have oversight of the Metropolitan Palliative Community Care Service;
- toured the inpatient palliative care ward at Bethesda Hospital; and
- accompanied a palliative care specialist during his ward round at Sir Charles Gairdner Hospital.

1.40 In the Great Southern, the committee:

- heard from local members of the community about their experience with palliative care;
- visited the hospital and hospice in Albany;
- toured a residential aged-care facility and met with staff and residents;
- visited the Denmark Hospital; and

Chapter 1

- met with local health professionals and WA Health officials to discuss the practical aspects of the provision of palliative care.

1.41 In the Kimberley, the committee:

- met with the staff of the Derby Aboriginal Health Service to discuss the services they provide;
- visited the Derby Regional Hospital;
- visited Mowanjum Aboriginal community, and met with locals and the community's manager;
- visited the Broome base of the Royal Flying Doctor Service and met with the on-call consultant emergency physician and the on-call clinical nurse specialist;
- met with the Kimberley Palliative Care Service in Broome; and
- toured a 55-bed residential care facility that provides both low and high care options.

Consideration of jurisdictions with legalised assisted dying

1.42 Several jurisdictions in Europe and North America have already legislated for assisted dying. The committee did not conduct visits to these jurisdictions; however, there is a wide-array of high quality reporting on practices in a variety of media including peer-reviewed journals. The reporting covers most aspects of assisted dying reform and the diverse views on the practice are represented, particularly in academic writing. The committee made extensive use of this published material in its consideration of the international experience with assisted dying.

1.43 Modern communications technology, including video conferencing, also allowed the committee to conduct hearings with witnesses located outside of Australia, including those who provide assisted dying services.

A note about the Australian Medical Association

1.44 The committee maintained a lengthy dialogue with the Australian Medical Association (WA Branch) (**AMAWA**) from the commencement of the inquiry. As an important body representing the interests of doctors in Western Australia, the AMAWA was one of the first organisations invited to provide a submission to the inquiry.

1.45 The AMAWA gave evidence at two hearings – the first in February 2018, the second in May. The second hearing gave the AMAWA an opportunity to report on the outcome of a symposium it hosted for its membership on end of life choices. The AMAWA made it clear in its submission and when giving evidence at hearings that it is opposed to the

introduction of assisted dying in Western Australia.¹³ It also acknowledged that there are a range of views within its membership, and the broader medical profession, about the issue. This fact is certainly reflected in the committee's experience – a number of doctors from a range of specialities gave evidence to the inquiry in support of reforming the law.¹⁴

- 1.46 The AMAWA also strongly indicated that any legislation introducing assisted dying in Western Australia should be developed in consultation with the medical profession.¹⁵ The committee agrees, and has recommended the formation of a panel comprising experts in law, medicine and health consumers to develop the legislation and an associated implementation framework.

The AMAWA's evidence

- 1.47 The AMAWA held a symposium on 5 May 2018 looking at a range of end-of-life care issues, including the current state of palliative care and discussion on voluntary assisted dying. The symposium was not a debate on the pros and cons of voluntary assisted dying.
- 1.48 The AMAWA indicated that the public is telling the medical profession that their experiences of end of life are not what they should be. Their view is that this meant that change was required to palliative care, principally that more resources are required. In particular, the funding model for palliative care needs to change – the patient's care journey must be captured no matter whether they are interacting with primary, hospice, or hospital care. The model should promote the ability for clinicians, patients and families to have the time to discuss advance care planning.¹⁶
- 1.49 Communication and coordination was identified as a big issue. Patients may be receiving good palliative care in the community but when a crisis occurred, patients are thrust into the hospital environment. The emphasis shifts to curing and fixing problems instead of providing comfort care. The AMAWA also identified the need to properly integrate palliative care into all areas of medical care.¹⁷
- 1.50 The AMAWA invited international speakers to the symposium. Each had direct experience with end of life care and held views on either side of the assisted dying

13 Submission No. 685 from Dr Omar Khorshid, President, Australian Medical Association (WA), 15 February 2018, p. 1; Dr Omar Khorshid, President, Australian Medical Association (WA), *Transcript of Evidence*, 18 May 2018, p. 13.

14 See for example, Dr Alida Lancee, Member, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 3 March 2018, p. 2; Dr Rodney Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, *Transcript of Evidence*, 13 April 2018, p. 2.

15 Submission No. 685 from Dr Omar Khorshid, President, Australian Medical Association (WA), 15 February 2018, p. 5.

16 Dr Omar Khorshid, President, AWA (WA Branch), *Transcript of Evidence*, 18 May 2018, p. 3.

17 Dr Omar Khorshid, President, AWA (WA Branch), *Transcript of Evidence*, 18 May 2018, pp. 2–3.

Chapter 1

debate. The AMAWA relayed to the Committee the views of their international speakers but wanted to give the strong message that:

if we go in this direction, any doctors that are involved should opt in to be involved and they should receive mandatory training—that is, training in the laws, obviously, to make sure that they are crystal clear on their responsibilities—that they have specific training in having the discussions, because these are really, really important discussions, and that they receive training in the methods that are going to be utilised to end somebody's life, and that they are also formally connected to a support system to make sure that they are not harmed as individuals.¹⁸

- 1.51 The AMAWA (and others) expressed concern about rising suicide rates in the Netherlands as a result of that country's end of life laws, although claims about increased suicide are disputed by other evidence received by the committee (for further information, see chapter 5).¹⁹ The AMAWA is also of the view that a request for assisted dying should go to a panel for approval, on the basis that individual doctors are not best positioned to make these types of end of life assessments.²⁰

This Report

Chapter outline

- 1.52 Chapter 2 examines the current legal arrangements for individuals to make their wishes about their end of life care known in advance, prior to any loss of legal capacity, including reforms to the *Guardianship and Administration Act 1990* in 2008 and the understanding by health professionals' and community members' of patient rights.
- 1.53 Chapter 3 looks at the provision of and access to palliative care in Western Australia and outlines the various service delivery models employed, principally inpatient and community settings.
- 1.54 Chapter 4 outlines the current lawful options available for people in Western Australia when they are at the end of their lives.
- 1.55 Chapter 5 examines the different models for assisted dying currently in operation in other jurisdictions around the world. Arguments opposing assisted dying are also considered in the context of the international experience.

18 Dr Omar Khorshid, President, AWA (WA Branch), *Transcript of Evidence*, 18 May 2018, p. 5.

19 Submission No. 642 from Mr Neil Francis, 23 October 2017, p. 46.

20 Dr Omar Khorshid, President, AWA (WA Branch), *Transcript of Evidence*, 18 May 2018, p. 6.

- 1.56 Chapter 6 looks at the Australian experience of successful and unsuccessful reform to end of life laws and considers any lessons that can be drawn from these experiences, particularly in relation to shaping proposed legislative reform.
- 1.57 Chapter 7 outlines the committee’s recommended framework for a voluntary assisted dying law in Western Australia.

Terminology

- 1.58 The language involved in the debate regarding assisted dying can be complex and confusing – proponents and opponents do not have a set of preferred definitions, and there is some disagreement amongst the medical profession about the definitions and language for current medical practice. To assist readers, the committee has included the following glossary to help introduce a consistent vocabulary to the debate about assisted dying in Western Australia.

Glossary of terms	
Advance Health Directive (AHD) (common law and statutory)	An AHD is a legally binding directive expressing future health care preferences for a time when lacking decision-making capacity. (see Chapter 2)
Artificial nutrition and hydration	Provision of nutrition and hydration by way of a percutaneous endoscopic gastrostomy (PEG) tube or nasogastric tube feeding.
Assisted suicide	This term is used in some jurisdictions to describe interventions which assist individuals to end their lives. It places emphasis on the person’s active decision-making and involvement. In Western Australia, procuring, counselling or aiding a suicide is a criminal offence. ²¹
Capacity	Also known as decision-making capacity, it means the ability to make a decision. (see Chapter 2)
Chronic disease and Chronic illness ²²	Chronic illness is the personal experience of living with the affliction that often – but not necessarily – accompanies chronic disease. Chronic disease is defined on the basis of the biomedical disease classification, and includes diabetes, asthma, organ failure and depression. While the terms chronic disease and chronic illness are often used interchangeably, they convey different meanings. ²³
Common law	Laws that are made by judges handing down decisions in the court. Laws are also made by parliaments passing acts – known as legislation or statutory laws.

21 Section 288 *WA Criminal Code Act 1913*

22 The term “chronic illness” is used in the inquiry’s terms of reference.

23 Carmel M Martin, “Chronic disease and illness care: Adding principles of family medicine to address ongoing health system redesign” *Can Fam Physician*, 2007, 53(12): 2086–2091.

Chapter 1

<p>Consent to medical treatment</p>	<p>In most cases, patients are entitled to decide whether or not they will receive medical treatment. The patient’s decision must be made in the context of relevant and understandable information about the risks and benefits of the treatment, as applicable to their circumstances.</p> <p>Some variations to the usual consent processes include:</p> <ul style="list-style-type: none"> • emergencies where treatment may be necessary to save a person’s life or avert serious injury to a person’s health and a person is unable to consent, in which case treatment may be provided without consent²⁴ • patients who lack capacity and for whom a relevant Advance Health Directives or common law directives may apply, or in their absence a substitute decision maker who may give or refuse consent on their behalf²⁵ • Treatment of involuntary patients under the <i>Mental Health Act 2014</i>²⁶
<p>Criminal Code (WA) – s 23(2) – Intention</p>	<p>Section 23(2) of the Criminal Code provides that unless the intention to cause a particular result is expressly declared to be an element of the offence, whether by act or omission, intention is immaterial.</p>
<p>Criminal Code (WA) – s 23B – Accident</p>	<p>Section 23B of the Criminal Code provides that a person is not criminally responsible for an event which occurs by accident. In everyday language an ‘accident’ generally means that the result was not intended; however, its legal meaning is more precise. In law, an event occurs by accident if it was unintended and unforeseen by the accused and not reasonably foreseeable by an ordinary person.²⁷</p>
<p>Criminal Code (WA) – s 259 – Liability for surgical and medical treatment</p>	<p>Section 259 of the Criminal Code provides that a person is not criminally liable for administering surgical or medical treatment, including palliative care, in good faith and with reasonable care and skill to another person for that person’s benefit if it is reasonable, having regard to the person’s state at the time and all of the circumstances.</p>

24 Section 110ZI (2) *Guardianship and Administration Act 1990*.

25 Section 110ZJ *Guardianship and Administration Act 1990*.

26 See section 178 *Mental Health Act (WA) 2014*

27 See, for example *Kaporonovski* (1973) 133 CLR 209, 231; (Gibbs CJ; Stephen J concurring), *Stanik* [2001] WASC 333, [38]; [83]; *Taiters* (1996) 87 A Crim R 507, 509; *Stevens* [2005] HCA 65, [16]; [66] – as cited in the Law Reform Commission Western Australia, *Review of the Law of Homicide: Final Report*, September 2007, chapter 4, p 151.

	<p>Section 259 also provides that a person is not criminally liable for not administering, or for ceasing to administer, surgical or medical treatment (including palliative care) if to do so is reasonable, having regard to the person's state at the time and all of the circumstances.</p> <p>The provision relating to not administering or ceasing to administer treatment was introduced at the same time as other legislated changes introducing advance health directives, enduring guardianship and the hierarchy of decision-makers in relation to the treatment and non-treatment of incapable persons.</p>
Criminal Code (WA) – s 261 – Consent to death immaterial	Section 261 of the Criminal Code provides that a person's consent to their own death does not affect the criminal responsibility of the person causing the death.
Criminal Code (WA) – s 262 and s 263 – Necessaries of life	<p>Section 262 of the Criminal Code imposes a duty to provide the necessaries of life to a person who has "charge of another who is unable by reason of age, sickness, unsoundness of mind, detention, or any other cause, to withdraw himself from such charge" and who is unable to provide themselves with those necessaries. A person who omits to perform that duty is criminally liable for the consequences to the life or health of the person to whom they owe the duty.</p> <p>Section 263 is in similar terms but which imposes the duty to provide the necessaries of life upon a person as the head of a family who has charge of a child under 16 years and who is a member of the household.</p>
Criminal Code (WA) – s 265 – Duty of person doing a dangerous act, surgical or medical treatment	Section 265 of the Criminal Code imposes a duty on persons doing a lawful act which is or may be dangerous to human life or health. It includes the requirement that persons administering surgical or medical care (including palliative care) "have reasonable skill and use reasonable care in doing such an act". The person who omits to perform that duty is criminally liable for the consequences to the life or health of the person to whom they owe the duty.
Criminal Code (WA) – s 273 – Death, acceleration, of	Section 273 of the Criminal Code deems a person who does an act or omits to do an act which hastens the death of another who is labouring under some disorder or disease arising from another cause, to have killed that other person.
Criminal Code (WA) – s 288 – Procuring a suicide etc	Suicide is the intentional taking of one's own life. Procuring, counselling and thereby inducing, or aiding another to kill him or herself is an offence in WA and is

Chapter 1

	<p>subject to a maximum penalty of life imprisonment (Criminal Code, s 288).</p> <p>In Western Australia, attempted suicide was an offence under the Criminal Code until section 289 was repealed in 1972.</p>
Doctrine of Double Effect	An ethical doctrine dating back to the 12 th century. (see chapter 4)
Dying with dignity	The Victorian Ministerial Advisory Panel noted that often advocacy groups use the term “dying with dignity” to describe voluntary assisted dying. The Panel noted however that this was problematic because it implies that people in similar circumstances who do not choose voluntary assisted dying are living, and will die, in an “undignified” manner. Many people, and their families, who are being supported by palliative care would say this support enables them to have a “dignified” death. ²⁸
Enduring Power of Guardianship (EPG)	A legal document that appoints a guardian, to make important personal, lifestyle and treatment decisions. Enduring guardianship was introduced into WA as part of a legislative reform package relating to consent to medical treatment in 2008. ²⁹ (see chapter 2)
Enduring Power of Attorney (EPA)	A legal document that enables a person to appoint a trusted person - or people - to make financial and/or property decisions on their behalf.
Euthanasia	<p>Euthanasia means the intentional termination of the life of a person, by another person, in order to relieve the first person’s suffering. According to the <i>Shorter Oxford English Dictionary</i>, it is derived from the Greek <i>eu</i>, meaning good, and <i>thanatos</i> meaning death, and so means a quiet and easy death.</p> <p>Euthanasia can be voluntary, non-voluntary or involuntary. Voluntary euthanasia means euthanasia performed in accordance with the wishes of a competent individual, whether those wishes have been made known personally or by a valid, written advance directive. Non-voluntary euthanasia is euthanasia performed on a person who lacks capacity. The explicit consent of the person is unavailable, such as where someone is in a persistent vegetative state, or in the case of a young child. Involuntary euthanasia means euthanasia performed</p>

²⁸ Ministerial Advisory Panel on Voluntary Assisted Dying, *Final Report*, July 2017, p 7. Accessed 19 April 2018.

²⁹ *Acts Amendment (Consent to Medical Treatment) Act 2008* (WA).

	<p>against the wishes expressed by a competent person or through a valid advance directive.³⁰</p> <p>Passive euthanasia is sometimes used to refer to the withdrawal, withholding or refusal of life-sustaining medical treatment.³¹</p> <p>Note however that in jurisdictions with voluntary assisted dying laws such as the Netherlands, Belgium and most European countries, involuntary cases (when a patient is competent but did not request euthanasia) and non-voluntary cases (when a patient is not competent and could not request euthanasia) are not deemed euthanasia, but would be referred to as ‘termination of life without a patient’s explicit request’.³²</p>
Futility (in medical practice)	For the purposes of this report, and other than when in a direct quote, this term is used to mean a medical assessment that treatment will not work, based on evidence and medical expertise, as opposed to an assessment that the treatment is not worth doing. ³³
Guardianship	This is distinct from enduring guardianship and refers to the appointment of a guardian by the State Administrative Tribunal (SAT). Such appointments are made under the <i>Guardianship and Administration Act 1990</i> to safeguard the best interest of adults with decision-making disabilities. These may be the result of intellectual disability, mental illness, acquired brain injury or dementia.

30 *Carter v. Canada (Attorney General)* 2012 BCSC 886, [38].

31 Ezekiel J Emanuel, Bregje D Onwuteaka-Philipsen, John W Urwin and Joachim Cohen, “Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe” *JAMA [Journal of the American Medical Association]*, 2016, 316(1):79-90, p 80. See also the evidence of Associate Professor Kirsten Auret, Academic in Palliative Care, University of Western Australia, Transcript of Evidence, 1 March 2018, p 5, in which she described this term as “old teaching” in WA.

32 Ezekiel J Emanuel, Bregje D Onwuteaka-Philipsen, John W Urwin and Joachim Cohen, “Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe” *JAMA [Journal of the American Medical Association]*, 2016, 316(1):79-90, 80.

33 Lindy Willmott, Ben White and Malcolm K Smith, “‘Best interests’ and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the *parens patriae* jurisdiction”, *Journal of Law and Medicine* (2014) 12(4), 920. The authors note that this is a contested concept that has eluded a shared definition despite a wealth of literature from the disciplines of medicine, ethics, law, nursing and philosophy. They state that the worth of a medical intervention is not just a medical issue but a value judgment which should involve the broader issue of what is in the best interests of the patient.

Chapter 1

	<p>In the absence of a close friend or family member of the represented person, the Public Advocate may be appointed by the SAT as a guardian of “last resort”.</p> <p>Administrators are also appointed under the <i>Guardianship and Administration Act 1990</i>. Their role is to ensure that financial and legal decisions are made in the best interests of the represented person.³⁴ Where there is no-one willing, suitable and available to take on the role of administrator, the SAT may appoint the Public Trustee (as the administrator of “last resort”).</p>
GAA	<i>Guardianship and Administration Act 1990</i> (WA)
Involuntary patient	An involuntary patient is a person who is under an involuntary treatment order (made under the <i>Mental Health Act 2014</i>). Treatment can be provided to an involuntary patient without their consent.
Palliative care	An approach to care that involves acceptance that the underlying condition is not responsive to curative treatment (or a decision has been made not to treat with curative intent.) ³⁵ (see paragraph 3.13 for committee comment regarding the definition of palliative care)
Palliative sedation (see also terminal sedation)	The use of medications intended to induce a state of decreased or absent awareness (unconsciousness) on a temporary basis in order to relieve the burden of otherwise intractable suffering as a respite. Sometimes referred to as terminal sedation.
<i>Parens patriae</i> jurisdiction	This is a jurisdiction exercised by the courts. The High Court has held that it ‘springs from the direct responsibility of the Crown for those who cannot look after themselves; it includes infants as well as those of unsound mind’. ³⁶ The jurisdiction is not defined and has been used by the courts ‘to deal with unanticipated situations where it appears necessary to do so for the protection of those who fall within its ambit’. ³⁷

34 Office of the Public Advocate (WA), *Administration*, as last updated 25 August 2015. Accessed 20 April 2018.

35 Professor Wendy Erber, Executive Dean Faculty of Health and Medical Sciences University of Western Australia, Email, 16 April 2018.

36 *Department of Health & Community Services v JWB & SMB* ("Marion's Case") [1992] HCA 15; (1992) 175 CLR 218, at 259.

37 La Forest J in *Re Eve* (1986) 31 DLR (4th) referred to by Kennedy J as “his celebrated judgment” in *Bryn Jones, An Infant by his Next Friend Jean Isabella Jones & Anor v Moylan* [2000] WASCA 361, [14].

Refractory symptom	A refractory symptom is one that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness. A refractory symptom may be subjective and, at times, non-specific. ³⁸
Terminal illness	Terminal illness, in relation to a patient, means an illness which, in reasonable medical judgment will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the patient, result in the death of the patient. ³⁹
Terminal sedation (see also palliative sedation)	The use of pharmacological agent(s) to reduce consciousness, reserved for treatment of intolerable and refractory symptoms for patients who have been diagnosed with an advanced progressive illness, until death. ⁴⁰ May be accompanied by the withdrawal or withholding of nutrition and hydration.
Treatment	Under the legislation relating to advance health directives, treatment is defined to include medical or surgical treatment, including palliative care and life-sustaining treatment, dental treatment, or other health care. ⁴¹
Voluntary assisted dying	The provision for self-administration of lethal medication where an eligible person is physically able to self-administer. In cases where the person is eligible but physically incapable of self-administration, a medical practitioner may administer or provide the medication. Also for the purposes of this report, voluntary euthanasia and assisted-suicide are referred to as voluntary assisted dying. Voluntary assisted dying is not currently legal in Western Australia.
Voluntary palliated starvation	Voluntary palliated starvation refers to the process which occurs when a competent individual chooses to stop eating and drinking, and receives palliative care to address pain, suffering and symptoms that may be experienced by the individual as he or she approaches death. ⁴²

38 Cherny, NI et al, *Journal of Palliative Care*, "Sedation in the management of refractory symptoms: guidelines for evaluation and treatment", (1994)

39 Taken from the *Rights of the Terminally Ill Act 1995* (NT).

40 Adapted from Mervyn M Dean et al, "Framework for Continuous Palliative Sedation Therapy in Canada", *Journal of Palliative Medicine*, vol 15(8), 2012, 870, p 870.

41 GAA Act 1990, s 3.

42 White, Benjamin P, Willmott, Lindy, & Savulescu, Julian "Voluntary palliated starvation: A lawful and ethical way to die?" *Journal of Law and Medicine*, vol 22, 2014, pp. 376-386, p 376.

Chapter 2

Advance Health Care Planning

Planning ahead

- 2.1 Many people worry about losing the ability to make their health care preferences known in the event that they lose decision-making capacity.⁴³ People also commonly worry about being kept alive in unacceptable circumstances with greatly diminished ability to advocate for their preferred care – for example, with dementia or in a persistent vegetative state following traumatic or non-traumatic brain injury.
- 2.2 Advance health care planning is a way for a competent adult to make decisions about the health care they want in the future, if they become unable to speak for themselves.
- 2.3 Advance health care planning may be as simple as a conversation with family and health professionals, or more intentional steps such as writing down wishes for medical treatment in an “advance care plan”. It can involve completing a legally binding Advance Health Directive (**AHD**). It is also possible to make an Enduring Power of Guardianship (**EPG**) to appoint another person as a substitute decision-maker with the power to make personal and health care decisions. It should also be noted that, although not a future *health care* decision, an individual might also choose to make an Enduring Power of Attorney (**EPA**) to appoint a substitute decision-maker to make *property and financial decisions* when decision-making capacity is impaired.
- 2.4 In Western Australia when a person is unable to make reasonable judgments in respect of any proposed medical treatment, and there is a need for a treatment decision, the *Guardianship and Administration Act 1990* (**GAA**) determines which treatment decision will be given precedence.⁴⁴

43 For example, whether to have or continue: dialysis, antibiotics to treat infections (such as pneumonia and UTIs), blood transfusions, chemotherapy, intubation, intensive care, invasive and non-invasive ventilator support, the activation (and de-activation) of electronic device implantation for heart failure, transplantation, nasogastric and PEG feeding, CPR and lifesaving surgery, and whether to receive pain relieving medication which may also have significant sedating effects.

44 Section 110ZE *Guardianship and Administration Act 1990*.

Box 1.1: the concept of ‘capacity’ – an overview

There is no single legal definition of capacity⁴⁵ in Australia. Under the law, there is a however a presumption that every adult person has capacity.⁴⁶ Generally, when a person has capacity they can:

- understand the facts and choices involved;
- weigh up the options and the consequences; and
- communicate the decision.

In everyday life, people who have capacity make decisions about where to live, what to buy, how and when to travel, when to see the doctor, and numerous other daily decisions that ordinarily enable them to live independently.

Capacity is decision specific and is about the decision-making process

Capacity is ‘decision specific’ which means that it relates to the decision in question – a person may have capacity for one decision (for example buying a train ticket) but lack capacity for another (for example entering into a mortgage agreement). It is also important to note that capacity is assessed in relation to a person’s decision-making *process* – not in relation to the actual decision made (what others consider a *bad* decision is not necessarily an indication of a lack of capacity).

Other key principles

Capacity for adults:

- May fluctuate – for example a person may *temporarily* lose consciousness, or be temporarily impaired by mental illness.
- Should always be presumed – substitute decision-making is a last resort.
- Should not be deemed to be lacking merely because of a person’s age, appearance, disability, behaviour, language skills or any other condition or characteristic.⁴⁷

Medical treatment decisions

In the case of a medical treatment decision, a person must be able to understand the nature and effect of the proposed treatment, weigh up the risks and benefits, and communicate their decision. A competent adult has legal capacity and they can consent to or refuse medical treatment.

45 Note: ‘capacity’ is sometimes used as a shorthand reference for competence, cognitive capacity, legal capacity, decision-making capacity, testamentary capacity or (in the case of mature minors) *Gillick* competence

46 *Re MB* [1997] 2 FCR 514 at [553] per Butler-Sloss LJ; *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (1992) 175 CLR 218 (*Marion’s case*) at [233] and *Rogers v Whittaker* (1992) 175 CLR 479 at [193]. See also section 4(2) (b) *Guardianship and Administration Act* 1990, and section 13(1) *Mental Health Act* 2014. Note: As children get older their capacity to understand information and consequences increases and they may be assessed as a ‘mature minor’ – see *Gillick v West Norfolk Wiesbach Area Health Authority* [1986] AC 112 at [188]-[189] per Lord Scarman. See also *Marion’s case* at [19].

47 [NSW Capacity Toolkit](#) pp. 33–35, website. Accessed 26 June 2018.

Why assess capacity?

Capacity to make a decision may need to be assessed when the decision in question is about something significant or has legal consequences.⁴⁸ There may also be ‘red-flags’ that alert others to the possibility of incapacity, for example:

*Short-term memory problems, language communication problems, comprehension problems, disorientation, delusions, hallucinations, changes in grooming and hygiene and sudden changes in personality.*⁴⁹

Different people are involved in capacity assessment, including solicitors, financial sector professionals, health professionals, community workers, carers, and family members. Capacity is assessed every day by general practitioners:

- to assist people to make legal documents;
- to assess whether a patient is able to give informed consent to medical treatment; and
- for reporting to the State Administrative Tribunal (SAT).

Capacity has a particular meaning when used in particular circumstances and there are specific legal tests for capacity. The test used will vary depending on the legal area to which the decision relates – for example, when a person makes a Will, an enduring power of guardianship or an advance health directive, each of the legal tests differ.⁵⁰

There are also specific legal tests of capacity for the appointment by the SAT of a guardian or an administrator,⁵¹ and in relation to making an individual an involuntary patient under the *WA Mental Health Act 2014*.⁵² In Western Australia, where legal capacity is contested it may result in matters going before the SAT, the Mental Health Tribunal or the WA Supreme Court for judicial determination.

In the SAT – a jurisdiction that deals with many incapacitated people – capacity assessment may be complex. In proceedings for guardianship and administration, there is a requirement for medical evidence if an applicant wants to rebut the presumption of capacity:

*The starting position is the person is able to make their own decisions—and they are. We all are. We have that right because we have that presumption of capability. We have to have medical evidence. We require the applicant to identify who are the relevant medical practitioners who can speak to capacity and if the applicant cannot provide the information, we will seek for that medical practitioner or medical practitioners to provide us with a medical report.*⁵³

48 NSW Department of Justice, *NSW Capacity Toolkit*, p.61, website. Accessed 21 June 2018.

49 WA Law Society, *When a Client's Capacity is in Doubt: Appendix B*, website. Accessed 26 June 2018.

50 See *Banks v Goodfellow* 1870 LR 5 QB 549 at [565]; See also ss4 (2) (b) and 110R (2) *Guardianship and Administration Act 1990*.

51 See sections 43(1) (b) and 64(1) (a) *Guardianship and Administration Act 1990*.

52 Section 15(1) *Mental Health Act 2014*.

53 Mrs Charlotte Wallace, Senior Legal Member, State Administrative Tribunal, *Transcript of Evidence*, 28 February 2018, p. 6.

Priority of treatment decisions

2.5 Given that an incapacitated person is unable to express their treatment preferences, the GAA has outlined a strict hierarchy as to who may be authorised to make decisions on their behalf. Currently, when there is not a valid AHD, the decision-making powers are delegated to those individuals deemed best able to make a decision that would most closely accord with the incapacitated person's best interests:

- in the first instance, if the patient has a valid AHD containing a relevant treatment decision, treatment must be given in accordance with the decision in the AHD.
- if there is no valid AHD, treatment must be authorised by an enduring guardian.
- if no enduring guardian has been appointed, then treatment must be authorised by the guardian.
- if there is no guardian, thereafter by the person who is first in order of the hierarchy of decision-makers.⁵⁴

2.6 There are three exceptions under the GAA to the priority of treatment decisions. A health professional is authorised to treat an incapacitated patient when:

1. Urgent treatment is needed to: save a patient's life; to prevent serious damage to health; or prevent significant pain or distress (and it is not practicable for the health professional to determine if an AHD has been made or a substitute decision-maker has been appointed),⁵⁵
2. In the case of a suicide attempt where urgent treatment is needed (despite the AHD or the decision of the substitute decision-maker),⁵⁶ or
3. An AHD exists, but there has been a change of circumstances that the maker could not have anticipated and a reasonable person in the same position would have changed their mind.⁵⁷

First person responsible

2.7 When there is no relevant AHD or EPG and there has not been a formal appointment of a substitute decision-maker, the GAA provides for a list of persons who can make treatment decisions on behalf of someone who has lost decision-making capacity. The particular person who is authorised to make treatment decisions is the first person

54 Section 110ZJ *Guardianship and Administration Act 1990*.

55 Section 110ZI *Guardianship and Administration Act 1990*.

56 Section 110ZIA *Guardianship and Administration Act 1990*.

57 Section 110S (3) *Guardianship and Administration Act 1990*.

responsible for the patient in the list contained in the GAA.⁵⁸ The list begins with the patient's adult spouse or de facto partner who lives with the patient; then the *nearest relative* (adult) who maintains a close personal relationship with the patient; then the primary unpaid adult carer; and finally, any adult person who maintains a close personal relationship with the patient.⁵⁹

2.8 The particular substitute decision-maker who is authorised to make treatment decisions is the first person responsible for the patient in the list of decision-makers under the GAA who is:

- of full legal capacity;
- reasonably available; and
- willing to make a treatment decision in respect of the treatment.

2.9 People often confuse 'next of kin' with authorised substitute decision-maker. The term 'next of kin' is not contained in the GAA and the next of kin may or may not be the person authorised to make treatment decisions under the GAA. The term 'nearest relative' is defined under the legislation.⁶⁰ The first person in order of priority is the spouse or partner, then a child, then a parent, then a sibling, a grandparent, an uncle or aunt and then a nephew or niece – providing that person is 18 years or over and reasonably available at the relevant time.

What happens when a person loses decision-making capacity?

2.10 According to the Public Advocate, Ms Pauline Bagdonavicius, the GAA provides a number of options for decision-making when a person loses capacity:

*These range from family or friends, whose decision-making authority comes from their place in the person's hierarchy of treatment decision-makers; through to planning documents which adults can make while they have the capacity, being an advance health directive and enduring power of guardianship; and, finally, the appointment of a guardian by the State Administrative Tribunal, whether they be a family member or friend or, as the last resort, the appointment of the Public Advocate as guardian.*⁶¹

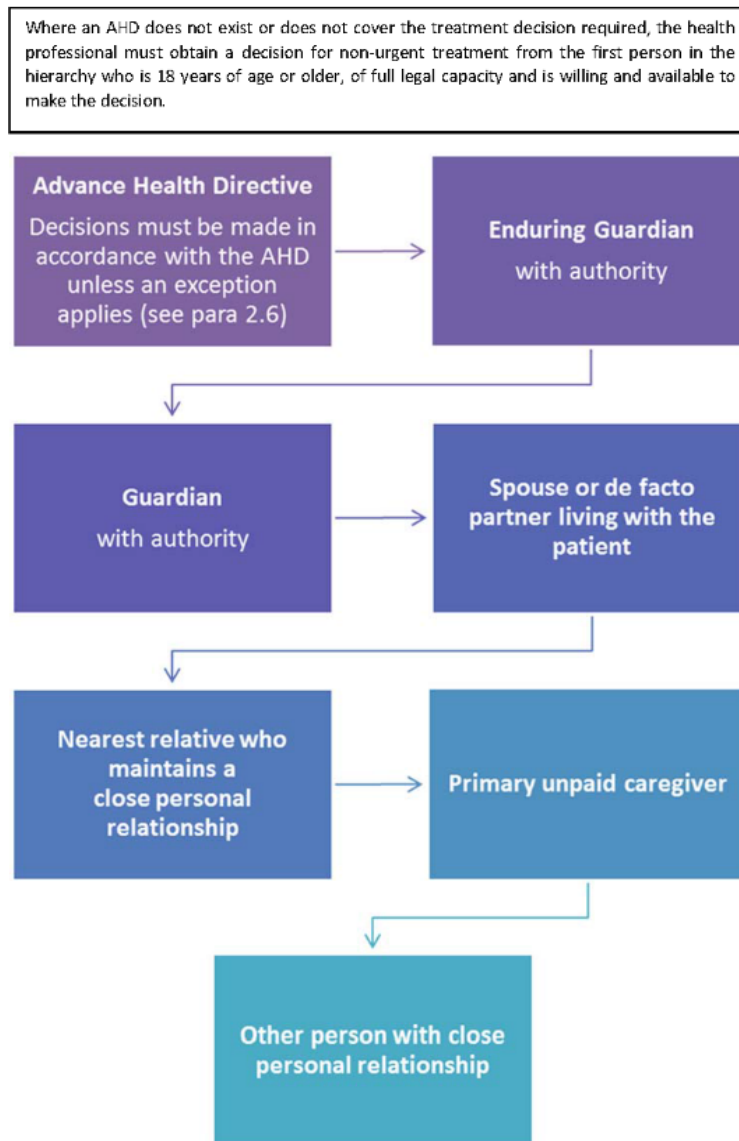
58 See sections 110ZD, 110ZE and 110ZJ *Guardianship and Administration Act 1990*.

59 Section 110ZD (3) *Guardianship and Administration Act 1990*.

60 See sections 3(1) and 110ZD (4) *Guardianship and Administration Act 1990*.

61 Ms Pauline Bagdonavicius, Public Advocate, Western Australia, *Transcript of Evidence*, 27 February 2018, p. 1.

Figure 2.1: Hierarchy of decision makers



2.11 The SAT can appoint a guardian or administrator when:

- an individual no longer has the capacity to make their own decisions;
- they are in need of a decision-maker; and
- the needs of the individual cannot be met in a less restrictive way.⁶²

2.12 All too often, people are reluctant to talk about what their wishes might be should an unforeseen medical crisis arise, leaving families, friends or carers to make decisions that

⁶² See Parts 5 and 6 *Guardianship and Administration Act 1990*.

they cannot always be sure reflect the wishes of their loved one. To avoid the situation where a decision-maker must be appointed, an individual with capacity can undertake advance health care planning to prepare for a time when they may be unable to make decisions for themselves.

2.13 There can be a heavy cost for failing to plan ahead for both the individual and for their loved ones. The committee received evidence that when patients are very unwell families are often forced to become involved in decision-making.⁶³ Active treatment may not always be the best option because it is not always a binary choice between life and death. Loved ones are often unprepared to make difficult choices about when treatment should be withheld or withdrawn.

2.14 When aggressive curative treatment is provided, a person may survive but in a significantly debilitated state. In his submission to the Inquiry, Dr Brien Hennessy, Head of Department, Anaesthesia, Sir Charles Gairdner Hospital, indicated that people often do not realise they are dying and it is too late to prepare an advance health directive. In his view, dying alone on an operating table in a room full of strangers is hardly preferable to comfort care at home or in hospital, surrounded by loved ones. It is essential that we normalise conversations around death, dying and end of life choices in the community:

I understand that many of the submissions made to the committee will be from the community who have had to watch their relatives die in circumstances that they feel could have been improved. We will all experience the impotent feelings associated with that situation at some point(s) in our lives. A natural response to those feelings of impotence is to try to improve the circumstances for those who will die in the future. I share this response; however, I make this submission from the viewpoint of a medical practitioner involved in the care of critically unwell people in a tertiary hospital, many of whom are dying.

Our elderly patients don't appear to realise that they are dying. One day they are conducting their lives getting frailer and frailer when suddenly an intercurrent illness lands them in hospital. They rapidly become critically unwell and come to the attention of the Medical Emergency Team via the in-patient deterioration detection and response processes. At this point treatment decisions need to be made. The patient is unable to assist because they are too unwell. The next of kin - family are then engaged to assist with this decision-making. Most often, none of these people have ever discussed end-of-life wishes and there is either no advanced directive or it is not available at 02:00hrs during the

63 Submission No. 398 from Dr Brien Hennessy, Head of Department, Anaesthesia, Sir Charles Gairdner Hospital, 19 October 2017, p. 1; Ms Marcelle van Soest *Transcript of Evidence*, 1 May 2018, p. 5; Mr Bruce Buchanan, *Transcript of Evidence*, 1 May 2018, p. 5.

resuscitation in the ward. Finding the correct person to represent the patient's wishes is also a hit and miss affair. Difficult and vague communications then ensue in a time-poor environment where the outcomes are literally life and death.

In this hospital over the last 17 years of Medical Emergency attendances in the wards, the data reveals 300 people over 80 years-old became critically unwell as per the scenario above. Six of those people were alive 12 months later. Those six people spent their last year making almost weekly emergency department presentations and lived very diminished physical and cognitive lives with none returning to their former living circumstances during that period. I wonder how many of them would have chosen to be one of the six if they had known what lay ahead.

My role as an anaesthetist mostly becomes entwined with end-of life-choices when patients who are dying get booked for a surgical procedure. The patient and family are correctly told that there is some terrible pathology that, left untreated, will probably result in imminent death. One of the treatments could be an operation. With the operation, the patient may have a chance of survival. Without the operation, the patient's chances of survival are even more remote. The patient and / or their NOK- family naturally see life and death as a binary outcome given such a choice, and therefore most consent for their relative to have an operation.

The problem is that although death is a single outcome, life is not. Life can be living independently back at home with full physical and cognitive capacity with people you love or it can be living in a vegetative state in a nursing home- with many shades of grey in-between these two extremes. Communicating this "third outcome" to a group of family members with disparate views whilst mum / dad lays dying nearby is a minefield. Families are usually not at their functional best at this time of stress. We call this a "goals of care" discussion where we try to describe what a good outcome and what a bad outcome might look like. Then we try to elucidate what the wishes of the patient might be given this situation before we negotiate a treatment path with appropriate boundaries.

Although the family can't mandate futile treatment, many will pressure critical care staff to become complicit in their demands to receive all treatments possible as a default position. This default setting may or may not have been the wishes of the patient- that remains unknown. This default position is not in the patient or community's best interests

as it is resource intensive and is ultimately unsuccessful. In my opinion, dying alone during resuscitation under anaesthesia in an operating room full of strangers, or shortly thereafter in an ICU or hospital ward is not a better death than comfort care in a hospital ward with family present. And unfortunately surviving critical care treatment in a debilitated state for a few months is the only other probable alternative. Herein lies the committees raison d'être.

To specifically address the first term of reference-

My experiences lead me to believe that we need to normalise conversations around death, dying and end-of-life choices in our community. I believe this because people don't realise that they are dying until it is too late to think about an advanced care directive. It is their misinformed belief that they will somehow know that they have a terminal illness before their terminal event and they will gather the flock around at home and "conduct" the perfect death. The data shows that they are most likely to have a very different experience where they will die suddenly in a hospital or nursing home from a terminal event that they didn't foresee. Therefore, to assist a person to exercise their preferences at their end of life, our community needs general education about how people are currently dying and that they need to speak to their family about their wishes before it is too late to do so. Clearly, this can't be legislated for. Ironically, it is a role for health promotion. What is a point for legislation however is that an advanced health care directive should not be limited to those who have chronic and/or terminal illnesses that they know about. Only a minority of people in my experience realise that they are dying of accumulated chronic illnesses. People need encouragement to have discussions with their family about their end-of-life choices and document those discussions in a format that is available when it is needed on a hospital ward at 2am whilst undergoing resuscitation.⁶⁴

Advance care plans

- 2.15 An advance care plan is a way for someone to record their wishes about their future care, when they are no longer able to communicate. It can be quite expansive and may include both personal care and treatment preferences. It is important to note that an advance care plan is only a *guide* for health professionals and is not a legally binding directive.

64 Submission No. 398 from Dr Brien Hennessy, Head of Department, Anaesthesia, Sir Charles Gairdner Hospital, 19 October 2017, p. 1.

- 2.16 Mrs Suzanne Greenwood, from Catholic Health Australia, gave evidence to the Inquiry that her organisation promotes its own advance care plans and encouraged people to think about all aspects of their care:

[...] it is a document that encourages individuals to think about: How do they want their end of life to look like? What will that time look like for them? Who do they want to have in the room? Do they want their pet brought into them if they are in an aged-care facility and their pet is being cared for by their son or daughter? Is there someone in their life that they want to meet with and say sorry to about something? Is there someone in their life that they have not told them they love them for a decade and they need that person to come in?⁶⁵

- 2.17 Several witnesses told the committee that an advance care plan was sometimes a mechanism to open up the conversation about treatment preferences, and could lead to preparation of more formal advance health directives.⁶⁶

Advance Health Directives

- 2.18 The concept of an advance health directive has been around since the 1980s but as far back as 1973, the Connecticut State Medical Society endorsed a ‘background statement’ to be signed by patients that included a binding directive:

I value life and the dignity of life, so that I am not asking that my life be taken, but that my life not be unreasonably prolonged or the dignity of life destroyed.⁶⁷

- 2.19 In England and Wales, it is possible to make an advance directive under the *Mental Capacity Act 2005*.⁶⁸ In New Zealand, patients have the right to use an Advance Directive to make a choice about future healthcare effective when the patient is no longer competent.⁶⁹ Each state and territory of Australia now has some form of legally binding advance health directive (see Appendix 5).

- 2.20 AHDs provide competent adults with a way to ensure their autonomous choices are honoured at a future time when they are unable to express their wishes. They are:

65 Mrs Suzanne Greenwood, CEO, Catholic Health Australia, *Transcript of Evidence*, 28 February 2018, p. 17.

66 Mrs Suzanne Greenwood, CEO, Catholic Health Australia, *Transcript of Evidence*, 28 February 2018, p. 17; Dr Alison Parr, *Transcript of Evidence*, 28 February 2018, p. 18; Ms Lana Glogowski, Executive Officer, Palliative Care WA, 14 December 2017, p. 2.

67 *The End of Life: Euthanasia and Morality*, James Rachels, Oxford University Press, 1986, p. 182.

68 See sections 24 – 26 *Mental Capacity Act 2005*.

69 Clause 7 *Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996*.

*founded on respect for personal autonomy and are intended to ensure a person's preferences can be honoured during any period of temporary or permanent impaired decision-making capacity, not only at end of life.*⁷⁰

- 2.21 In Western Australia, adults can make a common law or statutory AHD containing legally binding treatment decisions in respect of their future treatment. Any person who is aged 18 or over and has full legal capacity⁷¹ can make an AHD containing treatment decisions for future health care. It is possible for a person to make an advance refusal of treatment, even if failure to treat will result in loss of person's life.⁷²
- 2.22 Some of the benefits of common law AHDs include that they can be a verbal directive and there are no rigorous formal requirements.⁷³ In addition, a person does not have to be medically informed of the consequences when an AHD is written. In the Canadian case of *Malette*, medical staff found a card containing a directive in a patient's pocket. The directive stated that the patient was a Jehovah's Witness and had firm religious convictions. She requested that no blood products be administered under any circumstances. The treating team went ahead, carried out a life-saving transfusion, and were found liable in battery:

*A doctor is not free to disregard a patient's advance instructions any more than he would be free to disregard instructions given at the time of the emergency.*⁷⁴

- 2.23 On the other hand, the lack of prescriptive requirement in common law AHDs can lead to difficulties for health professionals who have to interpret a document in a variety of circumstances.⁷⁵

Common Law AHDs

- 2.24 There are no formal requirements as to what constitutes a common law advance directive – it can be oral or in writing. There is also no requirement that when making a common law advance directive that the person receive information about the treatment

70 A National Framework for Advance Care Directives, Australian Health Ministers' Advisory Council (Website) September 2011, p. 5.

71 See 'Capacity' above at p. 26.

72 Sonia Allan and Meredith Blake, *The Patient and the Practitioner: Health Law and Ethics in Australia*, LexisNexis Butterworths, 2014, para. 3.106. p. 94

73 *Hunter and New England Area Health Service v A* [2009] NSWSC 761 at [40]; *HE v NHS Trust* [2003] 2 FLR 408 at 417; *W Healthcare NHS Trust v H* [2005] 1 WLR 834.

74 *Malette v Shulman* (1990) 67 DLR (4th) 321.

75 See for instance the 23 July 2004 decision of the Deputy State Coroner in the Finding Upon Inquest into the death of GKP (4088/03).

that he or she is requesting or refusing. Further, a direction may be given for any reason, including for religious, social or cultural reasons.⁷⁶

- 2.25 A common law AHD will be valid providing it is made voluntarily and the maker is not subject to inducement or coercion by another person. The first case in Australia that affirmed the legality of common law advance health directives was delivered in August 2009 in New South Wales. Justice McDougall made it clear that a valid directive must be respected:

*If an advance care directive is made by a capable adult, and is clear and unambiguous, and extends to the situation at hand, it must be respected. It would be a battery to administer medical treatment to the person of a kind prohibited by the advance care directive.*⁷⁷

- 2.26 During travel to the Kimberley, members of the committee visited the Derby Aboriginal Health Service (DAHS). DAHS has a template document for Aboriginal patients including some Aboriginal terms so that the document can be easily understood and patients can give directions regarding their future care. Whilst not in the prescribed statutory form it likely operates as a common law directive. DAHS nursing staff will initiate conversations with a patient who will then sit down with a doctor to discuss their future treatment preferences. The committee was advised by DAHS staff and management that at the end of life many Aboriginal patients in and around Derby indicate a strong preference to be able to die on country, and this preference is often contained in the common law AHDs created via the DAHS template.

Statutory AHDs

- 2.27 Following amendments to the GAA in 2008,⁷⁸ it is now also possible to make a statutory AHD.⁷⁹ A statutory AHD is legally binding which means a health professional must comply with the AHD except in very limited circumstances. The maker of a statutory AHD:

- must have full legal capacity;⁸⁰
- must understand the nature and consequences of the treatment they are consenting to or refusing;⁸¹

76 [QUT – End of Life Law in Australia](#) (website) Accessed 6 June 2018.

77 *Hunter v New England Area Health Service v A* [2009] NSWSC 761, per McDougall J at [40].

78 *Acts Amendment (Consent to Medical Treatment) Act 2008*.

79 Part 9B, Division 4 *Guardianship and Administration Act 1990*.

80 Section 110P *Guardianship and Administration Act 1990*.

81 Section 110R (2) *Guardianship and Administration Act 1990*.

- must use the form prescribed under the GAA, and have the document properly witnessed,⁸² and
- is encouraged to seek legal and medical advice but this is not mandatory.⁸³

2.28 Similar to a common law AHD, a statutory AHD must be made voluntarily, and without inducement or coercion by another person.⁸⁴ A treatment decision in an AHD operates when the maker of the AHD has lost decision-making capacity. The treatment decision then operates as if made by the person at that time and as if the person had full legal capacity.⁸⁵

2.29 A health professional must comply with the terms of a statutory AHD unless there is an urgent need for treatment, or the treatment is needed because of a suicide attempt (as outlined at paragraph 2.6) or when:

- There is a change of circumstances that the maker could not have anticipated (for example a new treatment); and
- The change would cause a reasonable person in the same position to change their mind.⁸⁶

The Role of the State Administrative Tribunal

2.30 Where there is doubt about the validity of an AHD, doubt about a particular treatment decision in the AHD or a change in circumstances that may have caused the maker to change their mind about their directive, a person who has a *proper interest in the matter*⁸⁷ may apply to the SAT for direction. The SAT can make a declaration as to the validity of the AHD, or the validity of a particular treatment decision contained in the AHD.⁸⁸ The SAT can also make a declaration that a person is *unable* to make reasonable judgments in respect of treatment to which a treatment directive applies, meaning that an existing AHD is operable.⁸⁹ The SAT may also declare that there has been a change of circumstances that would have caused a reasonable person in the position of the maker to change their mind.⁹⁰

82 Section 110Q (1) (a) *Guardianship and Administration Act 1990*.

83 Section 110Q (1) (b) *Guardianship and Administration Act 1990*.

84 Section 110R (1) *Guardianship and Administration Act 1990*.

85 Section 110S (1) *Guardianship and Administration Act 1990*.

86 Section 110S (3) *Guardianship and Administration Act 1990*.

87 This would ordinarily be a family member, carer, or health professional involved in the care of the person.

88 Section 110W (1) *Guardianship and Administration Act 1990*.

89 Section 110X (1) *Guardianship and Administration Act 1990*.

90 Section 110Z (1) *Guardianship and Administration Act 1990*.

- 2.31 Mrs Charlotte Wallace, a Senior Legal Member of the SAT, explained the jurisdiction of SAT:

We have jurisdiction to declare the instrument itself valid or invalid and we can also declare a treatment decision within it valid or invalid. We have jurisdiction to recognise instruments created in other jurisdictions here in Western Australia. We have jurisdiction to declare the maker of the instrument to lack capability to make reasonable judgements about themselves in relation to a treatment decision in the instrument. We can also give direction in relation to the construction of it and its terms and the exercise of it. We can also declare a treatment decision within the instrument. We can revoke it on the basis of a finding that the person has changed their mind about that particular treatment decision.⁹¹

- 2.32 Despite the broad jurisdiction of the SAT in relation to AHDs, Mrs Wallace also informed the committee that during the previous five years there have been only seven applications in relation to AHDs. In her opinion that number was an indication of the low take-up of AHDs by the community:

To talk about seven in five years in respect of advance health directives, you can read into that that they are probably not being used in the community, because if they were being used, we would definitely see higher numbers than that.⁹²

Enduring powers of guardianship

- 2.33 An enduring power of guardianship (EPG) is a legally binding document whereby an individual can appoint another person to make personal and healthcare decisions, in the event that they lose decision-making capacity.⁹³ The person making the EPG is called an ‘appointer’ and is effectively *giving* power to the guardian to make personal and treatment decisions on their behalf.
- 2.34 The power can be limited in terms of the guardian’s functions and the circumstances in which the guardian may act – it may also give directions about the manner of performance of those functions.⁹⁴ An EPG has effect, subject to its terms, at any time the appointer is unable to make reasonable judgments in respect of matters relating to their person.⁹⁵

91 Mrs Charlotte Wallace, Senior Legal Member, State Administrative Tribunal, *Transcript of Evidence*, 28 February 2018, p. 1.

92 Mrs Charlotte Wallace, Senior Legal Member, State Administrative Tribunal, *Transcript of Evidence*, 28 February 2018, p. 2.

93 Part 9A *Guardianship and Administration Act 1990*.

94 Section 110G *Guardianship and Administration Act 1990*.

95 Section 110F *Guardianship and Administration Act 1990*.

2.35 Where an EPG is unclear or disputed, it is possible to apply to SAT for direction. Mrs Wallace told the committee that the SAT's jurisdiction in relation to EPGs is very similar to AHDs:

It is very similar to the advance health directives. We can declare the instrument valid or invalid. We can revoke it and vary it. We can recognise instruments created in other jurisdictions here in WA. We can give directions in relation to the construction of it and the exercise of it. We can declare that the maker of the instrument lacks capability to make reasonable judgements in respect of matters relating to themselves. It is a very similar kind of mirror provision to advance health directives.⁹⁶

Being clear about health care preferences is important

2.36 Consistent with other elements of end of life care, there is a reluctance to talk about advance health care planning and the take-up rate for these important medical documents, including legally binding instruments, is low. The committee received evidence from many witnesses that:

- AHDs are poorly understood by both the health profession and the wider community – consequently they are under-utilised;⁹⁷
- some health professionals and health service providers prefer non-binding advance care plans to legally binding AHDs,⁹⁸ and
- some health professionals do not follow valid AHDs.⁹⁹

Lack of understanding by health professionals and the wider community

2.37 Palliative Care WA (PCWA) told the committee that there is very limited understanding of advance health care planning, including AHDs, in the community:

96 Mrs Charlotte Wallace, Senior Legal Member, State Administrative Tribunal, *Transcript of Evidence*, 28 February 2018, pp. 3-4.

97 Ms Georgie Haysom, Head of Research, Education and Advocacy, Avant Mutual, 28 February 2018, p. 2; Ms Lana Glogowski, Executive Officer, Palliative Care WA, *Transcript of Evidence*, 14 December 2017, p. 2; Mrs Charlotte Wallace, Senior Member, State Administrative Tribunal, 28 February 2018, p. 3.

98 Ms Natalie Joseph, Manager, Clinical Services, Catholic Homes WA, *Transcript of Evidence*, 28 February 2018, p. 18; Dr Alison Parr, Director Medical Services, St John of God Health Care, *Transcript of Evidence*, 28 February 2018, p. 20.

99 Submission No. 42 from Mr Bruce Buchanan, 2 October 2017; Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 2.

*Advance care planning is a valuable tool to facilitate end of life choices that is unfortunately very underutilised in WA and poorly understood by the community and health providers.*¹⁰⁰

- 2.38 The committee is aware of at least one instance in which a patient's attempt to have their AHD included in their medical record at a major tertiary hospital was unsuccessful. According to a PCWA phone log, an individual had:

*called to report that she had asked the staff (registrar) at reception Oncology, Fiona Stanley Hospital, to file her AHD on patient record. No one had seen one before and didn't know what to do. Reception made a few phone calls including patient records, but could not advise her. Seemed to think that it was admissions job. Advised her to give copy to GP for her record and ask her upload to My Health Record, (she doesn't have a scanner to do it herself) and that GP also forward copy to Oncologist to include on her patient file there.*¹⁰¹

- 2.39 Although GPs are familiar with the clinical impact and functionality of AHDs, the Royal Australian College of General Practitioners (**RACGP**) acknowledged that understanding of the legal effect of an AHD is more limited.¹⁰²

- 2.40 The RACGP also indicated that it would be receptive to the idea of providing more education in this area for GPs in order to address this shortcoming.¹⁰³ The committee received evidence repeatedly that education about AHDs, EPGs, and the hierarchy of decision makers demands more government attention. The need for education of health professionals on the law relevant to end of life care is critical. Evidence indicates clinicians have poor knowledge of the laws relevant to the validity and effect of advance directives and the correct substitute decision-maker. Doctors are time-pressured so are unlikely to engage in training to understand the complexities of the law unless they consider such training to be worthwhile. However, risk of harm to the patient and legal risk to the doctor could provide sufficient incentive.¹⁰⁴

100 Ms Lana Glogowski, Executive Officer, Palliative Care WA, *Transcript of Evidence*, 14 December 2017, p. 2.

101 Ms Lana Glogowski, Executive Officer, Palliative Care WA, Letter – supplementary material, 18 May 2018.

102 Dr Timothy Koh, Chair, Royal Australian College of General Practitioners, *Transcript of Evidence*, 14 December 2017, p. 1.

103 Dr Timothy Koh, Chair, Royal Australian College of General Practitioners, Letter – Response to questions on notice, 12 February 2018.

104 White, et al, 'Doctors' Knowledge of the law on withholding and withdrawing life-sustaining medical treatment', *MJA*, vol. 201, (4), 18 August 2014, p. 3. White and colleagues propose additional training at each of the three stages of medical education – undergraduate (by universities and the Australian Medical Council); training for interns and junior doctors (by hospital executives, clinical leads and the Medical Board of Australia); and specialist college

The uptake rate is low

2.41 Associate Professor Meredith Blake and Dr Craig Sinclair, public health law academics, indicated the low uptake of advance health care planning in the community:

Research in Australia has shown that the uptake of formal advance care planning (ACP) instruments is low, (14% of the general adult community), with uptake in Western Australia being lower than other states (7.5%).¹⁰⁵

2.42 In their submission to the Inquiry, Associate Professor Blake and Dr Sinclair also reported on health promotion around end of life in the community. These included:

- community forums organised by the WA Cancer and Palliative Care Network and Palliative Care WA;
- awareness raising events, associated with National Palliative Care Week and ‘Dying to Know Day’, organised by the Albany Death Café; and
- research undertaken with the Noongar community in the Great Southern region of Western Australia found support for the use of ‘whole of community’ approaches to raising awareness, rather than health professionals broaching the topic with individual patients in clinical situations.¹⁰⁶

2.43 In the committee’s view, this patchwork approach to community education is not adequate, and does not address education of health professionals regarding their legal obligations.

Preference for non-binding advance care plans

2.44 The committee was encouraged by the evidence of Ms Janet Wagland of Brightwater Care Group that indicates that Brightwater staff actively promote advance health directives to determine patients’ preferences:

In disability services we often are looking at more of an advance care directive approach, rather than an advance care plan, because the care plan tends to be something that you are doing with the family. The advance care directive is something we are doing with the person themselves, with, of course, family input, and we have a lot of conversations generally with people with Huntington’s disease who lose

training (including non-elective training programs by the colleges and the Australian Medical Council)

105 Submission No. 584 from Associate Professor Meredith Blake and Dr Craig Sinclair, 23 October 2017, p. 2.

106 Submission No. 584 from Associate Professor Meredith Blake and Dr Craig Sinclair, UWA, 23 October 2017, p. 3.

*the ability to swallow, and yet have a very high metabolic rate so have high food intake requirements. We have a lot of conversations about their choices, as they get to a point where they are no longer able to swallow safely, about whether they would like to have enteral feeding, or whether they would prefer us just to continue providing what oral intake we can.*¹⁰⁷

- 2.45 The Albany Hospital's palliative care team also explained how they assist their patients to place their AHDs on the hospital record and actively promote legally binding directives in the community. The hospital now has several hundred AHDs on file. This is a relatively high number given the generally low uptake figure across the population. In the Kimberley, DAHS is working with local Aboriginal and non-Aboriginal patients to assist them to prepare their AHDs. They have developed a template guide including local language to enable clearer understanding. These examples demonstrate that a proactive, resourced plan to improve uptake does work.
- 2.46 However, Catholic Health Australia, St John of God Health Care and Catholic Homes WA expressed strong concerns about reliance on legally binding advance health directives, and a clear preference for advance care plans. Mrs Greenwood from Catholic Health Australia told the committee that advance health directives are 'very cold clinical documents'.¹⁰⁸ Ms Natalie Joseph from Catholic Homes WA told the committee that her organisation does not promote advance health directives, and does not find them helpful *because they are legally binding:*

*And we do not promote them, because we do not find them helpful, because they are legally binding in this state, and we find nothing will take the place of good ongoing conversations with the doctor and family as things change along the whole palliative journey, as opposed to saying, "Yes, they've done that; let's tick that box. That's done. We don't have to worry about that anymore." It is not as cut and dried without palliative care. We do not promote them at all.*¹⁰⁹

- 2.47 Dr Alison Parr from St John of God Health Care also expressed concern about AHDs due to possible coercion, uncertainty about the patient's current views, how old the document was, and what advice the person received when making the directive.¹¹⁰ She told the committee that St John of God is adopting Goals of Patient Care, a WA Health

107 Ms Janet Wagland, General Manager, Community, Brightwater Care Group, *Transcript of Evidence*, 1 March 2018, p. 2.

108 Mrs Suzanne Greenwood, CEO, Catholic Health Australia, *Transcript of Evidence*, 28 February 2018, p. 17.

109 Ms Natalie Joseph, Manager, Clinical Services, Catholic Homes WA, *Transcript of Evidence*, 28 February 2018, p. 18.

110 Dr Alison Parr, Director Medical Services, St John of God Health Care, *Transcript of Evidence*, 28 February 2018, p. 18.

initiative, which Dr Parr described as ‘more a discussion around the advance care plan’.¹¹¹

- 2.48 WA Health first piloted the Goals of Patient Care in 2015.¹¹² Many private and public hospitals now include a document in the medical record known as the “Goals of Patient Care” which is used to initiate a discussion between health professionals and their patients. The aim of the discussion is to ‘select the most medically appropriate agreed goal of patient care that will apply in the event of clinical deterioration’. Whilst this is a form of advance care planning it is important to note that although the document is prepared and signed by health professionals, it is not a legally binding statutory directive; however, it may be evidence of a verbal common law advance health directive.

Failure to honour advance health directives

- 2.49 The committee is concerned that patients’ legal rights regarding their health care preferences are being downplayed, and in some cases ignored. This seems to be occurring in both private and public health care settings. Evidence received indicates that some health professionals are disregarding advance health directives.¹¹³
- 2.50 The committee heard evidence that this can occur in any health setting including emergency and acute care.¹¹⁴ The committee also heard that the treating doctor may consider the directive not to be in the patient’s best interests and/or that such expressed wishes do not fit with the health care provider’s policies.¹¹⁵
- 2.51 Mr Bruce Buchanan drew the committee’s attention to a failure by his wife’s health care provider to follow her express written advance health directive. Mrs Buchanan was both a registered nurse and a registered midwife and had worked as a health educator for over twenty years. She was diagnosed with a neurological illness:

*My wife was diagnosed with an incurable progressive neurological illness, the principal effect of which was that she had progressive muscular weakness, resulting over time in an inability to walk, move, talk and swallow. Her chest muscles were affected also, with decreasing ability to draw breath, making pneumonia probable.*¹¹⁶

111 Dr Alison Parr, Director Medical Services, St John of God Health Care, *Transcript of Evidence*, 28 February 2018, p. 20.

112 http://ww2.health.wa.gov.au/Articles/F_1/Goals-of-patient-care

113 Submission No. 42 from Mr Bruce Buchanan, 2 October 2017; Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 2.

114 Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 2; Dr Alida Lancee, General Practitioner, *Transcript of Evidence*, 5 April 2018, p. 6.

115 Ms Natalie Joseph, Manager, Clinical Services, Catholic Homes WA, *Transcript of Evidence*, 28 February 2018, p. 18; Dr Alida Lancee, General Practitioner, *Transcript of Evidence*, 5 April 2018, p. 6.

116 Submission No. 42 from Mr Bruce Buchanan, 2 October 2017.

- 2.52 Mrs Buchanan completed an AHD with her General Practitioner. Mr Buchanan was present at the time. He told the committee that she clearly stated there was to be 'no action' in the event of pneumonia:

When provision was entered for 'no action' in the event of pneumonia, my wife specifically mentioned that she hoped she would contract pneumonia, as it results in a painless death.¹¹⁷

- 2.53 When she subsequently became unwell and he could no longer care for her, Mrs Buchanan went into an aged care facility. On admission, a copy of the AHD was provided to the home and Mr Buchanan went through it carefully with the registered nurse in charge of his wife's care. Despite this careful planning so that her health care preferences would be honoured – during any period of time when she could not speak for herself – Mrs Buchanan was given treatment against her wishes. Mr Buchanan explained the devastating consequences:

My wife became unwell. The aged care facility called a medical practitioner who diagnosed pneumonia. It was a weekend and although the on-call practitioner may not have been aware of the provisions of my wife's AHD, the care facility certainly was aware and permitted antibiotic to be administered, resulting in my wife's recovery from the pneumonia. The next day she spoke briefly for the last time – three words.

Thereafter my wife declined rapidly, suffering rashes and bedsores, inability to speak and severe discomfort (relieved by painful morphia injections). She died fourteen days after having been 'saved', during thirteen days of which she suffered pain, indignity and distress. I also was affected.

Subsequently I spoke to the GP with whom my wife had completed her AHD and asked why my wife's wishes had not been followed. He stated that such failure to adhere to the provisions of an AHD was 'common', (my emphasis), whenever the practitioner concerned thought that a period of "reasonable life" might be enjoyed by a patient so saved / resuscitated.

Irrespective of any possible legitimacy of the GP's approach, my wife experienced "reasonable life" for one afternoon only following her being

117 Submission No. 42 from Mr Bruce Buchanan, 2 October 2017.

'saved' from pneumonia. Her sufferings were greatly exacerbated by the failure to comply with her AHD wishes.¹¹⁸

- 2.54 Mr William Philip told the committee about his wife's explicit verbal directive, that is, a common law advance health directive that she provided to her treating doctor. If she were to lose capacity and be unable to communicate her wishes in the future, she did not want further aggressive treatment. After being hospitalised in August 2016 with pneumonia, she very clearly told her doctor that:

she did not want any further treatment, she did not want under any circumstances to go back to hospital and if she reached the point where she did not have any future other than that sort of care, she wanted to be kept pain free and fear and anxiety free with sufficient opiates to keep her knocked right out and just let her go.¹¹⁹

- 2.55 However, when she became ill again with pneumonia in October 2016, the doctor wanted to admit her back into hospital insisting to Mr Philip that the pneumonia could be treated. Following a discussion with the doctor Mr Philip reluctantly agreed to admit his wife to hospital. She was successfully treated for pneumonia but lost all ability to communicate and in December 2016 she rapidly deteriorated. Mr Philip described his dispute with the doctor about subsequent admission and the trauma of his wife's final days in hospital:

The doctor and I had a fairly long and intense discussion about whether or not she should be admitted to hospital. In the end, the doctor made the point that she was not suffering from an immediately terminal condition, that she was lingering along quite nicely, but the pneumonia was treatable, and if the doctor did not treat that pneumonia, then the doctor was in breach of her, I presume, Hippocratic oath, insofar as she should have been able to treat that and it was not necessarily artificially prolonging my wife's life, so she went back to hospital. I am too much of a gentleman to scream too loudly. She was there for about 10 days and they certainly treated the pneumonia but from there on she was incapable of any kind of interchange or thought or discussion. She could start a sentence, she would get about four words into it and it would trail off into gobbledegook—not words, but bits of words. She deteriorated quite significantly during December 2016 and at the end of December between Christmas and New Year she was fitted with this perfusion apparatus that provides direct access to the painkillers and things that she was on. However, in the next 10 days she basically

118 Submission No. 42 from Mr Bruce Buchanan, 2 October 2017.

119 Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 2.

*drowned slowly. Her lungs continued to fill up. No matter what the doctors did, they were not able to do anything about it, nor were they able to put her out sufficiently that she was unaware of it. On the Wednesday before she died, she was absolutely terrified. She could not breathe properly, even tipping the bed up that her feet were five feet off the ground and her head was a foot off the ground and trying to help drain out her lungs. Her eyes were bugging out and she was throwing herself around; she was terrified and that should not have happened. The palliative care people came that day, they helped stabilise her and they were as good as they possibly could have been. I think they were there three or four times that day and she should have settled down, but from then on she just gradually quietly drowned. And the palliative care people were doubling the medication that she was on every day, and it still was not taking away consciousness nor anxiety.[...] I think that if that was God's will, it is a pretty dodgy prospect.*¹²⁰

2.56 It is evident, that in many cases there can be a real cost for the person and for their loved ones when active treatment is pursued, regardless of an earlier express refusal of treatment.

2.57 A number of health professionals expressed concern about AHDs including the lack of central storage which resulted in poor understanding of when an AHD had been made and whether an individual's circumstances or wishes may have changed.¹²¹ The committee acknowledges this is a particular challenge in acute and emergency settings.

Finding 1

There is a very low uptake of advance health care planning instruments in Western Australia. This is due, at least in part, to poor understanding amongst health professionals and the general community.

Finding 2

There are many reasons why there is low uptake of advance care planning instruments, not least of which is the natural reluctance to contemplate our own frailty and mortality. In addition, advance care planning can be a lengthy process and health professionals may be unprepared to talk about death and dying with their patients.

120 Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 2.

121 Mr Mark Cockayne, General Manager, Health Care WA, Silver Chain Group, 14 December 2017, p. 5; Ms Grace Buchanan, Committee Member, Palliative Care Nurses Australia, 14 December 2017, p. 2.

Finding 3

There is widespread evidence that the community and health professionals do not *understand* advance care planning, particularly legally binding instruments.

Finding 4

Advance care plans and Goals of Patient Care are valuable tools to assist individuals to plan for future care, and they might be evidence of a verbal common law advance health directive, but they are not legally binding and do not ensure a person's preferences can be honoured during any period of temporary or permanent impaired decision-making capacity.

Finding 5

Some health providers are promoting non-binding 'advance care plans' over legally binding advance health directives, and others are, for various reasons, failing to honour express health care preferences contained in valid AHDs.

Statutory Template

2.58 Consistent with the evidence that AHDs are poorly understood, the committee also received evidence that the statutory template offers little guidance.¹²²

2.59 In November 2015, the Department of the Attorney General provided a report into the Statutory Review of the *Guardianship and Administration Act 1990*. The Attorney General noted that:

*The Department of Health has received feedback from health professionals and consumers/patients indicating that the current advance health directives form is difficult to complete and interpret a patient's wishes. The Department submits this is having an impact on uptake and suggests there are alternative formats of forms available in other jurisdictions such as the ACT, Queensland and South Australia.*¹²³

2.60 This finding expressed in the 2015 report remains a significant problem that is likely to be impeding the uptake of AHDs. Dr Alida Lancee provided the committee a New South Wales guide that provides significantly greater assistance for the maker of an AHD.¹²⁴

122 Dr Alida Lancee, General Practitioner, *Transcript of Evidence*, 6 April 2018, p. 6.

123 Department of the Attorney General, *Statutory Review of the Guardianship and Administration Act 1990*, November 2015, p. 37.

124 NSW Department of Health, [Making an Advance Care Directive](#), website. Accessed 3 July 2018.

Finding 6

The current template for statutory advance health directives and supporting information is difficult for individuals to complete and can be difficult for health professionals to interpret.

Finding 7

The current template suffers from a lack of guidance for people completing it. In other jurisdictions, examples are provided. Some of these medical conditions and treatments include but are not limited to:

- dialysis, antibiotics to treat infections (such as pneumonia and UTIs); blood transfusions; chemotherapy; radiation therapy; intensive care; intubation; invasive and non-invasive ventilator support; the activation (and de-activation) of electronic device implantation for heart failure; transplantation; nasogastric or PEG feeding; CPR and lifesaving surgery; receiving pain relieving medication which may also have significant sedating effects and receiving only comfort care.

Electronic Register

2.61 The committee heard evidence repeatedly from individuals and health professionals that there is a strong need for a centralised electronic register for AHDs.¹²⁵ Currently, some hospitals and doctors accept AHDs and others do not, but there is no co-ordinated central database. Health professionals cannot be certain that a patient has an AHD, and if they do have one, health professionals may not be able to access the document in a timely manner.

2.62 In his submission to the Inquiry, Dr Derek Eng indicated the need for improvements to communication systems and processes and that a register is required:

Improvements to communication systems and processes should be considered a priority in any proposed legislative framework changes. A registry that allows health practitioners to easily access individuals' advanced health directive's will certainly improve appropriate delivery of care for patients wishing to limit unwanted medical or surgical intervention.¹²⁶

2.63 In its 2015 submission to the Attorney General, the Law Society of Western Australia recommended the creation of a register and stated that:

125 See for example Dr Brien Hennessy, Head of Department, Anaesthesia, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 30 April 2018, p. 12; Mr Mark Cockayne, General Manager, Health Care WA, Silver Chain Group, 14 December 2017, p. 5

126 Submission No. 557 from Dr Derek Eng, Palliative Care Specialist, 23 October 2017, p. 8.

Without a register, unless persons inform a relative or their doctor that they have made an AHD (many do not) it will not be known that they have made one. It is unlikely a person will carry their AHD with them at all times. In the event of a life threatening accident or illness affecting a person's ability to communicate their wishes, it is likely their wishes will not be carried out.¹²⁷

2.64 The Public Advocate also informed the Attorney General that AHDs had been:

[...] well received by the community although one area of frequent discussion has been the registration of the power as many community members see this as a way of ensuring doctors will be aware of the document.¹²⁸

2.65 On the other hand, during that inquiry WA Health recommended there be no register and indicated that if a register was established:

- registration should be compulsory,
- patients should have to ensure the registered AHD reflected their current wishes,
- there should be 24-hour access to the register, and
- access should be limited to appropriate health professionals and staff.¹²⁹

2.66 In its final report, the Department of the Attorney General expressed concern regarding the resourcing of a 24-hour register, and that there be sufficient protection for health professionals who did not find an AHD after having searched the register – if a document was later produced and treatment was not in line with the document. In the end, the Attorney General elected not to proclaim the statutory provision that would have established a register.¹³⁰

2.67 The committee notes the evidence of Associate Professor Blake and Dr Craig Sinclair that compulsory registration is problematic given that common law AHDs are explicitly preserved in the GAA. They also posited that the inertia around the establishment of a register might be associated with the work being undertaken by WA Health towards electronic records:

127 Law Society of Western Australia – Submission to Statutory Review of the Guardianship and Administration Act 1990 – website. Accessed 26 June 2018.

128 Department of the Attorney General, *Statutory Review of the Guardianship and Administration Act 1990*, November 2015, p. 36.

129 Department of the Attorney General, *Statutory Review of the Guardianship and Administration Act 1990*, November 2015, p. 37.

130 Section 11 (110ZAA) Acts Amendment (Consent to Medical Treatment) Act 2008.

We note that other jurisdictions (e.g. NSW Ministry of Health) are pushing ahead with electronic systems for storing and communicating advance care planning documentation. In jurisdictions such as Wisconsin, where advance care planning is well developed, such systems are a core part of the electronic records system, and communicate across the public and private health care sectors.¹³¹

- 2.68 The current lack of a centralised electronic data-base, and the need for education of health professionals in order to ascertain the legal substitute decision-maker was highlighted in the evidence of Dr Hennessy:

The role of the advanced health care directives, enduring power of attorney, enduring power of guardianship should be crystal clear so that the difficult discussions at 2am are at least held with the correct person representing the patient's wishes and are not vague in content. The clinical staff who attend pre-terminal events need to know who to speak with regarding the patients delegated wishes. The methodology for discovering this information needs to be such that it can be easily known by clinicians who have never met the patient before and are busy performing resuscitation. It cannot be a phone call or computer login away or it may as well be kept on the moon. Health IT in this state is an absolute disgrace. Therefore, the solution for availability of this crucial information needs to circumvent that.¹³²

- 2.69 There has been a view amongst the health professional bodies that the Commonwealth My Health Record (**MHR**) would provide a repository for AHDs. It is clear from the evidence (as at May 2018) received that there had been very little uptake of the MHR by the community across Australia.¹³³ The committee notes MHR now operates on an opt-out basis.

- 2.70 Whilst MHR provides a repository for AHDs there are limitations to its effectiveness for this purpose. For example, health professionals are not compelled to search the record. For this reason MHR is unlikely to provide a satisfactory register for Western Australian statutory advance health directives in the current circumstances.

131 Professor Blake and Dr Sinclair, Supplementary Information and answers to questions on notice, p. 7.

132 Submission No. 398 from Dr Brien Hennessy, Head of Department, Anaesthesia, Sir Charles Gairdner Hospital, 19 October 2017, p. 2.

133 See for instance Dr Timothy Koh, Chair, Royal Australian College of General Practitioners, *Transcript of Evidence*, 14 December 2017, p. 2.

- 2.71 Dr Hennessy also told the committee that the current health IT system is very poor and if people were to store their AHDs it must be done properly on a system that is going to work when needed:

It has just always been higgledy-piggledy and an added-on system from a primary system from the 1990s. It is built on a Windows platform from 1999 and has not been upgraded since. The logins change so frequently; you have to log in five times to find a patient's blood pathology results, their cardiology results, their X-ray results, to give you access to when they are going to come and have an operation. It is just so clunky in comparison with other systems that are used internationally where you can just walk into a patient's room and everything is just there and available on my own smartphone because it knows who I am and it knows I have walked into a particular patient's room and just loads all their stuff onto my phone and I can just look straight through it. There is no login required, nothing difficult. My wife commented that when she was at a hospital in New York recently she could just walk in there, look at all the patient's results, order the radiotherapy for that particular person and walk out in four minutes. She said that that would take her nearly six hours here. Why is there that difference? Because they value their clinicians' time there; it is worth something, whereas here it is not. It is terrible. The reason I made that comment was because I think that if we were to ask people to store their advance health directives, it should not be on some IT system that is not going to work when it is needed.¹³⁴

Finding 8

Lawful advance health directives are not stored centrally and are not readily accessible to health professionals when required.

Increased education, promotion and use of advance care planning instruments

- 2.72 There is an obvious lack of knowledge and understanding in the community and amongst health professionals about advance care planning for end of life, particularly in relation to legally binding instruments. It is especially troubling to the committee that since the introduction in 2008 of advance health directives, enduring powers of guardianship and the hierarchy of decision makers, there seems to have been very little progress towards informing and educating health professionals regarding their legal obligations. It is vitally

134 Dr Brien Hennessy, Head of Department, Anaesthesia, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 30 April 2018, p. 12.

important that the WA Government take the lead role in providing and coordinating health promotion and legal education.

- 2.73 It is essential to encourage everyone to make their wishes known for end of life care. Not least because families and loved ones will have the authority and confidence to make treatment decisions that prevent the loss of choice and dignity and provide comfort and quality at the end of life.¹³⁵ Individuals have a right to expect their wishes to be carried out. An effective way to promote this outcome is greater uptake and use of advance care planning instruments, combined with a community and health profession that is well educated in and respectful of such instruments.

The question of dementia

- 2.74 In their submission to the Inquiry, Alzheimer's WA stated that it was important that 'people with dementia have access to end of life planning and advanced care directives as part of their future planning options'.¹³⁶ Equal access to lawful options should occur for all people in all aspects of society.
- 2.75 As at January 2018, there was an estimated 425,416 Australians living with dementia and it is now the second leading cause of death for all Australians. Dementia is responsible for 5.4 per cent of all deaths in males and 10.6 per cent of all deaths in females each year, and is the leading cause of death for females.¹³⁷
- 2.76 According to Dr Craig Sinclair, dementia has overtaken cancer to become the most feared medical condition.¹³⁸ Given the profound effect it has on the sufferer and their family, it is easy to see why. There is no denying that dementia will present increasingly significant challenges to the community in coming decades as Australian society continues to age.

Recommendation 1

The Attorney General, in consultation with the Minister for Health, appoint an expert panel to review the relevant law and health policy and practice – and provide recommendations in relation to the following matters:

- the establishment of a purpose-built central electronic register for advance health directives that is accessible by health professionals 24 hours per day and a

135 Michael A. Ashby, The Futility of Futility: Death Causation is the 'Elephant in the Room' in Discussions about Limitation of Medical Treatment, *Bioethical Inquiry* (2011) 8:151–154 – Citing Detering, K.M., A.D. Hancock, M.C. Reade, and W. Silvester. 2010. The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *British Medical Journal* 340: 1345–1354.

136 Submission No. 639 from Ms Ronda Parker, Alzheimer's WA, 23 October 2017, p. 2.

137 [Dementia Australia – Key facts and statistics](#) – website. Accessed 28 June 2018

138 Dr Craig Sinclair, Research Fellow, UWA, *Transcript of Evidence*, 26 February 2018, p. 11.

mechanism for reporting to Parliament annually the number of advance health directives in Western Australia.

- a requirement that health professionals must search the register for a patient's advance health directives, except in cases of emergency where it is not practicable to do so.
- amendments to the current Western Australian template for advance health directives in order to match, as a minimum, the leading example across Australia, taking into account Finding 7 (see page 48).
- consider how the increasing numbers of people diagnosed with dementia can have their health care wishes, end of life planning decisions and advance health directives acknowledged and implemented once they have lost capacity.

Recommendation 2

The Attorney General, in consultation with WA Health, and relevant health professional bodies, undertake an immediate and extensive program to educate health professionals about:

- the nature, purpose and effect of advance health directives and enduring powers of guardianship;
- how to identify a valid advance health directive; and
- how to identify the lawful substitute treatment decision-maker.

Recommendation 3

The Attorney General, in consultation with WA Health, provide greater education for the wider community about:

- advance health directives;
- enduring guardians; and
- the hierarchy of medical treatment decision-makers.

Recommendation 4

WA Health immediately develop a strategy to ensure that when an AHD is provided by a patient to a hospital, it is easily accessible and stored prominently on the medical record – until there is a central database.

Recommendation 5

The Minister for Health recommends to the Council of Australian Governments an amendment to the Medicare rebate schedule to include preparation of advance health directives with general practitioners.

Recommendation 6

The Minister for Health report to Parliament annually on the number of advance health directives held on hospital medical records in Western Australia.

Chapter 3

Palliative Care

- 3.1 Palliative care is a relatively new field of health care practice, with its origins tracing to the late 1960s when Dame Cicely Saunders established the first modern hospice in the UK. Canadian physician Balfour Mount later coined the term 'palliative care'.¹³⁹
- 3.2 It has long been held that palliative care should neither hasten nor postpone death – indeed, this premise can be found in the World Health Organisation's definition:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*¹⁴⁰

139 Syme, R, *Time to Die*, Melbourne University Press, Melbourne, 2016, p. 81.

140 World Health Organization, *Who Definition of Palliative Care*, 2018, np. Available at: <http://www.who.int/cancer/palliative/definition/en/>. Accessed on 28 May 2018. The website includes a separate but similar definition of palliative care for children.

3.3 Palliative care is intended to assist in relieving symptoms and would usually commence once a patient has accepted that curative treatments are no longer appropriate. According to the University of Western Australia, palliative care is:

[...] an approach to care that involves acceptance that the underlying condition is not responsive to curative treatment (or a decision has been made not to treat with curative intent.)¹⁴¹

3.4 There is some evidence suggesting there is not always a clear delineation made by health professionals, patients and families between curative care and symptom management as the goal of health care.¹⁴²

3.5 The committee received a wide range of evidence relating to palliative care in Western Australia. Broadly speaking, the evidence covered a range of disparate areas, including:

- individual stories about experiences with palliative care – some positive and some negative;
- expert testimony from medical professionals, including palliative care specialists, providing details about the palliative care model, and the clinical outcomes it seeks to achieve;
- evidence from officials within the WA Health about the funding, design and delivery of palliative care in Western Australia, including in rural and remote regions of the state.

3.6 The committee also conducted investigative travel to various locations in Western Australia in order to gain an improved first-hand understanding of palliative care service delivery.

3.7 In the Great Southern, the committee:

- heard from local members of the community about their experience with palliative care;
- visited the hospital and hospice in Albany;
- toured a residential aged-care facility and met with staff and residents;

141 Professor Wendy Erber, Executive Dean Faculty of Health and Medical Sciences, University of Western Australia, Electronic Mail, 16 April 2018, np.

142 Dr Omar Khorshid, President, AMA (WA Branch), *Transcript of Evidence*, 18 May 2018, p. 3; Professor Doug Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Services; WA Country Health Services; Royal Perth Hospital, *Transcript of Evidence*, 9 March 2018, p. 3.

- visited the Denmark Hospital; and
- met with local health professionals and WA Health officials to discuss the practical aspects of the provision of palliative care.

3.8 In the Kimberley, the committee:

- met with the Derby Aboriginal Health Service to discuss the services they provide;
- visited the Derby Regional Hospital;
- visited Mowanjum, a remote Aboriginal community, and met with locals and the community's manager;
- visited the Broome base of the Royal Flying Doctor Service and met with the on-call consultant emergency physician and the on-call clinical nurse specialist;
- met with the Kimberley Palliative Care Service in Broome, which provides specialist palliative care advice to support local doctors and nurses; and
- toured a 55-bed residential care facility, Germanus Kent House, that provides both low and high care options.

3.9 In Perth, the committee:

- visited Silver Chain's Service Centre, each member then accompanied a Silver Chain nurse on a community patient visit;
- toured the Brightwater high-care facility, Ellison House, that provides residential care for people with advanced Huntington's disease;
- met with the palliative specialist team and the clinical team who have oversight of the Metropolitan Palliative Community Care Service;
- toured the inpatient palliative care ward at Bethesda Hospital; and
- accompanied a palliative care specialist during his ward round at Sir Charles Gairdner Hospital.

3.10 Overwhelmingly, those who gave evidence affirmed the importance of palliative care as a means of providing physical, emotional and – where appropriate – spiritual relief for the symptoms experienced by many at the end of their lives.

3.11 All of the evidence received pointed to the ongoing importance of palliative care, and the respect that patients and their families have for those who make palliative care their career and purpose. The committee noted a marked lack of consistency in the use of the

term palliative care by both professionals, patients and families, including the nature and extent of the clinical activities it encompasses and how early it should begin.

- 3.12 The bulk of this chapter outlines how, where and when palliative care is delivered in Western Australia. The committee then examines the evidence as to how service delivery could be improved.

Definitions

- 3.13 Throughout the evidence gathering process, the committee noted the terms ‘end of life care’, ‘palliative care’ and ‘specialist palliative care’ were often used interchangeably. This often made it difficult to gain an accurate understanding of what people meant when they described palliative care. This was further complicated by a general lack of consensus amongst the evidence as to when palliative care should commence and the nature of the clinical services that it should encompass. The committee has found the UWA definition of palliative care (see paragraph 3.3) helpful in its deliberations and notes that definition still leaves plenty of room for competing interpretations.

The changing nature of illness and death means more demand for palliative care

- 3.14 With the advent of the antibiotic era in the 1930s, death rates associated with many infectious diseases fell dramatically.¹⁴³ Over time, death from chronic illnesses became the most common cause of mortality. As a result, for much of the population, death has become predictable. In 2016, there were 14,839 deaths in Western Australia. As many as 70 per cent of those were clinically expected.¹⁴⁴
- 3.15 Almost every person in Western Australia who has an expected death will require some form of end of life care.

The process of dying differs from person to person

- 3.16 Even though death may be increasingly predictable, not all deaths from terminal illness and life-limiting disease are the same. Some patients may experience a period of relatively high function after diagnosis, followed by a short sharp decline and then death – this is common with a cancer diagnosis. Others, typically those with chronic organ failure, lose function more slowly with intermittent periods of serious illness before death. Those who are frail or have a progressive neurodegenerative disease – such as dementia or motor neurone disease – are more likely to have a long period of relatively

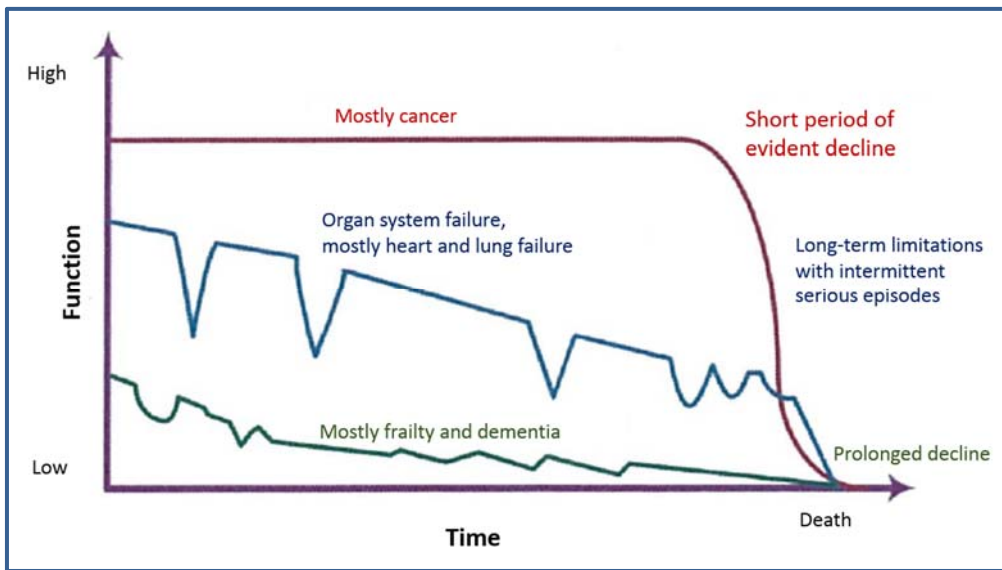
143 W.A. Adedeji, ‘The Treasure Called Antibiotics’, *Annals of Ibadan Postgraduate Medicine*, vol. 14, no. 2, 2016, p.56.

144 Ms Amanda Bolleter, Program Manager, Palliative Care, Department of Health, *Transcript of Evidence*, 13 December 2017 – Session One, p. 2.

poor quality of life before death.¹⁴⁵ Advances in medicine and clinical practice also mean that people with life-limiting illnesses are living longer and often with more than one condition,¹⁴⁶ which could affect their illness trajectory and further complicate their treatment options.

3.17 This differing experience of illness and, ultimately, death is described as an illness trajectory. Figure 3.1 below provides a representation of three typical illness trajectories experienced by those suffering from cancer, organ failure and frailty and dementia.

Figure 3.1 Trajectories of chronic conditions¹⁴⁷



3.18 People’s care needs will change as their illness progresses. WA Health recognises four stages of a patient’s illness or end of life trajectory in its End of life Framework:

Table 3.1 End of Life Trajectory identified by WA Health¹⁴⁸

Stage One	Advancing disease	Known advanced disease with evidence of disease progression and/or symptoms, patient likely to die in the next 6–12 months
Stage Two	Increasing decline	Increasing frailty and symptom burden, not responding to treatment patient likely to die in the next month
Stage Three	Last days of life	Irreversible clinical deterioration, life expectancy one week or less
Stage Four	Death and bereavement	Death of patient

145 Grattan Institute, *Dying Well*, Melbourne, September 2014, p. 6.

146 Submission No. 587 from St John of God Health Care, 23 October 2018, p. 4.

147 Submission No. 616 from Department of Health, 23 October 2018, p.4. [adapted from Lynne and Adamson(2003)]

148 Department of Health, *End of Life Framework*, report prepared by WA Cancer and Palliative Care Network, Department of Health, 2017, p. 4.

3.19 While acknowledging every patient's circumstances are different, the Framework presents a linear outlook for patients at the end-of life. The Palliative Care Outcomes Collaboration (PCOC) – a national program administered by the University of Wollongong that measures and benchmarks patient outcomes in palliative care – identifies five similar phases of a patient's trajectory:

- stable;
- unstable;
- deteriorating;
- terminal; and
- bereavement.¹⁴⁹

3.20 PCOC considers the phases to be non-sequential, noting a patient can move back and forth between the first three phases before finally entering their terminal phase.¹⁵⁰ The terminal phase generally relates to the hours, days, or occasionally, weeks when a patient's death is imminent. It is sometimes referred to as the period when a patient is 'actively dying'.¹⁵¹

The symptoms experienced at end of life

3.21 As patients transition to the terminal phase of illness, their symptoms can become more complex. WA Health has identified five symptoms associated with patient care during the terminal phase:

- laboured breathing (dyspnoea)
- nausea and vomiting
- pain
- respiratory tract secretions
- terminal restlessness/agitation/delirium¹⁵²

149 Palliative Care Outcomes Collaboration, *Clinical Manual*, report prepared by S. Clapham and A. Holloway, Palliative Care Outcomes Collaboration, Health Services Research Institute, University of Wollongong, NSW, April 2018, p. 26.

150 Ibid.

151 Submission No. 587 from St John of God Health Care, 23 October 2018, p. 3.

152 Department of Health, *WA Cancer and Palliative Care Network Evidence based clinical guidelines for adults in the terminal phase 2nd Edition*, report prepared by WA Cancer and Palliative Care Network, Community Medications Project, Department of Health, 2011, np.

Box 3.1 Palliative Care Outcomes Collaboration (PCOC)

PCOC is a national program, federally funded and run out of the University of Wollongong. PCOC uses 'standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care'.¹⁵³ The core aim of the program is to improve overall palliative care practices.¹⁵⁴

Participation in PCOC is voluntary and there are currently 14 participating specialist palliative care service providers from Western Australia:¹⁵⁵

- Albany Community Hospice
- Bethesda Hospital
- Metropolitan Palliative Care Consultancy Service - North Team
- Metropolitan Palliative Care Consultancy Service - South Team
- Royal Perth Hospital
- Royal Perth Hospital - Nurse Practitioners
- Kalamunda Hospital
- Greater Southern Regional Palliative Care Service
- Silver Chain Hospice Care Service - East Team
- Silver Chain Hospice Care Service - North Team
- Silver Chain Hospice Care Service - South Team
- St John of God - Murdoch Community Hospice
- St John of God Bunbury Hospital
- St John of God Geraldton Hospital

While many health professionals regard PCOC data as useful, including WA Health, the committee heard a different view from the WA Palliative Medicine Specialist Group. They claim the 'tools that [PCOC] use are open to a lot of debate as to whether they are actually valid and applicable across all palliative care services'.¹⁵⁶

The committee appreciates PCOC data can be useful and sees the benefits in benchmarking performance for the sector, but the evidence suggests the data is open to flexible interpretation. The committee is concerned PCOC data is being manipulated, or used selectively, to support specific claims in the end of life choices debate.

3.22 Fatigue is also a common symptom experienced by patients at the end of life. In fact, according to patient self-assessments provided to PCOC, fatigue is the most common distress inducing symptom.¹⁵⁷

3.23 These symptoms are not limited to patients in the terminal phase, although they are usually more complex as death approaches. Throughout their illness trajectory, patients may experience all, none or a combination of the symptoms, the level of intensity may

153 Patient Outcomes in Palliative Care, Western Australia July-December 2017, March 2018.

154 Patient Outcomes in Palliative Care, Western Australia July-December 2017, March 2018.

155 PCOC, *List of services included*, July to December 2018, np. Available at: <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow244955.pdf>. Accessed on 7 June 2018 and Email from Amanda Bolleter, 12 June 18.

156 Dr Anil Tandon, WA Palliative Medicine Specialist Group, *Transcript of Evidence*, p.4.

157 Professor Kathy Eagar, Palliative Care Outcomes Collaboration, Electronic Mail, 13 June 2018, np.

vary and the symptoms may fluctuate over time. The level of suffering and distress a patient experiences with these symptoms is measured subjectively and is an important guiding factor for health professionals when considering treatments.¹⁵⁸

3.24 When treating symptoms, health professionals must also consider the side-effect profiles of prescribed medications; whether the patient is taking other medications; the dosages of those medications and their effectiveness. Treating patients at the end of their lives can be very complex because of the:

- combination and severity of symptoms;
- co-morbidity of conditions;
- effectiveness, dosage and side-effects of medication; and
- the subjective nature of patient measures of their experiences.

Specialist palliative care

3.25 When symptom management becomes complex the patient may be referred to a specialist palliative medical service. WA Health defines specialist palliative care as care:

*undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. The role of specialist palliative care services includes providing consultation services to support, advise, educate and mentor specialist and non-specialist teams to provide end of life and palliative care and/ or to provide direct care to people with complex palliative care needs.*¹⁵⁹

3.26 There are 27 palliative care medical specialists in Western Australia, with approximately 20 currently practicing in palliative care.¹⁶⁰

Palliative care is more than care during the terminal phase of an illness

3.27 Traditionally, palliative care was limited to cancer patients, or patients with similar illness trajectories, who were in the final stages of their disease. Since the 1960s, however, palliative care has continued to evolve and, according to the WA Palliative Medical Specialist Group, referral to palliative care no longer means an end to active

158 Dr Anil Tandon, Chairman and Dr Mary McNulty, Member, WA Palliative Medicine Specialist Group, Response to questions on notice, 29 April 2018, np.

159 Department of Health, *WA End of life and Palliative Care Strategy 2018-2028*, WA Cancer and Palliative Care Network, Government of Western Australia, 2018, p. 3.

160 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, p. 10.

treatment.¹⁶¹ In fact, Palliative Care WA (**PCWA**) believes ‘palliative care should be available to anyone with life-limiting disease whose quality of life is being impacted by their symptoms’.¹⁶² The committee also received evidence from Bethesda Health Care suggesting end of life care should also be accessible to ‘those who become increasingly frail, even without a life-threatening illness’.¹⁶³

3.28 Unfortunately, there remains a misconception that palliative care is just for the final days or weeks of life or only for people with cancer.¹⁶⁴ Many patients and their families are reluctant to involve palliative care in their treatment out of the mistaken fear and misunderstanding of what it represents.¹⁶⁵ To abate these fears and misconceptions PCWA, in its evidence to the inquiry, highlighted that ‘palliative care respects the informed patient choice with an emphasis on very detailed communication between the palliative care professional and the person’.¹⁶⁶

3.29 According to the Australian and New Zealand Society of Palliative Medicine, palliative care should offer ‘a support system to help patients live as actively as possible until death’.¹⁶⁷ Furthermore, palliative care is:

*applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*¹⁶⁸

3.30 Palliative care is therefore about improving quality of life through medical treatment for those facing life limiting illnesses and it may commence significantly earlier than the terminal phase of an illness.

3.31 It is clear that the decision to commence palliative care is a difficult one for patients and their families. The decision involves an acknowledgement that the patient cannot be cured of the illness or disease that is afflicting them. Early referral to specialist palliative care may improve quality of life, but ultimately, and consistent with the principle of

161 Submission No. 630 from WA Palliative Medical Specialist Group, 23 October 2018, np.

162 Ms Cait Calcutt, Project Officer, Palliative Care WA, Response to questions on notice, 19 December 2017, p. 1.

163 Lunney, Lynn & Foley (2003) ‘Patterns of functional decline at the end of life’ – Journal American Medical Association – 289(18) in Ms Yasmin Naglazas, Chief Executive Officer, Bethesda Health Care, Letter, 17 April 2018, p. 3.

164 Ms Cait Calcutt, Project Officer, Palliative Care WA, Response to questions on notice, 19 December 2017, p 3.

165 Submission No. 611 from Silver Chain Group, 23 October 2017, p. 6.

166 Dr Elissa Campbell, President, Palliative Care WA, *Transcript of Evidence*, 14 December 2017, p. 9.

167 Submission No. 674 from Australian and New Zealand Society of Palliative Medicine, 1 November 2018, p.4 of *Position Statement*.

168 Submission No. 674 from Australian and New Zealand Society of Palliative Medicine, 1 November 2018, p.4 of *Position Statement*.

patient autonomy, specialist palliative care should commence only when the patient is ready for it to commence.

Where do people receive palliative care treatment?

- 3.32 Consistent with access to medical care across Western Australia generally, how patients access palliative care will vary depending upon their socio-economic status and whether they are located in the regions or in the Perth metropolitan area.
- 3.33 State-wide leadership in the provision of palliative care is provided through the WA Cancer and Palliative Care Network (**WACPCN**). Established in 2006, the WACPCN aims to improve palliative care practice by coordinating services, providing advice, setting standards and funding programs so patients across the state have access to quality and timely palliative care.¹⁶⁹
- 3.34 WA Health funds palliative care in Western Australia on an inpatient, community care or consultancy basis.¹⁷⁰ Palliative care services are focused around “episodes of care”, which are periods of contact between a patient and a palliative care service occurring in a single setting. An episode of care ends when the setting of care changes. Typically, a patient receiving palliative care is likely to have more than one episode of care.¹⁷¹ For example, a new episode of care commences on admission to hospital and would come to an end on discharge.
- 3.35 Specialist palliative care is currently provided across 28 government and non-government services through inpatient, community and consultancy models:¹⁷²

“Inpatient” - episodes of care are those for which the intent of the admission was for the patient to be in hospital overnight. This includes those patients who were admitted and died on the day of their admission.

“Community care” - episodes where the patient received palliative care either in their home or a residential aged care facility.

“Consultancy” – Palliative care consultancy services are teams of specialist doctors and nurses who provide palliative care advice to assist treating teams across all areas of the hospital. Palliative care

169 Submission No. 616 from Department of Health, 23 October 2018, p. 3.

170 Dr Russell Weisz, Director General, Department of Health, Response to questions on notice, 9 March 2018.

171 Palliative Care Outcomes Collaboration, *Clinical Manual*, report prepared by S. Clapham and A. Holloway, Palliative Care Outcomes Collaboration, Health Services Research Institute, University of Wollongong, NSW, April 2018, p. 12

172 Dr David Russell-Weisz, Director General, Department of Health, Response to Questions on Notice, 16 May 2018, np.

consultancy advice may include: pain and symptom management, including emotional and spiritual distress; assistance with decision-making and family/patient communication; discharge planning; linking in with community palliative care services and/or possible admission to the hospital's palliative care unit.

3.36 WA Health provided a list of the 28 services currently accredited to provide specialist palliative care:¹⁷³

- Glengarry Hospital (Private)
- Silver Chain Hospice Care Service
- Kalamunda Hospital
- St John of God Subiaco Hospital (Private)
- WA Paediatric Care Service
- Royal Perth Hospital
- Hollywood Hospital (Private)
- Sir Charles Gardiner Hospital
- Bethesda Hospital (Public/Private)
- Metropolitan Palliative Care Consultancy Service (MPaCCS)
- St John of God Murdoch (Private)
- St John of God Community Hospice (Public/Private)
- Fiona Stanley Hospital
- Rockingham General Hospital
- Kimberley Regional Palliative Care Service – Broome
- Pilbara Regional Palliative Care Service – Port Hedland
- St John of God Geraldton Hospital (Public/Private)
- Midwest Regional Palliative Care Service – Geraldton
- Geraldton Community Service
- Goldfields Regional Palliative Care Service - Kalgoorlie
- Wheatbelt Regional Palliative Care Service - Northam
- Bunbury Hospital – Bunbury
- St John of God Bunbury Hospital (Public/Private)
- South West Regional Palliative Care Service – Bunbury
- Busselton Hospital – Busselton
- Albany Community Hospice (Public/Private)
- Albany Hospital - Albany
- Great Southern Regional Palliative Care Service - Albany

3.37 The models of care available at each of these facilities differ and it would not be correct to suggest the level of palliative care provided is equal across them all. For example, four of the WA Country Health Service regions only have access to consultative specialist palliative care. Without access to inpatient or community specialist palliative care patients do not have the same level of choice as patients in the other parts of the state.

3.38 Western Australia is unique in that the majority (55 per cent) of palliative care-related hospitalisations occur in private hospitals (both metropolitan and regional). This is

173 Dr David Russell-Weisz, Director General, Department of Health, Response to questions on notice, 21 June 2018, np. Note: Joondalup Health Campus was included in the list provided by the Department, but as it is still in development, it was not included in the list of current facilities.

attributable to WA Health's practice of establishing public contracts with private facilities for the provision of inpatient palliative care beds.¹⁷⁴

- 3.39 In addition to the services provided by WA Health, there are other avenues for people to seek advice and support when they or their loved ones are facing a life-limiting illness. PCWA hosts a 1-300 number, initially established for administrative purposes; this number has become a *de facto* support-line providing information on a wide variety of palliative care matters.¹⁷⁵ People can also access support and advice from disease-specific groups like the Motor Neurone Disease Association of WA, Huntington's WA, and Multiple Sclerosis WA.

Palliative care in Metropolitan Perth

- 3.40 WA Health provides patients with access to specialist palliative care through dedicated hospital units, hospices, general hospital wards, and in the community through Silver Chain Hospice Care and the Metropolitan Palliative Care Consultancy Service.

Inpatient

- 3.41 Access to inpatient specialist palliative care is limited in Perth. There are only four dedicated specialist palliative care units – Bethesda Hospital, Kalamunda Hospital and both the St John of God run Murdoch Hospital and separate Community Hospice.¹⁷⁶ Some hospitals, including Sir Charles Gairdner, have an on-site consultative specialist palliative care team, who can provide consultancy and direct care for patients admitted in any ward across the hospital. Joondalup Health Campus is currently in the early stages of establishing a palliative care consultancy service.¹⁷⁷
- 3.42 On-site specialist palliative care is currently not available at Osborne Park Hospital, Midland Health Campus (public and private), Armadale Hospital, Fremantle Hospital, Peel Health Campus and Joondalup Health Campus¹⁷⁸ (in development). If patients in these hospitals are at end of life, they may receive palliative care from their treating teams. If their symptoms become complex, access to specialist palliative care is available through a 24-hour telephone consultancy service. In certain cases, when the patient's needs are particularly complex they may require a transfer from their place of care to a dedicated specialist palliative care unit.¹⁷⁹

174 Submission No. 587 from St John of God Healthcare, 23 October 2017, p. 9.

175 Ms Lana Glogowski, Executive Officer, Palliative Care WA, Letter, 18 May 2018.

176 Ms Amanda Bolleter, Program Manager - WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2017 – Session one, p. 3.

177 Ms Amanda Bolleter, Program Manager - WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 18 May 2018, p. 34.

178 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, p. 2.

179 Ms Amanda Bolleter, Program Manager – WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 18 May 2018, p. 12.

Finding 9

Access to inpatient specialist palliative care in Perth is limited.

Finding 10

Apart from a small number of private beds at Glenngary Hospital, there is no inpatient specialist palliative care hospice in the northern suburbs of Perth.

Recommendation 7

The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.

Community Care – Silver Chain Hospice Care

- 3.43 Another unique feature of Western Australia’s specialist palliative care delivery is the contract with Silver Chain Hospice Care (Silver Chain) to provide high-quality community care in metropolitan Perth enabling patients to be cared for in the place of their choice. Silver Chain is a hospital-level accredited service funded by the State Government to provide community-based specialist palliative care at no out-of-pocket cost to the patient.¹⁸⁰
- 3.44 Access to the service requires a referral from a medical practitioner, either a GP, a hospital doctor or specialist, or a nurse practitioner.¹⁸¹ Every referred patient is assessed within 24 hours and, despite being formally funded for approximately 420 people, Silver Chain currently provides services to over 650 patients.¹⁸² In 2016–17, Silver Chain provided care to 5,170 people with a life-limiting illness; 2,163 Silver Chain patients died during this period of whom 74.8 per cent died in their own home.¹⁸³
- 3.45 Silver Chain employs a multidisciplinary team of specialist nurses, medical consultants, GPs, allied health professionals, social workers, counsellors and chaplains, care aides and volunteers to provide a range of palliative care needs in the community.¹⁸⁴ Specialist palliative care physicians are available to assist with the most complex palliative care needs, but if the complexity of the care requires a hospital admission, Silver Chain will make the necessary referral with permission from the patient.¹⁸⁵

180 Ms Amanda Bolleter, Program Manager - WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2017 – Session One, p. 6.

181 Mr Mark Cockayne, General Manager, Health Care WA, Silver Chain Group, *Transcript of Evidence*, 14 December 2017, p. 8.

182 Dr Mary McNulty, Palliative Care Medical Specialist, Silver Chain, *Transcript of Evidence*, 27 February 2018, p. 16.

183 Ms Amanda Bolleter, Program Manager - WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2017 – session one, p. 6.

184 Submission No. 611 from Silver Chain, 23 October 2018, p. 1.

185 Professor Evans, Chief Advisor – Public Policy, Silver Chain Group, *Transcript of Evidence*, 14 December 2018, p. 12.

Finding 11

Silver Chain is providing community palliative care to more patients than for which it is funded.

Recommendation 8

The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.

Community Care – Metropolitan Palliative Care Consultancy Service

- 3.46 The Metropolitan Palliative Care Consultancy Service (**MPaCCS**) is a mobile specialist palliative care team, funded by WA Health and administered by Bethesda Health Care, which aims to build the capacity of residential, mental health, disability care and correctional facilities to care for residents at the end of life.¹⁸⁶
- 3.47 MPaCCS admits more than 1,100 patients and visits over 200 care facilities of different types annually; access to the service is via referral from the care facility.¹⁸⁷

Community Care – Residential aged-care

- 3.48 Improvements in and increased access to good quality in-home care services has enabled people to remain at home for much longer than previously expected. Consequently, many residents are entering care with greater levels of frailty and several comorbidities. Despite these increasing care requirements, few WA aged-care providers employ or formally contract specialist clinicians to provide care for these complex cases.¹⁸⁸
- 3.49 Without appropriate or sufficient resources, staff at aged-care facilities are likely to refer patients to acute settings rather than treating the patients themselves. This usually involves an ambulance transfer after hours in response to a perceived crisis.¹⁸⁹ This is far from ideal. Wherever possible, according to National Palliative Care guidelines, residents should remain in their familiar environment and if referral to a specialist palliative care service is required, it should occur, not in a time of crisis, but following discussions between the patient and the treating team.¹⁹⁰

186 Submission No. 616 from Department of Health, 23 October 2018, p.7.

187 Ms Yasmin Naglazas, Chief Executive Officer, Bethesda Health Care, Letter, 17 April 2018, p. 6.

188 Submission No. 640 from Braemar Presbyterian Care, 23 October 2018, np.

189 The National Palliative Care Program, *Guidelines for a Palliative Approach in Residential Aged Care*, report prepared by Edith Cowan University, National Health and Medical Research Council, Australian Government, May 2006, p.40.

190 The National Palliative Care Program, *Guidelines for a Palliative Approach in Residential Aged Care*, report prepared by Edith Cowan University, National Health and Medical Research Council, Australian Government, May 2006, p.40.

- 3.50 The MPaCCS program aims to address many of these issues by providing additional support to residential aged-care facilities to build the capacity of staff to manage the palliative care needs of residents and avoid unnecessary hospital transfers.¹⁹¹
- 3.51 WA Health also provides the Residential Care Line (**RCL**), an interface between residential aged-care facilities and the public health system. The RCL provides specialist clinical support to aged-care facilities relevant to a specific patient's needs. This service is not limited to palliative care.¹⁹²
- 3.52 In 2016–17, MPaCCS provided over 925 episodes of care and the RCL delivered over 12,000 service events to residential aged-care facilities.¹⁹³ Together MPaCCS and the RCL provide support to patients in residential aged-care enabling them to receive care in the location of their choosing.

Palliative care in Rural and Regional WA

- 3.53 WACPCN established the Rural Palliative Care Model in 2008 in order to:
- provide services for patients with life limiting illness, regardless of diagnosis;
 - address the palliative care needs of patients and their families during their illness trajectory;
 - deliver care in any setting – hospital, palliative care units, residential care or in-home; and
 - identify partnerships between specialist palliative care services and primary care providers.¹⁹⁴
- 3.54 As in most health care settings, but particularly in the regions, primary care providers assume a critical role in caring for people with life limiting illnesses. The Rural Palliative Care Model promotes partnerships between these primary care providers and specialist palliative care teams or services to 'provide the best possible care' according to the 'needs of each individual'.¹⁹⁵

191 Mr Luke Hayes, Acting Manager, Purchasing and Contracting, Department of Health, *Transcript of Evidence*, 13 December 2017 – Session One, p. 4.

192 Mr Luke Hayes, Acting Manager, Purchasing and Contracting, Department of Health, *Transcript of Evidence*, 13 December 2017 – Session One, p. 4.

193 Mr Luke Hayes, Acting Manager, Purchasing and Contracting, Department of Health, *Transcript of Evidence*, 13 December 2017 – Session One, pp. 4 & 8.

194 Department of Health Western Australia, *Rural Palliative Care Model*, report prepared by WA Cancer and Palliative Care Network, Department of Health, Western Australia, 2008, p. 18.

195 Department of Health Western Australia, *Rural Palliative Care Model*, report prepared by WA Cancer and Palliative Care Network, Department of Health, Western Australia, 2008, p. 23.

- 3.55 The Rural Palliative Care Program, funded by WA Health, works across all rural regions and aims to provide coordination of palliative care services via capacity building, direct care and consultative services. As at October 2017, the Program employed 19.1 full-time equivalent (**FTE**) health professionals across the rural regions who provide direct care, but also had a significant role in providing education and training to health, community and aged-care professionals in these areas.¹⁹⁶
- 3.56 Across regional and rural Western Australia there is also reliance on Telehealth to provide acute healthcare services including palliative care. In this context, Telehealth enables outpatient consultations between metropolitan-based specialists and regional-based patients via videoconferencing.¹⁹⁷ At this stage, these Telehealth services are only available during business hours.¹⁹⁸
- 3.57 While general practitioners and nurses provide the majority of palliative care in rural and regional WA, once a patient's condition becomes too complex, specialist palliative care may be required to provide extra symptom management.¹⁹⁹
- 3.58 Each of the seven WA Country Health Services' regions – Goldfields, Great Southern, Kimberley, Midwest, Pilbara, South West and Wheatbelt – has a Specialist Palliative Care Team comprising a nurse manager, a senior social worker, a clinical nurse and an administrative assistant. These teams work with local GPs and can link with a palliative care specialist in Perth (via a 24-hour phone service) or a visiting specialist palliative care consultant.²⁰⁰
- 3.59 Access to specialist palliative care requires a referral from the patient's GP. The referral goes to the regional specialist palliative care team, the patient is then triaged and, if appropriate, the specialist team coordinates and monitors their treatment.²⁰¹ The GP continues to provide the care but with the specialist palliative support of the regional team.
- 3.60 When the specialist team becomes involved, it does not necessarily require a patient transfer. Where possible care will continue to be provided at a location of the patient's

196 Submission No. 616 from Department of Health, 23 October 2017, p. 5.

197 Government of Western Australia, WA Country Health Service, *Telehealth*, 2011, np. Available at: <http://www.wacountry.health.wa.gov.au/index.php?id=telehealth>. Accessed on 20 July 2018.

198 Mrs Marion Anne Slattery, Director of Nursing and Midwifery, WA Country Health Service, *Transcript of Evidence*, 18 May 2018, p. 14.

199 Mrs Marie Baxter, Executive Director of Nursing and Midwifery, WA Country Health Service, *Transcript of Evidence*, 18 May 2018, p. 6.

200 Mrs Marion Anne Slattery, Director of Nursing and Midwifery, WA Country Health Service, *Transcript of Evidence*, 18 May 2018, p. 5.

201 Mrs Marion Anne Slattery, Director of Nursing and Midwifery, WA Country Health Service, *Transcript of Evidence*, 18 May 2018, p. 31.

choosing – at home, a residential aged-care facility or at the local hospital.²⁰² Unfortunately, there is limited infrastructure in rural and remote communities to support patients who wish to die at home.²⁰³

- 3.61 According to WA Health, all regional hospitals can accept patients with specialist palliative care needs. Some regional resource centres have specific palliative care beds, but others can “flex” a bed to a palliative care bed if required.²⁰⁴

Access to palliative care is not equal across regional areas

- 3.62 To gain an understanding of the inequity with access to palliative care across regional Western Australia the committee undertook investigative travel to both the Kimberley and the Great Southern regions. WA Health confirmed these sites as useful to provide insights into the difference in palliative care provision throughout the state.

Great Southern – Brief summary of visit

- 3.63 The committee was advised that Albany, and by extension the Great Southern, has the strongest regional specialist palliative care provision in the state.²⁰⁵ While in the region, the committee visited the Albany Hospice, Albany Health Campus, a residential aged-care facility, and the Denmark Health Facilities. The committee also held a series of hearings and invited members from the local community to give evidence.
- 3.64 The Albany Health Campus provides inpatient specialist palliative care and consultative palliative care for the whole of the Great Southern region under the clinical lead of Professor Kirsten Auret. Professor Auret also has oversight of the Albany Hospice – an eight-bed, not-for-profit, community facility.
- 3.65 While provision of specialist palliative care services in the Great Southern is well regarded, the level of hands-on care drops away as the distance from Albany increases. Within Albany, patients have access to 24-hour palliative care services. Denmark Hospital offers 8-hours per day Monday to Friday, with a specialist palliative care registered nurse on-site two days per week. In Mt Barker, dedicated palliative care services are only available 7-hours per week.

202 Mrs Marion Anne Slattery, Director of Nursing and Midwifery, WA Country Health Service, *Transcript of Evidence*, 13 December 2017 – Session one, p. 7.

203 Submission No. 684 from WA Country Health Services, 5 December 2017, p. 3.

204 Mrs Marie Baxter, Executive Director of Nursing and Midwifery, WA Country Health Service, *Transcript of Evidence*, 18 May 2018, p. 3.

205 Telephone conversation between committee Principal Research Officer and Ms Amanda Bolleter, Program Manager, Palliative Care, Department of Health, 20 December 2017.

3.66 At the public hearings the witnesses told personal accounts of their individual experiences with caring for family members at the end of life, many of the witnesses believe palliative care provision is adequate in Albany most of the time.²⁰⁶

Kimberley – Brief summary of visit

3.67 The model for palliative care service delivery in the Kimberley is very different to that in the Great Southern region. The vast geographic area and dispersed population adds to the challenge of providing effective palliative care in the Kimberley.

3.68 While in the region, the committee visited the Derby Aboriginal Health Service, Derby Regional Hospital, the Kimberley Palliative Care Service, Germanus Kent House (provider of high-care residential-care), and the Broome Base of the Royal Flying Doctor Service (RFDS).

3.69 Access to palliative care in Derby is very limited and staff from the Derby Aboriginal Health Service (DAHS) identified several gaps for consideration by the committee:

- The need for more staff on the ground to provide care for local communities;
- Problems with the coordination of care;
- The lack of opportunity for people to die at home; and
- Issues with securing ongoing funding.

3.70 DAHS also indicated the decision to transfer some services to Broome has not been successful, largely due to the lack of connectedness to the Derby community. Health providers in Broome do not have a solid understanding of the needs of the Derby community including their wishes about care.

3.71 The committee was very impressed with the staff and facilities at the RFDS base in Broome. The RFDS provides a wide-range of health services including care for people at end of life who need transportation between hospital and home, but they have a limited role in the provision of palliative care.

3.72 The committee also visited Germanus Kent House, a 55-bed aged care facility in Broome. Twelve of the beds are designated for patients with dementia and the facility provides palliative care with assistance from the Kimberley Palliative Care Service.

206 See for example Ms Jenny Rickerby, individual citizen, *Transcript of Evidence*, 7 March 2018, pp. 3-4 and Mrs Montefiore, individual citizen, *Transcript of Evidence*, 7 March 2018, p. 2.

In-home care is not always preferred

- 3.73 Many submitters and witnesses told the committee that 70 per cent of people wish to die at home. This statistic originated with a 2006 South Australian study that asked individuals over the age of 15 where they would prefer to die 'if they were dying of a terminal illness'.²⁰⁷
- 3.74 It may well hold true for healthy people or even people in the early stages of a chronic or terminal illness, but as their health deteriorates many people may, and do, change their mind. In fact, the Centre for Independent Studies identified research that found the preference for home care reduced as death became imminent, with carers' preference for home care reducing from 92 per cent to 42 per cent, and patients' preference shifting from 90 per cent to 50 percent in the last week of life.²⁰⁸
- 3.75 WA Health's three models of specialist palliative care – inpatient, community and consultative – each have their merits and theoretically provide individuals with options when deciding their preferred place of care. It can be assumed the level of hands-on specialist palliative care will always be greatest in a dedicated inpatient palliative care unit or hospice. However, many patients may not want or require that level of care; their symptoms may be adequately managed in a community/home setting.
- 3.76 The complexity of many palliative patients' illness trajectories means it is rarely an either-or situation. Many people will receive care in a hospital setting, in addition to care they may receive in the community with support from Silver Chain or MPaCCS. The settings of care are not mutually exclusive and effective palliative care will rely upon coherent integration between in-home care providers, treating doctors, hospitals and specialist palliative care providers. WA Health needs to ensure people can transition seamlessly between care settings when the want or need arises.
- 3.77 People's experiences at end of life will vary. One person may wish to receive active treatment in a dedicated palliative care unit until they die; another may elect to stay at home even if their symptoms could be better managed in hospital; others may move between inpatient and community settings. It is important to understand that this is a matter of individual choice that must be respected and supported.

Limitations of community palliative care

- 3.78 The committee received evidence that there are difficulties with continuity of care under the existing palliative care models.²⁰⁹ Patients receiving care at home may require more

207 Dr Jessica Borbasi, 'Life Before Death: Improving Palliative Care for Older Australians', *The Centre for Independent Studies*, Report No. 34, November 2017, p. 14.

208 Dr Jessica Borbasi, 'Life Before Death: Improving Palliative Care for Older Australians', *The Centre for Independent Studies*, Report No. 34, November 2017, p. 14.

209 Department of Health, *The End of Life Framework*, report prepared by WA Cancer and Palliative Care Network, Government of Western Australia, 2017, p. 8.

complex care than they are capable of receiving. Transfer of care is not always seamless or even possible.

3.79 Individuals have a choice to be cared for in their preferred setting, but there are limitations to what can be provided in the community as indicated by Marcelle Van Soest:

*Silver Chain was wonderful but upping the morphine did no good. It did no good for the pain; it was useless. They put a push-pump in him with the morphine—in a person with no fat under his skin, it was hideously cruel.*²¹⁰

3.80 The committee is concerned that the emphasis on community care is coming at the expense of optimal symptom relief and may also be placing carers and family under significant pressure in dealing with very distressing and unmanageable situations. Patients should be afforded autonomy to make their own health care decisions; this includes deciding the best setting of care.

Recommendation 9

WA Health should conduct an independent review, from a patient’s perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care (see Finding 18).

Barriers to effective end of life care

3.81 Australia ranks second internationally for the quality of its palliative care²¹¹ and the WACPCN is making progress to ensure Western Australians have access to the end of life treatments of their choosing.

3.82 However, the committee heard considerable evidence to suggest a lack of understanding in the community and even in the medical profession that is creating a barrier between patients and the palliative care that is available to them. The following factors contribute to a general confusion and apprehension towards palliative care:

- avoiding discussions about death;
- not fully understanding what palliative care means and recognising when it should begin; and
- not knowing how to access and navigate palliative care services.

210 Ms Marcelle Van Soest, Private Citizen, *Transcript of Evidence*, 1 May 2018, p.1.

211 *The 2015 Quality of Death Index Ranking palliative care across the world*, report prepared by The Economist Intelligence Unit, Commissioned by Lien Foundation, 2015.

We should all talk about death

- 3.83 Inherently, as a society, we do not like to talk about death – this includes the medical profession. Perhaps it is because doctors are trained as “healers” so death can be seen as a “failure” or because patients are not ready to accept their own demise so doctors “do everything” to prolong their life.
- 3.84 Either way, death is inevitable and if we want to increase the likelihood of dying a “good death” people – patients, families, carers and health professionals – must talk about it.
- 3.85 According to senior palliative care specialist, Professor Doug Bridge:

When both the doctor and the patient avoid the reality of death, the result can be a prolonged, distressing, agitated, fearful, lonely death, on a hospital bed, entangled in tubes, instead of in the embrace of a loving family.²¹²

- 3.86 The committee consistently heard from health professionals that access to specialist palliative care in the early stages of a diagnosis might improve ‘quality of life, mood, coping ability, symptom management and death in the preferred place of choice’.²¹³ However, this would require ‘personal, clinical and societal recognition of death and the process of dying’.²¹⁴

Finding 12

Access to specialist palliative care in the early stages of a diagnosis might improve remaining quality of life, mood, resilience, symptom management and allow for death in the patient’s preferred location. These benefits would be more readily available to patients if difficult discussions about death and dying took place earlier.

More patients could benefit from referral to palliative care

- 3.87 As indicated previously (see paragraph 3.28 above) there continues to be a misconception that palliative care is only for cancer patients in the last days or weeks of life.
- 3.88 A comprehensive study using data from 2009 and 2010 starkly illustrates that palliative care services remain overwhelmingly accessed by patients suffering from cancer. The study compared the number of deaths in Western Australia from diseases considered amenable for palliative care (12,817) with the number of patients who accessed

212 Professor Doug Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Services; WA Country Health Services; Royal Perth Hospital, *Transcript of Evidence*, 9 March 2018, p. 2.

213 Submission No. 685 from Australian Medical Association (WA), 15 February 2018, p. 3.

214 Michael Ashby, ‘How we die: A view from palliative care’, *QUT Law Review* Vol. 16, Issue 1, p. 7.

specialist palliative care in the last year of life (5,932).²¹⁵ The research found three things of particular interest to the committee:

- only 46.3 per cent of patients with diseases amenable to specialist palliative care actually accessed the service in their last year of life;
- only 14.2 per cent of the patients who accessed specialist palliative care died from non-cancer related diseases despite comprising 40 per cent of the deaths studied; and
- cancer patients were over-represented amongst the cohort receiving palliative care.²¹⁶

3.89 The study reveals that more can be done to promote understanding of palliative care in the community and with health professionals. It also reveals that health professionals may not be actively referring non-cancer patients into palliative care.

Finding 13

More can be done to promote understanding of palliative care in the community and with health professionals to ensure that more non-cancer patients who could benefit from palliative care are receiving it.

3.90 According to the WA branch of the Australian Medical Association (**AMAWA**), in '2015/16 there were 2,811 deaths in Western Australian from conditions considered appropriate for palliative care'.²¹⁷

3.91 The AMAWA figure is lower than that identified in the study referred to above at para 3.88. The same study found that in 2009 and 2010, 53.7 per cent of deaths in WA were from conditions amenable to receiving palliative care.²¹⁸ It is also noteworthy that cancer accounts for one-third of all deaths in Western Australia each year.

3.92 The committee notes the discrepancy in the number of deaths in Western Australia from conditions considered amenable to receiving palliative care reported by WA Health and the AMAWA.

3.93 The committee's view is that there is a considerable number of people with conditions considered amenable to receiving palliative care but are not accessing it.

215 Rosenwax et al, 'A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?' *BMC Palliative Care*, 2016.

216 Rosenwax et al, 'A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?' *BMC Palliative Care*, 2016, p. 5.

217 Submission No. 685 from Australian Medical Association (WA), 15 February 2018, p. 2.

218 Rosenwax et al, 'A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on?' *BMC Palliative Care*, 2016, p. 3.

- 3.94 The committee was told of a simple, but perhaps rough guide for determining if a patient was suited for palliative care – the “surprise test”:

... primary care clinicians are asked the question: ‘would you be surprised if the patient were to die in the next year?’ If the answer is ‘no’, a shift of care to a palliative approach is implemented.²¹⁹

Finding 14

There is inconsistency in the data regarding the number of patients with conditions amenable to receiving palliative care. This is perhaps reflective of the uncertainty regarding which diseases or conditions are appropriate for palliative care.

- 3.95 The committee received evidence from a witness whose experience with Western Australia’s health care system demonstrated the difficulty of gaining access to palliative care services (see Case Study 3.1).

Case study 3.1 ²²⁰

Ms Cait Calcutt told the committee of her late partner who died in 2014. Prior to 2014 Ms Calcutt admits little understanding of palliative care, although she had been caring for her partner ‘who was diagnosed with three chronic life-limiting diseases in his early 40s [...] He had survived two cancer diagnoses in eight years and he was living with the disabling consequences of surgeries, treatments, opioids, medications and dealing with chronic pain’.

Her partner’s GP was experienced in caring for patients with chronic disease but the complexity of his many illnesses also meant having to coordinate fragmented care, which included ‘surgeons, endocrinologists, gastroenterologists, neurologists, pain specialists, psychiatrists, psychologists and pharmacists’. At the beginning of 2014, her partner’s health deteriorated rapidly and, while in hospital, he was told his carcinoma had returned and that he had 12, but probably six, months to live. He was not referred to the hospital palliative care team or to a palliative care service and was discharged from the hospital.

Shortly after his discharge, he suffered another health crisis that resulted in an emergency hospital admission. It was only at this point that the palliative care team became involved, ‘not at the request of the doctor but at the urging advocacy of a family member, who was a health professional and knew the hospital and its systems’.

According to Ms Calcutt, ‘the introduction of the palliative care team to [her] partner’s care was immediately transformative’ for them both. He was transferred to in-hospital hospice care, where ‘the treatment was focused on the whole person for the first time and there was clear, honest and caring communication with my partner and our family’.

219 Michael Ashby, ‘How we die: A view from palliative care’, *QUT Law Review* Vol. 16, Issue 1, p. 9.

220 Ms Cait Calcutt, Personal and Project Officer, Palliative Care WA, *Transcript of Evidence*, 9 April 2018, p. 2.

3.96 Despite previous experiences with cancer and multiple life-limiting conditions, the health professionals had never had an honest conversation about the dying process with Ms Calcutt or her partner. The referral to palliative care services only came at the insistence of their family friend. Anecdotally this demonstrates the committee's concern that health professionals, even specialists, may not recognise the need for palliative care or may not know how to refer their patients into the service.

Recommendation 10

WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services with the aim of making those services available to more Western Australians.

Health Promotion – a necessity

3.97 Ms Calcutt's experience demonstrates the need for coordinated health promotion. Dr Alison Parr, the Director of Medical Services for St John of God Health Care believes there is a:

*need for public and professional education in relation to the benefits of palliative care, including early referral and the need to raise awareness of referral pathways; the need to build capacity for provision of appropriate care; the need to respect the choice of individuals and to promote advance care planning.*²²¹

3.98 WA Health partially funds the Palliative and Supportive Care Education services. This service, although based with the Cancer Council of WA, provides education across all diagnoses.

3.99 PCWA runs an independent information line and provided a copy of the phone log to the committee to demonstrate the number and complexity of calls they receive from the community and health professionals seeking advice on palliative care matters.

3.100 They have received calls from GPs looking for palliative care literature; seeking advice regarding access to services; and advice regarding treatment and medication. As for families and patients, the type of advice provided includes:

- advance care planning;
- how to access palliative care services from Silver Chain, inpatient hospitals, hospitals and from within aged-care facilities; and

221 Dr Alison Parr, Director of Medical Services, St John of God Health Care, *Transcript of Evidence*, 28 February 2018, p. 3.

- how to understand and navigate the palliative care system and clarifying what is happening to them.

3.101 WA Health, with the WACPCN, has made progress in recent years to improve access to and coordination of palliative care in WA, but evidence suggests there remains uncertainty in the community. The Palliative Care WA telephone log demonstrates this. It also highlights the need for a fully funded community telephone support and information line for palliative care services.

Recommendation 11

To improve understanding of palliative care in Western Australia, WA Health should:

- establish a consistent definition of palliative care to be adopted by all health professionals;
- provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community;
- encourage knowledge sharing by palliative care specialists with their generalist colleagues; and
- establish a palliative care information and community hotline.

Poor coordination and communication – impacting continuity of care

3.102 With more patients requiring multiple episodes of care, the lack of communication between GPs, carers in the community, and hospitals has been recognised as a barrier to a patient’s continuity of effective palliative care.

3.103 The AMAWA believes better communication between care providers could not only improve continuity of care, but also ‘prevent hospitalisations for patients at the end of life, and decrease inappropriate treatments through sharing of advance care plans’.²²²

3.104 The WA Palliative Medicine Specialist Group also identified this as a ‘major problem’ at a state-wide level with ‘huge risks for the patients when they move from one place of care to another’.²²³ According to Dr Anil Tandon, a palliative medicine specialist, this is even an issue between hospitals within Perth as each one uses slightly different forms so information documented about a particular patient, including treatment decisions, does not necessarily get transferred with them from site to site.²²⁴

222 Submission No. 685 from Australian Medical Association (WA), 15 February 2018, p.3.

223 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, p. 12.

224 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, pp. 12-13

- 3.105 To address the continuity of care issues across care settings the WACPCN has developed the 'Goals of Patient Care' form, a 'state wide integrated medical form which identifies and records a patient's goals of care'.²²⁵ Goals of Patient Care was piloted across the state's health services, including south metro, north metro, east metro and WACHS and the full rollout will depend on individual sites.²²⁶ The WA Palliative Medicine Specialist Group expects that the Goals of Patient Care form will enable the same form to be used across care settings – 'in an ambulance, in a nursing home and in a hospital', and it will link with the current IT systems used in health care.²²⁷
- 3.106 It is concerning to the committee that legally binding AHDs, which are documents created by patients that contain their healthcare preferences, are not afforded the same priority by WA Health as Goals of Patient Care. If these can be rolled out across the health system, including in ambulances, then the same should be possible for AHDs.

Finding 15

In giving priority to Goals of Patient Care, WA Health is elevating these documents as a form of advanced care planning. This is inconsistent with respect for patient autonomy. Whilst Goals of Patient Care are a valuable tool for clinicians, advance health directives are the legal standard for recognising patient preferences when patients cannot speak for themselves.

Access to effective Palliative Care in Western Australia

- 3.107 Even if the factors that contribute to effective palliative care are in place – the patient accepts the need for palliative care and engages with it early; health professionals are willing and able to refer the patient to palliative care; and the patient's treatment history and wishes are well documented – accessibility remains an issue.
- 3.108 Accessibility of palliative care differs markedly across the state as demonstrated earlier during the discussion on palliative care delivery in Western Australia.
- 3.109 Western Australia has the lowest number of publicly funded inpatient palliative care beds per head of population.²²⁸

225 Submission No. 616 from Department of Health, 23 October 2017, p. 9.

226 Ms Amanda Bolleter, Program Manager, WA Cancer and Palliative Care Network, *Transcript of Evidence*, 18 May 2018, p. 44. For more information on Goals of Patient Care, see paragraph 2.48.

227 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, p. 13.

228 Submission No. 611 from Silver Chain Care Group, 23 October 2018, p. 1.

Finding 16

Access to hands-on specialist palliative care is limited for metropolitan and non-metropolitan patients.

Finding 17

Western Australia has the lowest number of publicly funded inpatient palliative care beds per head of population.

- 3.110 According to WA Health, public hospices usually only accept patients with very short life expectancies – the average length of stay for a patient is only 10 days. Patients, regardless of their condition, expected to live for many weeks or longer may not be accepted because they will “block” the beds.²²⁹ Essentially, the limited number of hospice beds requires a high level of patient turn over.
- 3.111 PCWA call logs and other evidence suggests there are a number of people for whom existing services cannot meet their needs. They are not yet close enough to death to qualify for hospice care, but challenging health or family situations mean they are unable or unwilling to receive palliative care in the home or other community settings. They will likely be accommodated in hospital wards or aged-care facilities. There is no obvious or agreed solution to this problem. Options include the development of intermediary stage or longer-term hospice facilities; increasing capacity in existing hospices to ensure there are enough beds; and developing new hospices in geographically dispersed areas outside current localities with a high concentration of hospice beds.

Finding 18

There is a gap in care for people who are seriously unwell but not close enough to death to be admitted for inpatient hospice care.

Socioeconomic Status a determining factor

- 3.112 According to PCWA, wealthier and better-educated Australians have better access to palliative care.²³⁰ WA Health highlighted evidence suggesting that palliative care services are often clustered in areas of high socioeconomic advantage,²³¹ but did not appear to have a plan in place to bridge this gap.
- 3.113 A recent report from the Australian Institute of Health and Welfare (**AIHW**) found that throughout Australia:

229 Mr David Ransom, Medical Oncologist and Co-director, WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2017 – session three, p. 2.

230 Dr Elissa Campbell, President, Palliative Care WA, *Transcript of Evidence*, 14 December 2017, p. 6.

231 Ms Amanda Bolleter, Program Manager, WA Cancer and Palliative Care Network, *Transcript of Evidence*, 18 May 2018, p. 34.

*[...] people living in areas classified as having the lowest socioeconomic status accounted for a higher proportion of palliative care-related hospitalisations in public hospitals than those living in other areas. [...] Conversely, the rate of public palliative care-related hospitalisations was lowest for those living in the highest socioeconomic status areas.*²³²

- 3.114 Implicit in the AIHW finding is the presumption that people within the lowest socioeconomic status areas are not receiving or accessing adequate ongoing palliative care treatments resulting in a higher number of palliative care related hospitalisations, whereas people in the highest socioeconomic status areas are accessing private hospital palliative care and other types of non-admitted patient palliative care.

Regional access to palliative care

- 3.115 The WACPCN does not dispute the geographical gaps in accessing palliative care in Western Australia. The Rural Palliative Care Model (see paragraph 3.53) has improved accessibility, but specific data around the gaps or the improvement is not collected.²³³
- 3.116 The WA Country Health Service (**WACHS**) offered a critical appraisal of the palliative care services available in the regions:

*General Practitioners (GPs) provide a substantial proportion of the palliative care provision in WACHS and also engage in end of life conversations with patients and carers. There is limited support from Palliative Care medical specialists and this gap is filled to some extent by the senior palliative care nurses. There is no medical oversight, coordination or governance of medical palliative care services across WACHS and a state wide approach would be of some benefit coupled with a comprehensive auditing program to ensure that contemporary standards are maintained. Policy is also somewhat lacking and developing strong policy approaches is a pre-requisite for improving and maintaining standards.*²³⁴

- 3.117 Anecdotally, the committee was told of patients transferring to Perth to receive specific palliative care treatments. It often comes down to choice – not all treatments are available in rural or remote areas. Patients may need to choose between staying close to home and receiving limited treatment or travelling to major hospitals in larger regional

232 Australian Institute of Health and Welfare, *Palliative care services in Australia*, web report – received via email 5 July 2018, Australian Government, last updated 23 May 2018, np.

233 Ms Amanda Bolleter, Program Manager, WA Cancer and Palliative Care Network, *Transcript of Evidence*, 13 December 2017 – session one, p. 6.

234 Submission No. 684 from WA Country Health Services, 5 December 2017, p. 5.

centres or the metropolitan area to receive the full suite of hands-on palliative care treatments.

3.118 Dr Mary McNulty, a palliative medicine specialist, told the committee of a patient who opted to forgo treatment to be at home. He had quite difficult symptoms to control, but wanted to die on his farm in the community he loved. For him, that was more important than receiving 24-hour expert palliative care support in Perth.²³⁵

3.119 Conversely, Dr Anil Tandon, also a palliative medicine specialist, told the committee of a patient who chose to leave his home in Esperance and travel to Perth for treatment:

Myself and the oncologist involved with this man, we have treatment available for him but it would take him three weeks away from Esperance to be in Perth. The other option would be just one week here for a short course of treatment. We do not think that the long course of treatment is useful for him. We had the conversation with him and he chose the long course even though we did not think it was a good idea to be away from Esperance for so long.²³⁶

3.120 In the majority of cases, local GPs and nursing staff manage the palliative care needs of their patients with the help of specialist consultants. In complex cases the specialist palliative care available in remote and regional Western Australia does not compare to that available in Perth or even other large regional centres like Albany.

Finding 19

There is limited access to palliative care medical specialists in regional Western Australia.

Finding 20

There is limited medical oversight, coordination or governance of medical palliative care services across WA Country Health Services.

Recommendation 12

The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.

Recommendation 13

The Minister for Health should ensure regional palliative care be adequately funded to meet demand.

235 Dr Mary McNulty, Palliative Care Specialist, Silver Chain, *Transcript of Evidence*, 27 February 2018, p. 14.

236 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, p. 14.

Palliative care for Aboriginal people

3.121 In its submission to the committee, the Aboriginal Legal Service WA (**ALSWA**) observed a number of barriers for Aboriginal people accessing palliative care services in Western Australia including:

- a general distrust in mainstream health care services felt by many Aboriginal people;
- a lack of knowledge and understanding about palliative care; and
- mainstream palliative care practices conflicting with cultural practices and beliefs concerning death.²³⁷

3.122 Ms Ronda Clarke from the Aboriginal Health Council of Western Australia (**AHCWA**) advised the committee that health services must understand and incorporate the cultural needs of Aboriginal people by:

*[u]nderstanding and embracing the holistic concept of health held by Aboriginal people. This holistic concept of health recognises the importance of connection to land, culture, spirituality, ancestry, family and community and how these affect the individual.*²³⁸

3.123 According to Ms Clarke the basic rules of hospitals and palliative care services ‘represent barriers for Aboriginal people in gaining access to and receiving culturally secure health and end of life services’.²³⁹ Furthermore:

*The stress and anxiety of being away from country, home and family and community may lead individuals to make their own end of life choices—for example, not staying in Perth for dialysis or treatment, returning to home to be with family and on country for end of life.*²⁴⁰

3.124 Both the ALSWA and the AHCWA agree Aboriginal community-controlled health services are best placed to provide health services to Aboriginal people experiencing terminal or chronic illnesses. These community-controlled health services offer a holistic model of care and their strengths lie in the experienced Aboriginal health professionals who provide health services to Aboriginal people within their communities.²⁴¹

237 Submission No. 670 from Aboriginal Legal Services of Western Australia, 30 October 2017, p. 3.

238 Ms Ronda Clarke, Outreach Services Project Officer, Aboriginal Health Council of Western Australia, *Transcript of Evidence*, 2 March 2018, p. 2.

239 Ms Ronda Clarke, Outreach Services Project Officer, Aboriginal Health Council of Western Australia, *Transcript of Evidence*, 2 March 2018, p. 4.

240 Ms Ronda Clarke, Outreach Services Project Officer, Aboriginal Health Council of Western Australia, *Transcript of Evidence*, 2 March 2018, p. 4.

241 Ms Ronda Clarke, Outreach Services Project Officer, Aboriginal Health Council of Western Australia, *Transcript of Evidence*, 2 March 2018, p. 3.

Kimberley Renal Service (KRS)

- 3.125 KRS cares for people with any form of kidney failure including Chronic Kidney Disease (CKD) at stage 1 to stage 5 of the disease.²⁴² Patients with stages 4 to 5 have to consider renal replacement therapy. KRS covers Broome (10 chairs for dialysis); Fitzroy (4 chairs); and Kununurra (6 chairs). Patients from Balgo have to travel six hours to reach a dialysis centre. KRS provides education, support, referrals and haemodialysis.²⁴³
- 3.126 At present there is no in-home clinical support for palliative care in the community. Typically, the terminal phase at end of life occurs in hospital. This is problematic for Aboriginal people who want to die on country and with their families and communities.
- 3.127 KRS treats Indigenous and non-Indigenous patients but the largest cohort is the Indigenous patients. According to the KRS, CKD affects at least 50 per cent of the Indigenous population in the Kimberley.²⁴⁴
- 3.128 Kimberley patients tend to progress rapidly through the five stages of the disease (2–5 years) compared to the general metropolitan population (5–10 years). Patients on dialysis have a life-expectancy of 6–7 years. Most patients would prefer to spend that time at home on country. Unfortunately, treatment in Perth to commence dialysis can take a considerable period of time, which may result in long periods off country. Given the trajectory to death, this is a large proportion of their life expectancy and is often not seen as their best option.
- 3.129 CKD is a significant contributor to the high mortality rates for Aboriginal people in the Kimberley.²⁴⁵ In order to provide effective support, patients in the Kimberley need culturally appropriate care that recognises the importance of dying on country. Furthermore, primary health care teams need to be involved in order to improve the effectiveness of treatments.

The palliative care workforce

- 3.130 A consistent message in the evidence seen by the committee has been the need for increased health promotion of end of life care. Greater awareness in the community will

242 The stages of chronic kidney disease are determined by the Glomerular Filter Rate (**GFR**). Glomerular filtration is the process by which the kidneys filter blood, removing excess wastes and fluids. A normal GFR is 90 or above. At stage 5 the GFR is less than 15 and the person will need dialysis or a kidney transplant.

243 There are two types of dialysis – haemodialysis and peritoneal dialysis. Peritoneal dialysis is the oldest form of dialysis (1923) and is always done in the home using a catheter placed into the abdomen. Haemodialysis involves vascular access and can be done at home or at a renal centre – it is given three times per week and lasts three-four hours.

244 Based on a telephone conversation with Ms Jenny Cutter, Manager, Kimberley Renal Services, 17 April 2018 and confirmed on 7 August 2018.

245 Based on a telephone conversation with Ms Jenny Cutter, Manager, Kimberley Renal Services, 17 April 2018 and confirmed on 7 August 2018.

inevitably lead to greater demand, which means that the workforce must be resourced to meet this demand. Unfortunately, the committee heard from senior medical professionals who identified inadequate resources dedicated to palliative care, and indicated these existing services were under-resourced and unequally distributed.²⁴⁶

3.131 There are approximately 20 specialist palliative care professionals currently practicing in Western Australia.²⁴⁷ Palliative medical specialists acknowledge general practitioners provide adequate palliative care in many cases; however, with the increasing demand and complexity of cases, more palliative medical specialists may be required. There are a few pathways to becoming a palliative medical specialist, one of which includes three years of specialist training.²⁴⁸

3.132 The committee agrees specialist palliative care is only one part of the broader palliative care landscape and supports the AMAWA position that palliative care ‘needs to be properly integrated into all medical care’.²⁴⁹ To achieve this, the level of palliative care training provided during medical school will need to increase. Currently, according to the University of Western Australia’s Faculty of Health and Medical Sciences, palliative care is covered during a one-week clinical placement in the final year where end of life care issues are explicitly addressed and assessed.²⁵⁰

3.133 In addition to physicians, palliative care nurses are critical to the delivery of palliative care, particularly in the regions. Western Australia is tied with South Australia as the state with the second lowest number of FTE palliative care nurses per capita.²⁵¹

3.134 In 2016 there were 369 palliative care nurses employed in WA, equating to 293.7 full-time equivalent positions. The committee was unable to locate state-specific data on the location of the workforce. National data indicates 72 per cent of palliative nurses work

246 Dr Brien Hennessy, Head of Department of Anaesthesia, Sir Charles Gairdner Hospital, Response to Questions on Notice, no date and Submission No. 685 from Australian Medical Association (WA), 15 February 2018, p.3.

247 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, p. 10.

248 Dr Keiron Bradley, Clinical Lead, WA Cancer and Palliative Care Network, *Transcript of Evidence*, 18 May 2018, p. 6.

249 Dr Omar Khorshid, President, Australian Medical Association (WA), *Transcript of Evidence*, 18 May 2018, p. 2.

250 Submission No. 409 from Faculty of Health and Medical Sciences, University of Western Australia, 19 October, p. 2.

251 Australian Institute of Health and Welfare, *Palliative care workforce tables 2016*, May 2018, np. Available at: <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>. Accessed on 5 July 2018.

in major cities, with 20.2 per cent working in inner regional areas and only one-half of a per cent work in remote or very remote regions.²⁵²

- 3.135 As the population ages and the need for end of life care increases, the state will need to ensure there is a workforce in place to meet the growing demand. While this is of concern to the committee and needs to be addressed, of greater concern is the geographic distribution of the palliative care workforce.

Finding 21

There are insufficient numbers of primary care workers providing palliative care in Western Australia.

Patient coding

- 3.136 Clinical coding is the process through which WA Health records the level of activity at its hospitals. It can be a complicated process, particularly where patients present with comorbidities. Accurately recording activity through proper clinical coding is a fundamental component of how Western Australia's health system is funded, and demand for services is estimated.
- 3.137 WA Health advised the committee of the two methods used for palliative care coding:²⁵³
- Palliative care "care type" – primary clinical purpose is palliative. To report this Care Type the patient must be receiving **specialist** palliative care in a facility recognised by WA Health as a **specialist** palliative care provider (see paragraph 3.36 for the list of recognised services).
 - Health services can report a diagnosis code for palliative care (z51.5). This code can only be assigned as an additional diagnosis and is assigned independent of the patient Care Type on admission.
- 3.138 The committee remains concerned patients requiring, or even receiving, palliative care are not being accurately recorded via the clinical coding process. The evidence received regarding Mt Barker Hospital adds to this concern. Mt Barker Hospital does not have an on-site specialist palliative care consultant, so patients cannot be admitted under the palliative care "care type". On its visit to the Great Southern Region, the committee was told by a senior health professional that up to 90 per cent of inpatients at Mt Barker Hospital receive palliative care. However, according to WA Health, only one patient had

252 Australian Institute of Health and Welfare, *Palliative care workforce tables 2016*, May 2018, np. Available at: <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>. Accessed on 5 July 2018.

253 Dr Russell-Weisz, Director General, Department of Health, Response to questions on notice, 21 June 2018.

been recorded as having a palliative care separation code in each of the two most recent reporting years.²⁵⁴

- 3.139 This is an indication that the palliative care provision is not being accurately captured in the clinical coding and is likely to have funding implications for this type of care. It will also negatively impact upon WA Health's ability to plan future resourcing needs across Western Australia.

Palliative care funding

- 3.140 The committee made several attempts to gain an understanding of how funding is distributed for palliative care in Western Australia. At the first public hearing with WA Health the committee asked a series of questions related to funding of palliative care services in Western Australia. In response to many of these questions, WA Health advised they were unable to provide the information because they were restricted by commercial-in-confidence requirements. The remaining questions related to funding were almost all taken as questions on notice.

- 3.141 The committee made multiple attempts to obtain specific funding breakdowns from WA Health. Ultimately the Clerk of the Legislative Assembly issued a summons to the Director General of WA Health. Unfortunately, the data that was presented to the committee was not in a consistent format, thus making comparison very challenging.

- 3.142 It is apparent to the committee that WACPCN do not collect or maintain the funding data themselves, but rather the information is kept by the individual Health Service Providers – WACHS, South Metropolitan Health Service, North Metropolitan Health Service, East Metropolitan Health Service and Child and Adolescent Health Service. It was unclear if the Community services funding data is also collated separately.

WA Health is aware of the shortcomings

- 3.143 WA Health acknowledges many of the difficulties and shortcomings in the provision of end of life care identified during the inquiry. In 2017, the Department launched The End of life Framework to provide a comprehensive and coordinated approach to end of life care throughout the state. Within the Framework the Department identifies and describes the following 11 gaps and challenges:

- an increasing demand for end of life care;
- changing patterns of disease, with an increasing number of people having complex health needs and dying from a range of comorbidities;

254 Dr Russell-Weisz, Director General, Department of Health, Response to questions on notice, 21 June 2018.

- the unpredictable nature of non-cancer diseases, which contribute to patients with dementia, frailty and/or multi-organ failure receiving less than optimal care;
- lack of adequate coordination and continuity of care across health settings;
- the number of patients that are admitted to acute hospitals at end of life, many of whom die in hospital despite expressing a wish to die at home;
- clinicians' ability to recognise and respond to clinical deterioration, discuss patients' goals of care and engage in open and honest conversations;
- the unique and challenging issues faced by rural and remote clinicians and communities;
- the need to provide targeted education and support to staff and clinicians working in primary health care, residential care facilities and generalist settings that can lead to system wide change;
- greater recognition of the role of Specialist Palliative Care teams, including appropriate and timely referral;
- the need for community awareness and understanding of death, dying, loss, palliative and end of life care and to recognise the limits of medical interventions; and
- aligning statewide end of life initiatives with the national policy agenda.²⁵⁵

3.144 To support the Framework and to build on models for palliative care in WA, WA Health has developed the *WA End of Life and Palliative Care Strategy 2018-2028* that identifies the following 6 priority areas:

- care is accessible to everyone, everywhere;
- care is person centred;
- care is coordinated;
- families and carers are supported;
- all staff are prepared to care; and

²⁵⁵ Department of Health, *The End of Life Framework*, report prepared by WA Cancer and Palliative Care Network, Government of Western Australia, 2017, p.3.

- the community is aware and able to care.²⁵⁶

3.145 The Strategy is very high level and the department intends to continue its consultation with the specialist palliative care and end of life sectors to develop an implementation plan.²⁵⁷

3.146 The Strategy is applicable to all services in WA, including specialist and non-specialist teams that support and care for people with life limiting illness and their families.²⁵⁸

3.147 According to the WACPCN Program Manager:

*Our expectation is that every health service across the state is able to provide end of life care, recognise when a patient is at end of life, provide appropriate management and care for that patient and their family, and refer for specialist palliative care if and when that is needed [...].*²⁵⁹

Palliative care remains critically important to providing good deaths

3.148 Modern medicine has changed the face of death in Australia; increasingly people are dying in old age, slowly and with multiple co-morbidities. The committee views access to effective palliative care as critical to ensuring as many Western Australians as possible experience a good death and believes patients should get to choose whether, how, where and when they receive palliative care.

3.149 Unfortunately, there are many barriers to the provision of effective palliative care in Western Australia, not least of which being the apparent lack of a consistent understanding of palliative care within the community and among health professionals.

3.150 As outlined in this chapter, WA Health offers three models of specialist palliative care: in-patient, community, and consultancy. The increasing complexity of the dying process means patients may need to transition between models of specialist palliative care; however, the evident lack of co-ordination and communication among health professionals can make any transition between models problematic. Furthermore, access to the three models is not equally distributed across the state, meaning many

256 Department of Health, *WA End of life and Palliative Care Strategy 2018-2028*, report prepared by WA Cancer and Palliative Care Network, Government of Western Australia, 2018, p. 2.

257 Ms Amanda Bolleter, Program Manager, WA Cancer and Palliative Care Network, *Transcript of Evidence*, 18 May 2018, p. 37.

258 Department of Health, *WA End of life and Palliative Care Strategy 2018-2028*, report prepared by WA Cancer and Palliative Care Network, Government of Western Australia, 2018, p. 1.

259 Ms Amanda Bolleter, Program Manager, WA Cancer and Palliative Care Network, *Transcript of Evidence*, 18 May 2018, p. 2.

Western Australians may have limited or conditional access to their preferred model of specialist palliative care.

- 3.151 The committee would be concerned if WA Health’s promotion of community care and reliance on the consultancy model was at the apparent expense of optimal symptom relief for patients.
- 3.152 The committee believes a comprehensive health promotion strategy aimed at the community and health professionals coupled with proper integration of palliative care into all medical care would help improve the understanding and delivery of palliative care in Western Australia.

Finding 22

Palliative care activity in Western Australia’s hospitals is not being accurately recorded. It is important that the extent and cost of palliative care service delivery is clarified.

Recommendation 14

Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit:

- The level of palliative care activity actually provided in Western Australia’s hospitals and compare it against the level of recorded palliative care activity.
- The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.

Limitations of palliative care

- 3.153 As discussed earlier in this chapter, end of life symptoms are broad and can include laboured breathing, nausea, vomiting, pain, respiratory tract secretions, terminal restlessness or agitation, delirium and fatigue. Individuals experience these symptoms subjectively, meaning that no two people will have the same sense of suffering as a result of similar symptoms. In addition, illness trajectories differ from patient to patient, making treatment more complicated. These complex symptoms at end of life are treated by palliative care specialists using a “holistic” approach encompassing physical, psychological and spiritual responses as needed.
- 3.154 There is no doubt that palliative care is often effective. The evidence from Ms Calcutt earlier in the chapter demonstrates the benefits of palliative care – her partner’s suffering was addressed in his final days. The committee also heard evidence from other individuals praising the value of palliative care, including Ms Jenny Paynter. Her mother

died of liver cancer and ‘received excellent care from people who cared; they were gentle, kind and patient’.²⁶⁰

3.155 Submitters were often forthcoming in their praise for those who choose to make caring for the dying their vocation, but the committee also heard from many people – including those in the medical profession – of situations where palliative care had not been able to alleviate the pain and distress caused by late-stage symptoms. The percentage of patients for whom palliative care was ineffective in relieving their symptoms varied; however, somewhere in the range of 2–5 per cent is consistent with the evidence.²⁶¹ The committee also received evidence from some health professionals that the figure may be even higher, perhaps as high as 30 per cent.²⁶²

3.156 Dr Megan Best, palliative care physician, academic and advocate, acknowledged patients still have bad deaths:

*I am sure you have heard from people who have witnessed terrible suffering at the end of life, as indeed I have myself. It should not happen but it still does, even in the most progressive institutions.*²⁶³

3.157 Dr Brien Hennessy, Head of Anaesthesia, Sir Charles Gairdner Hospital, agreed that many patients experience refractory symptoms at end of life:

*The big picture here is that pain and suffering remains a significant issue in a significant proportion of people despite expert care. This is not a failure of resourcing or provision of services (which remains the biggest problem) but rather a lack of pharmacological and psychological efficacy to manage overwhelming nociception and psychological suffering.*²⁶⁴

3.158 In response to further questions, Dr Hennessy added:

I believe that it is unrealistic to expect no period of suffering at the end of life when severe pathology exists. Tolerability of that suffering is a very individual experience and is highly variable. [...] I see people

260 Submission No. 460 from Ms Jenny Paynter, 20 October 2017, np.

261 Dr Elissa Campbell, President, Palliative Care WA, *Transcript of Evidence*, 14 December 2018, p. 8 and Dr Peter Beahan, supplementary evidence provided at hearing 26 February 2018 p. 1.

262 Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 30 April 2018, p. 3.

263 Dr Megan Best, Palliative Care Specialist and Academic, *Transcript of Evidence*, 1 May 2018, p. 2.

264 Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital, Letter – Response to Questions on Notice, 25 May 2018, np.

*suffering due to the fact that not all pain is 100% treatable and because there are inadequate resources dedicated to palliative care.*²⁶⁵

3.159 The committee heard harrowing evidence from individuals like Mr William Philip whose wife, Maxine, died in January 2017, three years after her initial diagnosis. According to Mr Philip:

*Palliative care is a wonderful and humane service, but it does not, and cannot, help in extreme circumstances such as Maxine's.*²⁶⁶

3.160 Very powerful evidence of one patient's pain and suffering not being alleviated by treatment in a specialist palliative care unit was provided in closed session. The witness told of her mother's death in a palliative care facility with access to top-quality specialist palliative care. The witness's mother was diagnosed with breast cancer; unfortunately, the presentation of her symptoms was unusual so by the time she received medical attention she was already very ill. She moved into a hospice just a few months after her initial diagnosis, and at first her symptoms seemed to improve, but soon:

*She was sleeping up to 22 hours a day. She got weaker and weaker physically. People were coming to visit her, and we could not even wake her up.*²⁶⁷

3.161 The witness then recounted the last few weeks of her mother's life:

She was still in a lot of pain and a lot of discomfort in this period here because, because if she is not using her muscles and stuff, then she is basically wasting, and that comes with discomfort. You are talking about continence as well. She could not eat a lot of food anymore. Her stomach was rejecting food. I would not say she had any quality of life from here on in.

[the day she died] I was at home. It was 4.00 am. I got a call from my auntie, who had flown in. She was with my mum. [...] "You need to come now, because your mum looks different." I went in, and it was dark because they had the nightlight on. My mum's eyes were pointing in different directions. They were grey. My mum had dark brown eyes. Her skin was grey and blue and yellow. She was sweating, but she was cold. Her mouth was open. She stank. Her teeth were apart, and her tongue was sticking that far out of her mouth. Her hands were twisted. Her back

265 Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital, Letter – Response to Questions on Notice, 25 May 2018, np.

266 Submission No. 682 from Mr William Philip, 24 October 2017, p.1. For further detail of his wife, Maxine's, circumstances, see paragraphs 2.55 and 3.184.

267 Identity withheld, *Transcript of Evidence*, p. 6.

was twisted. Her shoulder was twisted. Her feet were twitching. She was dancing in her own bed, and she was making this choking sound that you see in horror movies.

I went up to her and grabbed her hand and tried to get her to say something to me. [...] My mum looked at me with one of her eyes. She looked straight at me. My mum knew what was going on, and her teeth were chattering and she was choking, but I swear she said my name. [...] That killed me, knowing that she could have been aware of what is going on in those final hours.

[a nurse spoke to the witness] "Look, it's her last, final hours, you want to just clear your schedules for the day. What's going to happen is we're going to give her morphine when she starts twitching. She will settle—give it some time to kick in—and just keep calling us when she twitches." So it was four or five cycles of madness. So my mum twitches, we call the nurse, they come within five minutes, they press a button to give her more morphine through a drip, or whatever the machine is that is in her — [...]

It takes her 15, 20 minutes to settle. There is peace and quiet for a little while—maybe half an hour if we are lucky—and then she starts twitching again, and then we call the nurse again and then they inject her again, and then we wait and then she twitches and then we inject and then we wait and then she twitches and then they inject and then we wait! It was the absolutely pointless. Then my mum was pronounced dead at 8.20.²⁶⁸

3.162 Despite this experience, the witness still stated the 'utmost respect for every single doctor and medical staff who came into contact with my mum'.²⁶⁹ Taken with what follows, this evidence appears to demonstrate the limits of palliative care in certain circumstances.

3.163 Other witnesses provided similar stories of grievous and irremediable suffering experienced by their loved ones. In particular, the committee received evidence about the illness trajectories experienced by those with neurodegenerative diseases, including:

- Motor neurone disease;
- Huntington's disease;

268 Identity withheld, *Transcript of Evidence*, pp.6-7.

269 Identity withheld, *Transcript of Evidence*, p.5.

- Parkinson’s disease; and
- Dementia

3.164 The following examples provided by witnesses offer insight into what it is like to experience these diseases.

Motor neurone disease

3.165 Motor neurone disease (**MND**) is the name given to the group of diseases in which the motor neurones undergo degeneration and die. Motor neurones are the nerve cells that control the muscles enabling people to move, speak, breathe and swallow. Amyotrophic Lateral Sclerosis (**ALS**), Progressive Muscular Atrophy (**PMA**), Progressive Bulbar Palsy (**PBP**) and Primary Lateral Sclerosis (**PLS**) are all subtypes of MND. People with MND progressively lose the use of their limbs and ability to speak, swallow and breathe, whilst their mind and senses usually remain intact. The average life expectancy is 2.5 years from time of diagnosis.²⁷⁰

3.166 According to the Motor Neurone Disease Association of WA (**MNDAWA**), current palliative care services offered to MND patients in Western Australia ‘are not adequate for all people with MND’.²⁷¹ This is perhaps a result of the many and complex symptoms experienced by MND patients at the end of life, including ‘pain, breathlessness, distress, anxiety [and], delirium’.²⁷² MNDWA estimated that between 10–15 per cent of people with MND would experience symptoms – typically pain and breathlessness – at end of life that cannot be adequately controlled:

There are some symptoms and distress that are impossible to adequately treat such as tenacious thick mucus in the back of the throat where the PwMND [people with MND] cannot cough and these cannot be controlled by a cough-assist machine; breathlessness where [non-invasive ventilation] is not tolerated and morphine is insufficient; and existential mental distress caused by being totally dependent. The fear of these impossible to control symptoms leads some PwMND to request an assisted earlier death from health professionals or can lead them to commit suicide while they are still capable of doing so.²⁷³

270 Submission No. 563 from the Motor Neurone Disease Association of WA, 23 October 2017, p. 1.

271 Motor Neurone Disease Association of WA, Letter – Response to Questions on Notice, 12 March 2018, p. 3.

272 Motor Neurone Disease Association of WA, Letter – Response to Questions on Notice, 12 March 2018, p. 4.

273 Motor Neurone Disease Association of WA, Letter – Response to Questions on Notice, 12 March 2018, p. 4.

3.167 The committee heard from Ms Janice Taylor whose husband was diagnosed with MND in April 2004:

The progression of the disease was so fast that every week, something new had to be dealt with at home. We had to get some new piece of equipment or we had to get someone else in to do something else. We had a little mini ward at home because we had people coming from Silver Chain to do the showering and all of that. We had hoists. We had an electric bed.

[...]

We had a schedule of duties and medications that he had to have every day, and we kept a little clipboard in the room, just like you do at a hospital. Everyone had to make sure he had his anxiety treatment. Towards the end, he had to have morphine. We had diazepam, temazepam; [...]

He did have a PEG tube. He could not eat enough food, orally, to support his body so the PEG tube feeding did give him a bit of extra nourishment and gave him a decent appearance. He looked quite well most of the time, but he could do nothing. In the end, I would say the last eight or nine weeks, he could do nothing at all. He had to be lifted out of bed by the hoist. He had to be taken into the shower still attached to his assisted breathing machine, so we had this extra-long transparent tube that was hooked up to the machine. He would get hoisted up with this mask on to go into the shower. It was not nice.

[...]

It was very hard to deal with—emotionally draining. He was a very intelligent man, so at a point in time, he called us all into our little bedroom that was turned into his little hospital room. We all got called in, immediate family: me, his twin sister, his younger sister, our two beautiful girls and he told us, “One day, I might say to you that I want this machine turned off.” He said, “I want you to know that when I do that, I really want it turned off and I want you to arrange it. Do not be sad; I will only say that when I think I cannot stand this any longer and cannot put up with this life any longer.” I can tell you, he had no quality of life. He did pass away in his sleep, which we were all grateful for, but he could do absolutely nothing for himself. He could not even hold a

*book up, could not do anything. He could not drink. He was like a trapped, beautiful, intelligent brain in a useless body.*²⁷⁴

Huntington's disease

- 3.168 Huntington's disease is a genetic disease affecting areas in the brain that control movement, thinking, and emotion. It has a slow progression, and symptoms gradually worsen over time. The onset of Huntington's disease is typically between the ages of 30 and 50 and 'physical symptoms are usually the first to cause problems and to be noticed, but at this point they are commonly accompanied by unrecognized cognitive and emotional ones'.²⁷⁵
- 3.169 Symptoms of Huntington's can vary from person to person, however, the progression of the disease can be roughly divided into three stages:

Early Stage – usually includes subtle changes in coordination, perhaps some involuntary movements (chorea), difficulty thinking through problems and often, a depressed or irritable mood. The effects of the disease may make the person less able to work at their customary level and they may be less able to carry out their regular activities at home.

Middle Stage – the movement may become more of a problem. Medication can be considered to provide relief from involuntary movement. Occupational and physical therapists may be needed to help maintain control of voluntary movements and to deal with changes in thinking and reasoning abilities. Diminished speech and difficulty swallowing may require help from a speech & language pathologist. Ordinary activities will become harder to do.

Late Stage – the person is totally dependent on others for their care. Choking can become a major concern. Involuntary movements may be severe or may cease. At this stage, the person can no longer walk and will be unable to speak. However, he or she is generally still able to comprehend language and retains an awareness of family and friends. When a person with Huntington's dies, it is typically from complications of the disease, such as choking or pneumonia and not from the disease itself.²⁷⁶

274 Ms Janice Taylor, Past Carer/Secretary, Motor Neurone Disease Association of WA, *Transcript of Evidence*, 2 March 2018, pp. 5-6.

275 Huntington's Western Australia, *What is Huntington's Disease?*, available at: <https://www.huntingtonswa.org.au/information/what-is-hd/>. Accessed on 22 July 2018.

276 Huntington's Western Australia, *What is Huntington's Disease?*, available at: <https://www.huntingtonswa.org.au/information/what-is-hd/>. Accessed on 22 July 2018.

3.170 Mr Bill Spanbroek told the committee about his stepson, Michael Watkins, who was diagnosed with Juvenile Huntington's. Mr Spanbroek and his wife looked after Michael at home and while he never got 'fidgety', a symptom typically associated with Huntington's, Michael lost his ability to swallow:

Eventually we had to have a PEG inserted and fed him intravenously through the PEG. Having done that, we had him at home for the last year. He was really in a bad condition. He lost bodily control over his bowels and could hardly walk, and then finally he finished up having a brain haemorrhage. We took him to the hospital where our neurologist was looking after him and he was given painkillers, morphine and what have you. We kept saying to the neurologist, "Peter, he is in pain." He said, "But I have given him the limit of morphine; I cannot give him anymore", and he said, "But he is not in pain." Well, I can tell you the last thing he said. He lifted his head from the pillow and said, "Bullshit". He was in hospital for five and a half weeks, and every night we drove home my wife and I said to each other, "He won't be there tomorrow." Five and a half weeks later, he passed away.²⁷⁷

3.171 Mrs Katherine McBarron, Michael's sister who was diagnosed as gene-positive for Huntington's at the age of 25 but is not yet symptomatic, also gave a brief account of Michael's last few weeks of life:

[...] he had an inability to speak. He was pretty much incapacitated in a hospital and we never spoke to him again after that; that was it. From that time that he fell over at home to the time he died, there was no communication at all.²⁷⁸

Parkinson's disease

3.172 Parkinson's disease is a disorder of the nervous system. It results from damage to the nerve cells in a region of the brain that produces dopamine, a chemical that is vital for the smooth control of muscles and movement.

3.173 The main symptoms of Parkinson's disease are:

- tremor or shaking, which usually begins in one arm or hand;
- muscle rigidity or stiffness;
- slowing of movement;

277 Mr Bill Spanbroek, *Transcript of Evidence*, 30 April 2018, p. 1.

278 Mrs Katherine McBarron, *Transcript of Evidence*, 30 April 2018, p. 5.

- stooped posture; and
- balance problems.²⁷⁹

3.174 Professor Max Kamien told the committee about a patient of his, an aeronautical physicist and avid swimmer who was diagnosed with a severe Parkinson’s-type disease seven years ago:

*In the last four years, he cannot speak, he cannot use his iPad, and he cannot keep his eyes open most of the time. His brain is all right.*²⁸⁰

3.175 According to Professor Kamien the patient’s ability to communicate is limited to using “thumbs-up” and “thumbs-down” motions.²⁸¹

3.176 Mrs Margo Bielby’s husband suffered from a range of life limiting illnesses, including Parkinson’s disease. She told the committee the difficulties encountered by her husband as a result of the disease:

*He had Parkinson’s disease, and he was down to shuffling from room to room. He could sit and read and sit and watch TV, sit and do Sudoku, and not much else. If he fell over he could not get up, and I could not lift him. I would have to run across the road and get the bloke across the road to come over and lift him up. He often could not get out of his chair on his own, so I bought him a lift chair. I had to help him dress, I had to help him shower, I had to help him back into bed—he could not get back into bed on his own. One night I had to get up five times to help him back into bed. I could not leave him.*²⁸²

Dementia

3.177 Dementia includes a number of illnesses with similar symptoms, such as loss of memory, intellect, rationality, social skills and physical functioning. The types of dementia include:

- Alzheimer’s disease (the biggest risk factor is increasing age, although Sporadic Alzheimer’s disease can affect any age);
- Vascular Dementia (the broad term referring to problems of circulation of blood to the brain);

279 Health Direct, *Parkinson’s Disease*, available at: <https://www.healthdirect.gov.au/parkinsons-disease>.

280 Professor Max Kamien, Medical Practitioner/Emeritus Professor of General Practice, *Transcript of Evidence*, 3 March 2018, p.3

281 Professor Max Kamien, Medical Practitioner/Emeritus Professor of General Practice, *Transcript of Evidence*, 3 March 2018, p.3

282 Mrs Margo Bielby, *Transcript of Evidence*, 1 May 2018, p. 1.

- Lewy Body disease (caused by degeneration and death of nerve cells in the brain causing abnormal structures in the brain);
- Frontotemporal dementia (progressive damage to the frontal and/or temporal lobes of the brain leading to reduced intellectual abilities and changes in personality, emotion and behaviour);
- Alcohol related dementia (for example, Korsakoff's syndrome and Wernicke/Korsakoff's syndrome);
- Down syndrome and Alzheimer's disease (by age 40 almost 100 per cent of people with Down syndrome who die have changes in the brain associated with Alzheimer's disease); and
- HIV associated dementia (a complicated syndrome made up of different nervous system and mental symptoms that can develop in people with HIV).²⁸³

Stages of dementia

3.178 Dementia progresses differently in different people but there are three widely recognised general stages of dementia:

*Dementia, especially Alzheimer's disease, can be broadly categorised into three phases: mild, moderate, and severe. People in severe or late stage dementia experience not only severe memory loss but physical symptoms such as being unable eat or swallow, limited or no speech, and inability to control bodily functions. People in these later stages require assistance with nearly all aspects of personal care.*²⁸⁴

The final, severe stage of dementia can produce a host of symptoms that cause significant suffering to individuals:

People in the later stages of dementia have an increased risk of experiencing unrecognised or poorly managed pain. They are vulnerable to accidents, injuries and falls and will often experience cognitive and speech difficulties that mean that they cannot communicate their pain. The symptoms of late stage dementia – immobility, swallowing difficulties, and incontinence – make people highly susceptible to recurring chronic infections and ulcers. In the United Kingdom, two thirds of people with dementia ultimately die from pneumonia (Alzheimer's Society, 2012). We also know that people with dementia

283 [Dementia Australia – Types of dementia](#) – website. Accessed 28 June 2018

284 [Talking about Alzheimer's Across Australia – Discussion Paper, April 2017](#), p. 5. Accessed 20 July 2018

are three times more likely to receive emergency interventions and invasive procedures than people of comparable age with a different terminal illness, such as cancer (Mitchell, 2006).²⁸⁵

3.179 Mr Nigel Haines' wife Suzie died of dementia in 2011. Mr Haines shared with the committee excerpts from a journal he kept during Suzie's illness:

Tenth of January, 2006. This is when Suzie was still living at home. Whilst there are moments when Suzie becomes quite lucid, this morning Suzie was very unsettled and was trying to ask questions about her illness. She eventually said that she was tired of being ill and wanted to go back to the way she was.

[...]

Sixteenth January. On Saturday evening, Suzie scared me like never before. During our time together, we have never really argued, certainly not with raised voices or nasty comments. But on Saturday evening around 9.30pm, she fell asleep in front of the TV as she normally does. I tried to gently wake her. She woke up startled and said to me something like "Now, I know what you are up to." I said, "What do you mean?" and she said, "Don't deny it". I carried on questioning her but her body language was very aggressive with her hand on hip pointing a finger to my face. She was mumbling incoherently and went around the house looking through the curtains saying, "Yes, I knew it." and "Yes, I thought so." This went on for about three quarters of an hour. As I said, it really frightened me because I could almost see hatred of me in her eyes and nothing I could say would calm her down. The panic attacks are increasing.

Twenty-fifth January. I am really struggling to cope now. Last night we had an early night but Suzie woke up at 4.45 am crying and saying she was frightened of the dark. It took around half an hour to calm her and then she was okay again. However, whilst she was having her shower she got upset when she put her head under the water. She became agitated and from then on it was a major job to get her dried and dressed. She was insisting that her panties were not hers and that her jumper and jeans were on back to front, which they were not.

[...]

²⁸⁵ Talking about Alzheimer's Across Australia – Discussion Paper, April 2017, p. 6. Accessed 20 July 2018

Fourteenth of February, Saint Valentine's Day. Suzie has been admitted to Joondalup Hospital's psychiatric ward after a nasty turn. She never returned home. [a quote from an] Email to friend: I saw Suzie today. I wept when I saw her sitting on a chair with her hands between her legs all hunched over. She recognised me and tried to smile. She is so confused and the medication keeps her in a zombie-like state. [...] Next week the brain scans will be done. This will give them an insight as to what else has gone wrong to cause such a drastic decline in her condition. It may also assist in giving a prognosis as to what quality of life and longevity she can expect. At the moment though, I am only interested in the fact that I can spend more time with my baby.

Third of March. Received a call from Peel hospital advising that their social carer arrangement did not cover after 9.30 pm and if Suzie became violent, would I give them permission to use padded hand and ankle cuffs. On the basis that it would minimise the risk to Suzie, and having absolutely no other alternative, I agreed. Thirty minutes after that, I received another call from Peel advising me that they had four staff members restraining Suzie and were attempting to administer sedatives directly into the bloodstream. They had called for an ambulance and she was about to be taken to Fremantle Hospital's psychiatric ward. At the moment I am unsure as to what they intend to do with Suzie because Fremantle is not equipped to handle ongoing violence; yes, they now class Suzie as a violent patient. [...]

On 7 March, Suzie was admitted to Fremantle psychiatric hospital. Today, I went and saw Suzie for the first time in 10 days due to having to go interstate on business. It was gut-wrenching. She looked so old and haggard and shuffled along. I could not keep the tears back and it took a few seconds for her to recognise me. She had a black eye from one of her violent bouts last week and she moved the top half of her body rather than turn her head at the neck. She is now under the Mental Health Act, which, whilst a formality, confirms that they can hold her against her will. At the last hospital she assaulted another patient. I spent just over an hour with her walking around the small garden they have and sitting for a few seconds before she would get up and gesture to me to do another lap. She mumbled most of the time and it was extremely difficult to understand what she was trying to say. Strangely, every time we sat down she looked at me and with a faint smile said, "I love you." I'm going up tomorrow to see her again and meet her latest doctor.

Twentieth of March. I went and saw the psychiatric team and in a nutshell they asked whether there was a DNR—do not resuscitate—in place. I confirmed there was and referred them to the notes provided to the previous hospital. [...] She has moments of aggression but more moments of loving. She would go up to one of the nurses and give them a hug. When she becomes aggressive they simply put her in her room until it passes. [...]

She has not recognised me for some time now. It is a gut-wrenching experience and I would not wish it on anyone. Seeing the person you love so much either with shoulders hunched over pacing the ward or curled up in the foetal position. I asked how long we could expect Suzie to endure this living nightmare—five, 10 or 15 years? The response was like a double-edged sword—so sad but with a sense of relief. I was told that if she was really unlucky, she would have to endure another five years but it was more likely to be two years or even as short as 12 months. As we know, it was indeed the worst-case scenario, another five years.

Fifth of June. Today when I visited, Suzie walked for a few paces and then curled up on the floor in the foetal position for a couple of minutes, then got up and repeated this for the 15 minutes I was with her. She has had four sessions of the electro-convulsive treatment [...]. I kissed her head and she became angry. I try to avoid doing anything that will upset her but if something interrupts her routine or you try to get her to do something that she is not happy to do, she becomes distressed. She is in a permanent state of angst.

Suzie was admitted to Greenfields aged-care facility in November 2006. I visited her every day that I was in the state, sometimes for only a minute, but enough time for me to kiss her, apologise for not doing anything to end her suffering and tell her I loved her. This is the last entry in my journal: Suzie passed away at 3.45 am on 9 May 2011 at the Greenfield's aged-care facility. For the last three years of her life, she was in a vegetative state, which is so demeaning and sad to see.²⁸⁶

Suffering at end of life is not confined to pain

3.180 As these stories highlight, suffering is not simply about the physical experience and manifestation of pain. Many of the other symptoms experienced by people suffering life-

286 Mr Nigel Haines, *Transcript of Evidence*, 30 April 2018, pp. 1–4.

limiting illnesses are harder for the medical profession to measure, even as health professionals acknowledge the symptoms.

3.181 It is not surprising, therefore, that anxiety is a common symptom for patients with late-stage Chronic Obstructive Pulmonary Disease (**COPD**) experiencing breathlessness²⁸⁷ given that “breathing problems” can, according to retired pharmacist Mr Ian Wood, mean ‘horrific feelings of choking, strangulation or drowning in your own saliva—not just being out of puff from walking uphill.’²⁸⁸

3.182 Dr Rodney Syme explains Dyspnoea, or breathlessness, as follows:

*Breathlessness like pain is not measurable. It can be observed [...] but the essence of breathlessness is a sensation, a perception, bound up with fear. It quintessentially encompasses the concept of distress, as opposed to pain; again, the unmeasurable component of physical symptoms that exist in the psyche.*²⁸⁹

3.183 Dr David Ransom, an oncologist, told the committee of a patient with suspected terminal delirium whom he encountered while making ward rounds at a hospital. This patient, a man in his early 70s with metastatic colon cancer, had deteriorated drastically over a 24-hour period:

*He is being nursed on a mattress on the floor because he is thrashing about in the bed and cannot be nursed in bed because he is a fall risk. They put the mattress on the floor and he was nursed on the floor and because he was so agitated, he had taken off all his clothes. So as you walked onto the ward, there is this guy lying on a mattress on the floor, no clothes on, and he has got mitts on his hands to stop him pulling out stuff. I thought, “Okay. This is not going to be an easy situation to deal with.”*²⁹⁰

3.184 Respiratory tract secretions are another common symptom for patients at end of life. According to neurologist Dr Robert Edis, many patients “lose” their cough, meaning they are unable to clear the thick mucus that accumulates at the back of the throat.²⁹¹ Mr William Philip (as noted at paragraph 2.55 above) described how his wife drowned

287 Chochinov, H.M. et al, ‘Dignity and Distress towards the End of Life across Four Non-Cancer Populations’, *PLoS ONE*, vol. 11 no. 1, p. 7, January 2016.

288 Ian Wood, National Coordinator and Spokesperson, Christians Supporting Choice for Voluntary Euthanasia, *Transcript of Evidence*, 13 April 2018, p. 3.

289 Syme, R, *Time to Die*, Melbourne University Press, Melbourne, 2016, p. 70.

290 Mr David Ransom, Medical Oncologist and Co-director, WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2017 – session three, p. 3.

291 Dr Robert Edis, Neurologist, Sir Charles Gairdner Hospital/Perron Institute Motor Neurone Disease Clinics, *Transcript of Evidence*, 2 March 2018, p. 4 and 7.

slowly from fluid accretion in her lungs. His wife had terminal cancer and became very sick with pneumonia:

in the next 10 days she basically drowned slowly. Her lungs continued to fill up. No matter what the doctors did, they were not able to do anything about it, nor were they able to put her out sufficiently that she was unaware of it. On the Wednesday before she died, she was absolutely terrified. She could not breathe properly, even tipping the bed up that her feet were five feet off the ground and her head was a foot off the ground and trying to help drain out her lungs. Her eyes were bugging out and she was throwing herself around; she was terrified and that should not have happened. The palliative care people came that day, they helped stabilise her and they were as good as they possibly could have been. I think they were there three or four times that day and she should have settled down, but from then on she just gradually quietly drowned.²⁹²

Existential suffering

- 3.185 Dr Tandon and others believe the hardest patients to provide adequate symptom relief for those enduring what he calls 'existential distress'.²⁹³ According to Dr Tandon, patients who are fearful of death, and who may not have accepted they are dying, can suffer existential distress. Palliative care specialists agree that existential distress or suffering can manifest as pain but this perceived pain is not responsive to traditional pain medications.²⁹⁴
- 3.186 Doctors for Assisted Dying Choice believes existential suffering can be caused by exhaustion or a diminishing quality of life and may not be linked to a fear of dying – whatever the cause, they believe existential suffering is not amenable to palliative care interventions.²⁹⁵
- 3.187 Ms Tracy Endersby, a palliative care nurse with 16 years' experience, told the committee she believes palliative care does a 'really good job of easing someone's physical pain' about '90 per cent of the time'.²⁹⁶ However, Ms Endersby continued:

292 Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 3.

293 Dr Anil Tandon, Chairman WA Palliative Medicine Specialist Group, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 27 February 2018, p. 5.

294 Professor Doug Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Services; WA Country Health Services; Royal Perth Hospital, *Transcript of Evidence*, 9 March 2018, p. 8.

295 Doctors for Assisted Dying Choice, Letter – supplementary material, 28 May 2018.

296 Ms Tracy Endersby, Nurse, private citizen, *Transcript of Evidence*, 7 March 2018, p. 4.

I think it is very hard to relieve somebody of emotional or spiritual pain. I also think that it really comes down to what people's tolerance is for their quality of life.²⁹⁷

3.188 It is not surprising that fear, anguish and anxiety are a common response to impending death, particularly if the dying process is accompanied by any of the distressing symptoms experienced during the terminal phase of an illness. Existential suffering is no less than any other distress encountered by those at end of life. This type of suffering may not be relieved by palliative care for some people.

Suffering is subjective and context dependent

3.189 Many people who shared their stories with the committee provided intimate detail about the suffering that their loved ones experienced in the final moments of their lives. In some instances, submitters emphasised that the dying person experienced personal growth and moved to acceptance *because* of those additional days spent alive, and *despite* the suffering they were experiencing. Many other submitters emphasised the pointlessness of the suffering encountered by their loved ones. They were dying; their trajectory to an inevitable demise certain. Extending their lives in such circumstances was viewed as extension of life without meaning.

3.190 These differing attitudes toward the meaning and purpose of suffering at the end of life speak to a profound philosophical difference separating proponents for assisted dying and those who are opposed to any such reform. The gulf between these two positions will not be bridged by this report, but it is nonetheless important to highlight the positions and to emphasise that both are values based and held with sincerity by their proponents. Both views can and should be respected irrespective of what legislative outcomes arise.

3.191 In saying that, it is also important to emphasise that suffering is both subjective and contextual. Only the individual experiencing it can define it and they alone are able to determine whether the context in which it occurs makes it somehow valuable. Dr Rodney Syme, the president of Dying with Dignity Victoria, illustrated this point very well:

A mother might be able to endure the pain of childbirth because its outcome is so profound and full of hope for the future, but that same woman dying painfully of breast cancer will be unlikely to find hope and value in this different pain. That same mother, perhaps with two young children and a husband whom she loves dearly, will be devastated by such circumstances, and her pain will be of a different kind to that of

297 Ms Tracy Endersby, Nurse, private citizen, *Transcript of Evidence*, 7 March 2018, p. 4.

*someone aged ninety with a similar condition who is nearing the end of their natural life.*²⁹⁸

3.192 Given that suffering and distress are both subjective and contextual, it must be acknowledged that some people's experience of suffering at end of life will not be completely palliated.

Finding 23

Too many Western Australians experience profound suffering as they die, in part due to inequitable access to palliative care; however, in the committee's view, even with access to the best quality palliative care, not all suffering can be palliated.

²⁹⁸ Dr Rodney Syme, *Time to Die*, Melbourne University Press, 2016, p. 69.

Chapter 4

Lawful options at end of life

- 4.1 There are currently several lawful options available to those with grievous and irremediable suffering due to terminal or life-limiting illness. Commonly, individuals choose comfort care and refuse further medical treatment in place of continued invasive treatments that incur distressing side effects. Less commonly, individuals suffering in extremis elect to refuse food and water – deliberately striving to hasten their death.
- 4.2 The committee has heard evidence of others who choose suicide – sometimes violently ending their lives when they are unable to undergo continued suffering caused by the symptoms of terminal or life-limiting illness.
- 4.3 Terminal sedation is another lawful option at end of life. Ordinarily, it is an option chosen by the treating doctor and may not be fully discussed with the patient. This option is usually only available in the last days and hours of life and is not widely offered, nor understood. Several witnesses described the sedation of a loved one right at the end of their life as the only effective means to relieve unremitting and distressing symptoms until death.
- 4.4 Although usually not a choice of individuals, there is also the prospect of a treating doctor refusing ongoing treatment due to futility. When medical treatment has reached its limits and it is no longer able to offer any benefit to a patient, a doctor may make the decision that further treatment is futile and stop active curative measures.
- 4.5 The committee heard from many individuals and health professionals regarding current options at end of life. Mr Nigel Haines told the committee about his wife Suzie’s long illness and prolonged death from dementia and implored the committee to:

*Do something, please.*²⁹⁹

- 4.6 Some health professionals also indicated the difficulties with the current options and that more must be done for Western Australians. Their views are summarised by Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital:

As legislators in this arena, please clarify what is acceptable practice and what is not acceptable practice for those clinicians involved in palliative care. I understand that this is very difficult given the breadth

299 Mr Nigel Haines, Individual, *Transcript of Evidence*, 30 April 2018, p. 7.

*of both community and health practitioner views [...] Consensus is unlikely to be reached but clear boundaries are required nonetheless.*³⁰⁰

- 4.7 In this chapter we outline the current lawful options available to patients and health professionals. It is clear there is significant work to be done in this area, by legislators and health professionals.

Refusal of medical treatment

- 4.8 Patients can, and do, choose to refuse medical treatment – including refusals that may result in death. Patient autonomy – the right to choose health care – emerged as a dominant medical ethical principle during the twentieth century and is usually associated with allowing patients to make their own health care decisions. The ethical principle of autonomy is contained in some form in most modern medical codes of conduct in the Western world.³⁰¹

What is the law on refusal of medical treatment?

- 4.9 The ethical position finds expression in law in the legal principle of self-determination articulated in 1914 by Justice Cardozo:

*Every human being of adult years and sound mind has a right to determine what shall be done with his own body.*³⁰²

- 4.10 Under common law, it is accepted that a competent person is not obliged to consent to medical treatment even if a refusal of treatment would result in the loss of the person's life.³⁰³ The right to bodily integrity is clear.³⁰⁴ Subject to some narrow exceptions,³⁰⁵ a person has the right to determine their own medical treatment.

300 Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital, Response to Questions on Notice, 25 May 2018.

301 For instance see [AMA Code of Ethics](#), 2.1.2; 2.1.5; and 2.1.6

302 *Schloendorff v Society of New York Hospital* 211 NY 125 at 129 (1914) per Cardozo J.

303 *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229. See also the United States (*Bouvia v Superior Court of Los Angeles County* 179 Cal App 3d 1127 (1986), 1137 and 1139-1141); Canada (*Nancy B v Hotel-Dieu Quebec* (1992) 86 DLR (4th) 385; *Malette v Shulman* (1990) 67 DLR (4th) 321, 328); the United Kingdom (*Airedale NHS Trust v Bland*, 857 (Lord Keith) and 864 (Lord Goff); *Ms B v An NHS Hospital Trust* [16]-[21]); New Zealand (*Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235, 245) and Australia (*Hunter and New England Area Health Service v A*, [9]-[15]).

304 *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449; See also *Re T (Adult: Refusal of Treatment)* (1993) Fam 95, 113 (cited with approval in *Ms B v An NHS Hospital Trust* [18] and *Hunter and New England Health Service v A* [15]).

305 See for instance, treatment provided in an emergency for an incompetent patient – section 110Z1 *Guardianship and Administration Act* 1990; treatment in relation to involuntary patients - section 175(1) *Mental Health Act* 2014; see also treatment of prisoners in accordance with section 95D *Prisons Act* 1981.

- 4.11 In fact, apart from those limited circumstances, a health professional who treats in spite of the refusal of consent by the person is acting unlawfully:

*The law treats as unlawful, both criminally and civilly, conduct which constitutes an assault on or a trespass to the person.*³⁰⁶

- 4.12 Further, adults are presumed to have capacity to consent to or refuse medical treatment unless, and until, that presumption is rebutted.³⁰⁷ For a valid refusal, a patient must have decision-making capacity, sufficient information to understand the nature and the effect of the treatment, and the decision must be voluntary. However, a competent adult can refuse medical treatment for any reason, even if there is no logical basis for that decision.³⁰⁸

Refusal of medical treatment is not suicide

- 4.13 Refusal of medical treatment is not characterised by the medical profession as suicide:

*[i]n clinical situations, if someone wants to end their life by refusing care (food or anything else) we DON'T usually call it suicidal behaviour (unless it's due to mental illness) – we would just call it 'refusing treatment' as there is no active act of trying to end life.*³⁰⁹

- 4.14 The legal position is also clear in relation to refusal of medical treatment:

*The legal concept of suicide, being the intentional taking of one's own life, is not engaged in a case where medical assistance is refused, even in the knowledge of certain death.*³¹⁰

- 4.15 Given this, a health professional withdrawing or withholding medical treatment – at the request of a competent patient – is not aiding a suicide.³¹¹

Do health professionals understand the law on refusal of medical treatment?

- 4.16 In his evidence to the committee, the Acting Chief Medical Officer for Western Australia, Professor David Forbes, indicated that the legal position is clear following the *Rossiter* case but noted that it may not be fully understood or accepted by the medical profession:

306 *Secretary, Department of Health and Community Services v J.W.B. and S.M.B (Marion's case)* (1992) 175 CLR 218 at per Mason CJ, Dawson, Toohey and Gaudron JJ at [8].

307 *MB* [1997] SCR 514 at [30].

308 *Re T (Adult Refusal of Treatment)* [1993] Fam 95 at [102].

309 Professor Steve Ellen, Director, psychosocial oncology program and the department of cancer experiences research, Peter MacCallum Cancer Centre, Honorary Clinical Professor, University of Melbourne, cited by Andrew Denton in further response to questions on notice, 13 May 2018, p. 7.

310 *X v The Sydney Hospitals Network* [2013] NSWCA 320 at [59]; *Re JS* [2014] NSWSC 302

311 Aiding a suicide is an offence under the WA Criminal Code – see section 288.

*[...] the medical establishment is not static. It changes. There are people coming into WA all the time, many of whom will have never heard of the Rossiter case. I also believe that there will be some practitioners who will be very uncomfortable with the ramifications of the Rossiter case and will be confronted by not intervening, and will have to work through that issue.*³¹²

- 4.17 Dr Timothy Koh, Chair of the Royal Australian College of General Practitioners (**RACGP**), indicated that although the case of *Rossiter* was not well known by GPs, refusal of medical treatment was a common part of general practice and well understood and respected by GPs consistently in Western Australia:

*It comes back to this idea of who makes the decision. In general practice, the way decisions get made is it is a shared decision-making model where your GP informs you of the benefits and risks of something and then you have the decision to make. If a patient refuses treatment, that might be quite a reasonable decision based on the analysis of benefits and risks or costs...It can happen when patients are competent and able to make decisions for themselves, or they have elected someone to do it on their behalf.*³¹³

- 4.18 It should be noted that, notwithstanding Dr Koh's comments above, there is no requirement for the patient's decision to refuse medical treatment to be a reasonable decision.

- 4.19 Catholic Health Care Australia referred the committee to its Code of Ethical Standards that outlines a *qualified* right of refusal:

*Patients have the moral right to refuse any treatment, **which they judge to be futile, overly burdensome or morally unacceptable**, and such refusals must be respected. In addition, healthcare practitioners may not override any refusal of treatment by a competent patient who is not mentally disturbed, clinically depressed or suicidal, irrespective of whether or not they agree with the patient's refusal.*³¹⁴

- 4.20 The committee is concerned that there may be some residual uncertainty on the part of health professionals regarding the absolute right of a competent patient to refuse medical treatment for any reason. The law does not require a patient to refuse on the

312 WA Department of Health, transcript of public hearing, p. 16

313 Transcript of public hearing 14 December 2017, pp. 10 – 11.

314 Catholic Health Australia, *Code of Ethical Standards*, at 1.16, p. 16 – sourced 28 May 2018. (emphasis added).

basis that treatment is futile, overly burdensome or morally unacceptable. A decision of a competent patient to refuse treatment may be made despite:

- the opinion or recommendations of a health professional;
- the practitioner feeling ‘uncomfortable’;
- others viewing the decision as unreasonable; or
- the refusal leading to death.³¹⁵

4.21 The decision to refuse treatment may occur in the context of a therapeutic relationship, but it is not a *joint* decision of the doctor and the patient. Whilst it is important that health professionals are consulted, the decision to refuse medical treatment is a decision for the patient. The extent to which the principle of self-determination prevails over the principle of the sanctity of human life in a case of refusal of medical treatment can be expressed this way:³¹⁶

*[[I]t is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so ...[t]o this extent, the principle of the sanctity of human life must yield to the principle of self-determination.*³¹⁷

4.22 WA Health publishes a Consent to Treatment policy³¹⁸ but this also does not provide sufficient information for health professionals in relation to a competent patient’s absolute right to refuse medical treatment.

Finding 24

There is uncertainty among some health professionals regarding the nature of the absolute right of a competent patient to refuse or consent to medical treatment.

Recommendation 15

WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical

315 “A decision to refuse medical treatment by a patient capable of making the decision does not have to be sensible, rational or well considered,” per Butler-Sloss LJ in *Re T* [1993] Fam 95 at 116.

316 Sonia Allan and Meredith Blake, *The Patient and the Practitioner: Health Law and Ethics in Australia*, LexisNexis Butterworths, 2014, at 3.101, p. 93.

319 *Airedale NHS Trust v Bland* [1993] AC 789 at [864] per Lord Goff.

318 WA Health, Consent to Treatment Policy, 2016.

treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.

Refusal of food and fluids

- 4.23 A competent individual can lawfully end their life by opting to stop eating and drinking. In accordance with the ethical principle of patient autonomy, and the legal principle of self-determination, the common law recognises the right of a competent adult to refuse food and water.³¹⁹
- 4.24 Similar to the unlawful provision of medical treatment, force-feeding a competent individual would ordinarily amount to a battery in civil law and/or an assault under the criminal law. 'The law treats as unlawful, both criminally and civilly, conduct which constitutes an assault on or a trespass to the person.'³²⁰

Is there a duty to provide the necessities of life?

- 4.25 Under the WA Criminal Code, a health professional who has someone under their care has a duty to provide the necessities of life.³²¹ 'Necessaries' includes the provision of food and fluids. In Australia, however, the courts have determined that where a lawful refusal is in place – that is, where a competent individual has directed the health professional not to provide nutrition and/or hydration – then the duty to provide necessities does not arise.³²²

A deliberate choice, or simply too tired to eat?

- 4.26 A number of health professionals who work in palliative care indicated to the committee that it was very rare for patients to decide to refuse food and water – with the deliberate aim of ending their life. Some of the health professionals who came before the committee were at pains to explain that patients naturally lose appetite and thirst at the end of life, and no longer wish to eat or drink:

It would be very, very common that people would lose their appetite altogether and that they would stop eating and drinking. That happens for a variety of reasons; one is a lack of appetite but the second is lack of energy, lack of thirst and being unwell generally that they are no

319 White, Willmott and Savulescu, Voluntary palliated starvation: A lawful and ethical way to die? *Journal of Law and Medicine*, 22, p. 376. See also the discussion by Martin CJ in *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [24].

320 *Secretary, Department of Health and Community Services v J.W.B. and S.M.B* (Marion's case) [1992] HCA 15 at [8].

321 Section 262 WA *Criminal Code Act* 1913.

322 *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [42] – [43] per Martin CJ; *H Ltd v J* (2010) 107 SASR 352 at [73] – [74] per Kourakis J.

*longer eating and drinking, and the body shuts down those desires for food and fluid.*³²³

- 4.27 However, the committee received evidence that the deliberate choice to end life – by refusal of food and water – is not an entirely uncommon practice. For example, Mr Bruce Buchanan gave the committee evidence about his wife’s decision to refuse food and water:

*She decided that she would not drink. She stopped drinking or would not drink one evening....she just clamped her mouth shut and she would not do anything. She was conscious for 36 hours or so. She was unable to speak. I was sitting by her bed holding her hand and every now and then I would squeeze her hand and she would squeeze back. That is how we communicated at that point. That was all of that day, and at about midday the following day there was no response when I squeezed her hand. She died about 24 hours after that, as far as I know quite painlessly.*³²⁴

- 4.28 Ms Janis Stanley provided a written submission to the Inquiry regarding her mother’s final days:

*My dear late Mother, at 103 years was only in a full aged care facility for the last few months of her life but found a way to end her suffering by starving herself to death and refusing all medications [...].*³²⁵

- 4.29 Professor Max Kamien also told the committee about a friend who had deliberately starved himself to death:

He developed an oesophageal pouch—that is a pouch on the oesophagus—and food gets caught in it. You have terribly bad breath. It is very difficult to swallow. The operation is very difficult. It nearly always cuts the recurrent laryngeal nerve which is the nerve that goes to the voice box. If he had that operation, he would never sing again. The other thing is the operation has a mortality rate in itself which is, depending on who does it, quite high. He said, “If I can’t sing, I can’t speak properly, and if there is the possibility that something goes wrong and I finish up a vegetable, like my brother, I will not have that

323 Dr Keiron Bradley, WA Health, *Transcript of Evidence*, 13 December 2017, p.2. See also Dr Timothy Koh, Chair, RANZCP, *Transcript of Evidence*, 14 December 2017, p. 11.

324 Mr Bruce Buchanan, Individual, *Transcript of Evidence*, 1 May 2018, p. 4.

325 Submission No. 473 from Ms Janis Stanley, 21 October 2017.

*operation” and he ceased food for four months and he starved to death.*³²⁶

- 4.30 Although in Mrs Buchanan’s case it was apparent that dehydration did not result in additional painful symptoms, there are cases where an individual does require palliation to address distressing symptoms. In those cases, a health professional may assist a dying patient to alleviate the symptoms of voluntary palliated starvation, which occurs when a competent individual chooses to stop eating and drinking. Palliative care is provided to relieve the symptoms associated with dehydration and starvation that may be experienced by the individual as death approaches.³²⁷

What is the law in relation to voluntary palliated starvation?

- 4.31 Although made in the context of refusal of *artificial* nutrition and hydration (a form of medical treatment) the decision in the *Rossiter* case has relevance. The case indicates that it does not matter *why* a person requires palliative care. The provision of such care is lawful, providing there is consent and the palliative care is not causing or hastening death. In the decision, His Honour Chief Justice Martin held that:

*The legal rights and obligations relating to the provision of palliative care are unaffected by the circumstance that the occasion for the provision of care comes about... if and to the extent that palliative care is administered with the informed consent of the patient, and does not have the effect of causing or hastening the death of that patient, no question of breach of legal obligation arises.*³²⁸

- 4.32 In a 2010 South Australian Supreme Court case, Justice Kourakis held that refusal to eat and drink would not constitute suicide:

*It is generally accepted as a matter of community standards, and in law, that a competent adult is not under a duty to take life sustaining medication and that a refusal to do so would not constitute suicide. Once that proposition is accepted it is difficult to maintain the proposition, that self-starvation is suicide as a matter of logic or by reference to consistent ethical principles.*³²⁹

326 Professor Max Kamien, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 2 March 2018, p. 12.

327 White, Willmott and Savulescu, Voluntary palliated starvation: A lawful and ethical way to die? *Journal of Law and Medicine*, 22, p. 1.

328 *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [52] – [53]. As highlighted in the case of *Rossiter* competent individuals can also refuse *artificial* nutrition and hydration (**ANH**) for instance via PEG³²⁸ feeding or via a nasal-gastric tube. Both are a form of medical treatment. Consequently, the same legal and ethical principles that apply to a competent patient’s refusal of medical treatment also apply to the refusal of ANH.

329 *H Ltd v J* (2010) 107 SASR 352 at [59].

- 4.33 Palliation under those circumstances would therefore be akin to the provision of palliation for a patient who has refused medical treatment.

*If refusing food and water is not suicide, those providing palliative care, with the intention of providing symptom relief rather than hastening death, in “assistance” of that aim, cannot be assisting a suicide.*³³⁰

- 4.34 Justice Kourakis’ judgment indicates that there are circumstances where refusal of food and water would not amount to suicide. In these cases, refusal of food and water is analogous with refusal of medical treatment.³³¹

- 4.35 White, Willmott and Savulescu contend that, ‘it can be both lawful and ethical to provide palliative care to reduce the suffering associated with such self-induced dying.’³³² They argue providing palliation should remain a decision of conscience for a health professional. However, conscientious objections have limits and a health professional who objects to providing care must respect autonomy and refer the patient to another practitioner.³³³

- 4.36 The committee received several personal stories about individuals choosing to refuse food and water in order to hasten an unavoidable death. One compelling case was provided by Dr Robert Edis, a neurologist, who told the story of one of his patients, Melanie, who suffered with advanced motor neurone disease (MND). The illness took a severe toll.

*She was a very intelligent young woman, from a big professional background. The loss of autonomy; the loss of dignity. She claimed that she had been sexually abused in the nursing home, and I said, “Melanie, that’s a terrible story, but I can’t go there.” The palliative care person took it up. She sent me an email: “Thank God some doctor is taking me seriously.” But it did not progress further, actually, with the nursing home. That was one of her complaints, and I believe—I suspect—it probably did happen.*³³⁴

330 White, Willmott and Savulescu, Voluntary palliated starvation: A lawful and ethical way to die? *Journal of Law and Medicine*, 22, p. 383.

331 Professor Steve Ellen, Director, Psychosocial Oncology Program & Cancer Experiences Research, Peter MacCallum Cancer Centre, Honorary Clinical Professor, University of Melbourne, cited with approval by Andrew Denton in further response to questions on notice, 13 May 2018, p. 7.

332 White, Willmott and Savulescu, Voluntary palliated starvation: A lawful and ethical way to die? *Journal of Law and Medicine*, 22, p. 386.

333 White, Willmott and Savulescu, Voluntary palliated starvation: A lawful and ethical way to die? *Journal of Law and Medicine*, 22, p. 386

334 Dr Robert Edis, Neurologist, Motor Neurone Disease Association WA (MNDWA), *Transcript of Evidence*, 2 March 2018, pp. 9-10.

4.37 Melanie could no longer tolerate her extreme suffering and elected to stop all food and water to hasten her death. She was provided with palliative care at Hollywood Hospital. Another hospice (where she had previously been an inpatient) refused to admit her again because staff were reluctant to provide palliation for her as she dehydrated, and starved herself to death. Fortunately, for Melanie, Hollywood Hospital agreed to take her in, and hospital staff provided her with palliation. Dr Edis described Melanie's transfer of care in her final days:³³⁵

You can only stay in a hospice for a maximum of about four weeks. So she was discharged to what was considered a very good nursing home, the high-dependency unit. She was there five days and then the staffing ratios, and her needs were so high, that she said, "Look, I just can't cope with this discomfort a lot of the time. Get me out of here." She called the ambulance from Fiona Stanley Hospital, and they came and said, "What are you doing? You're in a nursing home. We can't take you to hospital." She called them three times, and in the end they did. She was then transferred to Fremantle Hospital, at the holding ward there, where we saw her, where she said, "Well, how can I end my life? I will not go back to a nursing home. I refuse." We said, "Well, you have to. There isn't anywhere else you can go." So she said, "What can I do?", and I said, "Well, there is this thing called terminal dehydration, stopping nutrition, and we can do that, and I will negotiate with the hospice to get you there, and you will die within eight to 14 days, but we will cover your symptoms. We will cover the distress of thirst in the first day or two and anything else, and when you are ready to go, you let us know, and I am sure I can get the palliative care people to turn it on."

So I rang the [hospice] head and she said, "If she comes back here, I'll have nurses going on sick leave. We can't take her back." So I said, "All right; I'll try Hollywood palliative care, because she has got private health cover." One of the good things about private health cover is that there is a majority of palliative care beds in WA that are under private health care only. If you have private health care, it gets you a palliative care bed, so it is very good to keep your private health cover up. I had an interview with the palliative care physician at Hollywood, who was very supportive, and she talked to her team about it and said, "We've got this young woman who is in distress. She's in the terminal phase of her motor neurone disease. She wishes to end her life in this way. Will you agree to participate?" The nursing staff all agreed. If anyone disagrees, they can opt out of the team. The palliative care people do it

335 Dr Robert Edis, Neurologist, Motor Neurone Disease Association WA (MNDAWA), *Transcript of Evidence*, 2 March 2018, p. 9.

*that way. She came over. She then died under those circumstances. It was a very peaceful death.*³³⁶

- 4.38 In the committee's view, Melanie was exercising a lawful right in very difficult circumstances and it is regrettable that she was forced to go to such lengths, and had to endure additional suffering before she died.

Finding 25

A competent person's absolute right to refuse to eat and drink is clear at law, but not well understood by some health professionals.

Finding 26

In the case of a refusal of food and water by a competent person at end of life, there is clinical and legal support for the position that it is similar to the refusal of medical treatment and therefore is not suicide.

Accordingly, in circumstances where a competent patient at end of life has elected to refuse food and water, it is appropriate that the person be provided with palliative care.

Recommendation 16

WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. Training should also include those working in aged care.

Futility

- 4.39 Whilst decisions around futility of treatment are usually not decisions made by patients, they are relevant to end of life choices.
- 4.40 Doctors are not under an obligation to administer medical treatment, including life-sustaining treatment, for a patient in their care, if on the exercise of good faith and competent clinical judgement they consider that the medical treatment would be futile.³³⁷ Consequently, doctors can, on the basis of futility, unilaterally decide to withhold or withdraw medical treatment and there is no legal right for patients to demand treatment.³³⁸

336 Dr Robert Edis, Neurologist, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 2 March 2018, p. 9.

337 Downie, Willmott and White, Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining treatment, *New Zealand University Law Review*, 26(1), pp. 25 – 59

338 Downie, Willmott and White, Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining treatment, *New Zealand University Law Review*, 26(1), pp. 25 – 59.

4.41 The legal basis for such unilateral decisions is either that futile treatment is not in the patient's best interests or that there is no *duty* to provide the treatment. Failure to provide the treatment does not then breach the criminal law regarding the necessities of life.³³⁹

4.42 The case law in Australia has generally considered futile treatment in circumstances where the patient lacked decision-making capacity, as opposed to patients who retain capacity. Evidently, the law in this area is complex:

*Law governing the withholding and withdrawing of life-sustaining treatment from adults who lack capacity is not only complex, it is also at times uncertain, internally inconsistent, inconsistent with good medical and ethical practice, and counterintuitive.*³⁴⁰

4.43 In the case of a person who lacks capacity, treatment could be withheld or withdrawn on three grounds –

1. unilateral decision by the doctor that the treatment was futile;
2. declaration by the court; or
3. an advance health directive.

4.44 It is important to note that in the case of incompetent patients the Supreme Court retains (*parens patriae*) jurisdiction to intervene, particularly where there is dispute as to what course of action is in the patient's best interests.

How do health professionals decide futility?

4.45 The President of the Australian Medical Association (WA Branch) (**AMAWA**), Dr Omar Khorshid, highlighted the difficulty of reaching a view that treatment is 'futile':

[i]t is impossible to come up with a completely concrete and universally agreed definition of "futility". Different doctors will have different opinions about when a treatment is futile or not. That might come from their own ethical framework, it might come from optimism that is unfounded, or it might come from personal experiences and so on. Doctors are people, and these decisions are made in consultation with families.

339 Willmott, White and Downie: Withholding and Withdrawal of 'futile' life-sustaining treatment: unilateral medical decision-making in Australia and New Zealand, *Journal of Law and Medicine*, 20(4), pp. 907 – 924.

340 Downie, Willmott and White, Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining treatment, *New Zealand University Law Review*, 26(1), p. 32.

[a]t the end of the day, it is for families and doctors together to make appropriate decisions. Sometimes families have unrealistic expectations and doctors may override those and say, "Look, we understand where you're coming from but this treatment has a zero per cent chance of working. We are under no obligation to provide it." Sometimes it is provided because it seems to be on balance the best thing to do, even though the doctor knows the treatment is futile, but because it will make that family or that patient happier. There are lots of examples I can think of where individual doctors disagree.³⁴¹

4.46 The Acting Chief Medical Officer, Professor David Forbes indicated that:

It is a journey; it is not a single point, and a decision I made today might be fuelled by my anxiety about a whole lot of things, and it might be very different to the decision I make in a week's time, when I understand the process. Good clinical services deal with this all the time, and they do help patients make those judgements. Sometimes people are not ready to give up a futile treatment because they are not ready to face death, but in a week's time they may be. These debates and discussions are constantly going on between doctors and patients and treating teams, and they are weighed up differently.³⁴²

4.47 In his written submission, Consultant Anaesthetist Dr Brien Hennessy commented on the difficulty of the discussions with family members around futile treatments:

[...] we try to elucidate what the wishes of the patient might be given this situation before we negotiate a treatment path with appropriate boundaries. Although the family can't mandate futile treatment, many will pressure critical care staff to become complicit in their demands to receive all treatments possible as a default position. This default setting may or may not have been the wishes of the patient – that remains unknown. This default position is not in the patients' or community's best interests, as it is resource intensive and is ultimately unsuccessful. In my opinion, dying alone during resuscitation under anaesthesia in an operating room full of strangers, or shortly thereafter in an ICU or hospital ward is not a better death than comfort care in a hospital ward with family present. And unfortunately surviving critical care treatment

341 Dr Omar Khorshid, President, AMA (WA Branch), *Transcript of Evidence*, 28 February 2018, p. 10.

342 Professor David Forbes, Acting Chief Medical Officer, Department of Health, *Transcript of Evidence*, 18 May 2018, p. 33.

*in a debilitated state for a few months is the only other probable alternative.*³⁴³

- 4.48 Catholic Health Australia expressed the view that most people, at end of life, do not want highly burdensome or futile treatments – they would like to be ‘left in peace as far as possible, but have their pain managed’.³⁴⁴

Is the discussion about futility avoided?

- 4.49 The committee also received evidence that conversations around futility were sometimes avoided, and as a default position, health professionals would do everything to prolong life, especially in hospitals. This was emphasised during the evidence of Ms Gillian Henderson:

*I have worked in hospital settings for many years where everything is done to prolong life and very rarely is the discussion had, which takes a lot longer in any situation, to discuss the other options.*³⁴⁵

- 4.50 A 2016 survey found that doctors nominated family or patient request and doctors being locked in a curative role as the main reasons for continuing the provision of futile care.³⁴⁶

Finding 27

Decision-making in the area of futility of treatment is fraught for patients, families and health professionals.

Recommendation 17

WA Health should provide ongoing professional development – beyond undergraduate training – for health professionals about the transition from curative to non-curative end of life care and effective discussions with patients and families about futile treatments

WA Health should consider how it might effectively educate the community about end of life decision-making, and implement appropriate health promotion in this area.

343 Submission No. 398 from Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital, 19 October 2017, p. 2.

344 Mrs Suzanne Greenwood, CEO, Catholic Health Australia, *Transcript of Evidence*, 28 February 2018, p. 7.

345 Ms Gillian Henderson, Individual, *Transcript of Evidence*, 30 April 2018, p. 4.

346 Willmott, et al: Reasons Doctors provide futile treatments at the end of life: A qualitative study, *Journal of Medical Ethics*, 42, pp. 496-503.

Terminal sedation

What is terminal sedation?

4.51 When normal medical treatments cannot relieve severe symptoms such as pain and agitation, health professionals will sometimes treat a dying patient with terminal sedation.³⁴⁷

4.52 Terminal sedation is the palliative care practice of gradually increasing doses of analgesics and/or sedatives, usually without providing nutrition or hydration, until a coma state occurs prior to death. Dr Keiron Bradley, a senior palliative care specialist with WA Health, confirmed that terminal sedation is a palliative care treatment to assist patients at the end of life:

*Palliative or terminal sedation is the use of medication to induce decreased or absent awareness in order to relieve otherwise intractable suffering at the end of life.*³⁴⁸

4.53 Professor Lindy Willmott, a legal academic specialising in public health, told the committee that terminal sedation is used when a patient is:

*approaching the end of life and has refractory symptoms—symptoms that just cannot be managed by the usual pain and symptom relief—so the person is sedated to the extent that he or she becomes unconscious, and he or she will remain that way until death.*³⁴⁹

4.54 Silver Chain observed that terminal sedation is ‘standard practice’ in palliative care and confirmed its use as a treatment at the end of life:

*[...] it is a practice where there is significant distress or suffering of the individual that may not be fully controlled or adequately controlled. It really is at the end of life; it may be within the last 24 to 48 hours of life.*³⁵⁰

4.55 The practice of terminal sedation occurs in Western Australia for patients at the end of life; however, the committee received evidence suggesting an inconsistent

347 Johannes JM van Delden, Terminal Sedation: a source of restless ethical debate, *Journal of Medical Ethics*, 2007, 33 (4): p. 187.

348 Dr Keiron Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2017 – session one, p. 28.

349 Professor Lindy Willmott, Australian Centre for Health Law Research, Queensland University of Technology, *Transcript of Evidence*, 26 February 2018, p. 7.

350 Mr Mark Cockayne, General Manager, Health Care WA, Silver Chain Group, *Transcript of Evidence*, 14 December 2017, p. 15.

understanding of the practice by medical professionals, patients and their families, and that it is contentious amongst some health professionals.

- 4.56 As discussed further in this chapter, many health professionals that came before the committee indicated that increasing doses of pain relieving or sedating medications at the end of life (such as would be the case in terminal sedation) could be justified by the ethical doctrine known as the doctrine of double effect (see paragraphs 4.75 to 4.105).

Terminal Sedation: Lack of consistent language and definition

- 4.57 It became apparent that differences exist between health professionals in their use of the terms “sedation”, “terminal sedation” and “palliative sedation”. Even amongst specialist palliative care doctors, there is no agreed language or definition.
- 4.58 Throughout this report, the committee has elected to use the phrase “terminal sedation” to refer to treatment whereby sedation during the terminal phase of an illness continues until a patient’s death.

When is terminal sedation an appropriate treatment?

- 4.59 In 2009, the European Association for Palliative Care (EAPC) published a recommended framework on sedation for patients at end of life:

Continuous deep sedation should only be considered if the patient is in the very terminal stages of their illness with an expected prognosis of hours or days at most. Transient or respite sedation may be indicated earlier in the patient’s trajectory to provide temporary relief whilst waiting for treatment benefit from other therapeutic approaches.³⁵¹

- 4.60 The Australian and New Zealand Society of Palliative Medicine Specialists (ANZSPM) supports the EPAC framework for use of sedation in palliative care.³⁵²
- 4.61 Dr Keiron Bradley told the committee that terminal sedation is ‘available for patients who are at the end of their life and have intractable suffering that is not relieved by other means.’³⁵³ Doctors therefore may administer terminal sedation to alleviate both physical and/or psychological suffering in patients.³⁵⁴

351 European Association for Palliative Care (EPAC), Recommended framework for the use of sedation in palliative care, p. 584.

352 Australian and New Zealand Society of Palliative Medicine Specialists, 2017 Palliative Sedation Therapy Guidance Document.

353 Dr Keiron Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, WA Health, *Transcript of Evidence*, 13 December 2017, p. 28.

354 Dr Keiron Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, WA Health, *Transcript of Evidence*, 13 December 2017, p. 28.

- 4.62 The AMAWA emphasised that terminal sedation is appropriate for patients only at the end of their lives in its evidence to the committee. They suggested that to use it an earlier time might be considered euthanasia:

*It is not a choice available to patients who do not need it, because then it would not be terminal sedation or palliative sedation anymore; it would be, actually, euthanasia. I would rather just characterise it as one of the number of techniques used to relieve suffering at the very end of life in the delivery of palliative care.*³⁵⁵

Terminal sedation is not a universally available treatment

- 4.63 The challenges associated with the terminology surrounding terminal sedation were demonstrated in evidence from two palliative care specialists – Dr Anil Tandon, from Sir Charles Gairdner Hospital, and Dr Mary McNulty, from Silver Chain. Both indicated that they do not provide terminal sedation, and both were of the view that it is not practiced in Western Australia. Dr McNulty suggested that terminal sedation would not be a legal practice, and would be reportable to the Coroner.³⁵⁶

- 4.64 However, both Dr Tandon and Dr McNulty indicated that they treat patients with sedation at end of life to deal with distressing symptoms. Dr McNulty:

*We make a distinction between using sedation for symptom relief at the end of life in a way that is appropriate, to actually taking a person and sedating them so that they die of sedation [...]*³⁵⁷

- 4.65 Dr Tandon:

*this is not to say that we do not use sedatives in people in the last hours and days of life. We definitely do, as Mary has already pointed out, in other situations when a person is dying within hours or days and they are distressed. But that is not terminal sedation.*³⁵⁸

- 4.66 Catholic Healthcare and St John of God Health Care also gave evidence that highlighted the terminology difficulties, and both seemed to indicate an understanding of terminal sedation that differed markedly to that of the AMAWA and WA Health. Mrs Suzanne Greenwood, CEO, Catholic Health Australia stated that:

355 Dr Omar Khorshid, President, AMA (WA branch), *Transcript of Evidence*, 18 May 2018, p. 15.

356 Dr Mary McNulty, Palliative Care Medical Specialist, Silver Chain, *Transcript of Evidence*, 27 February 2018, pp. 8-11

357 Dr Mary McNulty, Palliative Care Medical Specialist, Silver Chain, *Transcript of Evidence*, 27 February 2018, p. 8.

358 Dr Anil Tandon, Palliative Care Medical Specialist, Sir Charles Gairdner, *Transcript of Evidence*, 27 February 2018, p. 10.

I think as Catholic providers, we would say that terminal sedation is really the administration of sedative medications in such a dose as a route to cause—to bring about—the patient’s death where death is the goal. So, of course, in that sense terminal sedation is not part of the practice of palliative medicine for Catholic providers of care. Certainly palliative sedation, though, is.³⁵⁹

- 4.67 Catholic Health’s account of terminal sedation also contrasted with the evidence of Professor Wendy Erber, Executive Dean of the Faculty of Health and Medical Sciences at the University of Western Australia (**UWA**). Professor Erber indicated that terminal sedation for unrelievable suffering is part of *good medical practice*.³⁶⁰ Further, according to Professor Erber’s colleague, Professor Kirsten Auret:

...there is a lot of confusion in these terms. I would think of them as relatively the same, so I probably would say we teach the term “terminal sedation” to the students rather than “palliative sedation”.... you will find that across countries even, quite how these terms are written about will vary slightly.³⁶¹

- 4.68 The committee heard evidence from some individuals who indicated they would have asked sooner for better pain relief for their loved ones – had they been aware that it was available.
- 4.69 The committee received confidential evidence from a witness regarding the protracted and painful death of her partner. Her partner had been admitted to a metropolitan hospice in Western Australia, and promised a peaceful death by his treating team. However, he endured many days of abject, appalling suffering. Finally, one of the nursing staff indicated to her that another treatment was available for her partner and that it would address his pain and distress. The witness recounted the final 17 days her partner spent in the hospital for the committee, and her evidence is reproduced at length over the following pages.

359 Mrs Suzanne Greenwood, CEO, Catholic Health Australia, *Transcript of Evidence*, p. 13. See also Dr Alison Parr, Director of Medical Services, St John of God Health Care, *Transcript of Evidence*, 28 February 2018, p. 13.

360 Professor Wendy Erber, Executive Dean, Faculty of Health and Medical Sciences, UWA, *Transcript of Evidence*, 1 March 2018, p. 3.

361 Associate Professor Kirsten Auret, Academic in Palliative Care, UWA, *Transcript of Evidence*, 1 March 2018, p. 5.

Case Study 4.1

In her own words, a witness explains the suffering of her partner until provided terminal sedation:³⁶²

Sometime during that period, he stopped drinking. He was no longer able to swallow so he was not allowed to drink in case he aspirated, although he was at that point still terribly thirsty, often begging for water. Our other child stayed on, and with our children and me by his side, my partner prepared for what he described as the good part—the restful, pain-free sleep.

Only it did not happen. Under sedation with an ever-changing cocktail of drugs, he was sometimes semiconscious, sometimes very anxious, restless, confused and disoriented. Most of all, he was in pain and completely bewildered by how far from what he had asked for his experience of dying actually was—how far from what he and we had believed could be achieved. And it just went on and on. It was interminable for us; I cannot imagine how he bore it. Attached to his body were four medication pumps, two butterfly ports for breakthrough medications, and a catheter. He wore a nappy. The usual regular blood pressure, blood oxygen level et cetera checks were made. He was washed daily, moved and moved again in an attempt to provide some sort of relief. The bed was constantly soaked by his perspiration, necessitating frequent changes of sheets and pillowcases. The bedsore specialist visited, and checked and treated a bedsore at the base of his spine and added socks et cetera. In other words, they continued to actively nurse him, all with a view to providing comfort but also all adding to his intolerable pain and distress. The main point to stress here is that any movement was painful. Even though they would sedate him first and then do the washing, bed linen et cetera, lying on his side was impossible for him—it was too painful because of the tumours in his pelvis and legs. He spent all his time on his back, but in order for all the necessary care to be carried out, he had to be turned on his side over and over. They would wash his front, turn him on his side, wash, turn him on the other side, wash, and then back onto his back. Even under such heavy sedation, he cried out, he groaned, he said no.

I protested and was told that it was in his best interests and he was not really in pain and that perhaps if it worried me I should leave the room.

Likewise, you can imagine the problems trying to change the bed linen a couple of times a day. In addition, he indicated every 20 minutes or so that he needed to be pulled up slightly and then laid back in a slightly different position, to try to be more comfortable. My child and I would sling an arm under his armpits each side and hoist him up in one quick move, or I would do it on my own when they was not there, but this does bad things to your lower back and quite understandably, nursing staff are not permitted to move a patient that way. They must use a slide sheet: you turn the patient on one side and ease the sheet under his body, then you turn him back onto his back and then onto the other side, ease the sheet under and then, grasping the sheet on either side you slide the patient up the bed. Again, being on his side was agony—four times for each move, several times a day. It was an unending nightmare.

Then there were the secretions. This is the polite term for the thick yellow liquid that builds up in the lungs and needs to drain once it reaches the throat. Again, my partner would be heavily sedated and we would prop him on his side and I would spend hours

swabbing the flow and wiping his face and neck until eventually the level dropped sufficiently and stopped and he could be laid back on his back [...].

Eventually his communication was limited to, “I love you”, and “Get me out of here”.

He indicated that he wanted to go home and take all the medication we had left in the house—anything to stop what was happening. I was beside myself; I was so tired, stressed, sad and desperate that I could not think straight.

Finally, in conversation with my friend, after I had conveyed to her our desperate situation she said, “you are too bloody polite. Go out into that corridor and make a fuss. Do whatever you have to do to get help for him. It must surely be possible to place him under some sort of anaesthetic—something that will put him in a coma.”

So I went out into the corridor and by chance, a senior nurse was on her way around with the drugs trolley. She called another nurse to take over and went and sat with me. I conveyed our desperation: the fact that my partner wanted to get out of there and that we had lost faith in the hospice’s ability to help us. She told me that there was another drug, which she believed, would have the effect that my partner wanted, but that our doctor did not believe in. I am not sure if she said, “believe in” or “agree with using it”. She told me its name, but I cannot remember what it was; I only heard it once. She said she was going to seek advice from a more senior doctor.

At the regular meeting of the doctors and nurses in staff the next day, when my partner’s doctor reported on his condition and the steps that were being taken to alleviate his suffering, she said, “Yes, but it’s not working, is it?” Discussion followed and it was agreed to place him on this other drug. Thank goodness for that nurse. We had never before been told by anyone that there were any other options available; we believed totally that everything had been laid out before us, that we had been provided with all the information and all the options, yet crucially important information had not been given us. We just could not believe it.

The drug was then administered and finally my partner was at peace; finally, he seemed to be without pain, in a deep, relaxed sleep. I hope that inside he was as comfortable as he appeared to us. Some days later—I cannot remember how many—he quietly passed away in his sleep, on his own.

Terminal sedation in Western Australia

- 4.70 The committee is satisfied that terminal sedation, as outlined in the evidence from UWA, the AMAWA and WA Health, is practiced in Western Australia for patients at the end of life, but that it is not offered consistently across palliative care settings. However, the committee could not locate any clear and accessible information on the extent of terminal sedation for patients in WA.

362 Identity withheld, *Transcript of Evidence*.

4.71 Given the evidence received by the committee that the practice is not regulated,³⁶³ nor specifically noted in patient medical records,³⁶⁴ it is not possible at present to quantify the extent of terminal sedation in Western Australia:

*Currently, there is no information about when and where this practice takes place and there are no safeguards nor consent protocols in place nor is the practice universally offered.*³⁶⁵

4.72 It is of concern to the committee that many patients at the end of life, and their family members are unaware of this treatment. In this context, it is also concerning that there is a lack of recording and data collection regarding this form of medical treatment.

4.73 The uncertainty among some health professionals regarding the legal status of terminal sedation at the end of life may lead to patients receiving less than optimal treatment, and continuing to suffer pain and other symptoms. Ms Georgie Haysom, from Avant Mutual, a medical insurer, indicated to the committee that practitioners:

*...express concern about providing increasing pain relief and sedation in the terminal phase of terminal illnesses because of the concern that they might be subject to prosecution, and that then, of course can lead to the potential for under-treatment of people's pain and symptoms.*³⁶⁶

4.74 Professor Willmott and her colleagues Professor Ben White and Ms Penny Nellar, in their submission, articulate some relevant legal and ethical considerations for the practice of terminal sedation:

- Whether the patient (or patient's family) are involved in the decision-making process, particularly where consent is obtained before this kind of sedation is provided;
- In what circumstances does it occur? For example, is it given to relieve physical symptoms only, or also to relieve psychological and/or existential suffering; and
- Whether artificial nutrition and hydration is provided or withdrawn during the period of sedation leading up to the patient's death.³⁶⁷

363 Dr Keiron Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2018, p. 30.

364 Mr Mark Cockayne, General Manager, Health Care WA, Silver Chain Group, Letter - response to question on notice, 15 February 2018, p. 4.

365 Dr Alida Lancee and Dr Richard Lugg, Doctors for Assisted Dying Choice, Letter, response to questions on notice, undated.

366 Ms Georgie Haysom, Head of Education and Advocacy, Avant Mutual, *Transcript of Evidence*, 28 February 2018, p. 2.

367 Submission No. 560 from Professors Willmott and White, and Ms Penny Nellar, 23 October 2017, p. 4.

4.75 There is no doubt that these considerations are complex, but it is important – for health professionals, patients and their families – that there is clarity and certainty regarding the practice of terminal sedation in Western Australia.

Finding 28

The committee received evidence from government agencies, medical professional bodies and medical educators providing a consistent explanation of terminal sedation and its use as an appropriate and lawful treatment option for patients suffering refractory symptoms at end of life.

There remains some confusion amongst health professionals as to the legal status and reasonableness of the clinical practice of terminal sedation and this confusion is likely to result in the denial of adequate symptom relief to some patients at end of life.

Recommendation 18

WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life. These guidelines should include an agreed name and definition of the treatment.

As per any other medical treatment, the requirement for informed consent must be clear.

The treatment must be specifically noted in the medical record as ‘terminal sedation’.

Doctrine of Double Effect

4.76 The WA *Criminal Code Act 1913 (the Code)* makes killing another person unlawful unless such killing is authorised, justified or excused by law.³⁶⁸ Depending on the circumstances, an unlawful killing will be classed as either murder or manslaughter. The Code also contains *deeming* provisions that outline the circumstances in which a person is deemed to have killed another, including:

- Any person who causes the death of another, directly or indirectly, by any means whatever, is deemed to have killed that other person;³⁶⁹ and
- A person who does any act or makes any omission which hastens the death of another person who, when the act is done or the omission is made, is labouring under some disorder or disease arising from another cause, is deemed to have killed that other person.³⁷⁰

368 Section 268, *Criminal Code Act 1913* (WA).

369 Section 270, *Criminal Code Act 1913* (WA).

370 Section 273, *Criminal Code Act 1913* (WA).

- 4.77 The effect of these provisions is that the conduct of a health professional – in administering potentially fatal doses of medications – is potentially criminalised under the Code.
- 4.78 A number of health professionals expressed a view that they are protected from prosecution by the operation of the medical ethical doctrine of double effect. According to the doctrine, a doctor is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures taken may incidentally shorten life, provided the doctor's *intention* is to treat the symptoms and not to cause the death.
- 4.79 The main difficulty with this is that the Code makes intention irrelevant unless it is expressly declared an element of the offence.³⁷¹ Consequently, unlike the offence of murder, manslaughter does not require proof of intention to kill or seriously injure.
- 4.80 If the law applies equally to all – health professionals and laypersons – a lack of intention does not therefore necessarily equate to non-criminal conduct. Under the law, doctors are not in a different category from other people: the question then becomes does the Code accept a different standard for health professionals, or does it provide a defence to the conduct?
- 4.81 Although there is uncertainty about the law in Australia in relation to the doctrine of double effect,³⁷² the most likely place for it in Western Australian law is section 259 of the WA Criminal Code. Section 259 effectively operates as a defence where a person is providing treatment, including palliative care, subject to specific conditions. Before turning to the defence at section 259 of the Code, we consider the history of double effect.

Where does it come from?

- 4.82 The doctrine of double effect is an ethical doctrine that derives from the 13th century thesis for the justification of self-defence by the Catholic theologian, St Thomas Aquinas:

*Nothing hinders one act from having two effects, only one of which is intended, while the other is beside the intention.... Accordingly, the act of self-defence may have two effects: one, the saving of one's life; the other, the slaying of the aggressor.*³⁷³

- 4.83 A person's act of killing another, if acting in self-defence, was thereby justified based on double effect – provided their intention was to prevent their own death or serious

371 Section 23 - *Criminal Code Act 1913* (WA)

372 See the overview provided by QUT End of life law in Australia – [Does the doctrine apply in Australia?](#) Website. Accessed 20 July 2018.

373 Alison McIntyre, 'Doing away with double effect', *Ethics* 111, no. 2, January 2001, p. 247.

assault; their conduct was necessary to prevent the death or serious assault; and their conduct was a proportional response to the attack.

How is it relevant to health care?

- 4.84 The doctrine of double effect initially applied in the health setting to justify termination of pregnancy where a continued pregnancy threatened a woman's life.³⁷⁴ Over time double effect developed as an ethical doctrine permitting health care professionals to administer potentially fatal medication, provided their intention was purely to treat pain and other symptoms. Proponents argue that the doctrine effectively distinguishes between intentional killing and merely foreseeing death as a possible side effect. One commentator declared the doctrine of double effect 'an ethical cornerstone in the medical treatment of the terminally ill'.³⁷⁵
- 4.85 The doctrine entered English law through the famous case of Dr John Bodkin Adams in 1957. As Justice Devlin noted, the doctrine permits the doctor to relieve pain, even if he incidentally shortens life by hours or perhaps even longer.³⁷⁶ Although accepted in many common law countries,³⁷⁷ it is apparent that the application and status of the doctrine of double effect remains uncertain in some jurisdictions.³⁷⁸

The scope of double effect

- 4.86 Double effect is not merely aiming at the good effect and tolerating the foreseeable bad effect. Moral philosophers generally agree that four conditions attach to the doctrine:
1. The nature of the act must be good, or at least morally neutral – the nature of the act providing symptom relief is morally good;
 2. The agent (health care professional) must *intend* only the good effect. The bad effect, even if foreseeable is tolerated but not intended – the intention must be to relieve distress not to hasten death;
 3. The bad effect must not be the means to the good effect – death must not be the means to relieve pain; and

374 Sonia Allan and Meredith Blake, *The Patient and the Practitioner: Health Law and Ethics in Australia*, p. 434.

375 T.E. Quill, The Ambiguity of Clinical Intentions (1993) 329, *New England Journal of Medicine*, 1039.

376 *R v Adams* [1957] Crim. L.R. 365. Interestingly, although acquitted and the doctrine of double effect given legal effect, following Dr Adams' death it emerged that he had been the beneficiary in 132 Wills, calling into question his 'pure' intentions. See also - Richard Huxtable, Get out of jail free? The doctrine of double effect in English law, *Palliative Medicine*, 2004, 18: p. 66.

377 E.g. *Airedale NHS Trust v Bland* [1993] AC 789 at 867 (England); *Compassion in Dying v State of Washington* 79 F. 3d 790 (1996) 822 (United States); *Auckland Health Board v Attorney-General* [1993] 1 NZLR 235 at 252, (New Zealand). Note also the legislative status of the principle in *Consent to Medical Treatment and Palliative Care Act* (1995) (SA) s 17.

378 Richard Huxtable, Get out of jail free? The doctrine of double effect in English law, *Palliative Medicine*, 2004, 18: p. 62.

4. There must be proportionality between the good effect and the bad effect – the person must be suffering significantly, and death will often be imminent.³⁷⁹ There is a treatment choice to make, and that choice is based on whether it is proportionate to a patient's condition.³⁸⁰

Intention versus foresight

- 4.87 In addition to the practical difficulty with respect to intention, another practical difficulty with the doctrine is the notion of intention versus the notion of foreseeability. Philosophers and ethicists have long debated the role and meaning of intention.³⁸¹ Blaise Pascal ridiculed Jesuit theologians for their view that good intentions can make a wrong act right.³⁸²

- 4.88 In the case of health professionals, ascertaining intention is notoriously difficult:

*The fine line between intention to relieve suffering and intention to end life is so fine as to be apparent only in the mind of the physician.*³⁸³

- 4.89 In the past the law would infer intention where consequences are foreseen, so that a person *intends* to cause a result if they foresee the harm as almost certain, rather than merely likely.³⁸⁴ More recently, in a decision in relation to the Queensland Criminal Code³⁸⁵ the High Court clarified the law, making it clear that knowledge or foresight of result, whether possible, probable or certain, is not a substitute for proof of specific intent.³⁸⁶ In effect, simply because a particular course of action – for example, the administration of a medication – is likely to result in a person's death, intent to cause that outcome cannot automatically be inferred.

When do doctors rely on the doctrine of double effect?

- 4.90 Given the ethical and legal difficulties, it is not surprising that the committee has received conflicting evidence about health professionals' reliance on the doctrine of double effect. According to Professor Gary Geelhoed, the Western Australian Chief Medical

379 Tom L. Beauchamp and James F. Childress (1994). Non-maleficence. In: *Principles of Biomedical ethics*, 4th ed, Ed T. Beauchamp and J. Childress. Oxford University Press, Oxford: pp. 206-11.

380 G Williams, The Principle of Double Effect and Terminal Sedation, *Medical Law Review*, 9, 2001, p. 41 - 53.

381 For example, see - Elizabeth Anscombe, *Intention*, Oxford, Basil Blackwell, 1958; and R.A. Duff, *Intention, Agency and Criminal Liability*, Oxford, Blackwell, 1990.

382 "For they content the world by permitting such actions; and they satisfy the Gospel by purifying intentions" Blaise Pascal, "Provincial Letters", in Peter Singer (ed.), *Ethics*, Oxford, Oxford University Press, 1994.p. 270.

383 Dr Peter Beahan, 'The Case for Voluntary Assisted Dying', *Medical Forum*, June 2018, p. 23.

384 *Cutter v The Queen* (1997) 94 A Crim R 152.

385 This is also relevant to Western Australian criminal practice as it is a code jurisdiction.

386 *Zaburoni v The Queen* [2016] HCA 12.

Officer (at the time of giving evidence), the doctrine is crucial to all doctors and part of basic training given that they will deal with death at some stage:

Speaking to many, many doctors, most doctors—I am sure all doctors—say they will come across death of patients at some stage, so it is something that is crucial to all of them. Every doctor I have ever raised it with, or talked about it with, knows what you are talking about, just because it is such an important topic, I guess.³⁸⁷

4.91 Dr Timothy Koh of the Royal Australian College of General Practitioners indicated to the committee that doctors continue to rely on the doctrine of double effect:

The doctrine of double effect appears to be similar in principle to the provisions of section 259 of the WA Criminal Code. This allows practitioners acting in good faith to provide beneficial medical treatment without the burden of criminal responsibility in the event of harm.³⁸⁸

4.92 The committee also heard evidence from Professor Wendy Erber, that:

In terms of the doctrine of double effect, I think people are particularly interested in it in terms of what do we teach the students about terminal sedation; I think that is often where it comes up. We formally teach them what palliative care is and what the faculty considers good medical practice.³⁸⁹

4.93 However, Dr Bradley indicated that medications for symptom control ‘do not hasten death’ provided the medications are given appropriately, and there is no need to rely on the doctrine of double effect.³⁹⁰

4.94 Similarly, Dr McNulty told the committee that:

We are very certain that the drugs we use do not hasten death, which is why we do not believe that we need the principle of double effect, because we actually are not doing anything to hasten death.³⁹¹

387 Professor Gary Geelhoed, Chief Medical Officer, Department of Health, *Transcript of Evidence*, 13 December 2017 – session two, p. 16.

388 Dr Timothy Koh, Chair, WA Branch RACGP, Letter - Response to question on notice, 12 February 2018.

389 Professor Wendy Erber, Executive Dean, Faculty of Health and Medical Sciences, UWA, *Transcript of Evidence*, 1 March 2018, p. 3.

390 Dr Keiron Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, *Transcript of Evidence*, 13 December 2017, p. 19.

391 Dr Mary McNulty, Palliative Care Medicine Specialist, Silver Chain, *Transcript of Evidence*, 27 February 2018, p. 6.

4.95 Dr Anil Tandon also informed the committee that pain medicines and sedatives at the end of life do not hasten death.³⁹²

4.96 It is claimed by some health professionals that they do not rely on the doctrine of double effect. In other words, they know how to administer opioids and other pain relieving or sedating medications with negligible risk. If this were the case, as Professor Richard Huxtable points out, 'any case where a patient has died following the administration of powerful analgesics (or sedatives) demands a hard look'.³⁹³

Some uncertainty regarding the doctrine

4.97 The WA Commissioner of Police initially informed the committee that a death associated with the doctrine of double effect would be reportable to the Coroner, and that the police would have a duty to investigate.³⁹⁴ Subsequently, in his response to questions on notice, the Commissioner indicated his view had changed and such a death did not fall within the definition of Reportable Death under section 3 of the *Coroners Act 1996*.³⁹⁵

4.98 It is evident that there is a lack of clarity around the status and application of the doctrine of double effect.

Section 259 WA Criminal Code

4.99 Section 259 of the Code provides that a person is not liable for administering (or not administering/ceasing to administer) surgical or medical treatment (including palliative care) if it is done (or not done) in good faith and in the exercise of reasonable care and skill:

- (1) A person is not criminally responsible for administering, in good faith and with reasonable care and skill, surgical or medical treatment (including palliative care) –
 - (a) To another person for that other person's benefit; or
 - (b) To an unborn child for the preservation of the mother's life,

If the administration of the treatment is reasonable, having regard to the patient's state at the time and to all the circumstances of the case.

- (2) A person is not criminally responsible for not administering or ceasing to administer, in good faith and with reasonable care and skill, surgical or medical treatment (including palliative care) if not administering or ceasing to

392 Dr Anil Tandon, Chairman, WA Palliative Medicine Specialist Group, *Transcript of Evidence*, 27 February 2018, p. 6.

393 Richard Huxtable, Get out of Jail free? The doctrine of double effect in English law, in *Palliative Medicine*, 2004; 18: p. 64.

394 Mr Chris Dawson, WA Commissioner of Police, *Transcript of Evidence*, 27 February 2018, p. 2.

395 Mr Chris Dawson, WA Commissioner of Police, Letter - response to questions on notice, 9 May 2018.

administer the treatment is reasonable, having regard to the patient's state at the time and to all the circumstances of the case.³⁹⁶

- 4.100 It is clear from the evidence that section 259 is where the RACGP considers the doctrine of double effect fits into the Code. Associate Professor Blake also indicated that section 259 is the appropriate provision under which to consider the doctrine of double effect:

*I think there is clearly a scope within that provision to accommodate that sort of situation, which the principle of double effect appears to try to address or has been applied in those sorts of instances.*³⁹⁷

- 4.101 The legislative history of section 259 does not include reference to 'double effect' or to 'terminal sedation'. The amendment in 2008 to insert "including palliative care" passed without debate. "Palliative care", in this context, encompasses the practice of terminal sedation. Section 259(1) captures the doctrine of double effect. The connection between section 259, the doctrine of double effect and palliative care is implicit. Whilst the doctrine of double effect already existed before 2008, the insertion of palliative care into section 259 provides clarity.

- 4.102 WA Supreme Court Chief Justice Martin's decision in the *Rossiter* case provides guidance:

*The third general principle, which can be stated, is that it is unlawful for any person, including any health professional, to administer medication for the purpose of causing or hastening the death of another person. It will be seen that these general principles cover the ends of a spectrum of possible facts and circumstances. Within that spectrum is the circumstance in which medication, which might be administered for the purpose of relieving pain or easing discomfort, might have the incidental effect of hastening death. Section 259(1) might well provide a defence to any criminal charge brought in such a circumstance. Whether or not it does will, of course, depend upon all the particular facts and circumstances of that case, including the condition of the patient and the palliative care provided. Within the range of possible facts and circumstances, the application of the provisions of subsection (1) of s 259 will depend critically upon the particular facts and circumstances of the individual case.*³⁹⁸

- 4.103 However, Doctors for Assisted Dying Choice implied that the current legal framework is subjective and grey in nature:

396 Section 259, *Criminal Code Act 1913* (WA).

397 Associate Professor Meredith Blake, Legal Researcher, UWA, *Transcript of Evidence*, 26 February 2018, p. 8.

398 *Brightwater Care Group Inc. v Rossiter* [2009] WASC 229 at [54] – [55].

*The current law relies on the apparent intent of the medical practitioner. An observer may not know this intent and may misinterpret the medication provided to relieve symptoms as an attempt to hasten death. Drugs used to sedate or relieve pain may also reduce respiration. Once this observer has this interpretation, they can report the death to the police, which would spark a murder investigation and charge. Only during a court proceeding, would the doctor be able to use the doctrine of double effect as a defence.*³⁹⁹

4.104 There have been only two prosecutions in Western Australia where a doctor was accused of administering fatal doses of medication. In both cases, neither practitioner relied on section 259 (or the doctrine of double effect).⁴⁰⁰ In one case, the jury acquitted after only 10 minutes deliberation. In the other case, the accused was convicted, but the conviction was overturned on appeal.

4.105 Fear of unwarranted prosecution may therefore be overestimated. This was highlighted in the evidence of Dr Omar Khorshid. When asked if there was a great fear in the medical profession, he responded:

*I can say very emphatically that no, that is not a fear. That has not been communicated to us by any of our members. That is proven by the lack of prosecutions over the decades. There have been a couple of cases. We actually had a legal expert from MDA National at our symposium to show us a couple of those cases that happened over the years, including a couple here in Western Australia, but doctors just have not been prosecuted. It is not fair to say that there is some terrible risk that they are going to be, and we do not fear that.*⁴⁰¹

Possible reform?

4.106 The committee received a submission that called for reform of the Code.⁴⁰² However, in the committee's view section 259 provides an appropriate defence to a charge of unlawful killing. A health professional is protected when they administer medications at end of life (as part of palliative care) if they do so in good faith; and with reasonable care and skill, by reference to the person and all the surrounding circumstances.

399 Dr Alida Lancee, Medical Practitioner, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 2 March 2018, p. 5.

400 Urologist, Dr Darryl Stephens and Manjimup doctor, Dr Zylvain Jemielita.

401 Dr Omar Khorshid, President, AMA (WA Branch), *Transcript of Evidence*, 18 May 2018, p. 14.

402 Submission No. 584 from Associate Professor Blake and Dr Craig Sinclair, UWA, 23 October 2017, p. 7.

Finding 29

There was no overwhelming call from the medical profession or the wider community for amendment to section 259 of the WA Criminal Code.

Finding 30

The doctrine of double effect is an ethical doctrine relied on by some doctors when providing palliative care at end of life. Although it has not yet been fully determined, it is likely enshrined as a defence under section 259 of the WA Criminal Code.

Finding 31

There is a fine balance in providing protection for both vulnerable patients and the health professionals who care for them at end of life. Section 259 of the WA Criminal Code gives appropriate weight to both parties so that all relevant matters can be assessed on a case-by-case basis.

Suicide

The incidence of suicide in Western Australia

- 4.107 In 2016, 2,866 people died from intentional self-harm (suicide) in Australia.⁴⁰³ In the same year, 371 people died from suicide in Western Australia. It is widely recognised that the reasons for suicide are complex and multi-factorial. Lifeline Australia cites crisis, recent difficult life events, depression, anxiety, misuse of alcohol or drugs, trauma or abuse in childhood, and physical illness or disability as some of the reasons people intentionally self-harm.⁴⁰⁴
- 4.108 In Australia, the Commonwealth Department of Health is responsible for the National Suicide Prevention Strategy and provides extensive programs and resources for the community and health professionals.⁴⁰⁵ In 2015, the WA Government launched the Suicide Prevention 2020 strategy,⁴⁰⁶ which aims to halve the number of suicides in ten years and to reflect current research and evidence-based approaches to suicide prevention.
- 4.109 In recent decades, suicide has been increasingly seen as a serious health issue whereas in the past a more punitive approach was taken.

403 Australian Bureau of Statistics – Causes of Death.

404 Lifeline.org, Self-harm, [Factors that may increase self-harm behaviour](#).

405 Life in Mind Australia, [Life in Mind - Suicide Prevention](#).

406 WA Mental Health Commission, [Suicide Prevention 2020](#).

Development of the law

- 4.110 In early English common law, the offence of suicide was known by the archaic Latin term *Felon de se*.⁴⁰⁷ Suicide was regarded by the Church as a mortal sin, and considered a felony at law. Consequently, civil rights were extinguished and personal property and some interests in land (such as leaseholds) were forfeited to the King.
- 4.111 From the middle of the nineteenth century, *attempted* suicide was also considered a criminal offence.⁴⁰⁸ As late as the 20th century, following a suicide, families were not permitted a private burial and the rites of the Christian church were also forbidden.

Current law in Western Australia

- 4.112 Suicide has never been a crime in Western Australia. However, an *attempt* to commit suicide was criminalised as a misdemeanour. An offender was liable to a maximum punishment of imprisonment with hard labour for one year. Attempted suicide only became lawful in Western Australia in 1972, following repeal of section 289 of the Criminal Code.⁴⁰⁹
- 4.113 Procuring, counselling or aiding another to kill themselves remains a serious offence under the WA Criminal Code carrying a maximum penalty of life imprisonment.⁴¹⁰ In addition, consent by a person to the causing of their own death, does not affect the criminal responsibility of the killer.⁴¹¹ Therefore, the survivor of a suicide pact who kills the other party is guilty of unlawful killing.

The evidence from the Western Australia Coroner

- 4.114 In Western Australia, a coroner has jurisdiction to investigate all reportable deaths – including those by suicide.⁴¹² The State Coroner provided the Inquiry with a report in relation to suicides in Western Australia for the period 1 January 2012 – 5 November 2017, where the deceased had a terminal or debilitating illness.⁴¹³

407 *Felo de se* is where a man of the age of discretion, and compos mentis, kills himself by stabbing, poison or any other way, in Hale, *Pleas of the Crown* (1800) I, 411, cited in Suicide and The Law, by the Honourable Sir John Vincent Barry, Melbourne University Law Review, Vol. 5, 1965.

408 Suicide and The Law, by the Honourable Sir John Vincent Barry, *Melbourne University Law Review*, Vol. 5, 1965, p. 5.

409 See section 10, Criminal Code No. 21 of 1972

410 Section 288 WA Criminal Code.

411 Section 261 WA Criminal Code.

412 Sections 3 & 19 *Coroner's Act* 1996

413 Mr Gary Cooper, Principal Registrar, Coroner's Court WA, supplementary information - Coronial Report: CR17-61.1, 24 May 2018.

- 4.115 The report was prepared by staff at the National Coronial Information System (NCIS),⁴¹⁴ and included 199 cases of relevance where the deceased had been diagnosed with a terminal or debilitating condition.
- 4.116 Some of the means of suicide included poisoning, hanging, gunshot, plastic bag asphyxiation, knife injuries, carbon monoxide poisoning and fire related deaths. Despite the reluctance of the NCIS report authors to attribute cause and effect, the committee notes that in many of the cases terminal or debilitating illness was a significant feature. Indicators of the relationship between these factors were evident in a number of cases, and these have been summarised in **table 4.1**.

Do people deliberately end their lives because of terminal or debilitating illness?

- 4.117 Drawing upon the data provided by the NCIS, the committee estimates that approximately 10 per cent of all suicides in Western Australia in any year are carried out by individuals suffering from a terminal or debilitating chronic illness.⁴¹⁵ Analysis of evidence from international jurisdictions reaches similar conclusions on the incidence of suicide amongst the terminally ill:

*In the UK it has been estimated that around one in ten suicides is in the context of a terminal or severe chronic illness [...], and 1 in 10 suicides in the USA has been determined to occur without an identifiable mental disorder [...].*⁴¹⁶

- 4.118 The committee also heard direct personal and tragic evidence about people who had attempted or completed suicide due to a terminal or debilitating condition. Professor Max Kamien informed the committee of his patient, a 65 year old medical physicist:

*She had disseminated breast cancer with severe bone pain. She came to see me—I am not her doctor, but I knew her from the hospital—and she asked me, as she had asked several of her specialist colleagues, what was the best way to kill herself. She put her affairs in order and she died at home alone. She ingested several concoctions that she had managed to acquire.*⁴¹⁷

414 The NCIS is an electronic database of coronial information containing case details from the coronial files of all Australian states and territories, except Qld, dating back to 1 July 2000, Qld data is contained from 1 January 2001. NZ data is available for deaths reported from 1 July 2007. (The report did not include cases that were still open at the time the report was prepared).

415 The NCIS indicated that there were 1,720 cases of intentional self-harm reported to the coroner for the period subject to the NCIS report (01/01/12 – 05/11/17). During that time, 199 cases were identified where the deceased had been diagnosed with a terminal debilitating physical condition. 199/1,720 is 11.5 per cent.

416 Submission No. 642 from Mr Neil Francis, Dying For Choice, 23 October 2017, p. 11.

417 Professor Max Kamien, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 2 March 2018, p. 3.

Table 4.1: Sample of coronial cases where a person with a terminal illness completed suicide.⁴¹⁸

<p>Case 59 – The deceased was an older female who died as a result of plastic bag and helium asphyxia. Approximately two weeks prior to her death [...] the deceased indicated to her surgeon that she was contemplating suicide rather than undertaking radical surgery, which was unlikely to be successful. The deceased was found unresponsive in her bedroom.</p>	<p>Case 134 – The deceased was an adult male who died due to hanging in his own home. In the weeks prior to his death, the deceased was suffering pain following recent colon surgery, which involved the removal of a colostomy bag. His treatment included daily medications, including Fentanyl patches and oral analgesia to manage pain, but the deceased remained anxious and depressed about his symptoms.</p>
<p>Case 63 – The deceased was an older male who died as a result of self-inflicted gunshot wound. A suicide note referenced the deceased’s ill health. The deceased was found in the garden and unable to be revived.</p>	<p>Case 143 – The deceased was a middle aged man who died due to mixed drug toxicity in his own home. A farewell letter, as well as several handwritten notes relating to the deceased’s illness and medical treatment were located. Post mortem toxicological analysis detected a fatal level of paracetamol in the deceased’s system.</p>
<p>Case 80 – The deceased was a middle aged man who died of combined effects of bronchopneumonia, prescription drug effect and inhalation of toxic fumes in his vehicle on a dirt track. The Coroner noted that the deceased was suffering an untreatable illness and was enduring gradual deterioration in quality of life. Toxicological analysis found a high level of carbon monoxide in his blood, due to the inhalation of motor vehicle exhaust fumes.</p>	<p>Case 146 – the deceased was a middle aged man who died due to carbon monoxide toxicity in his vehicle parked on his own property. He had indicated to his family and friends that he would rather take his own life...than face ongoing medical procedures due to his cancer. He left a suicide note referencing medication he planned to use.</p>
<p>Case 84 – The deceased was a middle aged female who died by hanging on her home property. She left notes indicating her intention to take her life due to the debilitating effect of her dental problems. The Coroner determined that the deceased took her life as a result of suffering from chronic pain that significantly affected her quality of life.</p>	<p>Case 153 – The deceased was an older man who died when he ingested a fatal amount of benzodiazepine medication in his own home. In the week prior to his death, the deceased told his son that he was fed up with his condition and did not wish to go to hospital. The deceased was located by his neighbour, deceased in bed.</p>
<p>Case 87 – The deceased was an older female who died of aspiration pneumonia. A suicide note found in her house stated that the deceased was in significant pain that she could not handle anymore, and indicated she had intentionally taken large amounts of paracetamol. Toxicological analysis found only therapeutic levels of medication, with the cause of death being aspiration. The investigation indicated that the deceased</p>	<p>Case 157 – The deceased was a middle aged man who died due to self-inflicted gunshot wound sustained in his own home. He had been diagnosed with a probable brain tumour. The Coroner found that the deceased’s concern over his quality of life being affected by the tumour was the reason he took his life.</p>

⁴¹⁸ Mr Gary Cooper, Principal Registrar, Coroner’s Court WA, supplementary information - Coronial Report: CR17-61.1, 24 May 2018.

possibly consumed scouring powder, however this could not be tested for toxicology.

Case 110 – The deceased was an older male who died as a result of hanging. He had mentioned to a friend that he was sick of his condition and at times wanted to end his life. He was discovered deceased at home.

Case 126 – The deceased was an older female who died due to self-inflicted sharp force injury sustained in her own home. A suicide note and a diary entry was found which highlighted the constant pain and discomfort the deceased was suffering.

Case 162 – The deceased was an older male who died after ingesting weed killer in his own home. He had a number of comorbidities. His pain resulted in a poor quality of life, and he had reported to his family that his pain was unbearable and the treatment was not giving him any relief.

4.119 Mr William Philip gave evidence of his wife’s attempted suicide some years prior to her eventual traumatic death:

My wife was always convinced that the end of life was something that should be dignified and comfortable if it possibly could. When she received the diagnosis of this adenoma, she thought that she was probably going to die of something like a ruptured bowel, a ruptured stomach or some complication thereof, and she was terrified. She had been, for quite some years before that, on various opiate drugs for a serious back injury which resulted from 50 years of hard lifting in nursing and she had accumulated quite a large supply of those which she took all at once. I was fully aware that she intended to do that. I was in the room when she took them. I was in the room when she took them. I did not assist her in any way, but I did not try to stop her and I promised that I would not call doctors or take her to hospital. I understood her intention to die. She was fully in her right mind and she was not going to go any further than she had to. She did not. She survived for four days at home with me keeping an eye on her and trying to make sure that she did not have any nasty complications if she did survive. Eventually it became obvious that firstly, the opiates had worn off and had not killed her and secondly, the benzodiazepines and various other drugs she was on she was in withdrawal from and she was becoming unmanageable. I then broke my promise and got an ambulance and got her down to the hospital.

I told the hospital what had happened and subsequently we had the police, psychiatric services and various other people really giving us a going over. I have been a justice of the peace for about 34 years and I

fully understood the laws relating to helping people die or what have you and the police eventually were satisfied that I had not. But it was a wracking situation and when my wife recovered in hospital and came home, the first thing she did was round on me and say, "Why didn't you smother me while I was unconscious?" Which was pretty horrible to hear too. However, she thought things through for a while and decided that she would not do that again and she would go along and try to make clear to people who were caring for her as her condition worsened that she did not want to be kept alive by artificial means, that she did not want her life prolonged to the detriment of any kind of standard of independence, dignity, comfort, continence et cetera.

She probably had a couple of quite reasonable years out of it living in a wheelchair and variously not being able to do a lot of the things that she wanted to, but she had a reasonable life.⁴¹⁹

4.120 The committee notes that morphine is not suitable for suicide. In his evidence Dr Brien Hennessy described morphine as 'an imperfect drug with a variable effect'.⁴²⁰

4.121 Dr Philip Nitzschke explained that the problem with morphine is that it is 'an extremely variable drug in terms of its effects on individuals'.⁴²¹

4.122 These observations were supported by the evidence provided by Mr William Philip about his wife's unsuccessful attempt to end her life by taking a large quantity of opiates.⁴²²

4.123 Ms Noreen Fynn gave evidence about the death of her husband, Clive Deverall:

At the end, the full force of symptoms had kicked back in. This included severe neuropathic pain, crippling headaches, insomnia and fatigue that would leave him unable to even walk to the corner of the street. His body was breaking down, his suffering was terrible to see and while he and the medical profession had tried everything, there was no prospect of a cure nor recovery and no hope. And so faced with this, he chose to end his own life on Election Day 2017. This was not a choice between life and death.⁴²³

4.124 Mrs Margaret Beilby gave evidence about the suicide of her husband:

419 Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 1.

420 Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital, *Transcript of Evidence*, 30 April 2018, p. 2.

421 Dr Philip Nitzschke, Director Exit International, *Transcript of Evidence*, 13 April 2018, p. 11.

422 Mr William Philip, Individual, *Transcript of Evidence*, 1 May 2018, p. 1.

423 Ms Noreen Fynn, Individual, *Transcript of Evidence*, 1 May 2018, p. 1.

My husband was a very active and busy person. He had been a teacher for 35 years and a deputy headmaster for 20 years, and sometimes acting principal. He spent his life in his shed. He built boats, he sailed yachts, he built model yachts, he sailed them internationally and nationally. He built model planes and flew them nationally and internationally. He supervised the building of our house and did all the woodwork inside and outside....He had always had asthma all his life, and he gradually got worse and worse until he ended up with COPD—chronic obstructive pulmonary disorder. By 2013 he was down to approximately 20 per cent lung capacity. He had Parkinson’s disease, and he was down to shuffling from room to room. He could sit and read and sit and watch TV, sit and do Sudoku, and not much else. If he fell over he could not get up, and I could not lift him. I would have to run across the road and get the bloke across the road to come over and lift him up.....he hated hospital. He did not want to go into hospital because he would lose control of his life, and he was scared that he would get so weak I would not be able to go on looking after him at home. So he joined Exit International and illegally imported Nembutal from China, and when it came he took it. He mixed it up, he drank it down, he drank a glass of port to take away the taste, because apparently it tastes awful, and to help the action of the drug, and then he sat back in his chair and went to sleep and died.⁴²⁴

4.125 Mr John Ireland gave evidence to the Inquiry about the suicide death of his mother who ‘was a very active woman at age 78. She then had a stroke [...]’:

... at 80 years of age, her quality of life was so intolerable that she took her own life by placing a plastic bag over her head, tying it tightly and dying from carbon dioxide poisoning.⁴²⁵

Finding 32

Approximately 10 per cent of all suicides in Western Australia in any year are carried out by individuals suffering from a terminal or debilitating chronic illness.

Are people deliberately ending their lives early?

4.126 It is not surprising that many of those who choose to take their lives as a result of a terminal or chronic illness are doing so earlier than they otherwise would want to on the basis that they fear some future loss of physical capacity. In relation to her husband Clive Deverall, Ms Fynn told the committee that:

424 Mrs Margaret Beilby, Individual, *Transcript of Evidence*, 1 May 2018, p. 2.

425 Mr John Ireland, Individual, *Transcript of Evidence*, 30 April 2018, p. 1.

*we are [...] in no doubt that had Clive known that he had the choice of voluntary assisted dying, we would have had him with us for a bit longer, and that is an absolute tragedy.*⁴²⁶

4.127 Dr Robert Edis cares for people with MND. He told the committee that:

I have one person at the moment, who has been a very strong man, and who is a member of Exit, and he is planning his death.

*I have had a number of people suicide because they just did not want to face those difficulties at the end, particularly without support.*⁴²⁷

4.128 The early ending of life was considered in the seminal Canadian case of *Carter vs Canada*. In February 2015, the Supreme Court of Canada ruled that the prohibition against physician-assisted dying violated the constitutional right to ‘life, liberty, and security of the person’. In its decision, the appeal court upheld the conclusion of the trial judge, Justice Smith, that:

*The prohibition on physician-assisted dying had the effect of forcing some individuals to take their own lives prematurely; for fear that, they would be incapable of doing so when they reached the point where suffering was intolerable.*⁴²⁸

What is the impact on families, loved ones and first responders?

4.129 The committee acknowledges that each of these deaths, and other suicides in similar circumstances, are devastating for families and friends.

4.130 In addition, police, ambulance officers and health professionals who act as first responders may also be traumatised. Western Australia’s Commissioner of Police indicated the effects on police officers:

Police officers suffer the same emotions and these are often very upsetting matters for all parties concerned. We take steps both from initial recruit training, through to those officers who are regularly attending such deaths from our coronial, homicide and the like squads. They may attend these as a far more frequent matter. We have appointed a clinical psychologist to assist police officers to ensure their wellbeing—particularly their psychological care—is being properly

426 Ms Noreen Fynn, Individual, *Transcript of Evidence*, 1 May 2018, p. 2.

427 Dr Rober Edis, Consultant Neurologist, Motor neurone disease association, *Transcript of Evidence*, 2 March 2018, p. 6.

428 *Carter v. Canada* (Attorney General), Supreme Court Judgments 2015 SCC 5. 35591. Feb 6, 2015.

*cared for. Yes, my answer is that it does have an effect on police officers.*⁴²⁹

Finding 33

The prohibition of a peaceful, assisted death has driven some terminally or chronically ill individuals to suicide using violent means.

Finding 34

Some individuals who suicide under these circumstances are driven to take their lives early. All deaths under these circumstances are tragic and very often traumatic and distressing to family, friends and first-responders.

Finding 35

It is impossible to quantify the number of people who attempt suicide and fail. However, there is evidence that many do and are left further debilitated.

Unlawful practices

4.131 There is evidence that some health professionals in Australia are already assisting people to die.

4.132 Professor Roger Magnusson systematically addressed the issue in the research contained in his book *Angels of Death: Exploring the Euthanasia Underground*, published by Melbourne University Press in 2002.⁴³⁰ The Victorian Inquiry also explored more recent evidence regarding existing underground and unlawful practices in its final report at chapter 6.3.⁴³¹

4.133 In their submission to the Inquiry, Doctors for Assisted Dying Choice told the Committee of a survey of unidentified Australian practitioners that indicated 35 per cent of doctors have, at the request of their patient administered medication to bring on death:

An anonymous survey of Australian medical practitioners indicated that 35% of doctors have, at the request of their patient, provided medical treatments with the aim to hasten death and shorten the duration of suffering for their patients. Because under the current laws, these

429 Mr Chris Dawson, WA Commissioner of Police, *Transcript of Evidence*, 27 February 2018, p. 7.

430 Professor Roger Magnusson explored the largely hidden world in which patients in extremis are sometimes helped to die. His qualitative, interview-based approach confirmed the unlawful involvement of health professionals in assisted deaths: *“Health care workers involvement in assisted death spans a broad range of action. These include referral and informal assessment of patients, prescribing, providing, stealing and administering drug cocktails, directing the euthanasia procedure, and concealing evidence. A variety of euthanasia strategies exist, including sudden overdoses, the gradual escalation of drugs to lethal levels, and the sudden withdrawal of the medicines or technology required to sustain life.”*

431 Parliament of Victoria, [Inquiry into end of life choices: Final Report](#), 2016, p. 181

*doctors could face criminal charges, these practices remain hidden and are unspoken. There is no information available regarding who these doctors are, who the patients were, whether they were terminally ill, what medication was used etc. In other words there are currently no safeguards, no transparency, no universal availability nor accountability for assisted dying practices by doctors.*⁴³²

The Committee's view on the options at end of life

- 4.134 The 20th century saw remarkable advances in medicine, extending average life expectancies, decreasing infant mortality and changing the way in which people die.⁴³³ According to Dr Rodney Syme, chronic illness has become the more common cause of death, and 'inevitable degenerative illnesses the cause of a high rate of placement of the frail elderly in institutional care, where they [die]'.⁴³⁴
- 4.135 Death is now more predictable and, as the discussions in this and preceding chapters on palliative care have demonstrated, health professionals provide a number of medical treatments for people as they approach the end of their lives. However, as the committee has outlined, those medical treatments may not always be appropriate for everyone.
- 4.136 The committee received evidence that symptoms at the end of life, and for those suffering with chronic or debilitating illness, can be severe and include: pain; breathlessness; nausea; severe fatigue; agitation; and delirium. Many individuals and health professionals also acknowledge psychological and existential suffering that accompanies the gradual loss of physical capacity and diminishing purpose in life. In some cases suffering is prolonged, especially for those with chronic or neurodegenerative conditions.
- 4.137 Dr Brien Hennessy told the committee that:

*The big picture here is that pain and suffering remains a significant issue in a significant proportion of people despite expert care. This is not a failure of resourcing or provision of services (which remains the biggest problem) but rather a lack of pharmacological and psychological efficacy to manage overwhelming nociception and psychological suffering.*⁴³⁵

432 Submission No. 402 from Doctors for Assisted Dying Choice, 19 October 2017 citing Neil D.A., Coady C.A.J., Thompson J., and Kuhse H., End of life decisions in medical practice: a survey of doctors in Victoria (Australia) *J. Medical Ethics*, 2007; 33: 721-725.

433 Grattan Institute, *Dying Well*, Melbourne, September 2014, p. 5.

434 Submission No. 316 from Dr Rodney Syme, 17 October 2017.

435 Dr Brien Hennessy, Head of Anaesthetics, Sir Charles Gairdner Hospital, Letter - Response to questions on notice, 25 May 2018.

4.138 Currently the lawful options for ending life may include refusal of medical treatment; refusal of food and fluids; decisions taken in relation to futility of treatment; terminal sedation or suicide. In many cases, these options do not result in a quick and peaceful death:

- Refusal of medical treatment or food and fluids requires determination, and in the case of the latter, individuals are not always lucky enough to find health professionals who are willing to provide palliation as they die.
- Equally, decisions based on futility of treatment can leave an individual despairing and continuing to endure painful suffering until their demise. They are left with little control over their death and no ability to choose the manner of their dying.
- In the case of terminal sedation, some people contend that there is little difference between it and voluntary assisted dying, and that the process is simply slower. Some practitioners and commentators describe terminal sedation as a slow form of euthanasia.⁴³⁶ There is therefore no 'bright line' that separates this practice from assisted dying. This form of sedation simply offers a slow dying process where the individual is unconscious throughout. In addition, the practice remains unrecorded and unregulated.
- In the case of suicide, people often suffer violent and lonely deaths that cause ongoing trauma and distress for those left behind. Worse still, people choose to suicide early to avoid the situation where they are suffering in extremis but physically unable to end their life.

4.139 The Western Australian community overwhelmingly expects to be able to exercise personal autonomy and self-determination. People want to be able to direct their own lives and have actual choice at the end of life.

4.140 The committee agrees with the submission of Mr James Hindle that 'the ultimate act of compassion is surely to allow someone to choose to end their suffering, even when we want them to stay with us'.⁴³⁷

Finding 36

Western Australians want to be able to exercise choice in dying. If there is a choice between a death accompanied by prolonged suffering and a death that is without such suffering, most Western Australians would choose the latter.

436 Dr Rodney Syme, *Time to Die*, Melbourne University Press, 2016, p. 21.

437 Submission No. 510 from Mr James Hindle, 22 October 2017.

Many people would value the opportunity to put their affairs in order and spend valuable time at the end of their lives with the people they love, knowing they had some control over the manner and timing of their death.

Chapter 5

International experience with voluntary assisted dying

Introduction

- 5.1 There is a small but growing number of international jurisdictions that allow for some type of assisted dying legislation in certain defined circumstances. Although these practices remain illegal in the vast majority of countries, recent trends suggest that the tide may be shifting in favour of liberalising the law.⁴³⁸
- 5.2 The committee has been aided by the thorough academic literature critiquing the operation of assisted dying legislation in the countries that have legalised the practice. It has not been possible to cite every publication that assisted the committee in its review of international practices; however, interested readers will be able to review the bibliography at Appendix 8 if they are seeking further information.
- 5.3 Given both the variety and complexity of the material published on the topic, the committee has sought to distil critical information about practices in jurisdictions where assisted dying is legal in terms of the:
- legislation in each jurisdiction;
 - model of assisted dying in use; and
 - most recently available statistics.
- 5.4 At the end of the chapter, the committee examines some concerns raised by submitters in relation to international experiences with assisted dying legislation.

A note on terminology

- 5.5 The vocabulary used throughout this chapter reflects the language adopted in the respective jurisdictions described below.

438 Downie, J., 'Permitting voluntary euthanasia and assisted suicide: Law reform pathways for common law jurisdictions', *QUT Law Review*, vol. 16, no. 1, March 2016, pp. 85–86.

The Netherlands

Legislative background

5.6 Although the Netherlands formally legislated for the practice of voluntary assisted dying⁴³⁹ in 2002, there had been a long process of incremental change prior to the introduction of the legislation.

5.7 In 1973, the courts recognised that a doctor could lawfully shorten a person's life to prevent serious and irremediable suffering, although voluntary euthanasia and assisted suicide remained punishable under the law.⁴⁴⁰ The decision prompted significant legal debate, although the underlying reasoning for the decision was unclear.⁴⁴¹ The courts provided clarity in 1984 when a voluntary euthanasia case reached the Dutch Supreme Court. The court reasoned:

1. *As a general rule, voluntary euthanasia and assisted suicide are punishable since the Penal Code defines both activities as a crime.*
2. *However, when a physician is confronted with a conflict of duties he or she may invoke the so-called defence of necessity. A conflict of duties occurs when honouring a patient's request to die with dignity is the only available means to end unbearable and irremediable suffering.*
3. *The criteria for accepting this defence of necessity are to be derived from professional and medical ethical opinions formulated by the medical profession.*⁴⁴²

5.8 Between 1994 and 2002, prosecutorial guidelines indicated when a doctor would or would not be charged in relation to ending a patient's life or assisting the patient to die.

The Dutch model

5.9 Although effectively decriminalised, both voluntary euthanasia and assisted suicide remain criminal offences in the Netherlands, even following the commencement of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* in 2002. However, physicians will not be prosecuted if they report their actions in assisting the death of a patient to a Regional Euthanasia Review Committee, and if they meet "due care" criteria.

439 *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*

440 Ben White and Lindy Willmott, 'How should Australia regulate voluntary euthanasia and assisted suicide?', *Journal of Law and Medicine*, vol. 20, 2012, p. 424.

441 The Royal Society of Canada, *End of Life Decision Making*, November 2011, p. 70.

442 The Royal Society of Canada, *End of Life Decision Making*, November 2011, p. 71.

In order to meet these due care criteria, the physician must:

1. be satisfied that the patient has made a voluntary and carefully considered request;
2. be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
3. have informed the patient of his situation and his prospects;
4. have concluded, together with the patient, that there is no reasonable alternative in light of the patient's situation;
5. have consulted at least one other independent physician who must have seen the patient and given a written opinion on the due care criteria at 1–4 above; and
6. have terminated the patient's life or provided assistance with suicide with due medical care and attention.

5.10 It is noteworthy that the due care criteria do not include a requirement for the patient to be suffering from a terminal illness.⁴⁴³ This has been justified on the basis that unbearable suffering with no prospect of improvement is not limited to the terminal phases of disease.⁴⁴⁴

5.11 In the Netherlands, voluntary euthanasia can be performed at a minor's request if the minor is aged between 16 and 18 and has a reasonable understanding of their own interests, and the parents or guardians have been involved in the decision-making process. The same conditions apply for minors aged between 12 and 16; however, in these cases the parents or guardians must consent to the decision.⁴⁴⁵ According to Dr Eduard Verhagen, a professor of paediatrics at Groningen University, five children were provided with voluntary euthanasia in the Netherlands between 2002 and 2015: a 12-year-old and four young people aged 16 to 17.⁴⁴⁶

5.12 A patient need not be competent at the time voluntary euthanasia is carried out, providing that a valid advance directive was completed at a time when the patient was competent.⁴⁴⁷

Most recent statistics on deaths under the Dutch law

5.13 In the four years following the commencement of the law in 2002, the number of people accessing voluntary euthanasia was reasonably consistent at approximately 2,000 each

443 Ben White and Lindy Willmott, 'How should Australia regulate voluntary euthanasia and assisted suicide?', *Journal of Law and Medicine*, vol. 20, 2012, p. 436.

444 The Royal Society of Canada, *End of Life Decision Making*, November 2011, p. 71.

445 Ben White and Lindy Willmott, 'How should Australia regulate voluntary euthanasia and assisted suicide?', *Journal of Law and Medicine*, vol. 20, 2012, p. 416.

446 AFP 'Dutch paediatricians: give terminally ill children under 12 the right to die', *The Guardian*, 19 June 2015. Available online at: <https://www.theguardian.com/society/2015/jun/19/terminally-ill-children-right-to-die-euthanasia-netherlands> (Accessed on 4 July 2017).

447 Ben White and Lindy Willmott, 'How should Australia regulate voluntary euthanasia and assisted suicide?', *Journal of Law and Medicine*, vol. 20, 2012, p. 436.

year.⁴⁴⁸ Since then, numbers have increased each year and in 2016 there were 6,091 reported cases of voluntary euthanasia representing some four per cent of all deaths in the Netherlands in that year.⁴⁴⁹

- Cancer was the most commonly reported condition, with 4,137 cases reported in 2016.
- More than half of those who accessed voluntary euthanasia were aged over 70.
- Eighty per cent of patients were able to die in their own homes.

Belgium

Legislative background

- 5.14 In September 2002, Belgium became the second country in the world to legalise voluntary assisted dying.⁴⁵⁰ At the same time that euthanasia was legalised, two other laws were also passed; the first is a law on palliative care, which provides that all patients in Belgium have a right to receive palliative care; the second is a law that stresses a patient's right to be fully informed of diagnosis and to consent to treatment decisions.⁴⁵¹
- 5.15 Prior to the enactment of the law in 2002, there had been several unsuccessful attempts at legalising voluntary euthanasia during the 1980s and 1990s.⁴⁵² Once enacted, the law was the subject of a legal challenge to the Constitutional Court on the grounds that it violated the right to life protected by Article 2 of the European Convention on Human Rights.⁴⁵³ The challenge was dismissed.
- 5.16 It is important to note that voluntary euthanasia was commonplace in Belgium even before the law was introduced in 2002.⁴⁵⁴ Furthermore, several studies have revealed the prevalence of the use of life-ending drugs without a patient's explicit consent *prior* to the enactment of the euthanasia law. The incidence of this practice has fallen since the introduction of the law.⁴⁵⁵

448 Neil Francis Assisted dying practice in Benelux: White Paper 1, p. 5.

449 Regional Euthanasia Review Committees, *Annual Report 2016*, p. 4.

450 *The Act on Euthanasia 2002*.

451 Chambaere, et al, 'Trends in Medical End of life Decision Making in Flanders, Belgium 1998–2001–2007', *Medical Decision Making*, vol. 31, no. 3, May-June 2010, p. 500.

452 Penny Lewis, 'Euthanasia in Belgium Five Years After Legalisation', *European Journal of Health Law*, vol. 16, 2009, pp. 125–126.

453 Penny Lewis, 'Euthanasia in Belgium Five Years After Legalisation', *European Journal of Health Law*, vol. 16, 2009, p. 126.

454 Deliens, et al, 'End of life decisions in medical practice in Flanders, Belgium: a nationwide survey', *The Lancet*, vol. 356, 25 November 2000, pp. 1806–1811.

455 Chambaere, et al, 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey', *Canadian Medical Association Journal*, vol. 182, no. 9, 15 June 2010, p. 900.

The Belgian model

- 5.17 The Belgian legislation defines euthanasia as termination of life upon request. Assisted suicide is not mentioned in the legislation; however, the body responsible for overseeing the law – the Federal Control and Evaluation Commission – has accepted cases of assisted suicide as falling under the law.⁴⁵⁶ As a result, a doctor may administer the lethal dose at the patient’s explicit request, or the patient may self-administer.⁴⁵⁷
- 5.18 In order to access voluntary euthanasia, the patient must be competent and must make a request that is voluntary, considered, repeated and made in writing, free from external pressure and of a durable nature.⁴⁵⁸ Durable means that the doctor must be certain of the ongoing and enduring nature of the request, and has the effect of requiring doctors to have had several conversations with patients over a reasonable period of time.⁴⁵⁹
- 5.19 There is no requirement that the patient be competent at the time of death; however, the patient must have made written end of life directions whilst competent that provided for voluntary euthanasia when:
- the patient becomes unconscious;
 - the patient has a severe and incurable accidental or pathological disorder; and
 - the situation is irreversible.⁴⁶⁰
- 5.20 The patient must also be in a ‘medically hopeless condition of continuous and unbearable physical and mental suffering that cannot be alleviated and that is resulting from a serious and incurable disorder caused by illness or accident.’⁴⁶¹
- 5.21 The treating doctor must consult another physician who will examine the patient and the medical record in order to ensure that the medical requirements have been met.
- 5.22 In 2014, Belgium’s laws were extended to permit voluntary euthanasia for competent terminally ill people under the age of 18 in restricted circumstances.

456 The Royal Society of Canada, *End of life Decision Making*, November 2011, p. 79.

457 Submission No. 686 from Dying for Choice, 23 October 2017, p. 57.

458 The Royal Society of Canada, *End of life Decision Making*, November 2011, p. 79.

459 Ben White and Lindy Willmott, ‘How should Australia regulate voluntary euthanasia and assisted suicide?’, *Journal of Law and Medicine*, vol. 20, 2012, p. 436.

460 Cohen-Almagor, R., ‘Euthanasia Policy and Practice in Belgium: Critical Observations and Suggestions for improvement’, *Issues in Law & Medicine*, vol. 24, no. 3 (2009), p. 206.

461 Section 3.1 of the Belgian Act quoted in The Royal Society of Canada, *End of life Decision Making*, November 2011, p. 79.

Most recent statistics on deaths under the Belgian law

- 5.23 The Belgian law requires the Federal Control and Evaluation Commission to report to the parliament every two years. The most recently available report, presented in October 2016, covers the period 2014–15.
- 5.24 In 2014, there were 1,928 reported cases of patients accessing either doctor administered or patient administered voluntary euthanasia services. In 2015, there were 2,022 reported cases, representing a slight increase.
- 5.25 During the two-year period:
- 62.8 per cent of patients were aged over 70 years;
 - no children under the age of 18 were reported as patients;
 - 67.7 per cent of patients accessing the euthanasia service were cancer patients; and
 - 44 per cent of patients were able to die in their own home.⁴⁶²

Luxembourg

Legislative background

- 5.26 Assisted dying was decriminalised in Luxembourg in March 2009.⁴⁶³ The legislation was not introduced in the parliament by the governing party, but by members of the opposition Socialist and Greens parties. After what has been described as a bitter debate, the bill passed with 30 votes for, 26 against and three abstentions.
- 5.27 Luxembourg is a constitutional monarchy, and at the time the bill passed the legislature, the Grand Duke was required to sign it into law. He refused to do so on the grounds of conscientious objection. In response, the legislature removed the requirement for the monarch to assent to bills before they become law.⁴⁶⁴

The Luxembourgish model

- 5.28 The Luxembourgish legislation defines voluntary euthanasia as an act performed by a physician that intentionally ends the life of a person at the express and voluntary request

462 Institute for European Bioethics, Analysis of The Seventh Report of the Federal Commission for Euthanasia Control and Evaluation to the Legislative Chambers (for the Years 2014 and 2015), available at: <https://www.ieb-eib.org/en/pdf/20161008-en-synthese-rapport-euthanasie.pdf>. Accessed 7 June 2018.

463 *Law of 16 March 2009 on Euthanasia and Assisted Suicide*.

464 'Luxembourg strips monarch of legislative role', AP Report, *The Guardian*, 12 December 2008, available at: <https://www.theguardian.com/world/2008/dec/12/luxembourg-monarchy>. Accessed 7 June 2018.

of that person. The definition of assisted suicide is similar; however, the termination of life is undertaken by the patient.

- 5.29 The provisions in Luxembourg’s legislation are broadly similar to those found in the Dutch framework and include a requirement that the request is made voluntarily and repeatedly. The patient’s medical situation must be one without a cure and without the prospect of improvement, and patients must report unbearable mental or physical suffering.⁴⁶⁵

Most recent statistics on deaths under the Luxembourgish law

- 5.30 Luxembourg’s legislation requires that the National Commission for Control and Evaluation report every two years on the practice of euthanasia and assisted suicide. The most recent report, published in May 2017, covers the period 2015–16.⁴⁶⁶

- During that period, 18 people exercised their option to access euthanasia or assisted suicide – eight in 2015 and 10 in 2016.
- 17 patients were aged over 60.
- 16 patients were suffering from cancer.
- Since legalisation in 2009, 52 individuals have accessed euthanasia or assisted suicide services.⁴⁶⁷

Switzerland

Switzerland operates under a unique model

- 5.31 The Swiss model for assisted dying is unique.⁴⁶⁸ Switzerland does not have a specific piece of legislation that decriminalises assisted suicide for medical purposes, instead the legal position is based on provisions of the Swiss Criminal Code that have been in operation since 1942. Article 115 of the Code criminalises assisted suicide unless the person providing the assistance does so from unselfish motives. Any person assisting in a suicide must demonstrate that they have done so without having self-serving ends.
- 5.32 According to the Swiss Ministry of Justice, self-serving ends would include assisting a death ‘to satisfy [...] material or emotional needs [...] the possibility of eliminating some major problem for the family, or other motives such as gaining an inheritance, relieving

465 The Royal Society of Canada, *End of life Decision Making*, November 2011, p. 80.

466 The report, in French, is available to download here:

<http://www.sante.public.lu/fr/publications/r/rapport-loi-euthanasie-2015-2016/index.html>.

467 ‘Slight rise in euthanasia cases for Luxembourg’, *Luxembourg Times*, 29 May 2017, available at: <https://luxtimes.lu/archives/2186-slight-rise-in-euthanasia-cases-for-luxembourg>. Accessed 7 June 2018.

468 Article 115 and Article 116 of the Swiss Criminal Code makes reference to ‘assisted suicide’.

himself of the burden of supporting the individual [...] or eliminating a person he hated.⁴⁶⁹

- 5.33 Unlike the other models outlined in this chapter, there are no formal requirements based in statute limiting access to assisted suicide. As a result, there are no eligibility criteria or other safeguards common to other jurisdictions. Similarly, there are no official statistics on the prevalence of assisted suicide in Switzerland; however, according to Dignitas – a Swiss non-profit organisation that helps people to end their lives – they have assisted in approximately 2,500 deaths during the previous 20 years. In 2017, the organisation assisted in 222 deaths.⁴⁷⁰

Oregon

Legislative background

- 5.34 In 1994, Oregon's citizens voted in favour of a ballot initiative to pass the *Dying With Dignity Act*. A ballot initiative is a type of direct democracy common in parts of the United States that allows for public votes on certain legislative proposals or constitutional amendments. The result of the ballot was close: 51.3 per cent of voters were in favour and 48.7 per cent were opposed.⁴⁷¹
- 5.35 The legislation finally came into operation in 1997; however, not before it had faced several legal challenges and a further ballot initiative to repeal the law.⁴⁷² This second public vote, held three years after the first, resulted in 60 per cent of respondents voting to retain the *Dying With Dignity Act* against 40 per cent voting to repeal.⁴⁷³
- 5.36 Throughout the late 90s and into the early years of the George W Bush administration, several attempts were made at the state and federal level to either restrict or overturn the legislation. Those attempts were not successful.⁴⁷⁴

469 The Royal Society of Canada, *End of Life Decision Making*, November 2011, p. 81.

470 Mr Silvan Luley, Board Member, Dignitas, *Transcript of Evidence*, 8 March 2018, pp. 2 & 5.

471 Oregon Secretary of State, *Oregon Blue Book*. Available at: <https://sos.oregon.gov/blue-book/Documents/elections/initiative.pdf> (Accessed 4 July 2018).

472 Ballot Initiative 51, which was held in November 2007.

473 Oregon Secretary of State, *Oregon Blue Book*. Available at: <https://sos.oregon.gov/blue-book/Documents/elections/initiative.pdf> (Accessed 4 July 2018).

474 The legal challenges to Oregon's assisted dying laws took place over a 10-year period commencing in 1995 and ending in 2005 with the US Supreme Court's ruling in *Gonzales v Oregon* upholding Oregon's laws. During that same period legislative proposals were made in an attempt to criminalise any action by a health professional in administering federally controlled drugs for the purpose of ending life. Those attempts failed, see *The Royal Society of Canada*, *End of Life Decision Making*, November 2011, p. 80.

The Oregon model

- 5.37 The Oregon model has been described by many submitters to this inquiry as 'restrictive'.⁴⁷⁵ The *Dying With Dignity Act* provides for physician-assisted death with the patient self-administering a lethal medication. The patient must be a capable adult, aged at least 18 years of age, and a resident of Oregon. The patient must also be suffering from a terminal illness that will lead to death within six months.
- 5.38 If a patient satisfies these criteria, the following steps must be followed:
- The patient must make two oral requests to the attending physician, separated by at least 15 days.
 - The patient must provide a written request to the attending physician, signed in the presence of two witnesses, at least one of whom is not related to the patient.
 - The attending physician and a consulting physician must confirm the patient's diagnosis and prognosis.
 - The attending physician and a consulting physician must determine whether the patient is capable of making and communicating health care decisions for him/herself.
 - If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder (such as depression), the patient must be referred for a psychological examination.
 - The attending physician must inform the patient of feasible alternatives to assisted death including comfort care, hospice care, and pain control.
 - The attending physician must request, but may not require, the patient to notify their next-of-kin of the prescription request.⁴⁷⁶
- 5.39 A patient can rescind a request at any time and in any manner. The attending physician will also offer the patient an opportunity to rescind his/her request at the end of the 15-day waiting period following the initial request to participate.⁴⁷⁷

475 See, for example, Submission No. 686 from Dying for Choice, 23 October 2017, p. 56.

476 Oregon Health Authority, *FAQs about the Death with Dignity Act*. Available at: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/faqs.pdf>

477 Oregon Health Authority, *FAQs about the Death with Dignity Act*. Available at: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/faqs.pdf>

5.40 Physicians must report all prescriptions for lethal medications to the Oregon Health Authority and pharmacists must be informed of the prescribed medication's ultimate use.⁴⁷⁸

Most recent statistics on deaths under the Oregon law

5.41 The Oregon Health Authority publishes an annual report based on mandatory data required under the *Dying With Dignity Act*. For the calendar year 2017:

- 218 patients had prescriptions written;
- 144 died from ingesting medication, including 14 who died from ingesting medication prescribed in a year other than 2017;
- 44 did not ingest medication and subsequently died from other causes;
- 44 patients had an unknown ingestion status:
 - 23 died, ingestion status unknown; and
 - 21 death and ingestion status pending.⁴⁷⁹

5.42 In 2017:

- 80.4 per cent of patients were aged 65 years or older;
- the median age at death was 74 years old;
- 76.9 per cent of patients were suffering from cancer; and
- 90.2 per cent of patients were able to die at home.⁴⁸⁰

5.43 The three most frequently reported end of life concerns were decreasing ability to participate in activities that made life enjoyable (88.1 per cent), loss of autonomy (87.4 per cent), and loss of dignity (67.1 per cent).⁴⁸¹

478 Oregon Health Authority, *FAQs about the Death with Dignity Act*. Available at: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/faqs.pdf>

479 Oregon Public Health Division, *Oregon Death with Dignity Act: 2017 Data Summary*, 9 Feb 2018, pp. 5–11. Available at: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>. Accessed on 12 June 2018.

480 Oregon Public Health Division, *Oregon Death with Dignity Act: 2017 Data Summary*, 9 Feb 2018, pp. 5–11. Available at: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>. Accessed on 12 June 2018.

481 Oregon Public Health Division, *Oregon Death with Dignity Act: 2017 Data Summary*, 9 Feb 2018, pp. 5–11. Available at:

Washington

Legislative background

5.44 The *Washington Death With Dignity Act* came into operation in 2009. Washington's legislation is substantially similar to the legislation in neighbouring Oregon.⁴⁸² As with Oregon, assisted dying became legal in Washington following a ballot initiative at which just under 58 per cent of three million voters voted in favour of 'allowing certain terminally ill competent adults to obtain lethal prescriptions'.⁴⁸³

The Washington model

5.45 Mentally competent adults who reside in Washington State are able to access the assisted dying scheme in Washington. The scheme is available to patients diagnosed with a terminal illness with six months or less to live. Patients self-administer the medication once a physician has issued a prescription. Similar to Oregon:

- the patient must make an initial oral request to a physician to access life ending medication and to have a prescription written;
- a second physician must then confirm, along with the first physician, the patient's diagnosis, prognosis and mental capacity;
- once this has occurred the patient must complete a written request for medication form;
- no sooner than 15 days after the initial oral request, the patient may then make a second oral request to his or her physician; and
- once these criteria have been met, the physician may then issue the prescription for the life ending medication.⁴⁸⁴

<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>. Accessed on 12 June 2018.

482 Dyer, et al., 'Assisted dying: law and practice around the world', *British Medical Journal*, vol. 351, August 2015, p 2.

483 Washington Secretary of State, *November 04, 2008 General election Results*, 26 Nov 2008. Available at: <http://results.vote.wa.gov/results/20081104/Initiative-Measure-1000-concerns-allowing-certain-terminally-ill-competent-adults-to-obtain-lethal-prescriptions.html>. Accessed on 12 June 2018.

484 End of Life Washington, *The Washington Death with Dignity Act: An overview for patients and families*, available at: https://endoflifewa.org/wp-content/uploads/2012/09/WA.DWDA_An_Overview_for_Patients_and_Families.10.2015.pdf

Most recent statistics on deaths under the Washington law

5.46 Under the legislation, the Washington Department of Health is required to report annually on the operation of the law. The most recent report was released in March 2018 and covers the 2017 calendar year:

- 212 patients had prescriptions written;
- 164 died after having ingested the medication; and
- 19 died without having ingested the medication.

5.47 In 2017:

- 74 per cent of patients were aged 65 years or older;
- 72 per cent of patients were suffering from cancer; and
- 88 per cent of patients were able to die in their own homes.⁴⁸⁵

Vermont

Legislative background

5.48 In May 2013, Vermont became the first state in the United States to pass a Death with Dignity Bill without using a ballot initiative put directly to the public. The first such bill had been introduced ten years earlier, and numerous subsequent attempts to pass the legislation had failed.

The Vermont model

5.49 The law in Vermont is largely identical to that in Oregon and Washington. It is open to mentally competent adults who reside in Vermont and who have been diagnosed with a terminal illness with six months or less to live. Patients self-administer the medication once a physician has issued a prescription.

Most recent statistics on deaths under the Vermont law

5.50 The first report outlining statistical information on the use of the assisted dying legislation was published by the Vermont government in January 2018. The report covers the period from May 2013 through June 2017.

- 52 prescriptions were issued:

485 Washington State Department of Health, *Death With Dignity Act Report*, March 2018, pp. 1–2. Available at: <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2017.pdf>.

- 83 per cent of prescriptions were for patients diagnosed as suffering from cancer;
- 14 per cent of prescriptions were for patients diagnosed as suffering motor neuron disease (**MND**); and
- Three per cent were for other causes.⁴⁸⁶
- 48 deaths were reported:
 - 29 patients had utilised the patient choice prescription;
 - 17 patients died from the underlying cause;
 - 1 died from other causes; and
 - 1 died from unknown causes.⁴⁸⁷

California

Legislative background

5.51 On 5 October 2015, California became the fifth jurisdiction (following Colorado and the District of Columbia) in the United States to allow terminally ill patients to receive assisted dying services. The *End of Life Option Act* was passed during a special session of the California legislature in late 2015 and came into effect on 9 June 2016. A number of legal challenges have been mounted against the legislation, and between 25 May and 15 June 2018, implementation of the law was halted following a court ruling that the Act was not validly passed by the legislature. That ruling has been stayed by a Court of Appeal, but legal proceedings remain ongoing.

The California model

5.52 Similar to most legislative approaches adopted in the United States, the California legislation takes as its basis the Oregon model in place since 1998. There are a few key differences:

- People who do not speak English can use an interpreter;

486 Vermont Agency of Human Services, *Report concerning patient choice at end of life*, 15 January 2018, p. 4. Available at: <https://legislature.vermont.gov/assets/Legislative-Reports/2018-Patient-Choice-Legislative-Report-12-14-17.pdf>

487 Vermont Agency of Human Services, *Report concerning patient choice at end of life*, 15 January 2018, p. 4. Available at: <https://legislature.vermont.gov/assets/Legislative-Reports/2018-Patient-Choice-Legislative-Report-12-14-17.pdf>

- the attending physician must discuss the request for medications with the patient (and their interpreter, if applicable) alone (patients in Oregon are free to bring anyone along);
- there is no waiting period between the written request and the writing of the prescription; and
- the attending physician must provide a separate form for the patient to complete within 48 hours prior to taking the medications.

Most recent statistics on deaths under the California law

5.53 California's Department of Public Health is required to report annually on the operation of the law. The most recently completed report was published in June 2018 and covers the 2017 calendar year.

- 577 individuals had prescriptions written in 2017:
 - 363 ingested and died from the drugs prescribed in 2017;
 - 86 did not ingest drugs and died from underlying illness;
 - 128 with undetermined outcomes; and
 - 11 individuals with prescriptions from 2016 ingested and died from the drugs in 2017.⁴⁸⁸

5.54 In 2017:

- 77 per cent of patients were aged between 60 and 89 years;
- 13.4 per cent of patients were aged over 90 years;
- 50.8 per cent were female;
- 83.4 per cent were receiving hospice and/or palliative care; and
- 72.7 per cent had at least some level of college education.⁴⁸⁹

488 California Department of Public Health, *California End of Life Option Act 2017 Data Report*, June 2018, p. 4. Available at: <https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADataReport.pdf>

489 California Department of Public Health, *California End of Life Option Act 2017 Data Report*, June 2018, p. 4. Available at: <https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADataReport.pdf>

5.55 In terms of illness affecting the patients:

- 68.5 per cent had malignant neoplasms (cancer);
- 9.4 per cent had neurological disorders such as MND and Parkinson's;
- 8.0 per cent had cardiovascular diseases;
- 4.5 per cent had chronic lower respiratory diseases (non-cancer);
- 3.7 per cent had cerebrovascular diseases; and
- 5.9 per cent had other underlying illnesses.⁴⁹⁰

Canada

Legislative background

5.56 The introduction of an assisted dying mechanism in Canada has been a long and somewhat complicated process involving numerous attempts at legislative reform at both the federal and provincial levels, in addition to several legal challenges questioning the prohibition of assisted suicide on the grounds of discrimination. Following a decision of the Canadian Supreme Court in February 2015, the Canadian Parliament passed the Medical Assistance in Dying bill in June 2016.⁴⁹¹

5.57 Prior to legalisation, there had been 12 attempts between March 1991 and May 2009 to legislate for the introduction of some type of assisted dying law at the federal level in Canada.⁴⁹² Quebec was the first place in Canada to pass legislation, with *An Act Respecting End of life Care* commencing operation in December 2015.⁴⁹³

5.58 The nation-wide legalisation of assisted dying in Canada came about following legal action launched by Kay Carter, a woman who was suffering from a severe case of spinal stenosis, and Gloria Taylor, who was suffering from Motor Neuron Disease. In 2012, the women won their case in the British Columbia Supreme Court which ruled that

490 California Department of Public Health, *California End of Life Option Act 2017 Data Report*, June 2018, p. 4. Available at: <https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADataReport.pdf>

491 A copy of the legislation can be accessed here: <http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent>

492 Downie, J., 'Permitting voluntary euthanasia and assisted suicide: Law reform pathways for common law jurisdictions', *QUT Law Review*, vol. 16, no. 1, March 2016, pp. 85–86.

493 The focus of the discussion in the rest of this section will be on the nation-wide model enacted in 2016. The Quebec model legalises medical aid in dying where an individual is at the end of life; has an incurable disease; is in an advanced state of irreversible decline; and is experiencing unbearable and intolerable suffering. See: Downie, J., 'Permitting voluntary euthanasia and assisted suicide: Law reform pathways for common law jurisdictions', *QUT Law Review*, vol. 16, no. 1, March 2016, p. 89.

prohibitions against assisted suicide in the Canadian Criminal Code violated their rights under the Canadian *Charter of Rights and Freedoms*. The case eventually proceeded to the Canadian Supreme Court, which held that the Criminal Code breached s7 of the Canadian *Charter of Rights and Freedoms*, which protects ‘the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice’.⁴⁹⁴

5.59 The Canadian Supreme Court issued a declaration that:

We have concluded that the laws prohibiting a physician’s assistance in terminating life (Criminal Code, s. 241(b) and s. 14) infringe Ms. Taylor’s s. 7 rights to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice, and that the infringement is not justified under s. 1 of the Charter. To the extent that the impugned laws deny the s. 7 rights of people like Ms. Taylor they are void by operation of s. 52 of the Constitution Act, 1982. It is for Parliament and the provincial legislatures to respond, should they so choose, by enacting legislation consistent with the constitutional parameters set out in these reasons.

The appropriate remedy is therefore a declaration that s. 241 (b) and s. 14 of the Criminal Code are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. “Irremediable”, it should be added, does not require the patient to undertake treatments that are not acceptable to the individual. The scope of this declaration is intended to respond to the factual circumstances in this case. We make no pronouncement on other situations where physician-assisted dying may be sought.⁴⁹⁵

The Court suspended the declaration of invalidity for 12 months in order to allow time for various governments to develop and implement legislation and regulations that would provide for assisted dying.⁴⁹⁶

494 Lindy Willmott & Ben White, 'Assisted dying in Australia: A values-based model for reform', in Ian Freckelton & Kerry Petersen (eds.), *Tensions and traumas in health law*, Federation Press, Sydney, 2017, pp. 491.

495 *Carter v. Canada (Attorney General)*, 2015 SCC 5 at [126] – [127]

496 Downie, J., 'Permitting voluntary euthanasia and assisted suicide: Law reform pathways for common law jurisdictions', *QUT Law Review*, vol. 16, no. 1, March 2016, pp. 85–86.

The Canadian model

5.60 Canada's legislation allows for both physician administered and self-administered ingestion of a lethal medication. Note, however, that Quebec's model, which predates the federal model, provides only for physician administered ingestion. To be eligible, a patient must:

- be eligible for health services funded by a Canadian government;
- be at least 18 years old and mentally competent;
- have a grievous and irremediable medical condition;
- make a voluntary request for medical assistance in dying that is not the result of outside pressure or influence; and
- give informed consent to receive medical assistance in dying.

5.61 Canada's legislation does not require that a patient be suffering from a fatal or terminal condition in order to access assisted dying. Instead, the patient must have a serious illness, disease or disability and be in an advanced state of decline that cannot be reversed. Furthermore, the patient must be experiencing physical or mental suffering that cannot be relieved under conditions that are acceptable to the patient. Finally, the patient must be at a point where natural death has become reasonably foreseeable. The College of Physicians and Surgeons of Nova Scotia has recently issued a guideline for doctors that defines reasonably foreseeable as either temporally proximate (sufficiently close) or the patient's cause of natural death has become predictable.⁴⁹⁷

5.62 Mental or physical disability is not a barrier to seeking assisted dying; however, eligibility will be assessed on an individual basis against the same eligibility criteria as other applicants.

5.63 The process for requesting assisted dying is largely similar to that in other jurisdictions. A patient must make a written request indicating that they seek medical assistance in dying. The written request must be signed by two independent witnesses. The patient's physician will then confirm that the patient is eligible to access assisted dying services. A second physician is then required to confirm the first physician's opinion.

497 College of Physicians and Surgeons Nova Scotia – [Guidelines Medical Assistance in Dying](#) – Website. Accessed 11 August 2018.

5.64 Once eligibility has been confirmed a 10-day “reflection period” commences. Once this period has passed, the patient is able to receive the service. Consent may be withdrawn at any time and in any form.⁴⁹⁸

Most recent statistics on deaths under the Canadian law

5.65 As with other jurisdictions that have legislated for assisted dying, there is a requirement for regular reporting on the incidence of the practice. The most recent report was published in October 2017 and covers the period between legalisation of assisted dying in December 2015 and June 2017:

- the total number of medically assisted deaths in Canada since legalisation is 2,149;
- between 1 January 2017 and 30 June 2017, there were 1,179 medically assisted deaths representing approximately 0.9 per cent of all deaths in Canada during that time;
- patients suffering from cancer represented 63 per cent of all cases amongst those seeking a medically assisted death; and
- the average age of those receiving a medically assisted death was 73.⁴⁹⁹

What does the international experience tell us?

5.66 Excluding Switzerland, which is unique among the jurisdictions, each of the jurisdictions examined above have many things in common in terms of their experiences in legislating for assisted dying:

- Gaining legislative support for assisted dying laws has been a difficult and lengthy process – even in Europe, where the practice is more established. As the following chapter on the Australian experience will demonstrate, this difficulty is also replicated closer to home.
- Gaining access to assisted dying or euthanasia is not a request capable of fulfilment on a whim – it requires a careful and repeated request, witnessed by independent parties.
- In each of the jurisdictions, more than one physician is required to confirm that the eligibility criteria have been met, which usually requires that a patient suffers from a terminal or chronic illness with irremediable suffering.

498 Government of Canada, *Medical assistance in dying*, available at:

<https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>

499 Health Canada, *2nd Interim Report on Medical Assistance in Dying*, October 2017, pp. 6–8.

- Finally, it is noteworthy that cancer is by far the most common illness underlying a request for assisted dying in all of the jurisdictions examined above.

5.67 There are also differences, of course, including whether a person must be legally competent at the time death occurs. All jurisdictions require competence at the time of the request, but not all jurisdictions will allow a patient to make a legally binding directive or request in the form of an advance health directive.

5.68 Similarly, there are important differences regarding the manner in which the lethal medication is ingested. Under the model adopted in the United States, ingestion of the lethal medication is self-administered, reflecting the fact that arguments for assisted dying were focused on respecting individual rights and patient autonomy. In European jurisdictions and Quebec, most cases of assisted dying occur following physician intervention.

Concerns about international experiences raised in the submissions

5.69 Many submissions from those opposed to legislative change expressed some concern about perceived unwelcome developments in the operation of the laws in international jurisdictions.

Slippery slope

5.70 The phrase “slippery slope” appears in approximately 100 submissions made to the inquiry, mostly in submissions from individuals and organisations expressing concern about any proposed changes to the laws relating to end of life choices in Western Australia. At the heart of any slippery slope argument is the contention that a minor initial change may lead to negative and unintended consequences in the future. Broadly speaking, the slippery slope arguments focused on claims that inevitably, the criteria for legal access to assisted dying will expand incrementally beyond whatever initial reforms are legislated. Two such scenarios include:

- expansion to include psychiatric illness; and
- expansion to include minors.

5.71 The committee explores these arguments in further detail below.

Expansion to include psychiatric illnesses

5.72 Many submitters drew the committee’s attention to the experience in the Netherlands and Belgium regarding the availability of euthanasia for patients suffering from some form of mental illness, most typically depression and/or anxiety. In its submission, the Australian Christian Lobby provided details of several cases in Belgium and the Netherlands where individuals described as being mentally unwell were provided with

euthanasia services. One such example involved a woman in Belgium who received euthanasia for ‘untreatable depression’:

*[Godelieve De Troyer] chose to end her life by lethal injection at her own request in a Brussels hospital in April 2012. Her son, Tom Mortier, alleges that at least two of the experts who assessed De Troyer did not agree that her depressive illness was beyond treatment.*⁵⁰⁰

5.73 Mr Richard Egan from Defend Human Life!, submitted to the committee that:

*Euthanasia has been approved for a 24 year old woman, known as Laura, on the sole grounds of her mental suffering based on suicidal ideation. Belgium now treats suicidal ideation by facilitating suicide.*⁵⁰¹

5.74 The Coalition for the Defence of Human Life provided a very clear definition of what the slippery slope entails in this context when it asked:

*[i]f we are going to offer to help someone die because they have an incurable physical disease, why not a psychiatric condition which causes them ‘unbearable’ suffering? After all, people experiencing these conditions can endure even greater and more prolonged suffering than is caused by many physical illnesses.*⁵⁰²

5.75 Voluntary euthanasia is available to patients suffering from mental illness in Belgium and the Netherlands. Those patients must still satisfy the eligibility criteria established for those suffering from other illnesses. It is not correct to characterise this as evidence of a slippery slope. In both the Netherlands and Belgium, the legal criteria for access to assisted dying has never been limited to persons suffering from a terminal or life limiting illness, meaning that access to euthanasia by those with a mental illness has been an element of the law in both countries since assisted dying practices were legalised. Indeed, voluntary euthanasia was available for people with mental illness in the Netherlands prior to legislative change in 2002.⁵⁰³

5.76 It is therefore not possible to characterise the Dutch and Belgian experience in relation to mental illness as a type of slippery slope that will – or even may – eventuate in Western Australia. That the mentally ill are able to access assisted dying in those countries is a direct result of a deliberate decision made when the laws were introduced. It has not come about as a result of a slow expansion of the practice in either country. Providing assisted dying to the mentally ill would only be possible in Western Australia if

500 Submission No. 591 from Australian Christian Lobby, 23 October 2017, p. 4.

501 Submission No. 5 from Defend Human Life!, 14 September 2017, p. 8.

502 Submission No. 428 from Coalition for the Defence of Human Life, 22 October 2017, p. 6.

503 Kim SYH, et al, 'Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 – 2014', *JAMA Psychiatry*, vol. 74, no. 4, April 2016, p. 363.

the parliament decides to adopt a broad category of eligibility, as is the case in the Netherlands and Belgium.

Finding 37

It is incorrect to describe the availability of euthanasia for mentally unwell persons in the Netherlands and Belgium as eventuating as a type of slippery slope through which an initially conservative approach to euthanasia was eroded over time. Since the practice was legislated for in both countries, eligibility for assisted dying has included persons suffering from mental illness.

Expansion to include minors

5.77 In its submission, The University of Notre Dame Australia expressed the view that:

*Euthanasia laws may be quite narrow when introduced, but are often later broadened, causing an increase in the number of deaths by euthanasia.*⁵⁰⁴

5.78 The submission goes on to outline the Dutch and Belgian experience of allowing for euthanasia for children:

*In 2014 Belgium became the first country in the world to abolish age restrictions on active euthanasia, altering its laws to allow children with capacity of any age to be euthanised. In the Netherlands, children over 12 may be euthanised with their parents' consent, but parental consent is not required after they turn 16. Since 2005, the Groningen Protocol in the Netherlands has legalised the active euthanizing of infants with poor prognosis. This has attracted strong criticism, including from the Catholic Church.*⁵⁰⁵

5.79 The Hon Greg Donnelly MLC, a member of the New South Wales parliament, provided a range of documentation to the committee, including correspondence he had received from the Rev Dr Steve Bartlett, a Baptist Church official:

in Belgium, what started as an intention to relieve physical suffering in terminally ill adults has resulted in a situation where euthanasia for sick children has now been legalised. Once a society passes over the boundary that says we do not assist people to kill themselves (assisted suicide), or actually kill them (euthanasia), where logically can it draw

504 Submission No. 610 from University of Notre Dame Australia, 23 October 2017, p. 7.

505 Submission No. 610 from University of Notre Dame Australia, 23 October 2017, p. 7.

*the line in the sand? In truth the line has already been crossed and to claim otherwise is being disingenuous.*⁵⁰⁶

- 5.80 In the case of Belgium, following amendments passed in 2004, there is no minimum age at which a child may access euthanasia; however, they must be capable of ‘discernment’ – in Australia this would be known as *Gillick* competence.⁵⁰⁷ It was ruled in *Gillick v West Norfolk and Wisbech AHA* that a child under 16 has the legal competence to consent to medical examination and treatment if they have sufficient maturity and intelligence to understand the nature and implications of that treatment.⁵⁰⁸
- 5.81 Since 2002, the law in The Netherlands has allowed for children to access voluntary euthanasia services in certain circumstances previously outlined in paragraph 5.11. In 2005, paediatric specialists at the University Medical Centre Groningen devised what has come to be known as the Groningen Protocol. The protocol identified the circumstances in which younger children, particularly infants, would be given access to voluntary euthanasia services.
- 5.82 These infants would only be eligible if they were found to have ‘a hopeless prognosis’ and, in the opinion of parents and medical experts, were experiencing ‘unbearable suffering’.⁵⁰⁹ After the release of the protocol, the Dutch government, in consultation with the Dutch Paediatric Society, issued a ruling that led to a prosecutorial guideline and to the creation of a committee of experts to advise the prosecutor in individual cases.⁵¹⁰
- 5.83 No changes were made to the Netherlands’ euthanasia laws in order to accommodate the practices identified in the protocol. The elements that made the protocol legal have been contained in the laws since 2002, and reflected practice in the Netherlands that had been well-established prior to the enactment of the legislation.⁵¹¹ The Groningen Protocol is therefore not an example of the slippery slope.
- 5.84 The committee acknowledges that the changes made to the Belgian law in 2014 represent an expansion in the scope of what was to have been acceptable when the legislation was initially introduced in 2002.
- 5.85 However, the committee does not accept that the expansion of the laws in Belgium points to the inevitability of the outcomes contended in the slippery slope argument.

506 Submission No. 681 from Mr Greg Donnelly MLC, 23 October 2017, p. 129.

507 Bhatia, et al, 'How should Australia respond to media-publicised developments on euthanasia in Belgium?', *Journal of Law and Medicine*, vol. 23, no. 4, 2016, pp. 835–848

508 Richard Griffith, 'What is Gillick competence?', *Human Vaccines & Immunotherapeutics*, vol. 12, no. 1, January 2016, p. 244.

509 Verhagen, E. and Sauer, P.J.J., 'The Groningen Protocol – Euthanasia in Severely Ill Newborns', *New England Journal of Medicine*, vol. 352, no. 10, March 2005, pp. 959–960.

510 The Royal Society of Canada, *End of Life Decision Making*, November 2011, p. 89.

511 The Royal Society of Canada, *End of Life Decision Making*, November 2011, p. 89.

The change occurred as a result of deliberate and considered legislative reform. Furthermore, opponents of assisted dying look to Belgium to support their argument while ignoring the equally valid experience of Oregon, which has seen no change to its laws and which remain just as restrictive as they were upon introduction in 1997.

Finding 38

Although Belgium expanded its law to make euthanasia available to legally competent minors in 2014, this should not be seen as supporting the slippery slope argument that further expansion of the assisted dying laws is somehow an inevitability. The experience in Oregon, where the law has undergone no change or expansion since its introduction in 1997, demonstrates the invalidity of any attempt to apply a universal slippery slope argument.

The safeguards will not work

- 5.86 Several submitters drew to the committee's attention an article in the *Canadian Medical Association Journal* by Kenneth Chambaere and others that examined the prevalence of euthanasia without consent in the Flanders region of Belgium. The University of Notre Dame Australia, for example, cited the article in the context of consent and euthanasia:

A further issue which has arisen in jurisdictions which have legalized euthanasia is that of consent. A report published in the Canadian Medical Association Journal alleged that one third of euthanasia cases in Flanders, Belgium are without explicit consent. In a five month period, out of 208 reported Flemish deaths involving 'life-ending drugs,' 142 were euthanised with 'an explicit patient request,' and 66 'were without an explicit request.' The authors note that the majority of the cases where consent was not provided were in 'vulnerable' patient groups.⁵¹²

- 5.87 The LJ Goody Bioethics Centre cited the article in support of a claim that Belgium had experienced a shift *toward* non-consensual euthanasia:

This shift to non-voluntary VAD has been quantified: of 208 VAD deaths in Flanders, Belgium in 2007, including many adults, 66 were carried out without an explicit request from the patient.⁵¹³

- 5.88 Peter McCullagh, a former member of the Australian Health Ethics Committee, submitted that:

Another frequent assertion, namely that decriminalisation would reduce the frequency of non-consensual euthanasia was nvalidated [sic] by the

512 Submission No. 610 from University of Notre Dame Australia, 23 October 2017, p. 8.

513 Submission No. 53 from LJ Goody Bioethics Centre, 4 October 2017, p. 8.

*EoLCRG's research. In a 2010 group survey published in the Canadian Medical Association Journal, Chambaere reported that euthanasia was undertaken in the absence of a request in 66 out of a series of 208 cases.*⁵¹⁴

- 5.89 These arguments rely upon the contention that the legalisation of consensual assisted dying will lead to an increase in non-consensual assisted dying. The Belgian experience is cited repeatedly in these arguments, but it is not clear how the legalisation of voluntary assisted dying will make more common a practice that always was and shall remain illegal.
- 5.90 Moreover, the article cited in these arguments does not support the conclusions that the proponents are attempting to make. Chambaere and his co-authors make clear that the rates of non-voluntary euthanasia in Belgium were high prior to legalisation in 2002. Indeed, according to one study in 2003, those rates were amongst the highest in the world.⁵¹⁵
- 5.91 Most critically, once voluntary euthanasia was legalised, the rate of non-voluntary euthanasia fell. In other words, the introduction of a legal framework for regulating end of life decision making reduced the level of unlawful activity – euthanasia without consent became much less common:

*We found that the use of life-ending drugs without a patient's explicit request occurred more often in Flanders, Belgium, than in other countries, including the Netherlands, where euthanasia is also legal. Flemish physicians have been shown to be more open to this practice than physicians elsewhere, which suggests a larger degree of paternalistic attitudes. **This being said, its occurrence has not risen since the legalization of euthanasia in Belgium. On the contrary, the rate dropped from 3.2% in 1998 to 1.8% in 2007.***⁵¹⁶

Finding 39

The published evidence does not support claims that legalisation of assisted dying results in an inevitable move toward the erosion of safeguards and an increase of non-voluntary euthanasia. Indeed, the evidence supports the opposite conclusion – introducing a legal framework for assisted dying reduces the incidence of unlawful activity, including non-voluntary euthanasia.

514 Submission No. 480 from Mr Peter McCullagh, 21 October 2017, p. 7.

515 Van der Heide, et al, End of life decision-making in six European countries: descriptive study', *The Lancet*, vol. 362, no. 9381, August 2003, p. 348

516 Chambaere, et al, 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey', *Canadian Medical Association Journal*, vol. 182, no. 9, June 2010, p. 900 [emphasis added].

Abuse of the vulnerable

5.92 Concerns about the impact of legalised voluntary assisted dying upon vulnerable population groups are another argument raised in submissions. These concerns are based on the reality that, as people age, or as a terminal illness progresses, people become increasingly dependent on those around them to provide the necessities of life. Dependency, in this context, may create vulnerability.

5.93 A range of different scenarios as to what constitutes vulnerability were offered to the committee. Broadly speaking, the scenarios tended to fall into the following categories:

- personal or institutional relationships that may lead to coercion or undue influence;
- age or disability, including cognitive disability; and
- inadequate access to resources.⁵¹⁷

5.94 The Australian Christian Lobby provided an example of potential personal coercion in its submission:

The old person who could choose death is now a burden for others through their own selfish choice to stay alive. Such a choice may well be resented by those required to care for them or pay for their care. Circumstances are not difficult to envisage in which such old people come to regard killing themselves as 'the right thing to do'.⁵¹⁸

5.95 The Australian Family Association expressed concern about a 'duty to die':

Australia's ageing population has seen an increase in elder abuse. Allowing voluntary euthanasia and assisted suicide opens the door for disabled, sick and elderly people to see themselves as a financial and emotional burden. The 'right to die' could become a 'duty to die'. No safeguards can protect against this.⁵¹⁹

5.96 Approximately 70 *pro forma* submissions were received from individuals who expressed their concerns in the following way:

Euthanasia and assisted suicide is a dangerous option for vulnerable people. Many elderly, disabled and chronically ill people already feel they are a 'burden' on their family and marginalised by society. Rather

517 Lindy Willmott & Ben White, 'Assisted dying in Australia: A values-based model for reform', in Ian Freckelton & Kerry Petersen (eds.), *Tensions and traumas in health law*, Federation Press, Sydney, 2017, p. 491.

518 Submission No. 591 from the Australian Christian Lobby, 23 October 2017, pp. 10–11.

519 Submission No. 489 from the Australian Family Association (WA Division), 21 October 2017, p. 2.

*than affirming the value of every person to our society, even presenting the legal option of physician assisted death for frail and dependent people further embeds the idea that they are 'better off dead' and their lives not worth living.*⁵²⁰

What the evidence says

5.97 Numerous studies have been carried out using data available in jurisdictions where assisted dying or voluntary euthanasia is legal, and those studies consistently find that vulnerable groups are not more likely than others to access assisted dying or euthanasia. Indeed, the judgment in *Carter v Canada*, one of the critical legal challenges that ultimately lead to the legalisation of assisted dying in Canada, found that:

*[...] the expert opinion evidence from persons who have done research into the question is that, with respect to [the Netherlands, Belgium and Oregon], the predicted abuse and disproportionate impact on vulnerable populations has not materialized.*⁵²¹

5.98 According to the joint submission from People with Disabilities WA and the Australian Federation of Disability Organisations:

*There is no evidence to suggest, from either Oregon or the Netherlands data, that people with disabilities are at heightened risk of assisted dying. Vulnerable groups generally including women, ethnic minorities, people from lower socio-economic circumstances, children, people with a psychiatric disability or dementia were not found to be at any heightened risk of assisted dying. People with psychiatric disability (mainly depression) constituted 20% of referrals to the Netherlands assisted dying process, but none progressed. Likewise, in Oregon, none of the 292 people who have accessed assisted dying did so due to mental illness.*⁵²²

5.99 In Oregon, a report published in 2017 that examined 18 years of publicly available data found that, of the 991 individuals who had died following administration of medication:

- 51.4 per cent were men;
- 96.6 per cent were white;

520 This was a *pro forma* submission received from multiple submitters. See, for example: Submission No. 125 from Ms Christina Pleiter, 10 October 2017.

521 *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1 S.C.R. 331 at [684].

522 Submission No. 679 from People with Disabilities WA and the Australian Federation of Disability Organisations, 15 November 2017, p. 11.

- 98.6 per cent had health insurance; and
- 71.9 per cent had some tertiary education.⁵²³

5.100 These findings are consistent with earlier published research. In 2016, a review of attitudes and practices of voluntary euthanasia and assisted dying in the United States, Canada and Europe concluded that those likely to access assistance to die are ‘older, white and well-educated.’⁵²⁴ An earlier study from 2007 examined the experience in the Netherlands over a 15-year period and the experience in Oregon over a nine-year period. The study concluded that those who received assistance to die ‘appeared to enjoy comparative social, economic, educational, professional and other privileges’.⁵²⁵

Impact on suicide prevention

5.101 The committee received approximately 70 submissions from individuals and organisations opposed to legislative change raising concerns about the impact of assisted dying upon broader suicide prevention measures in the community:

*Legalising assisted suicide and euthanasia sends a confusing message about suicide prevention. As a society, we are actively committing ourselves to reducing the tragedy of suicide – except, it seems, for those who are old and unwell. This is an inexcusable double standard.*⁵²⁶

5.102 There is no doubt that this is a difficult area, and one that proponents of assisted dying must take seriously. Effectively, these submitters are asking the committee to consider the importance of sending a consistent message about the importance of preventing all premature deaths, including those who are suffering at the end of their lives.

Distinguishing between suicide and assisted dying

5.103 It is important not to conflate suicide with assisted dying. It is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one’s life in the face of unbearable suffering. This distinction has not been disputed by evidence provided to the committee by experts in the field of psychiatry.

523 Blanke et al, 'Characterizing 18 years of the Death with Dignity Act in Oregon', *JAMA Oncology*, vol. 3, no. 10, 2017, p. 1403; Lindy Willmott & Ben White, 'Assisted dying in Australia: A values-based model for reform', in Ian Freckelton & Kerry Petersen (eds.), *Tensions and traumas in health law*, Federation Press, Sydney, 2017, pp. 491.

524 Emanuel et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe', *JAMA*, vol. 316, no. 1, 2016, p. 79.

525 Battin et al, 'Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients and Vulnerable Groups', *Journal of Medical Ethics*, vol. 33, no. 10, 2007, p. 591.

526 This was a *pro forma* submission received from multiple submitters. See, for example: Submission No. 479 from Ms Rebecca Sampang, 21 October 2017.

5.104 The Western Australian Branch of the Royal Australian and New Zealand College of Psychiatrists (**RANZCP**), indicated that while an assisted death '[...] may be an understandable choice in the context of unbearable suffering, suicide is a tragic outcome for individuals who suffer from mental illness'.⁵²⁷ The WA Branch Chair of the RANZCP, Dr Elizabeth Moore, made the distinction even clearer in her evidence before the committee:

Suicide itself is a really complex area. It has been shown in a number of studies that the actual act of suicide— somebody may think about ending their life as suicide—can be quite spontaneous. This gives us a lot of decision points in order to try to alter that person's perspective. This is a different scenario. When a person is not expected to live for a certain amount of time, that they have unbearable pain or suffering, I think this is a very different scenario from actually saying that the person wants to suicide in the parlance that we are now talking about suicide prevention.⁵²⁸

5.105 Furthermore, on the question as to whether assisted dying would undermine suicide prevention efforts, Dr Moore stated:

No; I do not, not if it is very carefully communicated. I think the communications and the discussions around death and dying—I notice WA Health has now put out an "End of life Framework", which I have read and I actually think is very good—is changing the culture around talking about death and dying, which really is our last frontier. Death is a part of life. If we as doctors have an ethical responsibility to try to assist people to have a good and dignified death, then we need to have more conversations around death and dying, especially in the cultural aspects of it.⁵²⁹

5.106 Western Australia's Chief Psychiatrist, Dr Nathan Gibson, was more conditional in his answer, but also agreed that it was possible to distinguish between temporary suicidal ideation and a desire to end suffering in the late stages of a terminal illness:

[...] I think the answer to the question is yes, but sometimes it can take time. I have seen individuals who have, for a range of reasons, maintained an intent to suicide, in the absence of mental illness, as opposed to individuals who, when their mental illness is treated, lose

527 Submission No. 391 from Royal Australian and New Zealand College of Psychiatrists (WA Branch), 18 October 2017, p. 5.

528 Dr Elizabeth Moore, WA Branch Chair, Royal Australian and New Zealand College of Psychiatrists, *Transcript of Evidence*, 28 February 2018, p. 6.

529 Dr Elizabeth Moore, WA Branch Chair, Royal Australian and New Zealand College of Psychiatrists, *Transcript of Evidence*, 28 February 2018, p. 6.

that intent to suicide. The issue there is that for those individuals that I have worked with over the years, they have often still had significant psychological distress due to issues in their lives and their childhood, so although there may not be a diagnosable mental illness per se, there are often still unresolved issues for those folk. I think there is still a requirement to make sure that we seek to provide proper psychological support and care for those individuals. But I believe there are individuals who, despite that, will still maintain a fixed view. It is not common—it is pretty rare, I think—but they are out there.⁵³⁰

Finding 40

It is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one's life in the face of unbearable suffering. Given this distinction, there is no inconsistency in ongoing suicide prevention campaigns and a decision to legislate for the introduction of a targeted assisted dying framework.

Suggestions of suicide contagion are not supported in the evidence

- 5.107 Many submitters suggested that jurisdictions which had legislated for assisted dying had seen an increase in overall suicide rates. The submissions referenced a paper by Jones and Paton published in the *Southern Medical Journal* and opined that:

[...] data from the US shows that the legalisation of assisted suicide is actually linked to an increase in the overall suicide rate, and a massive 14.5% rise of suicides among over 65s. (D Jones and D Paton (2015), *How does legalization of physician assisted suicide affect rates of suicide? Southern Medical Journal*, 180 (10), pp. 599-604).⁵³¹

- 5.108 Jones and Paton sought to 'test the change in rates of non-assisted suicides and total suicides (including assisted suicide) before and after the legalization of PAS [Physician Assisted Suicide].'⁵³² The authors relied upon US Centers for Disease Control and Prevention data on suicides between 1990 and 2013 and compared the change in suicide rates pre and post assisted death legalisation in Oregon, Washington, Vermont and Montana. They used regression analysis to determine the association between non-assisted suicides and legalisation of PAS, while accounting for some factors known to influence suicide rates, including:

530 Dr Nathan Gibson, Chief Psychiatrist, WA Health, *Transcript of Evidence*, 14 December 2017, p. 17.

531 This was a *pro forma* submission received from multiple submitters. See, for example: Submission No. 263 from Ms Stephanie Mitchell, 15 October 2017.

532 Jones, D.A., & Paton, D., 'How does legalization of physician-assisted suicide affect rates of suicide?', *Southern Medical Journal*, vol. 108, no. 10, October 2015, p. 601.

*the proportion of the population that is black, the proportion that is Hispanic, the proportion of the population that adheres to a recognized religion, the unemployment rate, the annual per capita disposable income, whether marijuana was legal for medical reasons, whether marijuana was decriminalized for recreational purposes, and whether a 0.08 blood alcohol content law was in place.*⁵³³

5.109 There is some dispute in the academic literature about the accuracy of Jones and Paton’s findings, including describing the findings as the result of a ‘faulty analysis’.⁵³⁴ A detailed review of their work in the *Journal of Ethics in Mental Health* made the following conclusion:

*Jones and Paton include the following statement[:] “the association [between the legalization of PAS and non-assisted suicide] is found to be positive and significantly so when we do not include state-specific trends” (2015, p. 602). It is reasonably foreseeable that non-statisticians would take this statement to mean that the paper’s statistical analysis showed that legalization of PAS leads to an increase in nonassisted suicide and, when state-specific trends are not included, to a large increase. A clearer statement, such as “when state-specific time trends are taken into account, there is no statistically significant association between legalization of PAS and non-assisted suicide,” would likely have increased the accuracy of media and others reporting on this finding.*⁵³⁵

5.110 Moreover, the data in European jurisdictions with assisted dying frameworks indicates that suicide rates either remained the same or fell. A 2014 Swiss government report shows that the suicide rate per 100,000 individuals has decreased steadily since 1942.⁵³⁶

Finding 41

The evidence supporting claims that suicide rates have increased in United States jurisdictions following the legalisation of voluntary assisted dying is disputed in academic literature.

533 Jones, D.A., & Paton, D., ' How does legalization of physician-assisted suicide affect rates of suicide?', *Southern Medical Journal*, vol. 108, no. 10, October 2015, p. 601.

534 Dembo et al, ' "For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying (MAID) where Mental Illness Is the Sole Underlying Condition', *The Canadian Journal of Psychiatry*, vol. 63, no. 7, April 2018, p. 453.

535 Lowe, M. & Downie, J., ' Does Legalization of Medical Assistance in Dying Affect Rates of Non-assisted Suicide?', *Journal of Ethics in Mental Health*, vol. 10, 2017, p. 5.

536 Dembo et al, ' "For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying (MAID) where Mental Illness Is the Sole Underlying Condition', *The Canadian Journal of Psychiatry*, vol. 63, no. 7, April 2018, p. 453.

Legislative frameworks determine how assisted dying is implemented

- 5.111 As this chapter has outlined, there are several different models for the provision of assisted dying currently in operation around the world. The models have many similarities and just as many differences. Each has lessons for Australia, but the starting point for discussion about the international experience of assisted dying is to acknowledge that the legislation in each jurisdiction sets the boundaries for accepted practice. In other words, assisted dying for those under 18 years of age, or for people who are not suffering from a terminal or other life limiting illness, is permissible in European jurisdictions under the law in specific circumstances. It is not permissible in North American jurisdictions because there are no provisions in the law allowing it to occur.
- 5.112 Where these practices do occur, as in Europe, they are not the result of a slippery slope away from the original intention of the law but the implementation of the laws as written.
- 5.113 This is not to say that the warnings raised by numerous submitters should not be taken seriously. Indeed, these submissions highlight the importance of framing the legislation in order to establish boundaries around assisted dying that are considered acceptable, ensure protection for vulnerable people, and reflect society's expectations.

Finding 42

Having weighed the evidence, the committee concurs with findings by similar parliamentary inquiries in Victoria and Canada that risks can be guarded against and vulnerable people can be protected.

Chapter 6

Legislation in other Australian jurisdictions

End of life laws have long been debated in Australia

6.1 Searching through the 128 years of publicly available Hansard records for the Western Australian parliament, the word “euthanasia” appears infrequently until the 1980s. Indeed, more than three-quarters of the recorded instances appear after 1995 – the year that the Northern Territory introduced its assisted dying legislation. If parliaments are truly the “mirror of the people”, then it can hardly be surprising that parliamentary debates reflect the growing interest in providing expanded end of life choices to the community.

6.2 The Legislative Council Hansard for 1 April 1981 contains the earliest evidence in the Hansard record of a community campaign to change Western Australia’s end of life laws. The Hon. WM Piesse, a National Country Party member, explained that she had received correspondence from the Western Australian Voluntary Euthanasia Society (**WAVES**):

The plea of the society, with some justification as they see it, is that people should be allowed to exit from this world without the stigma at law of having committed suicide, or they should be helped out by somebody, and it should not be called -murder" or "manslaughter".⁵³⁷

6.3 Mrs Piesse was not sympathetic to the Society’s arguments:

The society is asking for the appropriate legislation to be changed so that voluntary euthanasia will not be a crime. That is a very dangerous step to take, but this attitude is gaining momentum throughout our society today.⁵³⁸

6.4 Her observation that legislating for voluntary euthanasia was gaining increasing support – even in the early 1980s – was prescient. The issue has not gone away and WAVES is still actively campaigning, albeit under a new name: Dying With Dignity Western Australia.⁵³⁹

6.5 The Australian Voluntary Euthanasia Society was also the subject of debate in the New South Wales Parliament in 1978. The parliament was considering decriminalising the act

537 Hon WM Piesse MLC, Member for Lower Central, Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 1 April 1981, p. 375.

538 Hon WM Piesse MLC, Member for Lower Central, Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 1 April 1981, p. 375.

539 Submission No. 565 from Dying with Dignity Western Australia, 23 October 2017, p. 1.

of attempted suicide and some members were concerned that decriminalisation might lead to further legal changes, including legislating for assisted dying.⁵⁴⁰

6.6 These 40-year-old debates in the Western Australian and New South Wales parliaments demonstrate that questions about how we die, and the extent to which suffering should remain an experience for many as end of life approaches, have been features of Australia's political landscape for many decades.

6.7 This chapter examines developments in Australian jurisdictions and outlines some important features of several of the most recently debated bills.

The Australian experience – failed attempts at reform

6.8 Between June 1993 and April 2016, 51 bills dealing with the legalisation of voluntary euthanasia or physician-assisted suicide were introduced into the various Australian parliaments at Federal, State or Territory level.⁵⁴¹ Since then three additional bills have been introduced in Australian parliaments:

- New South Wales: Voluntary Assisted Dying Bill 2017
- Tasmania: Voluntary Assisted Dying Bill 2016
- Victoria: Voluntary Assisted Dying Bill 2017

6.9 Only the Victorian legislation has been successfully enacted. The Tasmanian bill was defeated at the second reading stage, and in New South Wales, the second reading of the bill was defeated in the Legislative Council.

The Northern Territory

Legislative Background

6.10 The Northern Territory became the first jurisdiction in the world to legislate for assisted dying in 1995 with the passage of the *Rights of the Terminally Ill Act (ROTTIA)*. The then Chief Minister of the Northern Territory, Marshall Perron, introduced the Rights of the Terminally Ill bill in the Northern Territory Legislative Assembly in February 1995. In his second reading speech, he explained that:

Through the laws in place today, society has made an assessment for all of us that our quality of life, no matter how wretched, miserable or painful, is never so bad that any of us will be allowed to put an end to it.

540 Mr James Cameron, Member for Northcott, New South Wales, Legislative Assembly, *Parliamentary Debates* (Hansard), 30 November 1978, p. 1193.

541 Willmott et al, '(Failed) voluntary euthanasia law reform in Australia: two decades of trends, models and politics', *UNSW Law Journal*, vol. 39, no. 1, April 2016, p. 4.

*I am not prepared to allow society to make that decision for me or for those I love.*⁵⁴²

- 6.11 Debate on the second reading of the Bill was adjourned and the parliament established the Select Committee on Euthanasia to examine in further detail the provisions of the proposed law. The committee reported in May 1995 but did not make any recommendations about whether assisted dying should be legalised; instead, the report recommended amendments to the original bill.⁵⁴³
- 6.12 The bill was passed by the Legislative Assembly on 25 May 1995 on a vote of 15 in favour and 10 against. The law was eventually overturned following the Commonwealth Parliament's intervention in 1997.

The Territory's model

- 6.13 The ROTTIA allowed for a person with a terminal illness experiencing pain, suffering and/or distress to an extent unacceptable to that person to request medical assistance to end their life. There was no requirement for the person requesting assistance to be a resident of the Northern Territory. The person requesting medical assistance was however required to meet a number of preconditions, including:
- The patient must be at least 18 years old.
 - Two medical practitioners, one of whom is the medical practitioner who received the request, are satisfied that the patient is competent and that the patient's decision has been made freely, voluntarily and after due consideration.
 - A qualified psychiatrist must also certify that the patient is competent to make the decision.
 - The patient, upon being informed of the nature of the illness, the likely course of the illness and the medical treatment that may be available must indicate that the treatment was not acceptable and that the patient has decided to end their life.
 - A second medical practitioner, who held prescribed qualifications or experience in the treatment of the terminal illness from which the patient is suffering, was required to have reviewed the case and to have discussed it with the patient.
- 6.14 There was also a seven-day period between when the patient first indicated to their medical practitioner their wish to end their life and the actual signing of the certificate

542 Hon Marshall Perron MLA, Chief Minister, Northern Territory, Legislative Assembly, *Parliamentary Debates* (Hansard), 22 February 1995, p. 2496.

543 Select Committee on Euthanasia, Parliament of the Northern Territory, *The Right of the Individual or the Common Good? Report of the Inquiry by the Select Committee on Euthanasia*. Available at: https://parliament.nt.gov.au/data/assets/pdf_file/0007/367963/vol1.pdf

of request. The death could take place no sooner than 48 hours after the signing of the certificate. The patient could rescind the request at any time and in any form.

- 6.15 The legislation allowed for both self-administration and physician assisted administration of a lethal medication.
- 6.16 The legislation also protected the right of a medical practitioner to refuse to assist a person for any reason. Medical practitioners who chose to provide the assistance were required to retain appropriate records of the patient's request and any other clinical notes.⁵⁴⁴
- 6.17 The Act included a prohibition on cremating the body of the deceased.
- 6.18 During the time that the legislation was in operation, four people were assisted to end their lives.⁵⁴⁵

Doctor may refuse to provide assistance

- 6.19 Section 5 of the ROTTIA provided that a medical practitioner did not have to provide assistance to a patient for any reason and at any time:

A medical practitioner who receives a request referred to in section 4, if satisfied that the conditions of section 7 have been met, but subject to section 8, may assist the patient to terminate the patient's life in accordance with this Act or, for any reason and at any time, refuse to give that assistance.

Evidence regarding the Northern Territory's legislation

- 6.20 At the time that the Northern Territory legislation became law, it was the first of its type anywhere in the world – Oregon's law had not yet come into force, as it was subject to lengthy legal challenges, and the Netherlands would only enact its legislative framework for assisted dying in 2002. As a prototype, it did not have the benefit of drawing upon the experiences in other jurisdictions, nonetheless it can serve as the basis for learning for other places, including in Western Australia.
- 6.21 To that end, the committee asked two key people associated with the creation and subsequent operation of the law – Marshall Perron and Dr Philip Nitschke – what they would do differently. Mr Perron identified three key changes:
- remove the compulsory requirement for psychiatric examination and make it optional only if either doctor considered it necessary;

544 A copy of the Rights of the Terminally Ill Act 1996 is available at:

https://legislation.nt.gov.au/api/sitecore/Act/Word_History?id=16253

545 Dr Philip Nitschke, Director, Exit International, *Transcript of Evidence*, 13 April 2018, p. 2.

- require that the person seeking assistance is a resident of the Northern Territory; and
- remove the prohibition on cremating the body of the deceased.⁵⁴⁶

6.22 Mr Perron reiterated that he would not change the absence of a defined term for the life expectancy of the patient:

That means that a person may well receive eligibility status months or years before they would ever need it, but they could get on with their lives knowing that the backstop was there that they sought so desperately. That is part of why I see not having any term, and terms are problematic, as you will have heard—six months, 12 months, or whatever. There is no need for a term. I stand by the definition of “terminal illness” in the Northern Territory legislation. I think it is a good one.⁵⁴⁷

6.23 Dr Nitschke had similar views as to the application of a time limit on life expectancy, expressing the view that it ‘may be wise to omit the time line completely.’⁵⁴⁸ Dr Nitschke also raised concerns that the Northern Territory’s legislation made it too hard for terminally ill patients to access the assisted dying service:

[...] what we got in that piece of legislation, that Rights of the Terminally Ill Act, was a piece of legislation that made very sick people jump through hoops. When the law passed, I found myself dragging very sick people—in the first case, Bob Dent—from doctor to doctor to get the signatures necessary to demonstrate eligibility to die. The irony of that was not missed on people like Bob Dent who was so sick, yet he said, “I have to qualify to be eligible to die.” I felt cruel having to drag him around to make him satisfy those onerous restrictions of that law. I saw the need for safeguards, but they were particularly difficult ones to comply with.⁵⁴⁹

6.24 Both Mr Perron and Dr Nitschke highlighted the resistance from the medical community in the Northern Territory at the time. According to Dr Nitschke, the legislation was popular with the “average Territorian” but the Australian Medical Association (**AMA**) was ‘very hostile’:

the AMA in particular fought hard to have that law overturned and when it was overturned, it was not just the church; it was not just John

546 Mr Marshall Perron, *Transcript of Evidence*, 13 April 2018, p. 2.

547 Mr Marshall Perron, *Transcript of Evidence*, 13 April 2018, p. 2.

548 Dr Philip Nitschke, Director, Exit International, *Transcript of Evidence*, 13 April 2018, p. 14.

549 Dr Philip Nitschke, Director, Exit International, *Transcript of Evidence*, 13 April 2018, p. 2.

*Howard and politicians in Canberra like Kevin Andrews who saw the end of that law, it was actually the work behind the scenes of the medical profession to try to undermine the legislation.*⁵⁵⁰

Victoria

Legislative background

- 6.25 Unlike most other Australian jurisdictions, there had been only one earlier attempt at legislating for the introduction of voluntary assisted dying in Victoria prior to the successful enactment of the law in 2017. That earlier bill was introduced into the Legislative Council in 2008 by the Australian Greens with support from a Liberal member, Mr Ken Smith. It was defeated at the second reading stage with 25 against and 13 in favour.
- 6.26 Both major parties opposed reforms allowing for assisted dying at the Victorian election in 2014. Clearly, however, the debate continued to evolve – both in the broader public and within political circles – and key people, including Victoria’s Minister for Health Jill Hennessy, came forward in support of law reform. In May 2015, a parliamentary inquiry was tasked with the responsibility of examining Victoria’s laws. The inquiry reported in June 2016 and recommended the legalisation of voluntary assisted dying.
- 6.27 In response, the Victorian government appointed a panel of experts to examine the committee’s recommendations and develop a legislative framework that would allow for safe and compassionate assisted dying. The panel of experts released its report containing 66 recommendations in July 2017.
- 6.28 Ms Hennessy introduced the Voluntary Assisted Dying Bill in Victoria’s Legislative Assembly in September 2017. The bill passed the Legislative Council in November of the same year and will come into force in June 2019.

Eligibility and the operation of the law

- 6.29 The *Voluntary Assisted Dying Act 2017* provides that Voluntary Assisted Dying (**VAD**) will be legal in Victoria from 19 June 2019. In order to access VAD, a person must meet a number of eligibility criteria, including that the person must:
- be aged 18 or over;
 - be an Australian citizen or permanent resident, ordinarily resident in Victoria, and, at the time of making a first request for VAD, have been resident in Victoria for at least 12 months;

550 Dr Philip Nitschke, Director, Exit International, *Transcript of Evidence*, 13 April 2018, p. 10.

- have decision-making capacity; and
- be diagnosed with a disease, illness or medical condition that is:
 - incurable;
 - advanced, progressive and will cause death;
 - is expected to cause death within six months; and
 - is causing suffering to the person that cannot be relieved in a manner that the person finds tolerable.

6.30 There is an exception for a person suffering from a neurodegenerative condition, where instead the condition must be expected to cause death within 12 months. Mental illness or disability alone are not grounds for access to voluntary assisted dying, but people who meet all other criteria, and who have a disability or mental illness, will not be denied access to voluntary assisted dying.

6.31 Discussions about accessing voluntary assisted dying may be initiated only by the person seeking access to the service. If a person wants to request access to voluntary assisted dying, they will need to be assessed by a suitably qualified doctor who will determine if the person is eligible. This initial doctor is referred to as the coordinating medical practitioner. If the person is eligible, the process is repeated with a second doctor (the consulting medical practitioner) who will need to conduct another assessment. The doctors have a duty to make sure the person is making a fully informed decision and is aware of the available palliative care options.

6.32 If the person wishes to proceed, they must make a written declaration that is witnessed by two independent individuals, confirming that they are making an informed, voluntary and enduring decision to access voluntary assisted dying. On receiving a final request, the doctor will apply for a permit from the Department of Health and Human Services to prescribe a substance that the person may use to end their life at a time of their choosing. The person must administer the substance themselves, unless they are physically unable to do so, in which case their doctor may assist.⁵⁵¹

6.33 Section 67 of the *Voluntary Assisted Dying Act 2017* requires that, following a patient's death, the medical practitioner who was responsible for the person's medical care, or who examines the body of the deceased person, must notify the Registrar of Births, Deaths and Marriages if they are aware the person was the subject of a voluntary assisted dying permit. They must also stipulate that:

551 <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview>

- the person has been prescribed the voluntary assisted dying substance;
- if the person has self-administered or been administered the voluntary assisted dying substance; and
- the disease, illness or medical condition that was the grounds for the person to access voluntary assisted dying.

6.34 This information is provided to the Voluntary Assisted Dying Review Board.

6.35 Any unused prescribed substance that has not been self-administered by the person must be returned to the dispensing pharmacist within one month of the notification of the person's death. The pharmacist will report the return of the substance to the Voluntary Assisted Dying Review Board.

Doctor may refuse to provide assistance

6.36 Section 7 of the *Voluntary Assisted Dying Act 2017* provides that a health practitioner may, on the grounds of conscientious objection, refuse to:

- provide information about voluntary assisted dying;
- participate in the request and assessment process;
- apply for a voluntary assisted dying permit;
- supply, prescribe or administer a voluntary assisted dying substance;
- be present at the time of administration of a voluntary assisted dying substance;
- dispense a prescription for a voluntary assisted dying substance.

Appeal mechanisms

6.37 Part 6 of the *Voluntary Assisted Dying Act 2017* allows for an “eligible applicant” to appeal to the Victorian Civil and Administrative Tribunal (**VCAT**) in relation to decisions made by either the coordinating or consulting medical practitioner regarding:

- the residential status of the patient; and
- the decision making capacity of the patient.⁵⁵²

6.38 Simply being a member of the patient’s family does not make a person an eligible applicant for the purposes of appealing decisions made by either the coordinating or consulting medical practitioner.

552 Part 6 *Voluntary Assisted Dying Act 2017* (Vic).

Voluntary Assisted Dying Review Board

6.39 The Voluntary Assisted Dying Review Board is responsible for monitoring and reporting on assisted dying under the legislation. Section 93 of the *Voluntary Assisted Dying Act 2017* outlines the powers and functions of the Board, which include:

- providing reports to each House of the Parliament on the operation of the Act and any recommendations for the improvement of voluntary assisted dying;
- promoting compliance with the requirements of the Act by the provision of information in respect of voluntary assisted dying to registered health practitioners and members of the community;
- referring any issue identified by the Board in relation to voluntary assisted dying that is relevant to the following persons or bodies—
 - the Chief Commissioner of Police;
 - the Registrar;
 - the Secretary of the Department of Health and Human Services;
 - the State Coroner; and
 - the Australian Health Practitioner Regulation Agency.

Evidence regarding Victoria's legislation

6.40 Unlike in the Northern Territory, when the Victorian parliament legislated for Voluntary Assisted Dying, it had the benefit of drawing upon the experiences of several jurisdictions that had already legalised the practice. Several individuals and organisations giving evidence to the committee drew attention to certain aspects of the Victorian model that they viewed as shortcomings.

6.41 Dr Rodney Syme, a medical practitioner and the Vice President of Dying with Dignity Victoria, raised concerns about the timelines for access to VAD:

The legislation confines assistance to people with a terminal illness with less than six months to live, with one exception, and that is people with a neurodegenerative condition. I argued strongly for a wider period of illness, for the simple reason that neurodegenerative illnesses are very slowly progressive and the suffering associated with them can last at least 12 months, unlike cancer, in which the terminal phase is a very

*much shorter period usually and can be reasonably well palliated, whereas neurodegenerative conditions cannot be well palliated.*⁵⁵³

- 6.42 Dr Syme also highlighted what he viewed as an important omission relating to persons suffering from chronic organ failure:

*The trajectory of their illness is quite different from those of people with cancer and very similar to people with a neurodegenerative illness. People with cardiorespiratory failure can have a terminal illness—the trajectory may be at least 12 months—interspersed with episodes of acute failure.*⁵⁵⁴

- 6.43 Dr Richard Lugg, a member of Doctors for Assisted Dying Choice, also raised concerns about what he called a ‘maximum expected duration test’ and he recommended that death should be reasonably foreseeable.⁵⁵⁵ Dying with Dignity Western Australia offered a similar view as to the timelines and noted that Canada had opted not to include timelines in its legislation. Instead, the patient’s death must be ‘reasonably foreseeable’.⁵⁵⁶

- 6.44 Other witnesses were concerned that the Victorian legislation created a model that was overly bureaucratic.⁵⁵⁷ Section 49 of the *Voluntary Assisted Dying Act 2017* provides that the Secretary of the Department of Health and Human Services must determine an application for a voluntary assisted dying permit. The same section allows the Secretary to deny an application if the ‘Secretary is not satisfied the request and assessment process has been completed as required by this Act.’⁵⁵⁸ The Secretary is authorised to delegate this role to another officer of the department.⁵⁵⁹

- 6.45 According to Mr Perron, the requirement to make a final application to a “public servant” is:

[...] a step which is totally unnecessary, completely out of the blue, and I guess the public servant in that case just does all the paperwork. He does not necessarily have any medical qualifications. They review that all the paperwork has been ticked off correctly. I think it is a complete

553 Dr Rodney Syme, Vice President, Dying with Dignity Victoria, *Transcript of Evidence*, 13 April 2018, p. 2.

554 Dr Rodney Syme, Vice President, Dying with Dignity Victoria, *Transcript of Evidence*, 13 April 2018, p. 2.

555 Submission No. 648 from Dr Richard Lugg, 23 October 2017, p. 4.

556 Mr Stephen Walker, Vice President, Dying with Dignity Western Australia, *Transcript of Evidence*, 13 April 2018, p. 4.

557 Mr Marshall Perron, *Transcript of Evidence*, 13 April 2018, p. 5; and Dr Alida Lancee, *Transcript of Evidence*, 5 April 2018, p. 7

558 Section 49 *Voluntary Assisted Dying Act 2017* (Vic).

559 Section 113 *Voluntary Assisted Dying Act 2017* (Vic).

*time-consuming step. It will take, if not hours, maybe days, to get such a permit. We are talking about people who are suffering so badly that they want to die. Let us not delay it any longer than we have to.*⁵⁶⁰

6.46 During debate on the clause in the Victorian parliament, assurances were given that the decision would be made within 24 hours, and that the Secretary's role would be to check:

*that the eligibility criteria have been addressed, verifying the clinical reports in relation to the prognosis in relation to the time frames by which they anticipate being at the end of their life and making other relevant assessments, including double-checking in relation to issues that would be of concern in relation to whether there was a view that mental health issues were relevant and whether there may have been therefore a question mark over capacity or questions over coercion that they may have had.*⁵⁶¹

New South Wales

Legislative Background

6.47 Reflecting the significant public debate generated by the brief operation of the ROTTIA in the Northern Territory, New South Wales' first attempt at legislating for voluntary euthanasia took place in 1997. Since that time, nine attempts have been made to legalise assisted dying with the most recent occurring in 2017. All of the bills introduced in New South Wales have been private members bills, although the most recent attempt was supported by a cross-party group including the Greens, the National Party and the Labor Party.

6.48 As with all previous attempts, the Voluntary Assisted Dying Bill 2017 failed to gain sufficient support on the floor of the parliament after failing to pass the second reading stage in the Legislative Council by a single vote.

Eligibility and the operation of the law

6.49 Under the New South Wales model, a person would have been able to access voluntary assisted dying services if they:

- were aged 25 years or over;
- were an Australian citizen or permanent resident ordinarily resident in New South Wales;

560 Mr Marshall Perron, *Transcript of Evidence*, 13 April 2018, p. 5.

561 The Honourable Gavin Jennings, Leader of the Government in the Legislative Council, Victoria, Legislative Council, *Parliamentary Debates* (Hansard), 21 November 2017, p. 6337.

- had decision making capacity;
- were suffering from a terminal illness, and as a result, had been experiencing severe pain, suffering or physical incapacity to an extent that was unacceptable to the person.

6.50 A terminal illness was defined as an illness that will, in reasonable medical judgment, result in the death of the person within 12 months.

6.51 The bill required two doctors to independently assess the person who had requested assisted dying. The second doctor must be a specialist in the field of medicine relating to the patient's terminal illness. Prior to referring to the second assessing doctor, the bill required the first doctor to offer a referral to a palliative care specialist. The patient did not need to accept this referral.

6.52 Once the two assessing doctors had found the patient met the illness and treatment criteria, a psychiatrist or psychologist would be required to confirm that the patient had the capacity to make the request and that the request had been made voluntarily.

6.53 Once these preconditions had been satisfied, a "request certificate" would be completed by the patient and the two assessing doctors. The certificate would have contained declarations as to the various matters and preconditions that each person was to have satisfied.

6.54 The assisted dying procedure could only take place once 48 hours had elapsed from the time the request certificate had been signed.

Doctor may refuse to provide assistance

6.55 Clause 11 of the New South Wales bill provided that a doctor could refuse, for any reason and at any time, to provide an assisted death to a person.

Appeal mechanisms

6.56 A "close relative" could apply to the Supreme Court for an order that a request certificate was not valid. The Court's consideration as to validity was limited to determining whether the patient:

- was eligible for assisted dying at the time the request was made;
- had decision making capacity at the time the request was made; and
- made the request voluntarily and after due consideration.

Voluntary Assisted Death Review Board

6.57 The functions of the New South Wales Voluntary Assisted Death Review Board were to be broadly similar to those contained in the Victorian legislation; however, the New South Wales bill differed in one important respect: the Board would review each assisted death as soon as practicable after it had received the required medical records.

Evidence regarding New South Wales' legislation

6.58 As the New South Wales bill was not enacted into law, it is perhaps not surprising that fewer witnesses made statements about the proposed law. Nonetheless, a few issues were highlighted for the committee by Mr Perron:

- The 12-month timeline for those suffering from a terminal illness contained in the New South Wales bill was preferred to the six-month timeline enacted in Victoria.
- The requirement that a person be 25 years old before accessing assisted dying was not preferred, especially as Victoria and most other jurisdictions set the limit at 18 years old.
- Consistent with his view that the requirement for psychiatric assessment in the ROTTIA was regrettable, Mr Perron also questioned the similar requirement in the New South Wales bill.
- The ability of a relative to challenge the validity of a request decision was 'burning the principle of autonomy'.⁵⁶²

6.59 Dr Brien Hennessy, the Head of Anaesthesia at Sir Charles Gairdner Hospital, indicated that the ability of health professionals to raise the issue of assisted dying was preferable to the model enacted in Victoria, where health professionals were forbidden from initiating a discussion on the matter.⁵⁶³

Tasmania

Legislative background

6.60 Prior to the introduction of the Voluntary Assisted Dying Bill 2016, there had been two earlier attempts at reforming end of life law in Tasmania. The first, a bill introduced in 2009 by an Australian Greens member of parliament, never made it to a vote on its second reading.⁵⁶⁴ The second bill was introduced in October 2013 and was defeated at the second reading stage by a single vote.

562 Mr Marshall Perron, *Transcript of Evidence*, 13 April 2018, p. 5.

563 Dr Brien Hennessy, Anaesthetist, *Transcript of Evidence*, 30 April 2018, p. 14.

564 The bill's progress is recorded here:

http://www.parliament.tas.gov.au/bills/Bills2009/37_of_2009.htm. Accessed on 3 July 2017.

6.61 The most recent attempt was a private members bill introduced into the Tasmanian House of Assembly and supported by the former Labor premier, Ms Lara Giddings, and Ms Cassy O'Connor, the Leader of the Tasmanian Greens. This third attempt was defeated 16 votes to eight.⁵⁶⁵

Eligibility and the operation of the law

6.62 A person eligible for an assisted death was to have been a competent adult, resident in Tasmania, making a voluntary request and suffering from an eligible medical condition. In order to have an eligible medical condition, the person must:

- be in the advanced stages of a serious, incurable and irreversible medical condition, whether caused by illness, disease or injury, as diagnosed by a medical practitioner who has specialised qualifications or experience in diagnosing and treating the medical condition; and
- be experiencing persistent suffering that is intolerable for the person as a result of their medical condition, or associated medical treatment, or complications resulting from them; and
- have no reasonably available medical treatment or palliative care options that would relieve the person's suffering in a manner that is acceptable to them, taking into account both the treatment and any consequences of the treatment; and
- have no reasonable prospect of a permanent improvement in the medical condition.

6.63 The person would have initiated three requests, including an initial oral request; a written request witnessed by two witnesses that met specified requirements; and a subsequent oral request. Two days would have separated the first two requests, and at least seven days the following two requests. A person would not have received an assisted death until a secondary medical practitioner confirmed the opinion of the primary medical practitioner on the key criteria of competence, voluntariness and eligible medical condition.

6.64 The person may have self-administered through oral ingestion or activation of a medical device, or the primary medical practitioner may administer the drugs.

Doctor may refuse to provide assistance

6.65 Consistent with other bills in Australia, the proposed Tasmanian legislation included protections for doctors and other health care providers who did not wish to provide assisted dying. However, health care providers had a duty to facilitate transfer of care.

⁵⁶⁵ Submission No. 626 from Dying with Dignity Tasmania, 23 October 2017, p. 3.

Registrar to review all deaths under the legislation

6.66 The Tasmanian bill provided for the creation of a registrar with statutory powers to review and report on assisted deaths. The functions of the registrar would have included:

- reviewing an assisted death for the purpose of monitoring compliance with the Act;
- investigating, reporting and making recommendations to the Minister on any matter relating to the operation or administration of the Act; and
- communicating to appropriate authorities any concerns the Registrar has about compliance or non-compliance with the Act.

6.67 The Registrar was also required to provide an Annual Report to Parliament.⁵⁶⁶

Lessons from legislative developments in Australia

6.68 In their evidence to the committee, voluntary assisted dying proponents were overwhelmingly positive in respect of the Victorian Government's achievement in establishing a legislative framework that gained sufficient support to become law. However, those same witnesses also sought to sound a warning about the limitations of the legislation. As outlined above, many were concerned that the desire to build as many safeguards into the law as possible may also have created a model that was overly restrictive and that did not adequately respond to the needs of people seeking to end their suffering at the end of their lives.

6.69 In addition to the Victorian example, other recent attempts referred to in this report to legislate for voluntary assisted dying provide useful guidance should Western Australia decide to expand the range of options available to people at the end of their lives.

Private members' bills seldom pass the parliament

6.70 Generally speaking, private members' bills do not enjoy a great success rate in terms of being enacted as laws. Indeed, in Western Australia, the pass rate of private bills is very low. During the 38th and 39th parliaments (the two most recent parliaments), 47 private members' bills were introduced and only four became law.

6.71 54 attempts have been made in Australia to legislate for some type of voluntary assisted dying since 1993. Only two of those attempts have been successful: in Victoria, as a result of a government bill; and in the Northern Territory as a result of a private bill introduced by the then Chief Minister. It is clear that government support is necessary if reforms to end of life laws are to be achieved.

566 The text of the bill is available on the Tasmanian Parliament's website:
http://www.parliament.tas.gov.au/bills/Bills2016/73_of_2016.htm

- 6.72 The evidence on this point is quite stark, and submitters in favour of reform were keen to highlight for the committee the importance of ensuring that any proposed legislation be treated as a government bill, rather than as the business of a single, private member. Mr Perron observed:

It requires cross-party support before a bill is introduced so that there is support to carry it through. The decision of the Victorian committee to recommend that it be a government bill was primarily because the government has carriage of it in the procedures of Parliament, and that makes a big difference even though the government members, of course, were all given a conscience vote on the issue. I point out that in your recommendations, if it gets that far, I urge you not to recommend that a private member take the matter up and introduce it, because I do not believe a bill would succeed on that basis in my reasonable experience.⁵⁶⁷

- 6.73 Mr Neil Francis, a long-time campaigner for reform to end of life laws, discussed the difficulty for private sponsors of assisted dying bills in managing stakeholder buy-in during the legislative drafting process.⁵⁶⁸ In respect of the Victorian legislation, his view is that government support was crucial to its ultimate passage through the parliament:

I believe the reason that the Victorian bill succeeded and is now an act—it will come into effect next year—is that it was government-sponsored and the government had resources to bring to bear, to formulate an expert committee to make recommendations to inform the writing of the bill that would then enjoy members' support.⁵⁶⁹

- 6.74 Mr Andrew Denton, the founder and director of Go Gentle Australia, was very clear in his view that for legislation to pass the parliament, it must be a government bill:

It is my absolute belief that for this legislation to pass, and not just to pass, but to pass properly framed and considered, it has to be a government bill, supported by the machinery and bureaucracy of government.⁵⁷⁰

Finding 43

With the exception of the Northern Territory, where the bill was introduced by the Chief Minister, private members' bills seeking reform to end of life laws have failed to pass any Australian parliament.

567 Mr Marshall Perron, *Transcript of Evidence*, 13 April 2018, p. 10.

568 Mr Neil Francis, *Dying for Choice*, *Transcript of Evidence*, 9 April 2018, p. 5.

569 Mr Neil Francis, *Dying for Choice*, *Transcript of Evidence*, 9 April 2018, p. 5.

570 Mr Andrew Denton, Director, Go Gentle Australia, *Transcript of Evidence*, 13 April 2018, p. 3.

Finding 44

Any bill seeking to introduce a legislative framework for assisted dying in Western Australia would require government support along with the expertise and resources of government.

Recommendation 19

The Minister for Health should ensure that any bill to introduce a legislative framework for voluntary assisted dying is introduced by the government.

Expected time until death

- 6.75 Jurisdictions both here in Australia and internationally have adopted varying approaches when considering whether access to assisted dying should be limited to those whose deaths are expected within a particular timeframe. Victoria adopted the approach common in the United States and limited access to those whose deaths from a terminal illness are expected to occur within six months. In New South Wales, it would have been 12 months if the legislation had been successfully enacted. In both states, a person suffering from a neurodegenerative condition could access assisted dying if death is expected within 12 months. As enacted in the Northern Territory there was no time frame for an expected death, as was the case in relation to the proposed Tasmanian legislation.
- 6.76 The committee has outlined in earlier sections of this chapter the specific feedback that was provided in relation to this issue. In general, proponents of assisted dying were not in favour of the creation of time frames, as they were viewed as arbitrary and clinically problematic. There is, however, an undeniable political element to the inclusion of these timeframes in the legislation.
- 6.77 The Canadian legislation does not include any time frames and instead requires that death is reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis having been made as to the specific length of time that the patient has remaining.

Finding 45

With regard to timeframes, whatever model of assisted dying is enacted in Western Australia should reflect the best possible clinical practice.

Initiating discussions with patients

- 6.78 The Victorian legislation prohibits medical professionals from initiating discussions with patients regarding assisted dying. As outlined in chapters two and four, the committee received significant volumes of evidence indicating that reluctance to discuss the full range of end of life options – from implementing an advance health directive through to

options for terminal sedation – creates deficiencies in the end of life care offered to palliative care patients.

- 6.79 To that end, the prohibition contained in the Victorian legislation should not be a feature of Western Australia’s legislation. Assisted dying should be considered as one of many clinical options available to patients for responding to terminal illness. Achieving the best possible clinical outcomes for a patient will require health professionals to discuss the full range of responses to the challenges encountered by many at the end of life.

Assessment by psychiatrist

- 6.80 The four Australian examples examined in some detail in this chapter adopt two distinct approaches to dealing with psychiatric assessment for a patient seeking an assisted death.

- 6.81 Both the Northern Territory and New South Wales required referral to a psychiatrist before assisted dying could be provided to a patient. In the Northern Territory, the psychiatrist was required to confirm that the patient was not suffering from a mental illness. In New South Wales, the psychiatrist would have confirmed that the patient had decision-making capacity in relation to the request for assistance and that the patient’s decision to request the assistance had been made freely, voluntarily and after due consideration.

- 6.82 In Victoria, a patient requesting assistance can be referred to a psychiatrist if either the coordinating or consulting doctors are unable to determine whether the person has decision-making capacity in relation to voluntary assisted dying. In Tasmania, the primary medical practitioner would have been able to refer a patient to a psychiatrist for any reason and at any time.

Protecting the right of health professionals to *not* participate

- 6.83 A common feature of all legislation in Australia and internationally is the protection afforded to health professionals who, for whatever personal reasons they might have, choose not to participate in providing assisted dying services. This is an important protection that should be made explicit in any Western Australian legislation, with the effect of removing any doubt that participation by all health professionals will be entirely voluntary.

Finding 46

In other jurisdictions, health professionals are afforded the opportunity to not participate in voluntary assisted dying services.

Recommendation 20

The Minister for Health should ensure that health professionals are not compelled to participate if any voluntary assisted dying framework is developed for Western Australia.

Final approval from senior bureaucrats

- 6.84 Some elements of the Victorian law are not commonly replicated in other jurisdictions. This includes the role of a senior bureaucrat in providing final approval for a patient's decision to choose to end their own life. It is difficult to contemplate any other scenario where it would be appropriate for the government to insert itself in the private medical decisions made by a patient in consultation with their doctors. Indeed, such intervention is not currently required for other end of life options open to patients – government permission is not required, for example, for a person to receive terminal sedation, or to refuse artificial food and hydration.
- 6.85 If assisted dying is the ultimate expression of a patient's autonomy, then government intervention in the process must be kept to a minimum. Ultimately, assisted dying is a decision made by a patient based upon treatment considerations provided in good faith by attending health professionals.
- 6.86 That is not to say that safeguards should not be built into the model. As the committee outlines in chapter seven; however, those safeguards must be designed to impede as little as possible on the ability of a competent person to exercise their autonomy in a timely fashion.

Chapter 7

Voluntary assisted dying

Introduction

- 7.1 Almost all religious traditions in Australia are linked by a common respect for the dignity and the value of human life, and those who do not accept theological ideas ordinarily consider that human life is intrinsically valuable. However, most people also accept that not every available resource is required to prolong life needlessly and individuals, at the end of life or without hope of cure, should be allowed to die.⁵⁷¹
- 7.2 As has been noted earlier in this report, even the best palliative care is not 100 per cent effective all of the time. A small but significant group of people will suffer with intractable symptoms at the end of life. In addition, many treatments for the relief of pain and other symptoms will have very unpleasant side effects and may cause further symptoms and distress.⁵⁷² In some cases, prolonging the dying process offers no recognisable benefit to a dying person.
- 7.3 Notwithstanding the evidence of many of those working in palliative care, including specialist physicians, regarding how rare it is for a person not to have a good death, the committee received extensive evidence about bad deaths. Some of those deaths occurred in the best palliative care facilities in Western Australia. It is clear that there are limits to modern medicine.
- 7.4 Equally, there are shortcomings with the current lawful options at end of life – those options are unsatisfactory for some people with grievous and irremediable suffering. Nevertheless, Western Australians do expect to be able to exercise personal autonomy in dying, just as they do in living.
- 7.5 In light of the evidence outlined in the preceding chapters, it is appropriate to make provision for Western Australians to have the option of voluntary assisted dying. This reform will give effect to the widely accepted ethical value of patient autonomy and reflect majority community expectations regarding death and dying. It will also provide relief to people who suffer with intractable symptoms towards the end of their lives.
- 7.6 The committee identified a number of features that should be included in any laws for assisted dying. This chapter provides an explanation for the committee's position on

571 *The End of Life: Euthanasia and Morality*, James Rachels, Oxford University Press, 1986, p. 7.

572 Fiona Randall and R.S. Downie, *The Philosophy of Palliative Care: Critique and Reconstruction*, Oxford University Press, 2006.

each of these elements. It concludes with a framework summarising the issues that should be considered by government.

Autonomy and self-determination

- 7.7 The committee received evidence from many people declaring that while they accept others exercising personal beliefs about end of life, they want the right to choose for themselves how they will die. The desire for autonomy has a long history and found expression in both the moral theories of Immanuel Kant and the ethical theory of classical utilitarianism. In 1859, John Stuart Mill famously declared that:

*The only purpose for which power can rightfully be exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, physical or moral, is not sufficient warrant[...] Over himself, over his own body and mind, the individual is sovereign.*⁵⁷³

- 7.8 Many witnesses expressed similar sentiments in their evidence to the inquiry. Mrs Margo Beilby told the committee about her husband, Mike, who experienced prolonged suffering at the end of his life and made the choice to import and ingest Nembutal:

*I very strongly believe that someone in Mike's position should be able to go to their doctor, explain their wishes (Mike's doctors were all very aware of his condition) and ask for a prescription for Nembutal. They should be able to take the prescription to a pharmacist and obtain the drug. Then they should be able to keep the drug beside them until they decide that the time has come. (I believe in places where doctor assisted dying is legal that many terminally ill patients never take the drug) And they should be able to have their family and friends around them while they die, if they so choose, without putting those people in danger of legal repercussions.*⁵⁷⁴

- 7.9 Mr Bill Spanbroek told the committee about the suffering endured by his son Michael who suffered with Juvenile Huntington's disease. He described watching his son waste away to less than 30 kilograms while experiencing 'gruelling' pain. Mr Spanbroek urged the committee to support legislative reform to allow voluntary euthanasia:

During this time in the Nursing Home, we watched so many patients with no Quality of Life, and having discussions with them, they expressed their freedom to end their life with dignity and compassion. I urge all MEMBERS of PARLIAMENT to consider support this very

573 *On Liberty*, John Stuart Mill, 1859.

574 Submission No. 27 from Mrs Margo Beilby, 29 September 2017.

*important legislation. For the matter of Humanity and Compassion we must come to a positive support and the PASSING of this BILL.*⁵⁷⁵

- 7.10 Mrs Jenny Rickerby described her father's cancer and slow death over two weeks as he starved himself to death. She told how the extended family visited him in his final days and supported her father in his decision, and that he would have chosen assisted dying if it were an option:

*We all believe the same thing now; that somebody should have that choice. I believe if dad had had a button he was capable of pushing to inject himself, he would have done it. As to whether he might have done it maybe too early for everybody or whatever, I mean nobody knows what a person is going to keep on going through as time goes by. But it is his decision, it is his life.*⁵⁷⁶

- 7.11 Mrs Patricia Marshall told the committee that end of life choices were not only about pain and about terminal illness:

*The medical model of managing the end of life when experiencing chronic or terminal illness and the role of palliative care is an insufficient model for many seniors. The questions of loss of self-autonomy and human dignity, conscious awareness of physical or mental deterioration and the realisation that meaningful participation in life has come to an end are very important considerations for the elderly and should be included in any discussion of end-of-life choices. The process of ageing brings an increasing awareness of one's own deterioration and detachment from what is perceived as a complete life. It is only when this process is directly experienced that it can be fully understood; therefore, it is necessary for those making decisions to change the law to take some advice from those who may choose a voluntary and dignified end to their life when they perceive it to be complete.*⁵⁷⁷

- 7.12 Mrs Grytsje Doust told the committee of her 76 year-old mother's diagnosis of acute leukaemia and her mother's choice of voluntary euthanasia in Holland:

My personal opinion about euthanasia going through these nine weeks with her, the process, the way it was handled by the doctors, the legal profession, the support, it was wonderful and it gave my mother a lot of power because she was in charge. She could say, "No, I don't want to go into hospital", "No, I don't want to do this", "This is how I want it; I want

575 Submission No. 497 from Mr William Spanbroek, 22 October 2017 [author's emphasis].

576 Ms Jenny Rickerby, Individual, *Transcript of Evidence*, 7 March 2018, p. 2.

577 Mrs Patricia Marshall, Individual, *Transcript of Evidence*, 7 March 2018, p. 1.

to be at home, “This is how I want it done with my family around me. I know there is no hope for me, that it is terminal”. It also prevented her to go through those last agonising maybe another couple of days or a week, because that is what it was leading to. It was becoming for her personally, because mentally she was still all there, it became very, very difficult. All in all it was—maybe it is a strange word to say—a beautiful procedure and it gave my mother such peace of mind. We supported her in that.⁵⁷⁸

Western Australia should legislate for voluntary assisted dying

- 7.13 Individuals exercise independence and autonomy in their daily lives and want to be able to make autonomous choices when they are dying. One of those choices should be to manage the place and time of their own death, through voluntary assisted dying.
- 7.14 Legislation for voluntary assisted dying must promote core values, for example: life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, privacy and reducing human suffering.
- 7.15 Consistent with the key principle of autonomy, voluntary assisted dying should provide for self-administration unless the person is physically incapable, in which case doctor-administration should be allowed.

Finding 47

An expert panel including health and legal practitioners and health consumers would assist in the development, consultation and implementation of legislative reform to allow for voluntary assisted dying.

Finding 48

An expert panel would be assisted in its considerations by a framework that canvasses the issues considered by this committee

Recommendation 21

The Minister for Health establish an expert panel including health and legal practitioners and health consumers to undertake consultation and develop legislation for voluntary assisted dying in Western Australia, and that this report, together with the Framework contained at the end of Chapter 7, be considered by that Panel.

Models for voluntary assisted dying

- 7.16 The route to legalisation of voluntary euthanasia or voluntary assisted dying has differed in each jurisdiction around the world where either or both are permitted. The various

578 Mrs Grytsje Doust, Individual, *Transcript of Evidence*, 30 April 2018, p. 3.

models for reform are grounded in either: human rights; the criminal defence of necessity; prosecution guidelines or legislative reform.

- 7.17 It is important for any proposed reform that it be relevant to the legal environment in Western Australia.

Rights based change

- 7.18 After many years of litigation, Canada eventually relied on a human rights model underpinned by the Canadian *Charter of Rights and Freedoms*. Australia, and indeed Western Australia, has no comparable Charter or Bill of Human Rights. Case law is also generally much less developed than in Canada.⁵⁷⁹ Legislative reform is unlikely therefore, to be constructed around a human rights model. However, a number of submissions suggested that any legislation should contain guiding principles.⁵⁸⁰ Some of the rights relied on in Canada could provide useful guiding principles for any Western Australian legislation – for example: autonomy, privacy, dignity, equality and life.

Criminal law defence of necessity

- 7.19 Although the Dutch have constitutionally entrenched rights,⁵⁸¹ euthanasia and assisted suicide is legalised in the Netherlands through a model based on the defence of necessity. The defence is available when a defendant faces a conflict between her duty to preserve life and her duty to relieve suffering.
- 7.20 Prior to codification and entry into law in 2002,⁵⁸² the legal basis upon which doctors were either not prosecuted, or acquitted for taking a life was the defence of necessity.⁵⁸³ Following codification, euthanasia and assisted suicide are no longer an offence where the person expressly requests assistance and the doctor follows the statutory *due care criteria*. Consistent with the earlier Dutch case law, the person must be experiencing unbearable and hopeless suffering and there must be no reasonable alternative form of relief. Arguably, underpinning the initial judicial agency of legal change in the Netherlands was the broad societal support for euthanasia.⁵⁸⁴
- 7.21 The defence of necessity does exist in the common law (which forms part of the law in Western Australia). However, the common law has excluded necessity. The defence of

579 Submission No. 560 from Professors Lindy Willmott and Ben White, Australian Centre for Health Law Research, QUT, 23 October 2017.

580 Submission No. 22 from Mr Kevin Rickson, Individual, 26 September 2017; Submission 94, Ms Dinny Laurence, Individual, 8 October 2017; Submission 560, Professor Lindy Willmott, Professor Ben White and Ms Penny Nellar, QUT, Australian Centre for Health Law Research, 23 October 2017; Submission 602, Dignitas, 23 October 2017.

581 Including in the Netherlands Constitution and through the entrenchment of the European Convention on Human Rights and the International Covenant on Civil and Political Rights.

582 *The Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*.

583 Penney Lewis, *Assisted Dying and Legal Change*, Oxford University Press, 2007, p. 76.

584 Penney Lewis, *Assisted Dying and Legal Change*, Oxford University Press, 2007, p. 98.

necessity is therefore not available in Western Australia as a defence to either homicide or euthanasia.⁵⁸⁵

Prosecution guidelines

- 7.22 Neither voluntary euthanasia nor voluntary assisted dying is lawful in the United Kingdom. Challenges to the law based on human rights have been unsuccessful.⁵⁸⁶ There has however been some reform in relation to assisted suicide. Following the 2010 decision of *Purdy*,⁵⁸⁷ the Director of Public Prosecutions was compelled to amend the Code for Crown Prosecutors to provide greater guidance in relation to assisted suicide.⁵⁸⁸ The code now sets out general principles to be followed by prosecutors. These principles have been criticised for lacking coherency, ‘fall[ing] short of articulating in a meaningful way how the factors are to be used in the decision-making process’.⁵⁸⁹ In addition, the code does not deal with voluntary euthanasia and discourages the involvement of health professionals.

Legislative change

- 7.23 In the United States, Oregon voters passed the first proposed physician assisted dying laws in November 1994 via a ballot initiative. A second ballot in 1997 confirmed the earlier result with a greater majority in favour. The Oregon courts have not recognised a right to assisted suicide so it is unlikely claims using rights could be used to expand the law in Oregon.⁵⁹⁰ Legislative change has now occurred in seven jurisdictions in America, most recently in Hawai’i with the *Our Care Our Choice Act*.
- 7.24 Legislative change also occurred in Belgium in 2001 where the Belgian Senate voted in favour of euthanasia and even earlier in the Northern Territory through the *Rights of the Terminally Ill Act* in 1995. There is debate as to whether the law on necessity is equally applicable in Belgium to cases involving euthanasia.⁵⁹¹
- 7.25 A statutory framework to permit and regulate euthanasia and assisted dying is the most common approach in the permissive jurisdictions.⁵⁹² Further, legislative reform offers an approach that removes the conduct from the realm of criminal law. Such reform is able

585 See for instance *Dudley and Stephens* (1884) 14 Q.B.D. 273; *Re A* [2001] Fam. 147; *Howe* [1987] A.C. 417 and *R (on the application of Nicklinson) v Ministry of Justice* [2012] EWHC 2381.

586 See for instance: *R (on the application of Nicklinson) v Ministry of Justice* [2012] EWHC 2381

587 *R(Purdy) v DPP (UK)* [2010] 1 AC 345.

588 Crown Prosecution Service, [Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide](#). Accessed 4 July 2018.

589 Ben White and Jocelyn Downie, [Prosecutorial Guidelines for Euthanasia and Assisted Suicide: Autonomy, Public Confidence, and High Quality Decision-Making](#), *Melbourne University Law Review*, 2012. Accessed 4 July 2018.

590 Penney Lewis, *Assisted Dying and Legal Change*, Oxford University Press, 2007, p. 153.

591 Penney Lewis, *Assisted Dying and Legal Change*, Oxford University Press, 2007, p. 154.

592 Submission No. 560 from Professors Lindy Willmott and Ben White, Australian Centre for Health Law Research, QUT, 23 October 2017.

to provide a clear process for decision-making and make provision for an oversight body.⁵⁹³

7.26 Therefore, the best model for reform in Western Australia is a discrete legislative framework that is contained in a stand-alone Act making voluntary assisted dying legal.

7.27 As noted earlier, across Australia, private members' bills are consistently less successful than government-led bills; consequently, a bill introduced by the Government is the preferred approach.

Finding 49

The best model for reform in Western Australia is a discrete legislative framework that is contained in a stand-alone Act making voluntary assisted dying legal.

Eligibility

7.28 Other jurisdictions have extensively explored eligibility criteria. Western Australians now also have the benefit of the Victorian legislation and are able to consider what is most relevant and suitable for our community.

7.29 A legislative scheme for voluntary assisted dying with appropriate safeguards is consistent with community expectations and may offer a measure of comfort to many people. However, the legislative framework must not be so complex, so formal and so rigid as to prevent proper access by individuals who are suffering at end of life. Whilst ground breaking, the Victorian approach is arguably too bureaucratic⁵⁹⁴ and it is preferable that the state not act as a gatekeeper.⁵⁹⁵

7.30 The relevant criteria for a person to be eligible should include that:

- the nature of the condition must be an advanced and progressive terminal, chronic or neurodegenerative condition;
- death must be reasonably foreseeable;
- the person must be experiencing grievous and irremediable suffering that is not able to be alleviated in a manner they find acceptable;
- the person must be aged 18 or over;

593 Submission No. 560 from Professors Lindy Willmott and Ben White, Australian Centre for Health Law Research, QUT, 23 October 2017.

594 The *Voluntary Assisted Dying Act 2017* (Victoria) runs to 130 pages, includes 118 provisions, plus consequential amendments, a Schedule of Forms and provides for Regulations; by contrast the Oregon *Death with Dignity Act 1997* has 22 main provisions and runs to twelve pages.

595 See Part 4 *Voluntary Assisted Dying Act 2017* (Victoria).

- the person must have decision-making capacity in relation to voluntary assisted dying; and
- the person must be a resident of Western Australia, and either a citizen or permanent resident of Australia.

7.31 The committee explores each of these criteria in further detail in the rest of the chapter.

Nature of the condition

7.32 The committee received personal evidence from individuals regarding terminal illnesses; advanced, progressive chronic illnesses (such as cardiovascular conditions, musculoskeletal conditions, and organ failure) and advanced, progressive neurodegenerative conditions (such as motor neurone disease and Huntington’s disease). The evidence made clear that suffering is not limited to terminal illness and any assisted dying legislation must include these other conditions where death is a reasonably foreseeable outcome.

7.33 It is clear to the Committee that some individuals will experience extreme suffering for months and even years prior to death. As noted earlier in the chapter on palliative care, Mrs Margo Beilby told the Committee about her once very active husband, Mike, a former deputy headmaster who suffered from Parkinson’s disease and chronic obstructive pulmonary disorder (**COPD**):

He had Parkinson’s disease, and he was down to shuffling from room to room. He could sit and read and sit and watch TV, sit and do Sudoku, and not much else.⁵⁹⁶

7.34 In her submission to the Inquiry Mrs Ailsa Rice described how her husband’s sister suffered a severe stroke and did not have an advance health directive in place:

despite her wishes she lingered for five long years in a nursing home fed liquid food through a tube inserted into her stomach and unable to do anything for herself. Her condition wasn’t a “terminal illness”, but there was no alternative available for her except to suffer a long, slow and isolated descent to death.⁵⁹⁷

7.35 Dr Rodney Syme told the committee that people who are not terminally ill might face severe disadvantage because of prolonged and intolerable suffering:

596 Mrs Margo Beilby, Individual, *Transcript of Evidence*, 1 May 2018, p. 1.

597 Submission No. 56 from Mrs Ailsa Rice, 5 October 2017.

[i]ntolerable suffering can apply to people with neurodegenerative illnesses, chronic cardio/respiratory failure and other organ failures [...] Suffering is the issue, not terminal illness, let me tell you.⁵⁹⁸

- 7.36 In his submission to the Inquiry, palliative care specialist, Dr Derek Eng, indicated he does not support assisted dying. He did however describe suffering in relation to advanced chronic illness:

In many cases, patients with chronic/incurable disease will welcome life prolongation. However, patients in their final months of life may consider life prolongation very burdensome. For example, a patient with heart disease who is in the final 12 months of their life will have several admissions to emergency departments and hospital wards for treatment of breathlessness.

Using heart failure as an example, the current medical paradigm for treatment of heart failure is “fluid restriction” and aggressive diuretic therapy. Initially, patients [...] improve and return to their “baseline” health. However, as the heart continues to fail, they will not be able to return to baseline health and become increasingly disabled by fatigue and breathlessness. Finally, they will be completely confined to a chair or bed. Most patients will experience several cycles of breathlessness – admission to hospital for aggressive treatment – discharge home – breathlessness, admission to hospital etc. This will occur until patients spend prolonged periods in hospital and minimal time at home. This is often the trigger for doctors to consider palliative care – often because they cannot get these patients “out of hospital” (and public hospital bed pressures rise).

Sadly, doctors are often so entrenched in the paradigm of “fixing” pathology that they are unwittingly committing patients (and their families) to prolonged physical and emotional suffering.⁵⁹⁹

- 7.37 There are individuals who experience suffering because of advanced and progressive terminal, chronic or neurodegenerative conditions. Any legislative scheme for voluntary assisted dying must be sufficiently responsive to provide for the people who need it most.

598 Dr Rodney Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, *Transcript of Evidence*, 13 April 2018, p. 3.

599 Submission No. 557 from Dr Derek Eng, Palliative Care Specialist, 23 October 2017, p. 5.

Expected time to death

- 7.38 Severe and intractable symptoms may be experienced for months, and even years, for those with chronic illnesses or neurodegenerative conditions:

*Prognosis is uncertain in many severely disabling progressive neurodegenerative terminal conditions. These conditions can cause prolonged severe and progressive suffering for years prior to eventual death. A time-based prognosis may not allow the option of an expedited death to those who need it most.*⁶⁰⁰

- 7.39 Mr Michael Walker told the committee about his personal struggle with Multiple Sclerosis. In his view, a precise time limit is inappropriate:

*Provided a person has an incurable and stressing condition, and I do, and it is confirmed to be on a path that is certain to end in a difficult death, then, without specifying three years, three months, 12 days, I am of the general view that the limits on any legislation should not be too precise and should not be too artificial about a “how many angels on the head of a pin”-type argument. To me, in the end, once the doctors have confirmed that the condition is not going to change and that the person is not a minor and there is nothing in the end that can be done in, we can pick a number. But within the next couple of years, the next few years, that person should have the right, I argue, to take his own life.*⁶⁰¹

- 7.40 In her submission, Ms Dinny Laurence described her mother’s slow death over seven years following a stroke in 2000:

*She had suffered a stroke in 2000 and said many times after that that she wanted to die. Instead, she was moved to the frail care unit of her retirement village where the loving and professional care of the staff kept her alive for 7 years as her body shrank and her mind steadily withdrew further. I remember her skeletal frame near the end; she was incontinent, not eating or drinking, and whimpered in pain at the slightest touch or movement. I could not believe how long this dying continued.*⁶⁰²

- 7.41 Mr Marshall Perron also told the committee that there is no need for an expected time until death:

600 Doctors for Assisted Dying Choice, letter, Response to questions on notice, undated, p. 16.

601 Mr Michael Walker, Individual, *Transcript of Evidence*, 1 May 2018, p. 2.

602 Submission No. 94 from Ms Dinny Laurence, Individual, 8 October 2017, p. 1.

[t]he Northern Territory legislation very deliberately did not have a term to terminal illness requirement. What I and my colleagues who passed the legislation intended was that once a person was diagnosed with a terminal illness, irrespective of how long they had to live or it was expected that they might live, if they were of a mind to go through the process of determining their own eligibility, once they determined that, they could then have the peace and comfort of knowing that if the suffering ever got bad enough, they had the option to return to the doctor and seek the final stages. That means that a person may well receive eligibility status months or years before they would ever need it, but they could get on with their lives knowing that the backstop was there that they sought so desperately.⁶⁰³

- 7.42 Witnesses indicated that an expected time until death is not always clinically justified.⁶⁰⁴ Dr Richard Lugg also highlighted the difficulty with progressive neurological conditions:

These conditions are quite rare, but the extended duration of their unbearable suffering is much longer, so the total quantum of suffering these people endure is often greater than those for people who have progressive conditions. Therefore, I do not think it is right to sweep them under the carpet. A maximum expected duration test is just not the appropriate way to manage these slower, progressive conditions. But what is required is that death should be reasonably predictable.⁶⁰⁵

- 7.43 Some individuals experience intractable suffering for months or years prior to their death, particularly those with chronic or neurodegenerative conditions. A time until expected death may unfairly exclude those people who would otherwise qualify for voluntary assisted dying. Therefore, a prescribed time is too restrictive and cannot be clinically justified. Further, whilst a certain timeline until death can be difficult to predict, people do need certainty about the options available to them.
- 7.44 A criterion of advanced and progressive terminal or chronic or neurodegenerative illness that is causing grievous and irremediable suffering for the person, should be sufficient without a prescribed timeline until death. Accordingly, legislation should provide that death be *reasonably foreseeable*.

603 Mr Marshall Perron, Former Chief Minister Northern Territory, Individual, *Transcript of Evidence*, 13 April 2018, p. 2.

604 Mr Michael Walker, Individual, *Transcript of Evidence*, 1 May 2018, p. 2; Dr Richard Lugg, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 26 February 2018, p. 11; Dr Rodney Syme, Medical Practitioner, *Transcript of Evidence*, Mr Ian Wood, Christians Supporting Choice for Voluntary Euthanasia, *Transcript of Evidence*, 13 April 2018, p. 6.

605 Dr Richard Lugg, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 26 February 2018, p. 11.

Finding 50

A criterion of advanced and progressive terminal or chronic or neurodegenerative illness, that is causing grievous and irremediable suffering for the person, would be sufficient without a prescribed timeline until death.

Recommendation 22

The Minister for Health should ensure that legislation require that death be *reasonably foreseeable* as a consequence of the condition.

Suffering

- 7.45 A number of jurisdictions include a condition that the person be subject to unbearable suffering. The Northern Territory legislation required suffering and/or distress to an extent unacceptable to the patient. The Victorian legislation requires suffering to the person that cannot be relieved in a manner that the person considers is tolerable. Canada requires grievous and irremediable suffering. This means that the person must be experiencing suffering that is extremely oppressive and that causes grief, great sorrow or great pain – such that it cannot be cured or remedied – in a manner acceptable to the person.
- 7.46 The committee received evidence from the Australian Federation for Disability Organisations that ‘unbearable suffering’ is value-laden and that there is a need for clarity in any legislation.⁶⁰⁶ Although arguably a complex concept, *grievous and irremediable* suffering best captures the sense of great suffering that is related to a medical condition in a less discriminatory manner. Regardless, it must be clear that the suffering is that which is experienced from the person’s point of view:

*Only a subjective assessment of the relevant standard of suffering promotes the value of autonomy.*⁶⁰⁷

- 7.47 Eligibility should require that the person is experiencing grievous and irremediable suffering related to a terminal, chronic or neurodegenerative illness that cannot be alleviated in a manner acceptable to the person.

Recommendation 23

That the Minister for Health ensure the eligibility requirement in the legislation include that the person is experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person.

606 Mr Patrick McGee, Manager, Policy Research Advocacy, Australian Federation of Disability Organisation, *Transcript of Evidence*, 27 February 2018, p. 5.

607 Supplementary Submission No. 560a from Professor Lindy Willmott and Professor Ben White, 8 February 2018, p. 505.

Age

7.48 Suffering at end of life can occur at any age. However, the Committee is of the view that voluntary assisted dying should only be accessible to adults, aged 18 or over. This is consistent with the presumption of capacity at age 18, and with the community expectation of autonomy for adults.

Capacity and capacity assessment

7.49 An individual must have decision-making capacity⁶⁰⁸ at the time of their request in order to be eligible for voluntary assisted dying.

7.50 Although capacity assessments can be complex, General Practitioners routinely assess capacity for:

- patients making decisions about consenting to or refusing medical treatment;
- individuals making legally binding instruments (such as enduring powers of guardianship, enduring powers of attorney and Wills);
- the State Administrative Tribunal when the SAT is determining capacity under the *Guardianship and Administration Act*; and
- referral under the *Mental Health Act 2014* when a person is suspected of needing an involuntary treatment order.

7.51 The committee received conflicting evidence about who should assess capacity. The evidence of the Chief Psychiatrist is that a decision on capacity should be made by a psychiatrist or equivalent specialist.⁶⁰⁹ Despite this, the committee is of the view that an assessment of decision-making capacity in relation to voluntary assisted dying should *not* routinely be undertaken by a psychiatrist or geriatrician.

7.52 Psychiatrist, Dr Roger Patterson, told the committee that the view held by the Chief Psychiatrist was not in keeping with the consensus in other jurisdictions, that general practitioners should ordinarily make the assessment:

He is out of step with every jurisdiction internationally and nationally. The Victorian legislation does not propose it. He is out of step with the Royal Australian and New Zealand College of Psychiatrists who say it should be considered, and he is out of step with the local branch who, as I say, recognise that there are practical logistical problems as to why it is not so. Curiously, Dr Gibson suggests it should be mandatory for

608 See the discussion in Chapter 2 on capacity.

609 Dr Nathan Gibson, Chief Psychiatrist, Western Australia, *Transcript of Evidence*, 28 February 2018.

voluntary-assisted-dying patients to see a psychiatrist, but not mandatory for patients going through the process of terminal sedation. I am not quite sure why he makes the distinction [...].

[T]he GPs know the patients over many, many years in many situations. A psychiatrist coming in cold, as it were, would have to start again. GPs are really well placed to make an assessment of cognitive capacity and psychiatric capacity, and if they are suspicious of any impairment, they would refer on. I think psychiatrists would be able and willing to get involved at that stage.⁶¹⁰

- 7.53 A requirement that there be a referral for specialist psychiatric capacity assessment is likely to involve considerable delay and access may be difficult for many individuals, especially those in regional areas. The Royal Australian and New Zealand College of Psychiatrists (WA Branch) acknowledged that there may be significant practical barriers to psychiatric assessments and recommended training for non-psychiatrically trained professionals:

There may, however, be significant practical barriers to psychiatrists carrying out mandated assessments of all patients seeking access to PAS in a timely way. Access to psychiatrists with relevant specialist expertise such as consultation-liaison or old age psychiatry can be variable given existing resource constraints. This is of particular concern in a population that is defined by their limited life expectancy.⁶¹¹

- 7.54 Under the law, there is a presumption of capacity for all adults. Individuals making life and death medical decisions – such as the decision to refuse medical treatment – are currently not required to undergo a psychiatric examination. For all of these reasons, the Victorian and Oregon models are preferable: a person should only be referred for specialist assessment in instances where a GP or other assessing doctor is uncertain about decision-making capacity. Therefore, in accordance with other medical treatment decisions:

- the person must have decision-making capacity in relation to voluntary assisted dying;
- GPs should be eligible to assess capacity; and

610 Dr Roger Patterson, Psychiatrist, Doctors for Assisted Dying Choice, *Transcript of Evidence*, 26 February 2018, p. 9.

611 Submission No. 391 from the Royal Australian and New Zealand College of Psychiatrists, 18 October 2017, p. 7.

- referral for an assessment by a psychiatrist or geriatrician should only be required when either of the assessing doctors is unable to determine decision-making capacity (for discussion about assessing doctors, see para 7.56).

Finding 51

An individual must have decision-making capacity at the time of their request in order to be eligible for voluntary assisted dying.

Residency

7.55 Only individuals who are ordinarily resident in Western Australia and are either a citizen or permanent resident of Australia should be eligible for voluntary assisted dying. The Victorian approach is appropriate in that responsibility for determining these matters should lie with the assessing doctors. Accordingly, the assessing doctors may satisfy themselves of the residency requirement, and citizenship or permanent residency status through documentary evidence, such as:

- a Western Australian driver’s licence;
- enrolment to vote in Western Australian elections;
- passport or birth certificate;
- medical records; or
- evidence that the individual owns or leases property in Western Australia.

Finding 52

Individuals wishing to access voluntary assisted dying in Western Australia must be either a citizen or permanent resident of Australia ordinarily resident in Western Australia, as defined by the expert panel.

Assessment

Assessing doctors

7.56 Consistent with all jurisdictions that permit voluntary euthanasia or voluntary assisted dying (except Switzerland) *two* doctors should be involved in the assessment of the person. Together with the most significant safeguard in the legislation, that is, that a request must be voluntary – the requirement for two doctors acts as a further safeguard to ensure that only those who are eligible have access to assisted dying. Further:

- either or both assessing doctors may be a general practitioner; and
- neither doctor is required to be a consultant or specialist in the disease or illness.

Eligibility criteria

7.57 Legislation must provide that each doctor independently satisfy themselves of all eligibility criteria, including that:

- the person is aged 18 or over, has permanent residency status or citizenship and is ordinarily resident in Western Australia;
- the request is voluntary and free from coercion or duress;⁶¹²
- the person has an eligible condition that is causing grievous and irremediable suffering; and
- death is reasonably foreseeable as a consequence of the condition.

When is specialist referral required?

7.58 General practitioners are at the coalface of primary health care. They have high-level diagnostic and therapeutic skills and are familiar with managing comorbidities, complexity and uncertainty. However, consultant or specialist involvement may be required for some conditions. A specialist referral should occur when either of the assessing doctors is unable to determine:

- The precise nature of the condition, in which case they must refer to a consultant or specialist in the relevant area.
- Whether the condition is advanced and progressive, in which case they must refer to a consultant or specialist in the relevant area.
- Whether death is reasonably foreseeable as a consequence of the condition.
- Capacity, in which case they must refer to a consultant psychiatrist or a consultant geriatrician as appropriate.

Procedure

7.59 The procedure for assisted dying should be developed by an expert panel (see Recommendation 21); however, in light of the experiences of other jurisdictions some of the relevant considerations are included below.

612 In this regard, the committee notes the evidence of the President of the Royal Australian College of General Practitioners, Dr Timothy Koh, who when asked whether he had concerns that vulnerable people were being influenced or coerced into refusing medical treatment responded, '[...] generally speaking, the answer is no. We do not see it and I think if there was a feel that coercion was happening, most GPs feel that they would be able to really detect that and they would just stop the process then and there, basically'.

7.60 A person who is seeking assisted dying must first make a verbal request to a doctor, followed by a signed written request, in a standard template form. The initial assessing doctor must provide a copy of the written request to the oversight body (see discussion at 7.86). On receipt of the written request the initial assessing doctor must then provide the patient with information regarding:

- the nature of the condition;
- the prognosis of the condition;
- any possible curative treatments;
- any available palliative treatments;
- the nature, effects and risks of the lethal medication that may be prescribed; and
- that the person's consent to assisted dying may be withdrawn at any time.

7.61 The initial assessing doctor must be satisfied that all eligibility criteria are met. The second assessing doctor must assess all eligibility criteria again and provide a written report to the initial doctor. The second assessing doctor must provide a copy of the written advice to the oversight body.

7.62 If both doctors are satisfied that all criteria are met the first assessing doctor may prescribe lethal medication (as determined by the expert panel) for the patient, and must provide instructions on the manner of use.

7.63 Timelines for each step in the process should be advised by the expert panel to ensure integrity in the process without unnecessary delay.

Reflection period

7.64 Similar to any other life and death medical treatment decision a person must have adequate time to reflect on the decision. Ordinarily, people want to live in even the most difficult of circumstances. Clearly, if someone makes a request for assisted dying that person has already reflected on his or her life and future. If they then make a verbal request, a written request, and undergo two clinical assessments, the person will have even more time to consider their decision.

7.65 An individual should not be forced to continue to experience prolonged grievous and irremediable suffering that cannot be alleviated in a manner that is acceptable to the person. Therefore, any final period for reflection should accommodate proper reflection and not be unnecessarily delayed.

Personal objection

- 7.66 Some health professionals will not wish to assist people who have made a request for assistance to die. Those health professionals should not be compelled to provide assistance and should be protected under the legislation; however, this should not be an impediment to a capable individual's autonomous request where they satisfy eligibility criteria.
- 7.67 Either health professionals should be required to provide a referral to an appropriate provider or there must be a publicly available service so that people can directly access a doctor willing to provide assistance.
- 7.68 The AMAWA made clear to the committee their views that individual doctors should not be compelled to assist and that they should not be compelled to refer on:

We would want it to be as tightly controlled as possible. A register is one way, but we would probably suggest even more control so that there is a single service or certain services that are defined and are well known to the public, so that the public can access them directly rather than having to go through their doctor necessarily. Obviously, some doctors are conscientious objectors and would not want to refer or be compelled to refer. If you have services that are well known—there are examples overseas of services that are well known—euthanasia and physician assisted suicide could be only available within those types of services, whether they be government or private probably does not matter.⁶¹³

- 7.69 Mr Andrew Denton, founder and director of Go Gentle Australia told the committee that health professionals are entitled to their beliefs regarding death and dying but they are not entitled to insist on those beliefs for others. Mr Denton gave evidence to the committee regarding the view held by some that suffering is part of the rite of passage of death:

[...] one of the elephants in the room in this conversation is a law that currently allows doctors to impose their personal belief systems. I have no issue with this belief; I just have issue with the law that allows them to impose that belief on others. There are doctors whose view of the world informs them that suffering is part of the rite of passage as you die. Of course, they are welcome to that belief, but the law currently gives them carte blanche to decide how much medication they give to a patient as they die. If that doctor's or that institution's core belief is that you do not assist someone to die and, what is more, that suffering is part of the deal, that is tough for that patient. One of the people I

613 Dr Omar Khorshid, President, Australia (WA Branch), *Transcript of Evidence*, 18 May 2018, p. 12.

interviewed in the course of my research was Professor Alex Broom, a professor of sociology at New South Wales University. He spent six months in a Catholic hospice observing what was going on. This was some years before this debate flowered in Australia. He observed in detail quite a disturbing level of disconnect between the values of that institution and what the patients wanted. Basically, as he put it, the important rites of passage that were important to that institution were mandating a way of dying which those patients did not necessarily want. To me, it is probably the most disturbing thing at the heart of this. There is now considerable testimony from patients within palliative care who died long and terrible deaths. It really bothers me that our law, without any question or scrutiny, allows doctors to choose exactly how they medicate those patients. They may well have a core belief that suffering is part of the deal. I think that is wrong.⁶¹⁴

- 7.70 Personal objections must not present an impediment to those lawfully seeking assistance to die. A referral system that is easily accessible must be available to individuals who are eligible for voluntary assisted dying. In addition, health service providers who hold an objection to assisted dying must be required to facilitate timely transfer of patients in their care to a suitable health provider when a patient requests assisted dying.
- 7.71 The legislation must also contain protections for those doctors who are willing to help those who ask for assistance to die. These include that a doctor is protected from prosecution or other repercussions when acting in good faith and exercising proper care and skill.

Non-discrimination

People with disabilities must have the same rights as others

- 7.72 Consistent with the United Nations Convention on the Rights of Persons with Disabilities (to which Australia is a signatory) individuals with a disability must be afforded the same legal rights as the rest of the community.⁶¹⁵ In the context of end of life care this means that, all individuals have:

[...] the right to be supported in making properly informed decisions about their medical treatment and should be given, in a manner that

614 Mr Andrew Denton, Founder/Director, Go Gentle Australia, *Transcript of Evidence*, 13 April 2018, p. 15.

615 Article 5 – Equality and non-discrimination: UN Convention on the Rights of Persons with Disabilities.

*they understand, information about medical treatment options, including comfort and palliative care.*⁶¹⁶

- 7.73 Both the Australian Federation of Disability Organisations (**AFDO**) and People with disabilities (WA) (**PWdWA**) support the position that people with disability should have access to voluntary assisted dying.⁶¹⁷ Further, they indicate that there is no evidence from overseas jurisdictions that people with disabilities are at heightened risk of assisted dying.⁶¹⁸
- 7.74 Nevertheless, the committee acknowledges that the request for assisted dying must be voluntary and not subject to coercion or inducement.
- 7.75 There are varying degrees of disability, and even the existence of cognitive impairment does not necessarily mean that an individual lacks decision-making capacity.

*Any safeguards which are put in place in relation to people with disability exercising their legal capacity, to protect against undue influence and/or abuse, must respect the rights, will and preferences of the person.*⁶¹⁹

- 7.76 Individuals must not be excluded from voluntary assisted dying solely because of disability.

People with mental illness have the same legal rights as others

- 7.77 Individuals with mental illness must be afforded the same legal rights as the rest of the community. The Chief Psychiatrist, Dr Nathan Gibson, told the committee that:

*If there is a set of legislation or a statute around this, individuals with mental illness who have terminal illnesses should have the same access to that legislation as anyone else, so they should not be discriminated against in that regard.*⁶²⁰

- 7.78 Providing an individual has capacity to make a voluntary request they should be eligible. In that regard, Dr Gibson told the committee that:

616 Submission No. 679 from People with disabilities WA and Australian Federation of Disability Organisations, 15 November 2018, p. 11.

617 Submission No. 679 from People with disabilities WA and Australian Federation of Disability Organisations, 15 November 2018, p. 12.

618 Submission No. 679 from People with disabilities WA and Australian Federation of Disability Organisations, 15 November 2018, p. 13

619 Australian Human Rights Commission, *Euthanasia, Human Rights and the Law*, Issues Paper, May 2016 – website. Accessed 10 July 2018

620 Dr Nathan Gibson, Chief Psychiatrist, Western Australia, *Transcript of Evidence*, 14 December 2017, p. 2.

*[...] having a mental illness does not preclude you from having capacity. Some people may have active mental illness, but have full capacity and still be able to make a very capacitous decision.*⁶²¹

7.79 Both Dr Gibson and Dr Elizabeth Moore told the committee that it is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one's life in the face of unbearable terminal suffering – in circumstances where voluntary assisted dying is available.⁶²²

7.80 As with any other individual, capacity must be presumed, but where there is uncertainty, the person should be referred for specialist assessment:

*We would suggest that if there was any reason to think that that person's balance of mind was affected, they would be referred to a specialist psychiatrist for that assessment.*⁶²³

7.81 Voluntary assisted dying should be for grievous and irremediable conditions. Whilst mental illness may cause extreme suffering, it is remediable. It therefore should not be the basis for an assisted dying request. Equally, the existence of a mental illness does not necessarily mean that an individual lacks decision-making capacity. Individuals should not be excluded from voluntary assisted dying because of a mental illness, if they meet all other eligibility requirements.

Medication

7.82 It is essential that any medication used for assisted dying be effective; however, it should be a matter of clinical judgment for the prescribing doctor (as determined by the expert panel).

Death certification

7.83 The explicit inclusion of voluntary assisted dying as either the manner of death or a contributing cause of death on a death certificate would provide Western Australians with a means to monitor assisted dying and its effects on mortality trends.

7.84 In Western Australia, there are three relevant documents:

- Medical Certificate Cause of Death – completed by the doctor certifying cause of death;

621 Dr Nathan Gibson, Chief Psychiatrist, Western Australia, *Transcript of Evidence*, 28 February 2018, p. 8.

622 Dr Nathan Gibson, Chief Psychiatrist, Western Australia, *Transcript of Evidence*, 14 December 2017, p. 17; Dr Elizabeth Moore, Chair, WA Branch, Royal Australian and New Zealand College of Psychiatrists, *Transcript of Evidence*, 28 February 2018, p. 2.

- Manual Death Registration Form – completed by the funeral director to register a death; and
- The Death Certificate – issued by the Registrar of Births Deaths and Marriages.

7.85 A record of voluntary assisted dying is essential for the regulation of the practice, together with accurate reporting of mortality trends and patterns. Accordingly, there must be appropriate amendment to each of the three relevant documents, above, and the provision of clear guidance to doctors.

Oversight of voluntary assisted dying

7.86 As the AMAWA has suggested there must be an independent oversight body to review and regulate voluntary assisted dying.⁶²⁴ The committee agrees that an appropriate oversight body should be established, authorised and resourced to:

- provide policy and strategic direction for the State of Western Australia;
- review all voluntary assisted dying deaths,
- provide community education and resources;
- provide health professional education and resources, including counselling and advice for practitioners;
- provide a telephone advice line;
- maintain a database of all relevant statistics related to assisted dying; and
- provide an annual report to Parliament.

Reportable deaths

7.87 For the purposes of the *Coroner's Act* 1996, a death would be a foreseeable death and specifically regulated in accordance with the voluntary assisted dying legislation. It would also be reviewable by the oversight body. The view of the WA Coroner is 'if it is a reportable death, the coroner needs to make a finding on cause of death and how the death occurred. A post-mortem examination will be something that the coroner will want. The extent will simply be dictated by the circumstances'.⁶²⁵ The Committee agrees with the coroner in the case of reportable deaths; however, in the Committee's view an assisted dying death should not automatically be reportable to the Coroner. In the case of assisted dying deaths a coronial investigation including a post-mortem examination should not be required for every assisted death but rather, there should be mandatory

624 Dr Omar Khorshid, President, AMA (WA Branch) *Transcript of evidence*, 18 May 2018, p. 13.

625 Ms Ros Fogliani, State Coroner for Western Australia, *Transcript of Evidence*, 1 March 2018, p. 2.

reporting to the oversight body established to review and regulate voluntary assisted deaths. In cases where the oversight body has concerns regarding the death; the conduct of the relevant doctor; or the circumstances of the death, it would be authorised to report the matter to the Coroner or to the Australian Health Professional Regulation Agency for investigation as appropriate.

- 7.88 The Oregon model requires that doctors report all prescriptions for lethal medications to the Oregon Health Authority. Together with reporting by the assessing doctors, a similar system in Western Australia would provide another point of oversight, and a mechanism for collecting relevant data.

Recommendation 24

The Western Australian Government develop and introduce legislation for voluntary assisted dying having regard to the recommended framework and following consultation with the Panel established under Recommendation 21.

- 7.89 The following contains the Voluntary Assisted Dying Legislation Framework:

VOLUNTARY ASSISTED DYING LEGISLATION FRAMEWORK

Preamble

The Government should introduce legislation to provide for voluntary assisted dying.

The legislation should not merely provide a criminal defence to those assisting an eligible person to die. Nor should it merely provide for a change to prosecution guidelines relating to the prosecution of those assisting an eligible person to die. Rather, the legislation should reform the law with a standalone Act that permits voluntary assisted dying to eligible people in accordance with strict criteria.

The WA Government should establish a panel of experts to consider the implementation of legislation for voluntary assisted dying, based on the elements contained in this framework.

Assisted dying

The legislation should provide for self-administration of lethal medication where an eligible person is physically able to self-administer. In cases where the person is eligible but physically incapable of self-administration, the legislation should permit a doctor to administer the lethal medication.

Eligibility

Eligible conditions

The legislation is intended to provide assisted dying for those for whom death is a reasonably foreseeable outcome as a result of an eligible condition.

An eligible condition is an advanced and progressive:

- a. terminal illness or disease;
- b. chronic illness or disease; or
- c. neurodegenerative illness or disease,

Where death is a reasonably foreseeable outcome of the condition.

The person's suffering

The person's suffering must not be temporary nor able to be treated or remedied in a manner acceptable to the person. The suffering:

- a. must be related to an eligible condition;
- b. must be grievous and irremediable;
- c. cannot be alleviated in a manner acceptable to the person; and
- d. must be subjectively assessed – that is, from the person's point of view.

Age

The person must be aged 18 years or over.

Capacity

In order to request assisted dying the person must have decision-making capacity in relation to a decision about voluntary assisted dying.

Residency

Eligibility requires ordinary residence in Western Australia and either Australian citizenship or permanent residency.

Assessment

Two doctors must assess the person. Either or both doctors can be a general practitioner and neither doctor is required to be a specialist regarding the person's disease or illness. Each doctor must be independently satisfied that:

- a. the person is aged 18 or over;
- b. the person is ordinarily resident in Western Australia;
- c. the request is voluntary, made without coercion or duress;
- d. the person has decision-making capacity in relation to a decision about voluntary assisted dying;
- e. the person has an advanced and progressive: terminal, chronic or neurodegenerative illness or disease;
- f. the person has grievous and irremediable suffering due to the disease or illness that cannot be alleviated in a manner acceptable to the person; and

- g. death is a reasonably foreseeable outcome of the condition.

Referral for specialist assessment

A person is not required to undergo consultant or specialist assessment except where either doctor is unable to determine:

- a. The precise nature of the disease or illness, in which case they must refer to a specialist in the relevant area of medicine.
- b. Whether the disease or illness is advanced and progressive, in which case they must refer to a specialist in the relevant area of medicine.
- c. Whether death is reasonably foreseeable.
- d. Capacity, and/or the absence of coercion, in which case they must refer to a consultant psychiatrist or a consultant geriatrician as appropriate.

Procedure

A person must make an initial verbal request to a doctor to access assisted dying. A doctor must include a record that a verbal request has been made in the medical record. Following this request, providing that the doctor does not personally object to voluntary assisted dying, they must provide the person with information regarding:

- a. the nature of the disease or illness;
- b. the prognosis;
- c. any possible curative treatments;
- d. any available palliative treatments;
- e. the nature, effects and risks of the lethal medication that may be prescribed; and
- f. that the person's consent to assisted dying may be withdrawn at any time.

The person must provide the initial assessing doctor with a signed written request using a standard template. The written request must be filed with the oversight body.

The doctor should then carry out the assessment as described above. If satisfied that the person meets the assessment criteria, the doctor should complete a standard template referral to a second assessing doctor.

The second assessing doctor must then also carry out the assessment as described above. The second assessing doctor must then provide the initial doctor with written advice regarding the outcome of the assessment. The written advice must be filed with the oversight body.

The initial assessing doctor must inform the person of the results of the assessment. If both doctors concur that the person meets the assessment criteria, and the person makes a further verbal request to access assisted dying, the initial

assessing doctor may provide the prescription for the lethal medication to the person and must provide instructions on the manner of use.

Timelines for each step in the process should be advised by the expert panel to ensure integrity in the process without unnecessary delay.

Reflection period

In order to provide a period of reflection a prescription for medication must not be filled sooner than prescribed under the legislation as determined by the expert panel.

Personal objection

At the time the patient makes the first verbal request, any doctor with a personal objection to providing assisted dying must inform the patient of the objection and offer to refer the patient to a doctor who is willing to provide assistance.

Where a person is an inpatient in a health service unwilling to provide assisted dying, that service must facilitate timely transfer to another service.

Non-discrimination

Mental illness

A person with a mental illness who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Disability

A person with a disability who meets the eligibility criteria shall not be denied access to voluntary assisted dying.

Medication

The choice of lethal medication for voluntary assisted dying should remain a clinical decision based on the prescribed list of medications for this purpose. The WA Government should review current federal laws in relation to scheduling of medication in Australia, and negotiate with the Federal Government and the Therapeutic Goods Administration for the use of the best medication(s) for assisted dying.

Pharmacists dispensing lethal medication(s) must report the dispensing of the medication to the oversight body.

Death Certification

Where an assisted death takes place it must be noted on death certification documents.

The WA Government should amend the:

- a. Medical Certificate Cause of Death – completed by the doctor certifying cause of death;
- b. Manual Death Registration Form – completed by the funeral director to register a death; and
- c. The Death Certificate – issued by the Registrar of Births Deaths and Marriages,

to make provision for the inclusion of voluntary assisted dying as a contributing cause of death, and to provide guidance for doctors and others who complete each of the documents.

Oversight

An oversight body must be established to:

- a. provide policy and strategic direction for the State of Western Australia;
- b. review all voluntary assisted dying deaths;
- c. provide community education and resources;
- d. provide health professional education and resources, including counselling and advice for practitioners;
- e. provide a telephone advice line;
- f. maintain a database of all relevant statistics related to assisted dying; and
- g. provide an annual report to Parliament.



MS A. SANDERSON, MLA
CHAIR

Appendix One

Inquiry Terms of Reference

On 10 August 2017, the Legislative Assembly agreed to the following resolution –

1. That a Joint Select Committee of the Legislative Assembly and Legislative Council on End of Life Choices be established.
2. That the Committee inquire into and report on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should –
 - a) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;
 - b) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions;
 - c) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation; and
 - d) examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and the implications for individuals covered by these instruments in any proposed legislation.
3. That the Joint Select Committee consist of eight members, of whom –
 - a) four will be members of the Assembly; and
 - b) four will be members of the Council.
4. The Standing Orders of the Legislative Assembly relating to Standing and Select Committees will be followed as far as they can be applied.
5. That the Joint Select Committee report to both Houses no later than twelve months after the Committee has been established.

The Legislative Assembly requested that the Legislative Council agree to a similar resolution.

On 23 August 2017, the Legislative Council agreed to the Assembly's resolution and the Committee was thereby established.

Appendix Two

Committee's functions and powers

On 10 August 2017, the Legislative Assembly agreed to the following resolution –

6. That a Joint Select Committee of the Legislative Assembly and Legislative Council on End of Life Choices be established.
7. That the Committee inquire into and report on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should –
 - a) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;
 - b) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions;
 - c) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation; and
 - d) examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and the implications for individuals covered by these instruments in any proposed legislation.
8. That the Joint Select Committee consist of eight members, of whom –
 - c) four will be members of the Assembly; and
 - d) four will be members of the Council.
9. The Standing Orders of the Legislative Assembly relating to Standing and Select Committees will be followed as far as they can be applied.
10. That the Joint Select Committee report to both Houses no later than twelve months after the Committee has been established.

The Legislative Assembly requested that the Legislative Council agree to a similar resolution.

On 23 August 2017, the Legislative Council agreed to the Assembly's resolution and the Committee was thereby established.

Appendix Three

Submissions received

#	Name	Position	Organisation
1	Mr Laurie Smith OAM JP		
2	Dr Anthony Nichols		
3	Mr Christopher Davis		
4	Mr Michael Perrott AM		
5	Mr Richard Egan		Defend Human Life!
6	Mr David & Mrs Kay Healy		
7	Mr Henry & Mrs Anneliese Wolton		
8	Mr Robert Thompson		
9	Sr Francisca Pedrosa		
10	Sr Cecilia McKay Isp		
11	Closed Submission		
12	Ms Susan van Kessel		
13	Ms Marion Beard		
14	Ms Anne O'Halloran		
15	Ms Catherine O'Connor		
16	Ms Kathleen Laffan		
17	Closed Submission		
18	Mrs Julie Howe		
19	Mrs Leigh Marvin		
20	Ms Elspeth O'Connor		
21	Mr Ralph & Mrs Joan Britto		
22	Mr Kevin Rickson		
23	Mr Marshall Perron		
23A			
24	Mr John Barich	State President	National Civic Council
25	Mr Ian Wood	National Coordinator	Christians Supporting Choice for Voluntary Euthanasia
25A			
26	Mr Matthew Handcock		
27	Ms Margo Beilby		
28	Mr Nigel Haines		
29	Mr Paul Clune		
30	Mrs Sherryl Stiles		
31	Ms Mary Anne Baljic		
32	Mr John Fowler		
33	Mr Eric Jas		
33A			

Appendix Three

34	Mrs Ann Harling		
34A			
35	Mrs Imelda Aslett		
35A			
36	Mr Stephen Klomp		
36A			
37	Mr Francis Donohoe		
38	Dr Kristine Klugman OAM	President	Civil Liberties Australia - WA
	Mr Bill Rowlings	Chief Executive Officer	
	Ms Margaret Howkins	Director	
39	Mr Aldo Becherelli		
39A			
40	Mrs Maria Parkinson	State President	Catholic Women's League of WA Inc.
41	Mrs Judith Wallace	Chairperson	Mount La Verna Retirement Village Inc.
42	Mr Bruce Buchanan		
43	Mr Daniel Regnard		
44	Mrs Betty Bouwman		
45	Mr Keith Anderson		
46	Ms Marina Re	Chief Executive Officer	Identitywa
47	Mr Michael Rose		
48	Mr Darryl Shirt		
49	Ms Norma Ryan		
50	Mr Graham-John Farmer		
50A			
51	Mr Peter Djekil		
52	Ms Eugenia Willock		
53	Rev Dr Joseph Parkinson	Director	L J Goody Bioethics Centre
54	Ms Lorna McLean		
55	Ms Marcelle van Soest		
56	Ms Ailsa Rice		
57	Ms Christine Foulkes- Taylor		
58	Closed Submission		
59	Ms Toni Collinge		
60	Mr Abram & Ms Thea Ziegelaar		
61	Mr Murray Hindle		
62	Mr/s B W Parry		
63	Mrs Louise Barker		
64	Mr Paul Forrestal		

Appendix Three

65	Dr Felicity Haynes		
66	Ms Sally Wylie		
67	Mr Mervyn Stokes		
68	Mr Ray c Miller		
69	Closed Submission		
70	Mr Willem Groenewold		
71	Ms Patricia Welling		
72	Ms Pauline Hinton		
73	Ms Jenny Costigan		
74	Mr Paul Ruys		
75	Mr Charles & Ms Deborah Leonard		
76	Mr Luigi Rosolin		
76A			
77	Ms Lesley Dowling		
78	Ms Pamela Gaunt		
79	Closed Submission		
80	Miss Annette Sutton		
81	Mr John Iriks		
82	Mr Michael Shanahan		
83	Closed Submission		
84	Mrs Carol Wren		
84A			
85	Ms Linda Williams		
86	Mrs Chris Mounsey		
87	Mr Ellen Leembruggen		
88	Mr Kevin Wringe		
89	Mr Adrian Price		
90	Ms Tracy Skippings		
91	Ms Wilma Brass		
92	Mr Iwan Boskamp		
93	Ms Colleen Smith		
94	Ms Dinny Laurence		
95	Ms Elisabeth Bosveld		
96	Ms Janette Huston		
97	Ms Rosemarie Powell		
98	Mr Vincenzo Monterosso		
99	Ms Rosalind Rennie		
100	Ms Carol O'Neil	WA Chapter Leader	Exit International
101	Em Prof Chilla Bulbeck		
102	Mrs Anne Smithdale		
103	Ms Jackie Curtis		
104	Ms Stephanie Woods		
105	Mr John Pascoe		

Appendix Three

106	Mr Andrew & Ms Jody van Burgel		
107	Ms Grace Gordon		
107A			
108	Mrs Pat De San Miguel		
109	Ms Tara Slobe		
110	Mr Chris Kim		
111	Mr Bryant De Vos		
112	Ms Gabbi Gamblin		
113	Mr David Stock		
114	Mr Terence Flanagan		
115	Mr Johannes Herrmann		
116	Mr Dunstan Hartley		
117	Mr Peter Walkemeyer		
118	Mr Tony Kelly		
119	Ms Brigitte Klebba		
120	Most Rev Timothy Costelloe	Roman Catholic Archbishop of Perth	
121	Ms Marilyn Rainier		
122	Ms Kara-Leigh Visser		
123	Ms Anne Marie Gregory		
124	Ms Mariska den Boer		
125	Ms Christina Pleiter		
126	Mr James Mumme		
127	Mr Jacob den Boer		
128	Mr Marino & Ms Carolyn Benvenuti		
129	Mrs Marguôt Scott		
130	Ms Gail Jones		
131	Ms Pam Metropolis		
132	Ms Margaret Boulger		
133	Closed Submission		
134	Ms Kim Dodwell		
135	Mr Simon & Ms Sue Stewart		
136	Ms Elaine Buchan		
137	Ms Lesley Barker		
138	Mrs Eleanor Sgherza		
139	Mr Martin Zydek		
140	Mrs Susan Regnard		
141	Dr Philip Nitschke	Founder & Director	Exit International
142	Mr Russell Ring		
143	Ms Josie Brown		

Appendix Three

144	Ms Joan F Knuppe		
145	Mr Donald Paterson		
146	Mr Octo Moniz		
147	Mrs Eileen Pedrotta-Parsons		
148	Dr Kathleen Jordan		
149	Mr David & Ms Elizabeth Thackrah		
150	Ms Pamela Le Page		
151	Fr Paul Pitzen	Chaplain	Catholic Ministry with Deaf and Hard of Hearing People of Western Australia
152	Dr Charles Slack		Family Council of WA
153	Mr Will Hepburn		
154	Mr Gerrit & Mrs Karina Ballast		
155	Mr Keith Morris		
156	Mr Adrian Hordyk		
157	Closed Submission		
158	Ms Gillian Henderson		
159	Mr Ronan McGinniss		
160	Mr Ashley Foster		
161	Mr/s B Lawrence		
162	Mr/s J Lucas		
163	Miss Monica Taylor		
164	Mr John Ireland		
165	Mr W Jack Apgar		
166	Ms Alison & Mr John White		
167	Ms Ann Foster		
168	Ms Jennifer Elloy		
169	Closed Submission		
170	Ms Morag Croft		
171	Ms Anne Mueller		
172	Ms Betty Trinick		
173	Mr Roelof van Duyn		
174	Ms Elizabeth Milward		
175	Mr David Winkel		
176	Ms Siobhan Page		
177	Mr Dathan Pleiter		
177A			
178	Ms Sally Westlake		

Appendix Three

179	Mr Dongwoo Oh		
180	Dr Katrina Haller		Right to Life Australia
181	Mr Geoff Kiernan		
182	Mr Gary Beilby		
183	Ms Emily McKenna		
184	Mr Colino Gomes		
184A			
185	Mr Peter Cullender		
186	Ms Jo Waite		
187	Mrs Sharyn Doyle		
188	Ms Eileen Brown		
189	Mr Harold Burdon		
190	Mr Kevin Hogan		
191	Mr Patrick Reid		
192	Ms Elizabeth Busuttil		
193	Mr George Arthur		
194	Ms Elizabeth Arthur		
195	Ms Elizabeth Bartell		
196	Mr Graham Rose		
197	Miss Amanda Fimister		
198	Ms Janice Watkins-Saxon		
199	Ms Kathryn Coulson		
200	Ms Wendy Hodgkinson		
201	Closed Submission		
202	Mr Ronald Cassels		
203	Mr Giovanni Georgiades		
203A			
204	Mr Dirk Plug		
205	Mr Michael Astle		
205A			
205B			
206	Ms Eva Lenz		
207	Ms Hendrina Mulder		
208	Dr Herm Zandman		
209	Mrs Gaye Matthews		
210	Ms Miriam Eikelboom		
210A			
211	Ms Mary Rath		
212	Dr Tim Coyle		
213	Mr Derek Bruning		
214	Ms Sarah Gaythwaite		
215	Ms Judith Ann Vasek		
216	Dr John Hayes		

Appendix Three

217	Mr Terrance Marbeck	Co-ordinator	Life is Precious Group
218	Mr Tony Pires		
219	Mrs Beverley Macri		
220	Ms Lois Anderson		
221	Mrs Deirdre Lyra		
222	Ms Anne Engelbrecht		
223	Mr Hugh Girod		
224	Closed Submission		
225	Mrs Janet Sigsworth		
226	Ms Terri Connell		
227	Miss Tracey Moynihan		
228	Mr Giulio di Somma		
229	Ms Suellen Horgan		
230	Mr Ian & Ms Dianne Mullins		
231	Mr Gaetano & Ms Robyn D'Aprile		
232	Ms Michelle Mattner		
233	Ms Yee-ling Lam		
234	Ms Amanda Varley		
235	Mr Gordon Gudgeon		
236	Mr Steve & Ms Helen Terpstra		
237	Mr Murray & Ms Zaharah Lumsden		
238	Mr Shane Shenton		
238A			
239	Mr Martin Oldenburger		
240	Ms Nicole Summers		
241	Ms Joyce Michael		
242	Ms Shaw Cheong		
243	Mr Andrew Pratt		
244	Mrs Cheryl Barich		
245	Mrs Joy & Mr Rigo Tidow		
246	Mrs Jane Cassels		
247	Ms Marina Pegrum		
248	Ms Phyllis Weldon		
249	Mr Michael Menezes		
250	Ms Mary Burke		
251	Mr Kevin Adair		
252	Ms Lynne Wilding		
253	Ms Wendy Stanford		
254	Ms S Jan Beauchamp		
255	Closed Submission		
256	Ms Maria Prinsloo		

Appendix Three

257	Mr Frank & Ms Annalisa Riolo		
258	Ms Claire Nockolds		
259	Mr Brian Nockolds		
260	Mrs Lorraine Schroeder		
261	Ms Tiffany van der Linde		
262	Ms Marie-Chantal Bertinazzo		
263	Mrs Stephanie Mitchell		
263A			
264	Ms Gail Wyatt		
265	Ms Eva Lager		
266	Mr Christopher Harkness		
267	Mr Craig Lyra		
268	Mr Paul Solarski		
269	Mr/s R B Thompson		
270	Ms Celia O'Grady		
271	Mr Michael Slattery		
272	Ms Lyn Wicks		
273	Mr Ray & Ms Gina McDonald		
274	Mr Richard Lethbridge		
275	Mr Nicholas Cowdery AM QC		
276	Mr Thomas Gourlay		
276A			
277	Mr Darryl & Ms Tracy Marsh		
278	Closed Submission		
279	Ms Robyn Hogan		
280	Ms Maxine Culley		
281	Mr Peter Musgrave		
282	Mr Paul & Ms Angela Ryan		
283	Mr Peter Beahan		
284	Ms Jennifer Lawrence	Chief Executive Officer	Brightwater Care Group
285	Ms Rosalie Smith		
285A			
286	Mr Malcolm Heyhoe		
287	Mr John Loreck		
288	Ms Brenda Reitsema		
289	Hon. John Kobelke JP		
290	Mr Garry & Ms Jan Grainger		

Appendix Three

291	Ms Kristy Ratcliffe		
292	Mr/s J.M. Williams		
293	Mr/s T.E. Williams		
294	Ms Val Waldron		
295	Mr Stephen Smith		
296	Ms Alicia Cheng		
297	Ms Judyanne Bowling		
298	Mr Gordon & Ms Beverley Cartledge		
299	Ms Celeste Saxon		
300	Mr Robert Semple		
301	Ms Alison Laird		
302	Ms Sheila Ann & Mr Geoffrey Wilkins		
303	Ms Sonia Albahari		
304	Mrs Delia Wray		
305	Ms Lesley Allnutt		
306	Mrs Marie Mosca		
307	Ms Fionuala Mallen		
308	Ms Elaine Holmes		
309	Ms Maxiema Lager		
310	Ms Nicolette Smith		
311	Mr/s R J Gornall		
312	Ms Phillippa Jarvis		
313	Closed Submission		
314	Mr Ashley Saunders	National Director	FamilyVoice Australia
315	Mr John Kennedy		
316	Dr Rodney Syme		
317	Mr Charles Horner		
318	Ms Catherine Kelly		
319	Mr Peter Brain		
320	Dr Lachlan Dunjey		Medicine with Morality
321	Ms Valerie Tester		
322	Mr Marcel Hulshoff		
323	Ms Sallie Fernandes		
324	Mr Chris Reibel		
325	Ms Karen Webb		
326	Mr Paul Moylan		
327	Mr James Cook		
328	Closed Submission		
329	Mrs Anna Cook		
330	Ms Audrey Gillett		
331	Mrs Aileen Pridmore		
331A			

Appendix Three

332	Mrs Olivia Litas		
333	Ms Marjorie Semple		
335	Ms Andrea Davini		
336	Mr Brendan Clifford		
337	Mr John Branchi		
338	Mr Richard & Ms Ruth Cooke		
339	Mrs Julie Bogoni		
340	Ms Anne Reid		
341	Ms Janet Holmes à Court AC		
342	Mrs Susan Bray		
343	Ms Inge Brandt		
344	Mr Peter & Ms Gillian Baddeley		
345	Ms Dorothy Radisich		
346	Mrs Lucy Devitt		
347	Ms Noreen Fynn		
348	Ms Sara Cox		
334	Dr Ian Catto		
349	Ms Sophie Dykstra		
350	Mr Adrian Reading		
351	Mrs Melissa Vaca		
352	Rabbi Dovid Y A Freilich OAM	Chief Rabbi Perth Synagogue	
353	Ms Marguerite Laurence		
353A			
354	Mr Leo Schoof		
355	Miss Anita Parker	Director	Perth Catholic Youth Ministry
356	Mr Dwayne & Ms Klazine Ballast		
357	Mr Andrew Vermeulen		
358	Mr Hilbert & Ms Anne Gunnink		
359	Closed Submission		
360	Ms Cheryl Blaikie		
361	Ms Hilary Walter		
362	Ms Maureen Wilson		
363	Mr/s J Ward		
364	Ms Joan Smith RSM		
	Ms Leonie O'Brien RSM		
	Ms Alma Della Marta RSM		
	Ms Joan Carroll RSM		
	Ms Marie Fitzgerald RSM		

Appendix Three

	Ms Alexandra Smolinski RSM		
365	Mr Peter Lewis	State Executive Officer	Knights of the Southern Cross WA Incorporated
366	Mr Bruno George		
367	Mrs Gene Matthews		
368	Mrs K Sephton		
369	Ms Gwen Langsford		
370	Mrs Kerry Neesham		
371	Ms Wendy Walters		
372	Mr David Greenhill		
373	Ms Elaine Greenhill		
374	Dr Suzanne Nenke		
375	Fr Gordon Howell		
376	Ms Margaret Taylor		
377	Dr John Carroll		
378	Ms M P Baker		
379	Mr Keith Watson		
380	Mr Otto Mueller		
381	Ms Janet Purdy		
382	Closed Submission		
383	Ms Louise Turpin		
384	Ms Tina Christensen		
385	Ms Pat Hall		
386	Dr Bryan Meyerkort		
387	Mrs Gillian Meecham		
388	Mrs Kathleen Neesham		
389	Mrs Joan Rencontre		
390	Ms Noreen Crawcour		
391	Dr Elizabeth Moore	Branch Chair	The Royal Australian and New Zealand College of Psychiatrists
392	Ms Caroline Jones		
393	Mr Bert & Ms Klazien Vermeulen		
394	Mr Andrew Hodge		
394A			
395	Mr Benjamin de Vos		
396	Ms Susan Maccora		
397	Ms Margot Lang		
398	Dr Brien Hennessy		
399	Mr Gordon Killow		
400	Ms Moira Kirkwood		

Appendix Three

401	Closed Submission		
402	Dr Alida Lancee	WA State Convenor	Doctors for Assisted Dying Choice
403	Mr Brian Aldrich		
404	Ms Susan Leggo		
404A			
405	Mr Derek Westera		
406	Mr Jesse Durdin & Ms Danielle Hendry		
407	Ms Terri Margaritis		
408	Mr Max Hidding		
409	Prof Wendy Erber	Pro Vice Chancellor and Executive Dean	Faculty of Health and Medical Sciences UWA
410	Senior Pastor Rob Furlong		Woodvale Baptist Church
411	Ms Janet Byl		
412	Mr Michael Walker		
413	Ms Morag Du Bois		
414	Mrs Kathryn Crees		
415	Mr Max Hidding	General Manager	"Have-a-Cuppa" Christian Outreach Centre
416	Mr Thomas Loreck		
417	Mr Les Williams		
418	Ms Berryl Phillips		
419	Ms Annette Williams		
420	Ms Janet Wallace		
421	Mr Tony Zdunic		
422	Ms Francine Cartaginesc		
423	Dr Frances Meyerkort		
424	Mr Frank Kosaras		
425	Mr Matthew Lim		
426	Mrs Angela Berry		
427	Ms Barbara Harris	Co-ordinator	Emmanuel Centre
428	Ms Johanna Banks	Research Officer	The Coalition for the Defence of Human Life
429	Closed Submission		
429A			
430	Prof Michael Quinlan		
431	Dr Alida Lancee		
431A			
431B			

Appendix Three

432	Mrs Chris Baker		
433	Mr Terrence Hann		
434	Ms Felicity Roux		
435	Dr Timothy Koh	Chair	The Royal Australian College of General Practitioners WA
	Dr Sean Stevens	Deputy Chair	
436	Mr Keith Collins		
437	Ms Natalie Matthews		
438	Ms Peta Quinlivan		
439	Ms Mary Nenke		
440	Mr Johannes Bonker		
441	Ms Phyllis Ringer		
442	Ms Tina Frost		
443	Prof David Scott	President	Australian and New Zealand College of Anaesthetists
	Ms Jo-anne Chapman	General Manager, Policy Safety and Quality	
444	Ms Bronia Karniewicz		Respect Life Office, The Catholic Archdiocese of Perth
445	Rev Margaret Court		Victory Life Centre
446	Ms Karen & Mr Brett Barnes		
447	Mr Peter Wilkins		
448	Closed Submission		
449	Ms Sarah Magee		
449A			
450	Mr John & Ms Joy Clark		
451	Mr Hugh Clift		
452	Ms Jenny Bosma		
453	Ms Joyce Parkes		
454	Mrs Gwen Wood		
455	Mr Graham Wood		
456	Sr M Elizabeth Foley ISSM	Community Leader	Schoenstatt Sisters of Mary
457	Mr Joseph Tuson		
458	Mr Terrence Ryan		
459	Miss Clare Phillips		
460	Miss Jenny Paynter		
461	Mr/s P A Keillor		
462	Mr Peter O'Meara	President	Right to Life Association Western Australia
463	Mr Rod Vladich		

Appendix Three

464	Ms Carol Filippi		
465	Ms Sarah Chevin		
466	Ms Paulie Diggins		
467	Ms Kathleen Cocking		
468	Mr Errol Turner	Chief Executive Officer	Southern Cross Care WA Inc.
469	Mr Pat Mahoney		
470	Dr Nathan Francis		
471	Closed Submission		
472	Ms Katarina Hertroijs		
473	Ms Janis Stanley		
474	Mr Cornelis Kleijn		
475	Ms Frauke Chambers		
476	Mr Laurence Van der Plas	Research Officer	Association for Reformed Political Action ARPRA
477	Mr Rob Jonquiére		
478	Ms Fayliesha Spyker		
479	Ms Rebecca Sampang		
479A			
480	Mr Peter McCullagh		
481	Mr Glenn Smith		
482	Mr Geoffrey Williams		
483	Ms Jacqueline Rose		
484	Ms Leanne Visser		
485	Ms Mary Ballantine	Chair	Catholic Association for Special Education Support
486	Mr Willem & Ms Ann Amoraal		
487	Mrs A Williams		
488	Ms Yvonne Stewart		
489	Ms Gillian Gonzalez	Vice President	The Australian Family Association Western Australian Division
490	Mr Arturs Galvans		
491	Ms Brenda Walker		
492	Mr Mark Cox		
493	Mr Graeme Wishart		
494	Mr Greg & Ms Susan Spaanderman		
495	Mrs Ruth Orpwood		
496	Ms Tanya Terpstra		Armada Free Reformed Youth
497	Mr Bill Spanbroek		
498	Mr Joseph Devitt		

Appendix Three

499	Mr Gavin & Ms Jenny Box		
500	Mr Andrew Partington		
501	Dr Cedric Spencer		
502	Mr Emanuele Graziani		
503	Mr Gerrit van Burgel		
504	Mr Andrew Devitt		
505	Ms Claire Patten		
506	Mr John McShane		
507	Mr Bruce & Ms Beverley Dufty		
508	Ms Shimone Spyker		
509	Mr Christopher MacFarlane		
510	Mr James Hindle		
511	Mrs Ingrid Plug		
512	Ms Carol Ann Norris		
513	Mr Paul & Ms Lisa Byl		
514	Mr Jose De Sousa		
514A			
515	Closed Submission		
516	Mr Wayne & Ms Cheronne van der Heide		
517	Ms Maggie Poole-Johnson		
518	Mr Gregory Kerry		
519	Dr Wilhelm Smithies		
520	Mr Hans van der Linde		
521	Closed Submission		
522	Mr Scott & Mrs Lynda O'Callaghan		
523	Mr Andrew Lansdown	Writer/Editor	Life Ministries Inc.
	Mr Dwight Randall	Director	
524	Ms Juliette Smith		
525	Dr Howard Watts OAM		
526	Ms Carol O'Neil		
527	Mr Daniel Lu		
528	Mr Leo Harris		
529	Mr David Hounsome		
530	Mr Douglas Bridge		
531	Ms Monique Bertino-Clarke		
532	Ms Clarissa Quek		
533	Mr Francesco & Mrs Carla Ceccarelli		
534	Mr Stewart van der Laan		
535	Mrs Nola Nicholls		

Appendix Three

536	Dr Miri Albahari		
537	Ms Ros Fogliani	State Coroner Western Australia	
537A			
538	Mr Frederick Maddison		
539	Mr Andrew Denton	Director	Go Gentle Australia
540	Ms Deirdre Fleming		
540A			
541	Ms Rachel Dockery		
542	Ms Anne De Sousa		
542A			
543	Mr James Handcock		
544	Ms Sarah den Boer		
545	Ms Georgie Haysom	Head of Advocacy	Avant mutual by doctors for doctors
546	Mr Terry Meo		
547	Ms Virginia Jealous		
548	Mr George McGillivray		
549	Mr Luke O'Callaghan		
550	Ms Pamela Martin		
551	Mr Durham Wilson		
551A			
552	Ms Mary Rose		
553	Mr Bert & Ms Agatha Veenendaal		
554	Mr Brad Page		
555	Mr Gerrit Griffioen		
555A			
555B			
556	Rev Ken Devereux		
557	Dr Derek Eng		
558	Mr Nicolaas Groenewold		
559	Mrs Maureen James		
559A			
560	Professor Lindy Willmott	Director	Australian Centre for Health Law Research
560A	Professor Ben White	Director	
	Ms Penny Neller	Centre Coordinator	
561	Ms Paula Payne	Executive Officer	Dying with Dignity Victoria
562	Ms Heather Gridley	Manager, Public Interest	Australian Psychological Society

Appendix Three

563	Mr Brendan Parker	Executive Officer	Motor Neurone Disease Association of Western Australia
564	Ms Jenny Monson	Chairperson	Busselton Hospice Care Inc.
565			Dying with Dignity Western Australia
566	Mr Daniel O'Connor		Disciples of Jesus Covenant Community Perth
567	Mr Michael Robinson		
568	Ms Pauline Bagdonavicius	Public Advocate	Office of the Public Advocate
569	Dr Pam Williams		
569A			
570	Closed Submission		
571	Ms Maria Dijkstra		
572	Mr Arie Hordyk		
573	Ms Rachel Graziani		
574	Ms Sarah Cowie	Director	Health and Disability Services Complaints Office
575	Mr Ed & Ms Jacinta Schoof		
576	Ms Emma Rose		
577	Ms Suzanne Greenwold	Chief Executive Officer	Catholic Health Australia
578	Dr Eihab Boulos		
579	Ms Cathryn Julius		
579A			
580	Ms Amy Harry		
581	Mr David Rowsome	Prayer Co-ordinator	The Canberra Declaration
582	Ms Carina Schutte		
583	Mr Johannes Leendert van Burgel		
584	Ass Prof Meredith Blake & Dr Craig Sinclair		
585	Ms Bernadette Brady	Executive Manager Mission	Catholic Homes WA
586	Mr Philip & Ms Vanna Smith		
587	Mr Tony Howarth AO	Board Chairman	St John of God Health Care Inc.
	Dr Alison Parr	Director Medical Services	
588	Mr Jacob Bergsma		

Appendix Three

589	Dr Ashwini Davray		
590	Mr Jim VanderPlas		
591	Mr Lyle Shelton	Managing Director	Australian Christian Lobby
592	Most Rev Peter A Comensoli	Bishop of Broken Bay	For the Bishops Commission for Family, Youth and Life, Australian Catholic Bishops Conference
593	Mr Eric Miller		
594	Ms Jenni Del Marco		
595	Mr Gerald & Ms Carolyn Den Boer		
596	Mr Reinier Dorgelo		
597	Ms Tina Jack		
598	Ms Vicky Burrows		Aboriginal Catholic Ministry
	Mr Reg Carnamah		
	Ms Donna Ryder		
599	Mrs Meta Van Der Plas		
600	Mr Harley Dekker		
601	Mr Reuben Kroeze		
602	Mr Ludwig Minelli & Mr Silvan Luley		Dignitas
603	Mr Carl Vermeulen		
604	Mr Ashley Reid	Chief Executive Officer	Cancer Council Western Australia
605	Mr Andrew Del Marco		
606	Dr Alice Phua		
607	Mr Gerrit & Mrs Allegonda van der Wal		
608	Mr Daniel Hewitt		
609	Ms Agnes McKay		
610	Prof Celia Hammond	Vice Chancellor	University of Notre Dame Australia
611	Dr Christopher H McGowan	Chief Executive Officer	Silver Chain
612	Mr Derek Boylen		
613	Mr Brendon Falzon		
614	Mr David Cameron		
615	Ms Hazel Dorville		
616	Dr David Russell-Weisz	Director General	Department of Health
617	Mr Adrian Bertino-Clarke		
618	Ms Gwen Anderson		
619	Dr Christine & Mr Peter Choo		

Appendix Three

620	Mr Sunny Miller		
621	Mr Trevor Harvey		
622	Mr Eric Natta		
623	Ms Heidi Rebecca		
624	Mr Johnson Kitto		
625	Mr Anthony Porrins		
626	Ms Margaret Sing	President	Dying with Dignity Tasmania Inc.
627	Mr Anthon Souman		
628	Ms Sandy May		
629	Mr Chester Wilson		
630	Dr Kevin Yuen	Chair	WA Palliative Medicine Specialist Group
631	Mr Christopher McDonald		
632	Ms Helena Coles		
633	Closed Submission		
634	Ms Elima Sykes		
635	Mr Warnar Spyker		
636	Mr Leon Yeap		
637	Mr David Somerville		
637A			
638	Ms Brenda Harvey		
639	Ms Rhonda Parker	Chief Executive Officer	Alzheimers WA
640	Mr Bill MacRae	Moderator	Braemar Presbyterian Care
	Mr Wayne Belcher OAM	Chief Executive	
641	Dr Catherine Yelland PSM		The Royal Australasian College of Physicians
642	Mr Neil Francis		DyingforChoice.com
643	Ms Mary Aerts		
644	Mr Jeremy Ervine		
645	Dr Sean Monahan		
646	Ms Marion Hayman		
647	Mr Colin & Mrs Kathleen Mitchell		
648	Dr Richard Lugg	Environmental Health Consultant	
649	Ms Noeline Carlson		
650	Mr John Foy		
651	Ms Gail Carbone		
652	Ms Iris Gulley		
653	Ms Pauline Allnutt		
654	Closed Submission		

Appendix Three

655	Dr Nathan Gibson	Chief Psychiatrist of Western Australia	
656	Ms Margaret-Anne Jude		
657	Mr Michael Archer		
658	Mr Mark Teale	Executive Officer	COTA WA
659	Mr Bob Stanley		
660	Mr Ron Chalmers		
661	Mr/s J Huxtable		
662	Ms Roberta Gripton		
663	Mr Lachlan Mills		
664	Mr Hugh Richardson		
665	Closed Submission		
666	Ms Barbara Paterniti		
667	Mr Edmund Wall		
668	Mr Richard Elphick		
669	Ms Felicity Mitchell	Policy and Engagement Officer	Carers Australia WA
670	Mr Dennis Eggington	Chief Executive Officer	Aboriginal Legal Service of Western Australia Limited
671	Ms Eritia Bax		
672	Ms Mandy Powrie		
672A			
673	Mr Mark Weaver		
674	Prof Meera Agar	President	The Australian and New Zealand Society of Palliative Medicine
	Ms Simone Carton	Chief Executive Officer	
675	Mrs Amanda Ross		
676	Mr Des Martin	Chief Executive Officer	Aboriginal Health Council of Western Australia
677	Ms Aida Barbosa		
678	Mr Stephen Duckett	Director, Health Program	GRATTAN Institute
679	Ms Samantha Jenkinson	Executive Director	People with Disabilities Western Australia
	Mr Ross Joyce	Chief Executive Officer	Australian Federation of Disability Organisations
680	Mr David Foletta		
680A			
680B			
681			

Appendix Three

681A	The Hon. Greg Donnelly, MLC		Parliament of New South Wales
682	Mr William Philip		
683	Mrs Rosemary Lorrimar		
684	Ms Melissa Vernon	Chief Operating Officer – Strategy and Reform	WA Country Health Service
	Ms Marie Baxter	Executive Director Nursing and Midwifery	
	Ms Margaret Denton	Executive Director Public Health and Ambulatory Care	
	Mr Jeffrey Moffet	Chief Executive	
685	Dr Omar Khorshid	President	Australian Medical Association WA Inc.
686	Closed submission		

Appendix Four

Public hearings

Organisations

Date	Name	Position	Organisation
13 December 2017 – Five sessions	Dr Keiron Bradley	Palliative Care Clinical Leave – WACPCN	WA Health
	Ms Amanda Bolleter	Program Manager, Palliative Care	
	Mr Luke Hays	Acting Manager, Purchasing and Contracting	
	Mrs Marie Baxter	Executive Director, Nursing and Midwifery, WACHS	
	Mrs Marion Slattery	Director, Nursing and Midwifery, WACHS – South West	
	Dr David Ransom	Medical Oncologist and Co-Director, WACPCN	
	Mr Kim Greeve	Project Officer, WACPCN	
	Professor Gary Geelhoed	Chief Medical Officer	
	Dr Lisa Miller	Clinician, Consultant Liaison Psychiatrist in Cancer and Palliative Care, WACPCN	
14 December 2017	Dr Timothy Koh	Chair	Royal Australian College of General Practitioners
14 December 2017	Mrs Grace Buchanan	Committee Member	Palliative Care Nurses Australia
14 December 2017	Professor Keith Evans	Chief Advisor, Public Policy	Silver Chain Group
	Mr Mark Cockayne	General Manager, Heath Care WA	
14 December 2017	Ms Lana Glogowski	Executive Director	Palliative Care WA
	Dr Elissa Campbell	President	
	Ms Caitlin Calcutt	Project Officer	
	Ms Natalie Panizza	Nurse Practitioner, Palliative Care, Royal Perth Hospital	
14 December 2017 and 28 February 2018	Dr Nathan Philips	Chief Psychiatrist	Office of the Chief Psychiatrist

Appendix Four

Date	Name	Position	Organisation
26 February 2018	Mr Paul Coates	Chief Executive Officer	Carers WA
26 February 2018	Associate Professor Meredith Blake	Legal Researcher	University of Western Australia
	Dr Craig Sinclair	Research Fellow	
26 February	Professor Lindy Willmott	Legal Academic	Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology
	Professor Ben White	Legal Academic	
26 February 2018	Dr Richard Lugg	Member	Doctors for Assisted Dying Choice
	Dr Peter Beahan	Member	
	Dr Roger Paterson	Psychiatrist, Member	
27 February 2018	Mr Wayne Belcher	Chief Executive Officer	Braemar Presbyterian Care
27 February 2018	Dr Anil Tandon	Chairman / Palliative Care Medical Specialist, Sir Charles Gairdner Hospital	WA Palliative Medicine Specialist Group
	Dr Mary McNulty	Palliative Care Medical Specialist, Sir Charles Gairdner Hospital	
27 February 2018	Ms Pauline Bagdonavicius	Public Advocate	Office of the Public Advocate, Department of Justice
27 February 2018	Ms Marina Re	Chief Executive Officer	Identity WA
	Mrs Gaye Matthews	Individual	
27 February 2018	Mr Chris Dawson	Commissioner of Police	WA Police Force
	Miss Amanda Forrester, SC	Director of Public Prosecutions	Officer of the Director of Public Prosecutions
27 February 2018	Ms Samantha Jenkinson	Executive Director	People with Disabilities WA
	Mr Ross Joyce	Chief Executive Officer	Australian Federation of Disability Organisations
	Mr Patrick McGee	National Manager, Policy Research Advocacy	

Appendix Four

Date	Name	Position	Organisation
28 February 2018	Ms Natalie Joseph	Manager, Clinical Services	Catholic Homes WA
	Ms Bernadette Brady	Executive Manager, Mission	
	Mrs Suzanne Greenwood	Chief Executive	Catholic Health Australia
	Mr John Fogarty	Executive Director	St John of God Health Care
	Dr Alison Parr	Director Medical Services, Palliative Medicine Consultant	
28 February 2018 and 18 May 2018	Dr Omar Khorshid	President	Australian Medical Association
	Dr Katharine Noonan	Policy and Research Lead (Clinical)	
28 February 2018	Mrs Charlotte Wallace	Delegate of Justice Jeremy Curthoys	State Administrative Tribunal of Western Australia
28 February 2018	Mr Chad Edwards-Smith	Head of Medical Defence Services	Avant Mutual
	Ms Georgie Haysom	Head of Research, Education and Advocacy	
28 February 2018	Dr Elizabeth Moore	Branch Chair	Western Australian Branch, Royal Australian and New Zealand College of Psychiatrists
	Ms Zoe Carter	Policy Officer	
1 March 2018	Ms Rosalinda Fogliani	State Coroner of Western Australia	Coroner's Court of Western Australia
	Mr Gary Cooper	Principal Registrar	
1 March 2018	Professor Wendy Erber	Executive Dean	Faculty of Health and Medical Sciences, University of Western Australia
	Associate Professor Kirsten Auret	Academic in Palliative Care	
1 March 2018	Ms Jennifer Lawrence	Chief Executive Officer	Brightwater Care Group
	Ms Janet Wagland	General Manager, Community	
2 March 2018	Professor Max Kamien	Medical Practitioner/Emeritus Professor of General Practice, University of Western Australia	Doctors for Assisted Dying Choice
	Dr Alida Lancee	Medical Practitioner	
	Dr Ian Catto	Medical Practitioner	

Appendix Four

Date	Name	Position	Organisation
2 March 2018	Mr Andrew Hirst	Executive Officer	Motor Neurone Disease Association Western Australia
	Mrs Karen Smart	Palliative care researcher/ Chairperson	
	Professor Samar Aoun	Palliative care researcher/Vice President	
	Ms Janice Taylor	Past Carer/Secretary	
	Dr Robert Edis	Neurologist	Sir Charles Gairdner Hospital/Perron Institute Motor Neurone Disease Clinics
2 March 2018	Dr Lachlan Dunjey	General Practitioner/ Convenor	Medicine with Morality
2 March 2018	Mr Mark Teale	Chief Executive	Council on the Ageing WA (Inc)
2 March 2018	Mrs Ronda Clarke	Outreach Services Project Officer	Aboriginal Health Council of Western Australia
	Ms Mel Shelly	Manager, Policy and Strategy	
8 March 2018	Reverend Margaret Court	Minister	Victory Life Centre
	Reverend Belinda Dover	Minister/Consultant	
	Mr Cameron Eastwood	Legal Practitioner	Eastwood Law
8 March 2018	Archbishop Timothy Costelloe	Archbishop	Catholic Archbishop of Perth
	Reverence Dr Joseph Parkinson	Director	LJ Goody Bioethics Centre
8 March 2018	Mr Laurence Van der Plas	Research Officer	Association for Reformed Political Action
	Mr Robert Van der Linde	Chairman	
8 March 2018 and 9 April 2018	Mr Silvan Luley	Board member	Dignitas – To live with dignity – To die with dignity
	Mr Ludwig Minelli	Founder and board member	
8 March 2018	Miss Johanna Banks	Research Officer	Coalition for the Defence of Human Life
	Mr Dwight Randall	President	
8 March 2018	Rabbi David John Freilich	Emeritus Chief Rabbi	Perth Hebrew Congregation and Western Australia
9 March 2018	Reverend Ashley Saunders	National Director	FamilyVoice Australia
9 March 2018	Reverend Peter Abetz	WA State Director	Australian Christian Lobby

Appendix Four

Date	Name	Position	Organisation
9 March 2018	Mr Richard Egan	Research Officer	Defend Human Life!
9 March 2018	Mr Peter O'Meara	President	Right to Life Association WA
9 April 2018	Mr Neil Francis	Professional Medical and Social Researcher	DyingForChoice.com
13 April 2018	Dr Phillip Nitschke	Director	Exit International
13 April 2018	Dr Rodney Syme	Medical Practitioner and Vice President	Dying with Dignity Victoria
13 April 2018	Mr Andrew Denton	Founder/Director	Go Gentle Australia
13 April 2018	Mr Murray Hindle	President	Dying with Dignity Western Australia
	Mr Stephen Walker	Vice President	
13 April 2018	Mr Ian Wood	National Coordinator and Spokesperson	Christians Supporting Choice for Voluntary Euthanasia
30 April 2018	Dr Brien Hennessy	Head of Anaesthesia Department	Sir Charles Gairdner Hospital
1 May 2018	Professor Margaret Somerville	Professor of Bioethics	University of Notre Dame Australia, Sydney
18 May 2018	Dr Keiron Bradley	Clinical Lead – WACPCN	Department of Health
	Ms Amanda Bolleter	Program Manager – WACPCN	
	Clinical Professor David Forbes	Acting Chief Medical Officer	
	Mrs Marion Slattery	Director, Nursing and Midwifery, WACHS	
	Mrs Marie Baxter	Executive Director, Nursing and Midwifery, WACHS	

Appendix Four

Individuals

Date	Name	Position
1 March 2018	Professor Michael Quinlan	Consultant General Physician
7 March 2018	Ms Maria Rosa	Private citizen
7 March 2018	Mr Kathleen Trendall	Senior citizen
	Mrs Patricia Marshall	Retired public servant
7 March 2018	Mrs Irene Montefiore	Co-convenor, Death Cafe
	Ms Tracy Endersby	Nurse
7 March 2018	Ms Jenny Rickerby	Private citizen
9 March 2018	Professor Doug Bridge	Senior Palliative Care Specialist, WA Faculty of Medicine and Health Sciences, WA Country Health Services; Royal Perth Hospital
5 April 2018	Dr Alida Lancee	General Practitioner
5 April 2018	Mrs Esther Humble	Private citizens
	Mr Matthew Humble	
9 April 2018	Ms Cait Calcutt	Personal and Project Officer, Palliative Care WA
13 April 2018	Mr Marshal Perron	Former MP, Northern Territory/ Private citizen
30 April 2018	Mrs Grytsje Doust	Private citizen
30 April 2018	Mr William Spanbroek	Private citizens
	Mrs Katherine McBarron	
30 April 2018	Mr Warnar Spyker	Private citizen
30 April 2018	Mr Nigel Haines	Private citizen
30 April 2018	Dr John Hayes	Member, Palliative Care WA/ Private citizen
30 April 2018	Mr John Ireland	Private citizen
30 April 2018	Ms Gillian Henderson	Private citizen
1 May 2018	Ms Noreen Fynn	Private citizens
	Ms Lisa Brumley	
1 May 2018	Ms Marcelle van Soest	Private citizen
1 May 2018	Mrs Beverley Macri	Private citizen
1 May 2018	Mrs Margaret Beilby	Private citizens
	Dr Gary Beilby	
1 May 2018	Mr William Philip	Private citizen
1 May 2018	Mr Michael Walker	Private citizen
1 May 2018	Mr Paul Byl	Private citizens
	Mrs Lisa Byl	
1 May 2018	Mr Bruce Buchanan	Private citizen
1 May 2018	Mr Andrew Vermeulen	Private citizens
	Mrs Hennie van der Schaaf	
1 May 2018	Dr Megan Best	Palliative Care Physician and Academic

Appendix Five

Advance care planning across Australia - advance health directives and enduring guardians

	<i>Are there advance directives?</i>	<i>Can a person appoint an enduring guardian or medical treatment decision-maker?</i>	<i>Relevant Legislation</i>	<i>Features</i>
Western Australia	Yes – <i>Advance Health Directive</i> – both statutory and common law directive	Yes – Enduring Guardian. With the same functions as a plenary guardian, unless limited by the power. Note: A plenary guardian is akin to a parent and (in relation to medical treatment) has power to make a treatment decision for the represented person. Certain treatment decisions not authorised (e.g. sterilisation)	Parts 9A & 9B <i>Guardianship and Administration Act 1990 (WA)</i>	Enduring guardians and AHDs introduced with the hierarchy of decision makers in 2008 – they provide for decision making when a person lacks treatment decision-making capacity.
South Australia	Yes – <i>Advance Care Directive</i> – both statutory and common law advance directive	Yes – formerly an Enduring Guardian – now an appointment of <i>substitute decision-maker/s</i> via an Advance Care Directive. With power to make decisions in respect of health care.	Previously section 25 <i>Guardianship and Administration Act 1993</i> provided for enduring guardian. Relevant legislation is now <i>Advance Care Directives Act 2013 (SA)</i>	The Advance Care Directive provides for the appointment of substitute decision-maker/s; statements of values and wishes to guide future health care; and binding refusal/s of health care in particular circumstances. The Advance Care Directive replaces an Enduring Power of Guardianship

Appendix Five

<p>Victoria</p>	<p>Yes – statutory <i>Advance Care Directive</i> and common law directive</p>	<p>Yes - a ‘<i>medical treatment decision-maker</i>’ However, an enduring power of attorney (with medical treatment decisions) or a Refusal of Treatment Certificate made under the previous legislation, which are in force immediately before 12 March 2018, still operate unless revoked or cease to be effective (in accordance with the previous Act)</p>	<p>See especially parts 2 & 3 <i>Medical Treatment Planning and Decisions Act 2016 (Vic)</i> Note: this Act repealed the <i>Medical Treatment Act 1988 (Vic)</i> and amended the <i>Powers of Attorney Act 2014 (Vic)</i></p>	<p>The <i>Medical Treatment Planning and Decisions Act 2016</i> commenced in March 2018 and deals with medical treatment decision-making. It introduced advance care directives and a supported decision-making regime. This enables a ‘support person’ to be appointed to support the person to make medical treatment decisions.</p>
<p>Tasmania</p>	<p>Yes – common law only</p>	<p>Yes – enduring guardian. With power to consent to any health care that is in the best interests of the represented person and to refuse or withdraw consent to any such treatment.</p>	<p>Part 5 <i>Guardianship and Administration Act 1995 (Tas)</i></p>	<p>The Tas Department of Health and Human services suggests a template form for a common law advance directive to complete an advance directive – the form also states that if a person lacks capacity to understand and complete the form a legally appointed enduring guardian or ‘person responsible’ can complete the form on their behalf. It would then operate more as an advance care plan, rather than a binding directive.</p>
<p>New South Wales</p>	<p>Yes – common law only</p>	<p>Yes – Enduring Guardian. With power to decide the health care that the person (appointor) is to receive.</p>	<p>Part 2 <i>Guardianship Act 1987 NSW</i></p>	<p>NSW Health has developed a template guide for a common law advance directive that includes information about dying and directions for medical care, including CPR, artificial ventilation, artificial feeding, renal dialysis and organ and tissue donation.</p>

Queensland	Yes – statutory AHD only	Yes – Enduring Power of <i>Attorney</i> . With power to do anything in relation to health matters but does not include special personal or special health matters (e.g. withholding or withdrawing life-sustaining measures)	<i>Powers of Attorney Act 1998</i> (Qld)	QUT End of Life Law Australia notes that common law advance directives were intended to have legal effect in Qld but the wording and structure of the guardianship legislation removed their legal effect.
Australian Capital Territory	Yes – <i>statutory Health Direction</i> and common law advance directive	Yes – an Enduring Power of <i>Attorney</i> . With power to make decisions about health care matters but not special health care matters (e.g. sterilisation, termination of pregnancy, ECT)	<i>Medical Treatment (Health Directions) Act 2006</i> (ACT) <i>Powers of Attorney Act (2006)</i> (ACT)	The statutory Health Direction takes effect on signing. A person does not have to have lost capacity. However, if a person has capacity health professionals must provide information and decide if the person still holds the same wishes.
Northern Territory	Yes – statutory <i>Advance Personal Plan</i> and common law advance directive	Yes - the person may appoint a <i>substitute decision-maker</i> in an Advance Personal Plan	<i>Advance Personal Planning Act 2013</i> (NT)	The NT Advance Personal Plan allows an individual to make legally binding Advance Consent Decisions about future health care; together with statements about views, wishes and beliefs in relation to future health, financial or lifestyle matters and to appoint substitute decision-maker/s. A statement in the Advance Personal Plan is considered to be an Advance Consent Decision if it provides consent or refuses consent to health care or it would be reasonable to conclude from the statement that the person would or would not want the health care, in the circumstances

Appendix Six

Legislative reform attempts in Australia

Jurisdiction	Name	Date Introduced	Who Introduced	Where Introduced
Commonwealth	Euthanasia Laws (Repeal) Bill 2004	3 March 2004	Lyn Allison (Australian Democrats)	Senate
	Australian Territories Rights of the Terminally Ill Bill 2007	8 February 2007	Bob Brown (Australian Greens)	Senate
	Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008	14 February 2008	Bob Brown (Australian Greens)	Senate
	Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2008	17 September 2008	Bob Brown (Australian Greens)	Senate
	Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2010	29 September 2010	Bob Brown (Australian Greens)	Senate
	Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2012	26 November 2012	Richard Di Natale (Australian Greens)	Senate
	Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015	2 December 2015	David Leyonhjelm (Liberal Democratic Party)	Senate
Australian Capital Territory	Voluntary and Natural Death Bill 1993	16 June 1993	Michael Moore (Independent)	Legislative Assembly
	Medical Treatment (Amendment) Bill 1995	20 September 1995	Michael Moore (Independent)	Legislative Assembly
	Medical Treatment (Amendment) Bill 1997	19 February 1997	Michael Moore (Independent)	Legislative Assembly
	Euthanasia Referendum Bill 1997	18 June 1997	Michael Moore (Independent)	Legislative Assembly
	Crimes (Assisted Suicide) Bill 1997	24 September 1997	Michael Moore (Independent)	Legislative Assembly
New South Wales	Voluntary Euthanasia Referendum Bill 1997	15 May 1997	Elisabeth Kirkby (Australian Democrats)	Legislative Council

Appendix Six

	Rights of the Terminally Ill Bill 2001	29 November 2001	Ian Cohen (Australian Greens)	Legislative Council
	Voluntary Euthanasia Trial (Referendum) Bill 2002	Notice of Motion 9 April 2002 (No First Reading)	Ian Cohen (Australian Greens)	Legislative Council
	Voluntary Euthanasia Trial (Referendum) Bill 2003	17 September 2003	Ian Cohen (Australian Greens)	Legislative Council
	Rights of the Terminally Ill Bill 2003	Notice of Motion 30 April 2003 (No First Reading)	Ian Cohen (Australian Greens)	Legislative Council
	Rights of the Terminally Ill Bill 2010	Notice of Motion 22 September 2010 (No First Reading)	Cate Faehrmann (Australian Greens)	Legislative Council
	Rights of the Terminally Ill Bill 2010	Notice of Motion 19 October 2010 (No First Reading)	Cate Faehrmann (Australian Greens)	Legislative Council
	Rights of the Terminally Ill Bill 2013	2 May 2013	Cate Faehrmann (Australian Greens)	Legislative Council
Northern Territory	Rights of the Terminally Ill Bill 1995	22 February 1995	Marshall Perron (Country Liberal Party)	Legislative Assembly
	Criminal Code (Euthanasia) Amendment Bill 1997	18 February 1998	John Bailey (Australian Labor Party)	Legislative Assembly
	Voluntary Euthanasia Bill 1995	9 March 1995	John Quirke (Australian Labor Party)	House of Assembly
	Voluntary Euthanasia Bill 1996	6 November 1996	Anne Levy (Australian Labor Party)	Legislative Council
	Voluntary Euthanasia (Referendum) Bill 1995	6 November 1996	Sandra Kanck (Australian Democrats)	Legislative Council
	Dignity in Dying Bill 2001	14 March 2001	Sandra Kanck (Australian Democrats)	Legislative Council
	Dignity in Dying Bill 2001	15 March 2001	Bob Such (Independent)	House of Assembly
	Dignity in Dying Bill 2002	8 May 2002	Sandra Kanck (Australian Democrats)	Legislative Council

Appendix Six

South Australia	Dignity in Dying Bill 2003	26 March 2003	Bob Such (Independent)	House of Assembly
	Dignity in Dying Bill 2003	24 September 2003	Bob Such (Independent)	House of Assembly
	Dignity in Dying Bill 2005	16 February 2005	Bob Such (Independent)	House of Assembly
	Voluntary Euthanasia Bill 2006	14 March 2007	Bob Such (Independent)	House of Assembly
	Voluntary Euthanasia Bill 2007	31 May 2007	Bob Such (Independent)	House of Assembly
	Voluntary Euthanasia Bill 2008	16 October 2008	Bob Such (Independent)	House of Assembly
	Consent to Medical Treatment and Palliative Care (Voluntary Euthanasia) Amendment Bill 2008	12 November 2008	Mark Pamell (Australian Greens)	Legislative Council
	Voluntary Euthanasia Bill 2010	24 June 2010	Bob Such (Independent)	House of Assembly
	Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill 2010	16 September 2010	Stephanie Key (Australian Labor Party)	House of Assembly
	Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill 2010	29 September 2010	Mark Pamell (Australian Greens)	Legislative Council
	Criminal Law Consolidation (Medical Defences – End of Life Arrangements) Amendment Bill 2011	10 March 2011	Stephanie Key (Australian Labor Party)	House of Assembly
	Voluntary Euthanasia Bill 2012	1 March 2012	Bob Such (Independent)	House of Assembly
	Ending Life with Dignity Bill 2013	7 February 2013	Bob Such (Independent)	House of Assembly
	Ending Life with Dignity Bill (No. 2) 2013	31 October 2013	Bob Such (Independent)	House of Assembly
Tasmania	Dying with Dignity Bill 2009	26 May 2009	Nicholas McKim (Australian Greens)	House of Assembly
	Voluntary Assisted Dying Bill 2013	26 September 2013	Larissa Giddings (Australian Labor Party)	House of Assembly

Appendix Six

			Nicholas McKim (Australian Greens)	
Victoria	Medical Treatment (Physician Assisted Dying) Bill 2008	28 May 2008	Colleen Hartland (Australian Greens)	Legislative Council
Western Australia	Voluntary Euthanasia Bill 1997	16 October 1997	Norm Kelly (Australian Democrats)	Legislative Council
	Voluntary Euthanasia Bill 1998	20 August 1998	Norm Kelly (Australian Democrats)	Legislative Council
	Voluntary Euthanasia Bill 2000	10 May 2000	Norm Kelly (Australian Democrats)	Legislative Council
	Voluntary Euthanasia Bill 2000	19 October 2000	Norm Kelly (Australian Democrats)	Legislative Council
	Voluntary Euthanasia Bill 2002	18 September 2002	Robin Chapple (Australian Greens)	Legislative Council
	Voluntary Euthanasia Bill 2010	20 May 2010	Robin Chapple (Australian Greens)	Legislative Council

Appendix Seven

Summary of other models

	Canada	Victoria	Northern Territory	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Minimum age	18	18	18	18	18	18	18	None	None
Residency requirement	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Capacity requirement	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	No. An advance directive written when a person had capacity can be acted upon.	No. An advance directive written when a person had capacity can be acted upon.
A person must be dying as a result of the condition?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Time frame for prognosis	Natural death is reasonably foreseeable.	6 months terminal condition; 12 months neurodegenerative diseases.	None	6 months	6 months	6 months	6 months	None	None

Appendix Seven

	Canada	Victoria	Northern Territory	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Is pain and/or suffering required?	Yes. Grievous and irremediable.	Yes. Enduring and unbearable suffering.	Yes. Severe pain or suffering.	No	No	No	No	Yes. A medically futile condition of constant and unbearable physical or mental suffering.	Yes. Suffering must be lasting and unbearable.
Mental illness alone does not satisfy eligibility criteria	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability alone does not satisfy eligibility criteria	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assessing health professionals	2 doctors	2 doctors	2 doctors and a psychiatrist	2 doctors	2 doctors	2 doctors	2 doctors	2 doctors (unless death not expected in near future, in which case, 3 doctors)	2 doctors

Appendix Seven

	Canada	Victoria	Northern Territory	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Genuine request	2 doctors must be of the opinion that the person has made a 'voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure'.	2 doctors must be satisfied that the person is 'acting voluntarily and without coercion'.	2 doctors must be satisfied that the request was made 'freely, voluntarily and after due consideration'	2 doctors satisfied that request is made voluntarily.	2 doctors satisfied that request is made voluntarily.	2 doctors satisfied that request is made voluntarily.	2 doctors satisfied that request is made voluntarily.	Doctor to be satisfied that the request is 'voluntary, well-considered and repeated, and is not the result of any external pressure'.	Doctor to be satisfied that the request is 'voluntary and well-considered'.
Information for patients	Patient informed of the means available to relieve suffering, including palliative care	Patient informed of diagnosis and prognosis; treatment options, including palliative care; risks and expected outcomes from ingesting substance.	Patient informed of the nature and likely course of illness and medical treatment and other support.	Patient informed of diagnosis and prognosis, risks and result of taking medication, and alternative treatment	Patient informed of diagnosis and prognosis, risks and result of taking medication, and alternative treatment	Patient informed of diagnosis and prognosis, risks and result of taking medication, and alternative treatment	Patient informed of diagnosis and prognosis, risks and result of taking medication, and alternative treatment	Patient informed about health condition, life expectancy, the possible palliative and therapeutic courses of action and their consequences.	Patient informed of the 'situation he was in and about his prospects'.

Appendix Seven

	Canada	Victoria	Northern Territory	Oregon	Washington State	Vermont	California	Belgium	Netherlands
Reflection period	No less than 10 days between a written request and the day on which assisted dying is provided.	At least 10 days must separate the final request to access assisted dying from the first request. The final request must also be at least one day after the assessment confirming the person is eligible.	At least 7 days between advising doctor and signing certificate. No less than 2 days after signing the certificate.	Two oral requests no less than 15 days apart and a written request.	No less than 15 days between first and second oral request. Prescription at least 48 hours after second request.	Two oral requests no less than 15 days apart and a written request. Prescription at least 48 hours after second request.	Two oral requests no less than 15 days apart and a written request.	Doctor is required to have had several conversations with patient over a reasonable period of time. No reflection period akin to North American models.	Legislation makes no provision for reflection period.

Appendix Eight

Bibliography

Adedeji, W.A. The Treasure Called Antibiotics, *Annals of Ibadan Postgraduate Medicine*, vol. 14, no. 2, 2016

AFP Dutch paediatricians: give terminally ill children under 12 the right to die, *The Guardian*, 19 June 2015. Available online at: <https://www.theguardian.com/society/2015/jun/19/terminally-ill-children-right-to-die-euthanasia-netherlands> Accessed 4 July 2018.

Allan, S and Blake, M. *The Patient and the Practitioner: Health Law and Ethics in Australia*, LexisNexis Butterworths, 2014.

Almagor-Cohen, R and Wesley, E, Euthanasia and palliative sedation in Belgium, *BMJ Supportive and Palliative care* 2018; 0: 1-7.

A Good Death is My Right: People with Dementia and Carers Response to the Voluntary Assisted Dying Bill Discussion Paper, Alzheimer's Australia Vic – Website. Accessed 17 July 2018.

Anscombe, E. *Intention*, Oxford, Basil Blackwell, 1958.

AP Report Luxembourg strips monarch of legislative role, *The Guardian*, 12 December 2008, Accessed 17 July 2018.

Ashby, Michael. How we die: A view from palliative care, *QUT Law Review* Vol. 16, Issue 1

Ashby, Michael. The Futility of Futility: Death Causation is the 'Elephant in the Room' in Discussions about Limitation of Medical Treatment, *Bioethical Inquiry* (2011) 8:151-154.

Australian and New Zealand Society of Palliative Medicine Inc. 2017 Palliative Sedation Therapy Guidance Document. Accessed 17 July 2018.

Australian Bureau of Statistics, Causes of Death, Australia, 2016. Accessed 17 July 2018.

Australian Human Rights Commission. *Euthanasia, human rights and the law*. <https://www.humanrights.gov.au/our-work/age-discrimination/publications/euthanasia-human-rights-and-law> Accessed 17 July 2018.

Australian Institute of Health and Welfare, *Palliative care workforce tables 2016*, May 2018, np. Available at: <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce> Accessed 17 July 2018.

Barry, J. V. Suicide and the Law. *Melbourne University Law Review*, Vol 5, 1965. Austlii.edu.au.

Battin MP, van der Heide A, Ganzini L, Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups *Journal of Medical Ethics* 2007;33:591-597.

Baume, P and O'Malley, E, Euthanasia: attitudes and practices of medical practitioners, *The Medical Journal of Australia*, Vol 161, 18 July 1994.

Appendix Eight

- Beahan, P. The Case for Voluntary Assisted Dying, *Medical Forum*, June 2018, p.23.
- Beauchamp, T. L. and Childress, J. F. (1994). Non-maleficence. In: *Principles of Biomedical ethics*, Fourth ed, Ed T. Beauchamp and J. Childress. Oxford University Press, Oxford: pp. 206-11
- Blake, M, Doray, O and Sinclair, C, Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice, *Psychiatry, Psychology and Law*, DOI: [10.1080/13218719.2017.1351904](https://doi.org/10.1080/13218719.2017.1351904).
- Blanke, C, LeBlanc, M, Hershman, D, Ellis, LL, Meyskens, F. Characterising 18 years of the Death with Dignity Act in Oregon, *JAMA Oncol*, 2017 Oct; 3(10): 1403 – 1406.
- Borbasi, J, *Life Before Death: Improving Palliative Care for Older Australians: Research Report 34*. The Centre for Independent Studies, November 2017.
- Burton, K, Crofts, T and Tarrant, S, *Principles of Criminal Law in Queensland and Western Australia*, Second Ed, Thomson Reuters, 2016.
- California Department of Public Health, *California End of Life Option Act 2017 Data Report*, June 2018, p. 4. Available at: <https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADatReport.pdf> Accessed 17 July 2018.
- Chambaere, et al, Trends in Medical End of life Decision Making in Flanders, Belgium 1998–2001–2007, *Medical Decision Making*, vol. 31, no. 3, May-June 2010, p. 500.
- Chambaere, et al, Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey, *Canadian Medical Association Journal*, vol. 182, no. 9, 15 June 2010, p. 900.
- Chambers, S. Assisted-dying legislation needs to include advance directives for dementia, *The Star*, 11 June 2017 - website. Accessed 17 July 2018.
- Cherny, N. I. Radbruch, L. European Association for Palliative Care (EPAC) recommended framework for the use of sedation in palliative care. *Palliative Medicine*. 23(7) 581 – 593.
- Cohen, J, Dierickx, S. How accurately is euthanasia reported on death certificates in a country with legal euthanasia: a population based study, *European Journal of Epidemiology*, 21 April 2018.
- Cole-Adams, K, *Anaesthesia: The Gift of Oblivion. The Mystery of Consciousness*, Text Publishing Company, 2017.
- Crofts, T, *Criminal Law in Queensland and Western Australia*, LexisNexis Butterworths, 2014.
- Dean, Mervyn M. Framework for Continuous Palliative Sedation Therapy in Canada, *Journal of Palliative Medicine*, vol 15(8), 2012, 870
- De Boer ME, et al, Advance directives for euthanasia in dementia: how do they affect resident care in Dutch nursing homes? Experiences of physicians and relatives, *J Am Geriatr Soc*, 2011 Jun;59(6), pp. 989 – 996.
- Deliens, et al, End of life decisions in medical practice in Flanders, Belgium: a nationwide survey, *The Lancet*, vol. 356, 25 November 2000, pp. 1806–1811.

- Dembo et al, For Their Own Good: A Response to Popular Arguments Against Permitting Medical Assistance in Dying (MAID) where Mental Illness Is the Sole Underlying Condition', *The Canadian Journal of Psychiatry* 1-6, 2018.
- Dementia Australia – Key facts and statistics Dementia Australia. Website. Accessed 17 July 2018
- Department of Health, Western Australia: WA Health – Storage of Schedule 8 medicines – Website. Accessed 17 July 2018.
- Department of Health, Western Australia. *Admission, Readmission, Discharge and Transfer: Reference Manual*. Department of Health, Western Australia; July 2017.
- Department of Health, Western Australia. *Advance Care Planning: A patient's guide*. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.
- Department of Health, Western Australia. *Advance Care Planning: A step-by-step guide for health care professionals assisting patients with chronic conditions to plan for care towards end of life*. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2014.
- Department of Health, Western Australia. *Evidence based clinical guidelines for adults in the terminal phase*, Second ed. Perth: WA Cancer and Palliative Care Network, Community Medications, 2010.
- Department of Health, Western Australia. *Palliative Care Medicine and Symptom Guide*. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.
- Department of Health, Western Australia. *Preparing an Advance Health Directive*. Produced by the Office of the Chief Medical Officer, Department of Health, Western Australia; 2016.
- Department of Health, Western Australia. *The End of life Framework*. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2017
- Department of Health, Western Australia. *Understanding the dying process: An information booklet for families*. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2015.
- Department of Health, Western Australia. *WA End of life and Specialist Palliative Care Strategy: 2018 - 2028*. Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia; 2018.
- Downie, J, Medical Assistance in Dying: Lessons for Australia from Canada, 17 *QUT L. Rev.* 127 (2017).
- Downie, J., Permitting voluntary euthanasia and assisted suicide: Law reform pathways for common law jurisdictions, *QUT Law Review*, vol. 16, no. 1. Austlii.edu.au. Accessed 17 July 2018.
- Downie J, Willmott, L, and White, B. Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining treatment, *New Zealand University Law Review*, 26(1),
- Duff, R. A. *Intention, Agency and Criminal Liability*, Oxford, Blackwell, 1990.
- Dworkin, G, Physician-Assisted Death: The State of the Debate, Steinbock, B, ed. *The Oxford Handbook of Bioethics*. Oxford, New York: Oxford University Press, 2007: 375 392.

Appendix Eight

- Dyer, et al., Assisted dying: law and practice around the world, *British Medical Journal*, vol. 351, August 2015
- Edith Cowan University, *Guidelines for a Palliative Approach in Residential Aged Care*, Australian Government Department of Health and Ageing, 2006.
- Ezekiel J Emanuel, Bregje D Onwuteaka-Philipsen, John W Urwin and Joachim Cohen, Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. *JAMA [Journal of the American Medical Association]*, 2016, 316(1):79-90
- Francis, N. *Assisted Dying Practice in Benelux: White Paper 1*. Accessed 17 July 2018.
- Glaskin, K, Tonkinson, M, Musharbah, Y and Burbank, V, *Mortality, Mourning and Mortuary Practices in Indigenous Australia*, Routledge, 2016.
- Guilbeau, C. End of life care in the Western world: where are we now and how did we get here? *BMJ Supportive and Palliative Care*, 2018; 0: 1 – 9. <http://spcare.bmj.com/> Accessed 17 July 2018.
- Health Canada, *Second Interim Report on Medical Assistance in Dying*, October 2017.
- Hedberg, K and New, C, Oregon's Death with Dignity Act: 20 Years of Experience to inform the Debate, *Annals of Internal Medicine*, 2017; 167:579 – 583.
- Heneka, N, Shaw, T, Rowett, D, Lapkin, S and Phillips, J. Opioid errors in inpatient palliative care services: a retrospective review, <http://dx.doe.org/10.1136/bmjspcare-2017-001417>.
- Howard, C, *Criminal Law*, Fourth Ed, The Law Book Company, 1982.
- Huxtable, Richard. Get out of jail free? The doctrine of double effect in English law, *Palliative Medicine*, 2004, 18.
- Institute Europeen de Bioethique, [Analysis of The Seventh Report of the Federal Commission for Euthanasia Control and Evaluation to the Legislative Chambers \(for the Years 2014 and 2015\)](#). Website. Accessed 17 July 2018
- Jones, D.A., & Paton, D., How does legalization of physician-assisted suicide affect rates of suicide? *Southern Medical Journal*, vol. 108, no. 10, October 2015, p. 601.
- Kenyon, P and D'Souza, M, *North West Ageing and Aged Care Strategy*, Australian Government, 2017.
- Kuhse, H et al, End of life decisions in Australian Medical Practice, *MJA*, 1997: 166: 191.
- Lewis, Penney, *Assisted Dying and Legal Change*, Oxford University Press, London, 2007
- Lewis, P. Euthanasia in Belgium Five Years After Legalisation, *European Journal of Health Law*, vol. 16, 2009, pp. 125–126.
- Life in Mind. [Suicide Prevention](#). Australian Government, Department of Health. Accessed 17 July 2018.
- Lifeline: Crisis Support. Suicide Prevention. [What is self-harm?](#) Accessed 17 July 2018.
- Lofmark, R, et al. Physicians' experiences with end of life decision-making: Survey in 6 European countries and Australia, *BMC Medicine*, 2008, 6:4.
- Lowe, M. & Downie, J. Does Legalization of Medical Assistance in Dying Affect Rates of Non-assisted Suicide? *Journal of Ethics in Mental Health*, vol. 10, 2017, p. 5.

Appendix Eight

- MacLeod, R, Vella-Brincat, J and MacLeod, S, *The Palliative Care Handbook: Guidelines for clinical management and symptom control*, HammondCare Media, 2015.
- Magnusson, Roger S, *Angels of Death: Exploring the Euthanasia Underground*, Melbourne University Press, 2002.
- Magnusson, Roger S, Underground Euthanasia and the Harm Minimisation Debate, *Journal of Law, Medicine and Ethics*, (2004) p. 486.
- Martin, Carmel M. Chronic disease and illness care: Adding principles of family medicine to address ongoing health system redesign *Can Fam Physician*, 2007, 53(12): 2086–2091. Accessed 17 July 2018.
- Mason, JK and McCall Smith, RA, *Law and Medical Ethics*, Fifth Ed, Butterworths, 1999.
- Mental Health Commission Western Australia. *Suicide Prevention 2020: Together we can save lives*. Government of Western Australia
- New South Wales Government, *Capacity Toolkit*, NSW Attorney General's Department, 2008. Accessed 17 July 2018.
- Nordqvist, C. Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 – 2014, *JAMA Psychiatry*, vol. 74, no. 4, April 2016, p. 363.
- Office of the Public Advocate (WA), *Advance Health Directives* (webpage) as updated 1 September 2016. Accessed 17 July 2018.
- Office of the Public Advocate (WA), *Enduring Power of Guardianship*, as lasted updated 1 September 2016. Accessed 17 July 2018.
- Onwuteaka-Philipsen, Brinkman-Stoppelenburg, A, Penning, C, de Jong-Krul, G, van Delden, J, van der Heide, A, Trends in end of life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey, *Lancet*, Vol 380. 8 September 2012
- Oregon Secretary of State, *Oregon Blue Book*. Available at: <https://sos.oregon.gov/blue-book/Documents/elections/initiative.pdf> Accessed 17 July 2018.
- Palliative Care Outcomes Collaboration, Clinical Manual, Australian Government Department of Health, April 2018.
- Parker, M. ed. Patient competence and professional incompetence: Disagreements in capacity assessments in one Australian jurisdiction, and their educational implications. 16 *Journal of Law and Medicine*, 25.
- Parliament of Victoria, Legislative Council: Legal and Social Issues Committee. *Inquiry into end of life choices: Final Report*. Victorian Government Printer, June 2016.
- Pascal, B. Provincial Letters, in Peter Singer (ed.), *Ethics*, Oxford, Oxford University Press, 1994.p. 270.
- Pidgeon, T, Johnson, C, Durrow, D, Yates, P and Banfeld, M, A survey of patients' experience of pain and other symptoms while receiving care from palliative care services, *BMJ Supportive and Palliative Care* 63, (2015) 315 – 322.
- Poisons Standard June 2018 – Website. Accessed 17 July 2018.
- Queensland University of Technology, End of Life Law in Australia, Accessed 17 July 2018.

Appendix Eight

Quill, T.E. The Ambiguity of Clinical Intentions (1993) 329, *New England Journal of Medicine*, 1039

Rachels, James, *The End of Life: Euthanasia and Morality*, Oxford University Press, 1986

Randall, F and Downie, R.S., *The Philosophy of Palliative Care: Critique and Reconstruction*, Oxford University Press, 2006.

Rietjens, J, Deschepper, R, Pasma, R and Deliens. L. Medical end of life decisions: Does its use differ in vulnerable patient groups? A systematic review and meta-analysis, *Social Science and Medicine*, 74 (2012) 1282-1287.

Rosenwax et al, A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? *BMC Palliative Care* 2016

Rosenwax et al, Who receives palliative care in Western Australia and who misses out? *Palliative Medicine* 2006; 20: 439 – 445.

Select Committee on Euthanasia, Parliament of the Northern Territory, *The Right of the Individual or the Common Good? Report of the Inquiry by the Select Committee on Euthanasia*. Available at: https://parliament.nt.gov.au/data/assets/pdf_file/0007/367963/vol1.pdf Accessed 17 July 2018.

Schuklenk, U, Van Delden, J.J. M, Downie, J, McLean, S. A. M. Upshur, R. and Weinstock. D. End of life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End of life Decision-Making. *Bioethics*. ISSN 0269-9702 online.

Skegg, P. D. G. 'Surgical Operation' Provisions in Commonwealth Criminal Codes, in *Medizin und Haftung*. Springer, Berlin, Heidelberg, pp. 581 – 595.

Stanford Encyclopedia of Philosophy, *Voluntary Euthanasia*. <http://plato.stanford.edu/entries/euthanasia-voluntary/> Accessed 17 July 2018.

Stevens, C and Hassan, R, Management of death, dying and euthanasia: attitudes and practices of medical practitioners in South Australia, *Journal of Medical Ethics*, 1994; 20: 41 46.

Swerissen, H and Duckett, S., 2014, *Dying Well*. Grattan Institute.

Syme, R, *Time to Die*, Melbourne University Press, 2016.

Titelius, R. Euthanasia Bid for WA, *Sunday Times*, 26 March 2017.

Towler, S, Chair, National Advance Care Directives Working Group, *A National Framework for Advance Care Directives*. The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, September 2011.

UK Director of Public Prosecutions. Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide – website. Accessed 17 July 2018.

United Nations Convention on the Rights of Persons with Disabilities

van Delden, Johannes JM. Terminal Sedation: a source of restless ethical debate, *Journal of MEDICAL Ethics*, 2007, 33 (4): p. 187.

Van der Heide, et al, End of life decision-making in six European countries: descriptive study', *The Lancet*, vol. 362, no. 9381, August 2003, p. 348.

- Victoria State Government, Health and Human Services. Ministerial Advisory Panel: Voluntary Assisted Dying. Final Report. Victorian Government, July 2017. Accessed 17 July 2018.
- WA Law Society. When a Client's Capacity is in Doubt: Appendix B, 2016. Accessed 17 July 2018.
- Ben White and Jocelyn Downie, Prosecutorial Guidelines for Euthanasia and Assisted Suicide: Autonomy, Public Confidence, and High Quality Decision-Making, *Melbourne University Law Review*, 2012 – Website. Accessed 17 July 2018.
- White, B, McDonald, F and Willmott, L, *Health Law in Australia*, Thomson Reuters, 2009.
- White, B and Willmott, L (2012) How should Australia regulate voluntary euthanasia and assisted suicide? *Journal of Law and Medicine*, 20, pp. 410 – 438.
- White, B, Willmott, L and Ashby, M (2011) Palliative care, double effect and the law in Australia. *Internal Medicine Journal*, 41(6), pp. 485 – 492.
- White, B, Willmott, L, Cartright, C, Parker, M and Williams, G. Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment, *Medical Journal of Australia*, 2014; 201(4): 229 – 232.
- White, B, Willmott, L and Savulescu, J, Voluntary palliated starvation: A lawful and ethical way to die? (2014) 22 *Journal of Law and Medicine* 376.
- Williams, G. The Principle of Double Effect and Terminal Sedation, *Medical Law Review*, 9, 2001, p. 41 - 53.
- Willmott, L, & White, B. 'Assisted dying in Australia: A values-based model for reform', in Ian Freckelton & Kerry Petersen (eds.), *Tensions and traumas in health law*, Federation Press, Sydney, 2017, pp. 491
- Willmott, L, White, B, and Downie J, Withholding and Withdrawal of 'futile' life-sustaining treatment: unilateral medical decision-making in Australia and New Zealand, *Journal of Law and Medicine*, 20(4), pp. 907 – 924
- Willmott, L, White, B, Gallois, C, Parker, M, Graves, N, Winch, S, Callaway, L.K, Shepherd, N, Close, E.: Reasons Doctors provide futile treatments at the end of life: A qualitative study, *Journal of Medical Ethics*, 42, pp. 496 – 503
- Willmott, L, White, B and Smith, Malcolm K. "Best interests" and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the *parens patriae* jurisdiction', *Journal of Law and Medicine* (2014) 12(4), 920

Appendix Nine

Statement of committee expenditure

In accordance with Legislative Assembly Standing Order 276, the committee's expenditure is provided below:

Expenditure item	Amount (\$)
Advertising	6,583
Consultants	5,885
Couriers	1,300
Miscellaneous	3,623
Postage	77
Printing	14,000
Staff costs	391,374
Travel	31,452
TOTAL	454,294

Note that costs of shared administrative expenses, including lease costs for committee accommodation, are not included.

Appendix Ten

Acronym List

Acronym List	
AFDO	Australian Federation of Disability Organisations
AHCWA	Aboriginal Health Council Western Australia
AHD	Advance Health Directive
AIHW	Australian Institute of Health and Welfare
ALSWA	Aboriginal Legal Service Western Australia
AMAWA	Australian Medical Association (WA Branch)
CKD	Chronic Kidney Disease
COPD	Chronic Obstructive Pulmonary Disease
DAHS	Derby Aboriginal Health Service
EPG	Enduring Power of Guardianship
GAA	Guardianship and Administration Act 1990
GP	General Practitioner
KRS	Kimberley Renal Service
MHR	My Health Record
MNDAWA	Motor Neurone Disease Association Western Australia
MPaCCS	Metropolitan Palliative Care Consulting Service
NCIS	National Coronial Information System
PCOC	Palliative Care Outcomes Collaboration
PWdWA	People With disabilities Western Australia
PCWA	Palliative Care Western Australia
RACGP	Royal Australian College of General Practitioners
RCL	Residential Care Line
ROTTIA	Rights of the Terminally Ill Act Northern Territory
SAT	State Administrative Tribunal
UWA	University of Western Australia
VAD	Voluntary Assisted Dying

Appendix Ten

WACHS	Western Australian Country Health Service
WACPCN	Western Australian Cancer and Palliative Care Network
WA Health	Western Australian Department of Health
WAPMSG	Western Australian Palliative Medicine Specialist Group

Minority Report

The Hon N.P. Goiran, MLC



Hon Nick Goiran MLC

The safe approach to End of Life Choices: License to Care not Licence to Kill

Minority Report by Hon N.P. Goiran MLC for the Joint Select
Committee on End of Life Choices submitted under Legislative Assembly
Standing Order 274

August 2018

Parliament of Western Australia

Author

Committee Member

Hon Nick Goiran MLC LLB B Com
Member for South Metropolitan Region

Legislative Assembly
Parliament House
Harvest Terrace
PERTH WA 6000

Tel: (08) 9222 7494
Fax: (08) 9222 7804
Email: eolcc@parliament.wa.gov.au
Website: www.parliament.wa.gov.au

**Published by the Legislative Assembly, Parliament of Western Australia, Perth.
August 2018.**

(Series: Western Australia. Parliament. Legislative Assembly. Committees.
Joint Select Committee on End of Life Choices. Report 1)

**Joint Select Committee
on End of Life Choices**

**The safe approach to End of
Life Choices: License to Care
not Licence to Kill**

Minority Report submitted under Legislative Assembly
Standing Order 274

Hon Nick Goiran MLC

Presented on 23 August 2018

Foreword

There was only one of the eight members of the Joint Select Committee on End of Life Choices (JSCEOLC) that attended every meeting and every hearing during the course of its year-long inquiry. There is only one of the 95 members of the Parliament of Western Australia that has served on both the JSCEOLC and the Select Committee on Elder Abuse (SCEA). Indeed I am the Chairman of SCEA in addition to being the co-chair of the Parliamentary Friends of Palliative Care. Prior to entering Parliament I was a Partner of a Western Australian law firm and supervised its civil litigation division. That division including a healthy practice in medical negligence law. It is with this background that I present this report.

The JSCEOLC was asked to inquire into and report on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices. In particular the Committee was asked to assess current practices (including the role of palliative care), review legislation both inside and outside Western Australia, consider what legislative change may be required (including an examination of any federal laws) and examine the role of Advance Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws.

It is readily apparent that the Committee has failed to fulfil the task given to it by the Houses.

During the Legislative Council debate on the motion to agree to the Legislative Assembly's request to form the joint committee, I moved to amend the terms of reference to add that the Committee 'examine the risks of introducing voluntary euthanasia, including the impact on suicide prevention.' My motion was unsuccessful with Hon Sally Talbot MLC assuring the House that 'we will be able to have those discussions within the existing terms of reference' and Hon Alannah MacTiernan MLC saying 'I urge members not to support this amendment.'

The very fact that there was such resistance to what should have been a simple amendment set the scene for what any dispassionate observer could have anticipated for the twelve months that followed.

To ensure that all members of the Parliament of Western Australia and the people of this State have a thorough assessment of the risks of voluntary euthanasia and assisted suicide, I submit this report in accordance with Standing Order 274.

I am convinced that the risks of legalising assisted suicide (however described or defined) are too great as the consequences are final. Indeed I am convinced that assisted suicide is a recipe for elder abuse. The safety of the people of Western Australia ought to be our highest law.

I also have serious concerns for the impact upon our desperate efforts on suicide prevention in Western Australia. Our ongoing suicide rate of around one person per day is tragic and we simply cannot afford the dangerous mixed message that comes with assisted suicide.

In contrast I remain encouraged by and grateful for our health practitioners in palliative care. There is no doubt that they are capable of providing world-class care and comfort for Western Australians suffering from a terminal or chronic illness. They simply need to be given the opportunity to provide it. Consequently, as a compassionate and caring Western Australian community our collective energies should be directed to improving the awareness of, access to, training of and resourcing of our palliative care service providers.

Assisted suicide is bad public policy. Our best public policy option is always care not killing.

A handwritten signature in blue ink, appearing to read 'Nick Goiran', is centered on a light pink rectangular background.

Hon Nick Goiran MLC

Contents

Executive Summary	vii
Findings and Recommendations	ix
1 Current End of Life Choices in Western Australia	1
<hr/>	
Palliative Care	1
What is Palliative Care?	1
Palliative care provision in Western Australia	4
Data on refractory symptoms	6
A comment on the Committee’s inquiry into palliative care	10
Refusal of Nutrition and Hydration	13
Refusal of Medical Treatment	17
Palliative Sedation	21
Palliative sedation therapy and terminal sedation— terminology that can confuse	21
Palliative sedation does not hasten death	23
Palliative sedation is a conventional medical practice in care for the dying	26
The doctrine of double effect is not relied on in palliative sedation	28
The morphine myth	30
Suicide and the Distinction between Palliative Care and Assisted Suicide	34
2 The Risks of Legalised Assisted Suicide—Casualties Guaranteed	37
<hr/>	
Autonomy, Self-Determination and Choice—The Basis of Calls for Assisted Suicide	37
Assessment of Competency	39
Optional referral for psychiatric assessment	39
Mandatory psychiatric assessment	44
The complexities involved in the assessment of capacity	46
Demoralisation and the wish to hasten death	50
Mandatory psychiatric assessment cannot eliminate error in capacity assessment	55

Voluntary and Informed Consent	58
Informed consent	59
Undue influence	61
Undue influence and elder abuse	65
Assisted Suicide and Disability Discrimination	73
Assisted Suicide and Suicide Prevention	83
An artificial distinction between ‘rational’ suicide and suicide generally	83
Conflict with existing suicide prevention programs	85
The assisted suicide of Dr David Goodall	88
Older age suicide	91
On becoming a society accepting of suicide	92
Western Australian Coronial data on suicides	94
Assisted Suicide and the Medical Profession	99
Assisted suicide fundamentally alters the role of the medical profession	99
The medicalisation of death	101
The false assertion that assisted suicide is only about patients and not their doctors	103
The question of whether assisted suicide should be administered by a profession outside of the medical profession	105
The low number of doctors likely to participate in an assisted suicide program	106
A Safeguard is Only as Good as the Doctor Enforcing it	109
Doctor bias toward assisted suicide	112
Doctor shopping	114
Medical Error in Diagnosis and Prognosis	116
Error in prognosis	116
Error in diagnosis	122
There is No Right to Receive Assistance from a Physician to Suicide	126
What Effect does Killing Patients have on Medical Professionals?	128
Wounded healers	131
Assisted Suicide Cannot Guarantee a ‘Good Death’	132
Trading Lives	141

3	Lessons Learned from Other Jurisdictions	149
<hr/>		
	The Lived Experience in Australia—The Northern Territory	152
	<i>The Rights of the Terminally Ill Act 1995</i> (NT)	153
	Lack of access to good palliative care	154
	A patient who was not terminally ill was euthanised	155
	Evidence of doctor shopping	156
	Patients with mental illness and undiagnosed demoralisation were euthanised	156
	Dr Nitschke—where is he now?	159
	The European Experience—The Netherlands	163
	Extension of the law to include euthanasia for psychiatric illness	165
	The rise of private organisations involved in offering euthanasia to patients deemed ineligible by their physician	167
	The ‘tired of life’ argument currently underway	167
	An erosion of medical standards in the care of the terminally ill	168
	The Regional Euthanasia Review Committees and their permissive findings	169
	‘Don’t go there’	172
	The European Experience—Belgium	174
	Amendment of the law to extend euthanasia to children	174
	Euthanasia for psychiatric illness	175
	Polypathology	177
	Use of life-ending drugs without explicit request	179
	Euthanasia and palliative care in Belgium	180
	The European Experience—Switzerland	181
	Dignitas—helping people suicide	183
	Helium experimentation in Dignitas assisted suicides	186
	The North American Experience—Canada	188
	Expansion of the model	189
	Problems with implementation of the current model	192
	The North American Experience—Oregon	196
	Medical errors in prognosis	197
	Optional referral for psychiatric assessment	198

Doctor bias toward euthanasia	199
Doctor shopping	200
Complications rates in Oregon	200
The requirement of ‘terminal illness’ is not strictly applied	200
Lack of safety around patient-administered lethal drugs	202
The Oregon suicide rate	203
Palliative care in Oregon	203
What happens when the law is violated in Oregon?	204
The Gaping Hole—Issues with Reporting, Investigation, Prosecution and Redress	206
A retrospective model of oversight	206
The self-reporting of doctors	208
The best witness is dead	211
What redress can be offered to the deceased patient?	212
Jurisdictions where Assisted Suicide Laws have Failed to Pass	216
The Victorian Model and Logical Incremental Extension	219
Heavy Criticisms of the Victorian legislation by Proponents of Assisted Suicide	219
Political pragmatism	221
One person’s safeguard is another person’s obstacle	224
Arbitrary eligibility criteria and discrimination	226
Restrictive legislation will be amended through logical incremental extension	229
Non terminal cases	234
The elderly	237
Children	238
Psychiatric illness	238
Alzheimer’s disease and dementia	239
Appendices	247
1 Letter from Palliative Care WA dated 15 May 2018	247

Executive Summary

1. On 23 August 2017, the Parliament of Western Australia established a Joint Select Committee of the Legislative Assembly and Legislative Council to inquire and report on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices. In particular the Committee was asked to—
 - (a) *assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;*
 - (b) *review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions;*
 - (c) *consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation; and*
 - (d) *examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and the implications for individuals covered by these instruments in any proposed legislation.*
2. Having considered the submissions made to the Committee and the transcripts of those called to give evidence, it is clear that as the law currently stands Western Australians have the following end of life choices available to them:
 - (a) Medical treatment, especially palliative care, and including if necessary palliative sedation therapy;
 - (b) The refusal of medical treatment;
 - (c) The refusal of hydration and nutrition; and
 - (d) Suicide.
3. Advance Health Directives and advanced care planning, including the utilisation of Enduring Powers of Guardianship and Enduring Powers of Attorney, are important means of communicating end of life choices to caregivers, and to ensuring that lawful wishes of the individual are followed.

4. While the final choice, of suicide, is a choice that is available to Western Australians, it is certainly not a choice which the state encourages or promotes. In fact, suicide prevention policies and programs have had long-standing bi-partisan support, as every life in this State matters. Nevertheless, Western Australians have the liberty to choose suicide. Herein lies the important distinction between liberty and license.
5. The choice that is currently not available to Western Australians is that of assisted suicide.¹ This Report concludes that, upon weighing the evidence as a whole, assisted suicide should remain illegal in Western Australia. While it is one thing to have the liberty to suicide, it is quite another for the state to grant medical practitioners a licence to kill patients through assisted suicide.
6. Chapter 1 of this Report considers the end of life choices currently available to Western Australians and how assisted suicide represents a radical departure from these accepted choices.
7. Chapter 2 identifies areas of risk involved in the legalisation of assisted suicide and the failure of ‘safeguards,’ including difficulties with the assessment of capacity and the determination of consent, and issues arising in disability discrimination, suicide prevention, elder abuse and the irreversible consequences of medical error.
8. Chapter 3 considers the experiences of six jurisdictions with legalised assisted suicide, including our own Australian experience in the Northern Territory, as well as experiences from Europe and North America.
9. The submissions and testimonies given to the Joint Select Committee on End of Life Choices cover the field of views on the controversial issue of assisted suicide, with strong opinions and a great depth of feeling held by individuals on both sides of the debate.

We all will die. How we die—and live at the end of life—is important, with implications for individuals, their families, and society. How we are cared for at the end of life matters.²

1 The term ‘assisted suicide’ is used in this Report to refer to both ‘voluntary euthanasia’ (where lethal medication is administered by a medical practitioner upon the request of a patient) and ‘physician-assisted suicide’ (where access to lethal medication is provided by a medical practitioner, and self-administered by the patient). ‘Suicide’ is defined as an action taken to intentionally end one’s own life, and despite cultural and historical connotations, the term is neither disparaging nor a judgment. Assisted suicide simply identifies both voluntary euthanasia and physician-assisted suicide, and provides clarity, as other terms such as aid in dying, medical aid in dying, dying with dignity and physician assisted dying could all equally be used to describe palliative care practices.

2 Snyder Sulmasy L and Mueller PS, ‘Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,’ Professionalism and Human Rights Committee of the American College of Physicians (2017) *Annals of Int Med* 167(8): 576.

Findings and Recommendations

Finding 1

Page 12

Specialist palliative care is a relatively new discipline within the medical profession.

Finding 2

Page 12

Palliative care is poorly understood within the Western Australian community.

Finding 3

Page 12

The provision of quality palliative care affirms a patient's right to choose their therapy, decline futile treatment, choose their place of dying, receive the best possible relief of symptoms and to refuse to prolong the dying process.

Finding 4

Page 13

Medical treatment, including palliative care is an end of life choice currently available in Western Australia, however:

- a) Patients with non-malignant diseases are under-represented in palliative care in WA; and
- b) access to good quality palliative care across the State is, in any event, currently highly variable.

Finding 5

Page 13

Data from the Palliative Care Outcomes Collaboration (PCOC) can be useful in comparing one service provider with another but it is not, nor is it intended to be, an academically rigorous tool to assess palliative care generally.

Recommendation 1

Page 13

The Minister for Health should consult with the Palliative Care Outcomes Collaboration (PCOC) and service providers to determine a data collection methodology that would set the lowest figures for unmanaged pain symptoms as the aspirational standard for every service provider.

Recommendation 2

Page 13

The Minister for Health should consult with palliative care service providers to ascertain the current deficit in capacity preventing equitable provision of specialist palliative care across Western Australia.

Recommendation 3**Page 13**

The Minister for Health should assess the recommendations made by Western Australia's peak body for palliative care and report to Parliament with a plan to:

- a) utilise co-design workshops;
- b) progress the Compassionate Communities model;
- c) introduce shared care models;
- d) increase the capacity of the Silver Chain Hospice Care Service model of care;
- e) build the capacity of existing outpatient clinics to facilitate Advance Care Planning;
and
- f) increase the availability and flexibility of Telehealth.

Finding 6**Page 16**

Loss of hunger and thirst occurs frequently as a normal part of the natural dying process.

Finding 7**Page 17**

Refusal of nutrition and hydration is an end of life choice currently available in Western Australia, however it is significantly distinguishable from assisted suicide as it is based on the right to inviolability and is in any case reversible.

Finding 8**Page 21**

Refusal of medical treatment is an end of life choice currently available in Western Australia, however it is significantly distinguishable from assisted suicide as it is based on the right to inviolability and is in any case reversible.

Finding 9**Page 33**

Palliative sedation, when competently administered, is a legal and ethical end of life choice currently available in Western Australia.

Finding 10**Page 33**

An expanding evidence base has repeatedly confirmed that the appropriate use of sedating or pain-relieving medications does not hasten death.

Finding 11**Page 33**

Palliative sedation does not hasten death.

Finding 12**Page 33**

Under-dosing and failure to make a specialist referral are problems that lead to unnecessary suffering and distress for patients and loved ones.

Finding 13**Page 34**

Under-dosing and failure to make a specialist referral occur because of a lack of medical training and, in some cases, outdated teaching.

Recommendation 4 **Page 34**
The Minister for Health should facilitate and monitor an improved communication protocol, and if necessary an improved communication pathway, between medical practitioners and specialist palliative care services.

Recommendation 5 **Page 34**
The Minister for Health should develop and roll out a community awareness program about specialist palliative care services.

Recommendation 6 **Page 34**
The Minister for Health should consult with palliative care specialists about mechanisms to improve the training and continuous professional education of all health practitioners about specialist palliative care services.

Finding 14 **Page 36**
A critical distinction between assisted suicide and the palliative care choices available to Western Australians at end of life is that the current choices available to patients are all reversible.

Finding 15 **Page 39**
Calls for the legalisation of assisted suicide are based on social theories of independence and individualism and values of autonomy, self-determination and choice.

Finding 16 **Page 39**
There is a distinction between personal autonomy and absolute personal autonomy.

Finding 17 **Page 54**
The stakes are high when an individual is given responsibility to distinguish between euthanasia requests that are a mis-expression of an underlying unresolved need, and those that reflect a personal philosophy of choice, despite optimal care.

Finding 18 **Page 54**
An assisted suicide regime with an optional referral for psychiatric capacity assessment does not safeguard against the assisted suicide of patients whose capacity is impaired by depression or other mental health considerations, in part because the ability to assess capacity is variable across medical practitioners.

Finding 19 **Page 55**
It is inherently complex to determine the influences on drivers to seek end of life in an individual with mental illness.

Finding 20	Page 55
A single psychiatric visit to assess capacity is inadequate to determine whether a psychiatric disorder is impairing the judgment of a patient seeking assisted suicide.	
Finding 21	Page 55
Diagnosing demoralisation is as important as diagnosing depression and other conditions when seeking to alleviate and manage psychological suffering.	
Finding 22	Page 55
Access to consultation-liaison psychiatry in Western Australia is poor.	
Recommendation 7	Page 55
The Minister for Health should develop a plan to increase the number of consultation-liaison psychiatrists in Western Australia.	
Finding 23	Page 55
The introduction of a legalised assisted suicide regime in Western Australia would present a grave risk to patients, especially those in an advanced stage of their illness whose wish for hastened death has not been assessed and addressed by a specialised consultation-liaison psychiatrist.	
Finding 24	Page 58
Mandatory psychiatric assessment cannot eliminate error in capacity assessments.	
Finding 25	Page 58
No assisted suicide regime, even with mandatory psychiatric assessment, can safeguard against the assisted suicide of a person suffering from a treatable mental illness.	
Finding 26	Page 61
A valid consent to medical treatment is dependent on the:	
a) capacity of the patient;	
b) patient’s knowledge of the treatment options; and	
c) the voluntariness of the decision.	
Finding 27	Page 65
Countertransference and/or undue influence from a medical practitioner would be two dangerous risks in any assisted suicide regime.	
Finding 28	Page 73
Elder abuse is a real and burgeoning problem in Western Australia.	

Finding 29	Page 73
The capacity of medical practitioners to identify elder abuse in their patients is incredibly variable in Western Australia.	
Finding 30	Page 73
Redress can be difficult in some elder abuse cases when the best witness lacks capacity to give evidence.	
Finding 31	Page 73
Redress in any assisted suicide case is an impossibility.	
Finding 32	Page 73
The presence of undue influence can be difficult to identify and is easily missed.	
Finding 33	Page 73
The introduction of a legalised assisted suicide regime in Western Australia would be a recipe for elder abuse.	
Recommendation 8	Page 73
The Minister for Seniors and Ageing should develop and roll out a comprehensive plan to tackle elder abuse in Western Australia.	
Finding 34	Page 82
Assisted suicide laws are, at their core, about disability.	
Finding 35	Page 82
Assisted suicide laws enshrine a negative message about living with a disability.	
Finding 36	Page 82
There can be no protection or safeguard in any law that begins with the implicit proposition that it is better for some people to be dead than disabled.	
Finding 37	Page 82
People with disabilities experience discrimination and inequity of access to health care in Western Australia.	
Recommendation 9	Page 82
The Minister for Disability Services should develop a plan, in consultation with people with disabilities, carers, the Minister for Health and health practitioners, to deliver equitable access to health care in Western Australia.	

Finding 38**Page 83**

An assisted suicide regime threatens to create a two-tiered system where individuals without a disability who express that they wish to end their life are referred to suicide prevention services, while individuals with disabilities who express that they wish to end their life are referred for lethal prescriptions.

Finding 39**Page 97**

An assisted suicide regime in Western Australia would send a message that suicide is a legitimate solution in certain circumstances.

Finding 40**Page 98**

Some proponents of assisted suicide endeavour to resolve the dilemma of inconsistency on suicide prevention by banishing the word 'suicide' from the debate in favour of the phrase 'assisted dying.'

Finding 41**Page 98**

The highly publicised case of Dr David Goodall involved circumstances of overt ageism, troubling signs of suicide celebration and a seeming absence of any suicide prevention measures at work.

Finding 42**Page 98**

The suicide rates in people aged 80 and above is a particular concern in Western Australia.

Finding 43**Page 98**

The reason for older age suicide is complex and usually multifactorial, and should not be confused with the misconception that such suicides are driven by suffering associated with chronic, debilitating or terminal illness.

Recommendation 10**Page 98**

The Minister for Mental Health, in consultation with the Minister for Seniors and Ageing, should expand suicide prevention programs to further target older Western Australians.

Recommendation 11**Page 98**

The Minister for Mental Health should direct the Mental Health Commission to conduct an urgent review, outside and separate to any other general review processes underway, into the effectiveness of Western Australia's current suicide prevention strategies and programs in light of the Dr David Goodall case.

Finding 44**Page 98**

Coronial data identified the suicide of 199 Western Australians with a terminal or debilitating condition between 2012 and 2017. Examination of the data reveals that 42 may be capable of being classified as suffering from a terminal condition and 157 with a debilitating one. Of the 42 cases, 27 can be identified as being in the advanced or terminal stage of illness. Of the 157 cases, 99 evidenced some level of mental ill-health.

Finding 45**Page 98**

A close and proper examination of the coronial data of suicides between 2012 and 2017 does not support the assertion that individuals suicide because palliative care is not an adequate treatment option, but rather confirms the multifactorial nature of suicide.

Finding 46**Page 108**

Governing medical bodies both inside and outside Western Australia discourage medical practitioners from participating in assisted suicide, even if the local law allows it or decriminalises it.

Finding 47**Page 108**

The licencing of medical practitioners to assist in the suicide of their patients alters the role of the medical profession.

Finding 48**Page 108**

There are multiple conflicts of interest for a medical practitioner assisting in the suicide of their patient.

Finding 49**Page 109**

An assisted suicide regime would improperly absolve a medical practitioner of responsibility for giving a lethal injection to their patient or for giving their patients a prescription to poison themselves.

Finding 50**Page 115**

A safeguard in an assisted suicide regime that involves a medical practitioner is only as safe as the practitioner is competent.

Finding 51**Page 115**

A safeguard in an assisted suicide regime that involves a medical practitioner is unable to protect against unconscious incompetence.

Finding 52**Page 116**

A safeguard in an assisted suicide regime that involves a medical practitioner is unable to protect against mistake, error or negligence.

- Finding 53** **Page 116**
Legalisation of assisted suicide will attract participation by medical practitioners who are also advocates of the practice.
- Finding 54** **Page 116**
Even if the risk of doctor bias toward assisted suicide is the same as doctor bias in general, the consequences are not comparable.
- Finding 55** **Page 116**
Doctor shopping is a clear danger of an assisted suicide regime, with no solution apparent.
- Finding 56** **Page 126**
There is a large body of evidence of medical error in prognosis.
- Finding 57** **Page 126**
Any safeguard in an assisted suicide regime is rendered useless in the event of medical error in prognosis.
- Finding 58** **Page 126**
There is a large body of evidence of medical error in diagnosis.
- Finding 59** **Page 126**
Any safeguard in an assisted suicide regime is rendered useless in the event of medical error in diagnosis.
- Finding 60** **Page 128**
Although a patient, or their substitute decision maker, is entitled to refuse lawful treatment, there is no entitlement at law by a patient to demand treatment.
- Finding 61** **Page 128**
The proposition that a patient has a right to received assistance to suicide is wrong both at law and in medical ethics.
- Finding 62** **Page 132**
The emotional and psychological effects on medical practitioners participating in assisted suicide are substantial and consequential.
- Finding 63** **Page 132**
The desensitisation of medical practitioners by participation in assisted suicide exacerbate the risk that already exists due to doctor bias.

Finding 64**Page 132**

The rate of psychological distress and attempted suicide by medical practitioners is high.

Recommendation 12**Page 132**

The Minister for Mental Health should direct the Mental Health Commission to develop, in consultation with medical practitioners and the Department of Health, a comprehensive mental health strategy for prevention, early intervention and crisis intervention for the whole of the medical profession.

Finding 65**Page 140**

Evidence of complication rates of physician assisted suicides in Oregon until 2010 are troubling. Complication rates after 2010 artificially declined as from this time reports of complications were only recorded if a physician was present at the time of administration.

Finding 66**Page 140**

Evidence of complication rates in Washington are equally troubling with multiple instances of regurgitation, one-third of patients taking in excess of one and a half hours to die, at least one patient suffering a seizure and another taking 30 hours to die.

Finding 67**Page 141**

Decades of experience in administering capital punishment, euthanasia and assisted suicide indicate complications are inevitable and this alone ought to militate against legalisation in Western Australia.

Finding 68**Page 147**

The onus is on those advocating for a change in the law to establish that such a profound change will be safe for the whole community. Anything less results in nothing more than the trading of lives.

Finding 69**Page 147**

The best possible outcome in an assisted suicide regime is that a person who was dying, dies sooner than they would have. The worst possible outcome in an assisted suicide regime is a wrongful death.

Finding 70**Page 162**

When assisted suicide was legal in the Northern Territory one patient, diagnosed with mycosis fungoides and receiving treatment for depression, was euthanised on the certification of an orthopaedic surgeon with no expertise in the condition, notwithstanding that a dermatologist and a local oncologist had assessed that the patient was not terminally ill.

Finding 71**Page 163**

When assisted suicide was legal in the Northern Territory one patient was euthanised even though he was jaundiced and suffering from a bowel obstruction and not advised of the palliative care and medical treatment available. The psychiatric certification in that case consisted of a 20-minute consultation paid for by Dr Philip Nitschke on the day the assisted suicide was scheduled.

Finding 72**Page 163**

Doctor shopping took place when assisted suicide was legal in the Northern Territory.

Finding 73**Page 163**

When assisted suicide was legal in the Northern Territory one patient, who had received counselling and anti-depressant medication for several years, was euthanised after a psychiatrist from another State certified that no treatable clinical depression was present, notwithstanding that neither the patient's adult sons nor the members of the community palliative care team who were caring for him were told he was being assessed for assisted suicide.

Finding 74**Page 163**

The clinical experience observed during the period when assisted suicide was legal in the Northern Territory demonstrates the inadequacies of safeguards and this experience alone ought to militate against legalisation in Western Australia.

Recommendation 13**Page 163**

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Northern Territory experience.

Finding 75**Page 173**

In 1973, Dutch courts interpreted a defence of necessity to permit a doctor to avoid liability for euthanasia and assisted suicide by pointing to his or her duty to reduce suffering or to respect the autonomy of the patient.

Finding 76**Page 173**

After 1973, Dutch courts elaborated on their interpretation of a doctor's defence of necessity, incrementally increasing the scope of practice of euthanasia in the Netherlands, including for psychiatric illness, albeit restricted to adults only.

Finding 77**Page 173**

In 2001 the Netherlands passed statutory law to fit the existing practice of euthanasia but extended it to allow for children as young as 12 to be euthanised subject to parental consent (even in the presence of disagreement between parents).

- Finding 78** **Page 173**
In 2005, the Netherlands endorsed the Groningen Protocol to further extend the practice of euthanasia to younger children, including newborns.
- Finding 79** **Page 173**
Consistent with the Northern Territory experience, assisted suicide in the Netherlands takes place notwithstanding disagreement amongst physicians about patient eligibility.
- Finding 80** **Page 173**
Doctor shopping in the Netherlands has now become commercialised by the emergence of at least one private organisation who will provide assisted suicide to patients whose own physician has declined.
- Finding 81** **Page 173**
The latest frontier in the Netherlands is a debate on whether assisted suicide should be extended to those who are ‘tired of life.’
- Finding 82** **Page 173**
In the Netherlands in 2011, the Regional Euthanasia Review Committee found that the attending physician failed to accurately diagnose the patient’s back pain.
- Finding 83** **Page 173**
In the Netherlands in 2012, the Regional Euthanasia Review Committee found that two cases of patients with dementia were not handled with due care.
- Finding 84** **Page 174**
In the Netherlands in 2013, an assisted suicide took place of a patient who had a broken thigh following an attempted suicide.
- Finding 85** **Page 174**
In the Netherlands in 2014, the assisted suicide of a woman over 80 years of age with chronic depression took place on the certification of a physician who was not a psychiatrist, who did not consult psychiatrists and was unaware of the Dutch Psychiatric Association Guidelines.
- Finding 86** **Page 174**
In the Netherlands in 2015, the Regional Euthanasia Review Committee found a lack of due care on a euthanasia carried out on a woman with a history of stomach pains from an undiagnosed cause.

Finding 87**Page 174**

In the Netherlands in March 2018, criminal investigations were confirmed as having been launched into four cases of euthanasia in 2017.

Finding 88**Page 174**

The defence of necessity also exists in Western Australian common law. It has, however, been expressly excluded as a defence to both homicide and euthanasia.

Finding 89**Page 174**

The experience observed of assisted suicide in the Netherlands demonstrates an incremental extension in the practice of assisted suicide, the commercialisation of doctor shopping, and the reality that no redress is available when safeguards inevitably fail.

Recommendation 14**Page 174**

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Netherlands experience.

Finding 90**Page 180**

Similar to the Netherlands, Belgium allows assisted suicide for patients diagnosed with a mental illness.

Finding 91**Page 180**

The abuse of practice in Belgium, including approval on the grounds of suicidal ideation, has led to at least 252 Belgian clinicians calling for a review of the law on assisted suicide.

Finding 92**Page 181**

In Belgium in 2012, a 44-year-old woman was euthanised by her psychiatrist on the grounds of unbearable psychological suffering notwithstanding her history of sexual abuse by a psychiatrist under the guise of therapy.

Finding 93**Page 181**

In Belgium in 2013, an adult male who had undergone gender reassignment surgery was euthanised on the grounds of unhappiness, notwithstanding that the patient's family had rejected him from birth due to his female biology.

Finding 94**Page 181**

Belgian physicians the subject of a peer-reviewed study in 2010 confirmed the use of life-ending drugs without an explicit request from the patient, including because they considered discussion would have been harmful or because they considered the decision was in the patient's best interest.

Finding 95**Page 181**

The experience observed of assisted suicide in Belgium demonstrates an extension in the law and practice of assisted suicide, the inadequacies of safeguards and the undeniable reality that no redress is available to patients after the event.

Recommendation 15**Page 181**

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Belgian experience.

Finding 96**Page 188**

Assisted suicide in Switzerland is based on a penal code that allows, by omission, for a person to assist another to suicide.

Finding 97**Page 188**

At least four assisted suicides in Switzerland have occurred while practitioners experimented with the use of helium, which results in agitated muscles, eyes opening and closing, and arms and legs twitching without coordination.

Finding 98**Page 188**

In Switzerland in April 2013, a retired Italian magistrate, aged 62, was assisted to suicide on the basis of a terminal illness diagnosed by Italian and Swiss doctors only for an autopsy to find no terminal illness.

Finding 99**Page 188**

The experience observed of assisted suicide in Switzerland underscores the inherent difficulty in testing the integrity of safeguards after the event whilst re-confirming the impossibility for redress by the victim after the event.

Recommendation 16**Page 188**

The Government and the Parliament of Western Australia should reject the advice of Dr Nitschke and rule out introducing an assisted suicide regime based on the Swiss model.

Finding 100**Page 195**

In 2016 the Canadian Parliament enacted an assisted suicide law for a person facing a reasonably foreseeable natural death, only to have the Supreme Court of Ontario interpret the provision so as to extend its application to a person not terminally ill but who has an irreversible deteriorating chronic illness.

Finding 101**Page 196**

In late 2016 the Canadian Government commissioned reviews to explore a further extension of assisted suicide laws to minors, to those making an advance request and to those where mental illness is the sole underlying condition.

Finding 102**Page 196**

In February 2018 a Canadian Court has ruled that physicians with a conscientious objection to assisted suicide are nevertheless obliged to refer their patient to a practitioner who will execute the assisted suicide.

Finding 103**Page 196**

In the first nine months following the passage of an assisted suicide law in Quebec it was found the law had been breached in 21 cases. In the second year of operation, breaches occurred in 31 cases.

Finding 104**Page 196**

In the short experience of the Canadian law on assisted suicide there has already been at least one case of a doctor assisting a suicide by lethal injection notwithstanding that the patient did not suffer a serious incurable illness.

Recommendation 17**Page 196**

The Government and the Parliament of Western Australia should reject the advice of Dying with Dignity WA (formerly known as the Western Australian Voluntary Euthanasia Society) and rule out introducing an assisted suicide regime based on the Canadian model.

Finding 105**Page 205**

The law on assisted suicide in Oregon has been in force for 20 years and requires a prognosis of less than six months to live.

Finding 106**Page 205**

The data from the Oregon Public Health Division between 1998 and 2015 indicates that the longest recorded duration between initial request for assisted suicide and ingestion of the prescribed lethal drug was 1009 days.

Finding 107**Page 205**

The data from the Oregon Public Health Division in 2015 indicates that the longest recorded duration between initial request for assisted suicide and ingestion of the prescribed lethal drug was 517 days.

Finding 108**Page 205**

The data from the Oregon Public Health Division between 1998 and 2015 indicates that in 4 of the 17 years there was at least one case where the duration between initial request for assisted suicide and ingestion of the prescribed lethal drug was more than two years.

Finding 109**Page 205**

The experience in Oregon demonstrates the inadequacies of safeguards due to consistent medical error in prognosis.

Finding 110**Page 205**

In Oregon a 76-year-old cancer patient was assisted to suicide by his cancer specialist notwithstanding the presence of depression and the non-concurrence of the original doctor who referred the patient to the specialist for treatment.

Finding 111**Page 205**

In Oregon an octogenarian cancer patient was assisted to suicide notwithstanding that two doctors, including her own physician, were concerned about the presence of depression and refused to prescribe the lethal drug requested.

Finding 112**Page 205**

The experience in Oregon demonstrates the ease with which the prolific practice of doctor shopping pierces the veil of even well intentioned safeguards.

Finding 113**Page 206**

The data from the Oregon Public Health Division for 2016 indicates that in 79.4 per cent of assisted suicides no physician or healthcare provider was known to be present at the time of ingestion of the prescribed lethal drug.

Finding 114**Page 206**

The rate of suicide among Oregonians has been increasing even when assisted suicides are excluded from the data set.

Finding 115**Page 206**

The inherent difficulty in prosecuting after the event is underscored by at least five assisted suicides in Oregon that occurred by illegal overdoses administered by a nurse.

Finding 116**Page 206**

The experience observed in Oregon should be reason alone to militate against legalisation in Western Australia.

Recommendation 18 **Page 206**

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Oregonian experience.

Finding 117 **Page 215**

None of the jurisdictions where assisted suicide has been legalised have yet developed a system that gathers reliable data on all requests and instead rely on the self-reporting of doctors notwithstanding the inherent conflict of interest present.

Finding 118 **Page 215**

Western Australia's Director of Public Prosecutions has no capacity to compel evidence from the sole surviving witness in an assisted suicide.

Finding 119 **Page 216**

There is no capacity for a victim of a wrongful assisted suicide to seek redress.

Finding 120 **Page 216**

Capital punishment was abolished in Western Australia, notwithstanding the extensive safeguards in the State's criminal justice system, due to the risk that an innocent person may be executed.

Finding 121 **Page 216**

Authentic oversight of an assisted suicide regime is made difficult by a reliance on self-reporting and is made impossible by the unavailability of the best witness.

Recommendation 19 **Page 216**

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime due to the known unresolved issues with reporting, investigation, prosecution and redress.

Finding 122 **Page 245**

A 2013 review by the High Court of Ireland of the available evidence from jurisdictions with assisted suicide produced the conclusions that the examples of abuse are deeply disturbing, that certain groups are vulnerable to abuse, and that the number of suicides remain strikingly high.

Finding 123 **Page 245**

Unlike other jurisdictions, there is yet to be any lived experience with the Victorian model of assisted suicide.

Finding 124**Page 245**

The Victorian model of assisted suicide has been heavily criticised by proponents of assisted suicide, with calls to extend the scope already made before the law has even come into force.

Finding 125**Page 245**

It is a political inevitability that once lawmakers introduce a right for one group of people that others will soon demand the extension of that right to them on the ground of equality.

Finding 126**Page 245**

Any restriction on eligibility within an assisted suicide regime is both arbitrary and discriminatory.

Finding 127**Page 245**

It is at best premature to base any assisted suicide regime on the untested Victorian model.

Recommendation 20**Page 245**

The Government and the Parliament of Western Australia should rule out introducing an assisted suicide regime based on the untested Victorian model.

Chapter 1

Current End of Life Choices in Western Australia

I have serious concerns about a community where we make arbitrary decisions about whose life is valuable enough to continue and whose should be ended under the law. A society should aspire to look after people who are struggling and to make sure that their lives are worth living. We should aspire to even better end-of-life care. We should aspire to better palliative care.

Dr Michael Gannon MBBS MRCPI FRANZCOG,
President of the Australian Medical Association (as he was at that time), May 2018

Palliative Care

What is Palliative Care?

- 1.1. Palliative care as a discipline is poorly understood by the community as well as by health care providers. Palliative Care WA identify that there is little information publicly available about palliative care, that health carers are not actively referring and display a reticence to discuss the issue of dying, and that a misconception exists that palliative care is just for the final days or weeks of life, or is only available for people with cancer.³
- 1.2. To palliate means to 'make (a disease or its symptoms) less severe without removing the cause.'⁴ Palliative care is an approach that improves the quality of life of individuals, including their family/carer, facing problems associated with a life-threatening illness or condition, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.⁵ It is well understood in palliative care practice that 'suffering is an affliction of the person, not the body.'⁶
- 1.3. Palliative care serves to maximise the quality of life of the individual and addresses their physical, social, financial, emotional and spiritual distress. Such distress not only

3 Palliative Care WA, JSCEOLC Response to Questions on Notice, 19 December 2017 at 3.

4 WA Cancer and Palliative Care Network, Department of Health (2018) *WA End-of-Life and Palliative Care Strategy 2018-2028* at 3.

5 World Health Organisation (2016) 'WHO Definition of Palliative Care'
<<http://www.who.int/cancer/palliative/definition/en/>>

6 Cassel E (1999) 'Diagnosing suffering: a perspective' *Ann Intern Med* 131(7) at 531-4.

Chapter 1

influences the experience of having a life-limiting illness, but also influences treatment outcomes.⁷

- 1.4. Palliative care affirms life and regards dying as a normal process, and intends neither to hasten nor to postpone death.⁸
- 1.5. Palliative care is broadly divided into specialist palliative care and non-specialist palliative care. Specialist palliative care services are services provided by health professional teams who have recognised qualifications or training in palliative care and who provide direct care to patients with complex palliative care needs or provide consultation services to support, advise and educate other healthcare teams who are providing end-of-life care. Non-specialist palliative care may be provided by a person's primary care team—for example, by their general practitioner (GP) or other doctor, such as a geriatrician or oncologist, and other healthcare professionals such as nurses, occupational therapists and social workers.⁹
- 1.6. Palliative care is more than relief of pain and includes non-physical care including the attendance of spiritual, psychological and relational needs. Palliative care practitioners seek to determine which aspects of an individual's experience cause distress or suffering and they address each of these in turn, including fear, a sense of hopelessness, loneliness and isolation.¹⁰ This focus on the holistic needs of the patient also recognises that palliative care must be delivered not only to the patient, but also to their family or carer.¹¹
- 1.7. Good palliative care helps patients and their families avoid both overtreatment and neglect of treatment. It enhances patient autonomy and decision-making capacity by improving symptom control and empowering patients to participate in their care. It affirms the patient's right to choose their therapy, decline futile treatment, choose their place of dying, receive the best possible relief of symptoms and to refuse to prolong the dying process.¹²

7 Kamal, LeBlanc and Meier (2016) 'Better palliative care for all: Improving the lived experience with cancer' *The Journal of the American Medical Association* 316(1) at 29-30.

<<https://www.ncbi.nlm.nih.gov/pubmed/27244674>> cited in WA Cancer and Palliative Care Network, Department of Health (2018) *WA End-of-Life and PC Strategy 2018-2028* at 3.

8 Palliative Care Nurses Australia, Jane Phillips, President, JSCEOLC Response to Questions on Notice, 29 January 2018 at 7.

9 Ms Glogowski, Executive Officer, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 1-2.

10 Ms Re, Chief Executive Officer, IdentityWA, JSCEOLC Response to Questions on Notice, 10 April 2018 at 2.

11 Ms Glogowski, Executive Officer, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 1-2.

12 Prof Bridge (2017) 'Palliative care, euthanasia and physician assisted suicide' *Med J of Aus InSight*, 20 March 2017, quoted in Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 9.

- 1.8. Patients who access palliative care are consistently shown to have fewer hospitalisations, shorter stays in hospital, reduced use of intensive care facilities and fewer admissions to emergency departments, amounting to significant cost savings in the health system. There is also increasing evidence that appropriate end-of-life and palliative care reduces unnecessary testing and futile treatments.¹³
- 1.9. Palliative care respects informed patient choice including the refusal of any or all medical treatments. This is achieved by emphasising communication with the patient and providing the best quality holistic care.¹⁴ Consent is obtained before making treatment changes, and treatment recommendations are generally made by a multidisciplinary team, rather than by an individual doctor. It is this focus on constant communication and multidisciplinary decision making that is absent from many other parts of the health care system. The focus on communication, and respect for the patient's values and wishes, assists in maintaining trust between health professionals and patients and the relationship between specialist palliative care professionals and patients is, from experience, far less likely to be compromised than in the health care system generally.¹⁵
- 1.10. Palliative care is a relatively new concept in medical care, and in only a few decades significant improvements in palliative care have been made, and new gains continue to be made, such that Associate Professor Ian Haines, MBBS, medical oncologist and palliative medicine specialist, writes:

*As an oncologist with 35 years' full-time experience, I have seen palliative care reach the point where the terminally ill can die with equal or more dignity than euthanasia will provide. It is now very effective and increasingly available for two of the three possible ways of dying, outside of sudden unexpected death, which are advanced cancer and chronic relapsing and remitting organ-specific disease such as heart or lung failure. Palliative care is also available for people with chronic progressive cognitive diseases such as dementia. This is the fourth way of dying and perhaps the most feared of all. Like Andrew Denton and others who have observed unbearable suffering in loved ones and the terrible failures of modern medicine in the past, I had once believed that euthanasia was the only humane solution. I no longer believe that.*¹⁶

13 Mrs Greenwood, Chief Executive, Catholic Health Australia, JSCEOLC Transcript, 28 February 2018, Session 1 at 2, citing Palliative Care Australia data.

14 Palliative Care WA, JSCEOLC Response to Questions on Notice, 19 December 2017 at 5.

15 Ibid.

16 Ian Haines, 'I believed that euthanasia was the only humane solution. I no longer believe that' *The Age*, 20 Nov 2016, quoted by Mr Richard Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 3.

Chapter 1

- 1.11. The WA Department of Health and the Australian Medical Association (WA) assert that palliative care is a human right and is fundamental to improving the quality of life, wellbeing and dignity of all individuals.¹⁷

Palliative care provision in Western Australia

- 1.12. Palliative care in Western Australia is provided in a number of settings. Specialist palliative care teams operate in some hospitals, providing consultancy and direct care for patients in the hospital setting. There are also designated palliative care units in metropolitan Perth, including Bethesda Hospital, St John of God Murdoch hospice, and the Kalamunda Hospital Anderton Ward. Community services, including Silver Chain, and the Metropolitan Palliative Care Consultancy Service also operate. The Silver Chain program is a successful program unique to Western Australia, with evidence that 80 to 85 per cent of people in their care who wish to die at home are able to achieve that goal. These statistics compare very favourably with national figures, where the wish to die at home is far less often achieved.¹⁸
- 1.13. Rural service provision is supported by telehealth and telephone advisory services.¹⁹ Mr Brett Hayes, of the WA Country Health Service and 2018 Nurse of the Year, established a pilot program to put telehealth in the home of palliative care patients to provide access to specialist nursing services and access to GP and specialist services when needed. This has been a very successful model of care in the Wheatbelt and is being introduced in the South West and Great Southern regions.²⁰
- 1.14. Education initiatives for metropolitan and rural health workers also exist, including the Palliative and Supportive Care Education service (PaSCE), based in the Cancer Council of WA (but providing palliative care education across all diagnoses), the Program of Experience in the Palliative Approach (PEPA) and the Talking about End of Life training program. The Goals of Patient Care program aims to improve decision-making and support shared decision-making for patients in a hospital setting and help to determine the goals of each individual patient.²¹ The Metropolitan Palliative Care Consultancy Service (MPaCCS) provides a specialist palliative care approach to residents of aged-care

17 See WA Cancer and Palliative Care Network, Department of Health (2018) *WA End-of-Life and PC Strategy 2018-2028*, at iii, referencing World Health Organisation (2014) 'Strengthening of palliative care as a component of comprehensive care throughout the course of life,' Geneva, Switzerland at 5; and Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 14.

18 Prof Evans, Chief Advisor, Public Policy, Silver Chain Group, JSCEOLC Transcript, 15 December 2017, Session 3 at 1.

19 Ms Bolleter, Program Manager, Palliative Care, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 2-3.

20 Mrs Baxter, Executive Director, Nursing and Midwifery, WA Country Health Service, Department of Health, JSCEOLC Transcript, 18 May 2018, Session 2 at 13.

21 Ms Bolleter, Program Manager, Palliative Care, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 3-4.

facilities to build the capacity of those facilities to manage the needs of those in their care to reduce hospitalisations.²²

- 1.15. However, access to good quality palliative care across Western Australia is currently highly variable, with data indicating that 60 per cent of WA residents who would benefit from access to palliative care are unable to do so.²³ Additionally, current palliative care services have insufficient capacity to meet growing demand.²⁴ After a declining death rate for several decades (as a result of public health initiatives and medical advances), the total number of deaths in Australia is now expected to grow at increasing rates year-on-year as a result of growing and ageing populations and the impact of chronic disease.²⁵ This increasing demand for specialist palliative care and end-of-life support in Western Australia presents an urgent problem for access to good quality palliative care in this state.
- 1.16. The Committee received much evidence that Western Australians living in rural and remote areas, Aboriginal and Torres Strait Islanders and persons from culturally and linguistically diverse (CALD) backgrounds experience inequitable provision of specialist palliative care services.²⁶
- 1.17. There is also evidence that patients with non-malignant diseases are under-represented in palliative care in Western Australia. In a 2006 study, more people with cancer (64 per cent) had received palliative care in comparison with other illnesses such as heart disease, dementia and organ failure (4-10 per cent). These non-malignant diseases are still under-represented in palliative care ten years on from this study.²⁷

22 Mr Hays, Acting Manager, Purchasing and Contracting, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 4.

23 Palliative Care WA, JSCEOLC Response to Questions on Notice, 19 December 2017 at 3

24 Ibid.

25 Australian Bureau of Statistics (2013) 3222.0 *Population Projections, Australia, 2012 (Base) to 2101*, quoted in Yasmin Naglazas, Bethesda Health Care, Further information to the JSCEOLC following visit to Bethesda Health Care facility, 18 April 2018, at 1.

26 For example, see AMA(WA), JSCEOLC Submission 685 at 3; WA Cancer and Palliative Care Network, Department of Health (2018) *WA End-of-Life and Palliative Care Strategy 2018-2028*, at 7, referencing Department of Health (2016) *Palliative Care Models of Care Review 2015-16: Outcomes Report*; Mrs Buchanan, Committee Member, Palliative Care Nurses Australia, JSCEOLC Transcript, 14 December 2017, Session 2 at 3-4; Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 14 December 2017, Session 5 at 9; Mrs Clarke, Outreach Services Project Officer, Aboriginal Health Council of WA, JSCEOLC Transcript, 2 March 2018, Session 4 at 4.

27 Aoun et al (2017) 'Bereavement support for family caregivers: The gap between guidelines and practice in palliative care,' *PLoS ONE* 12(10): e0184750 <<https://doi.org/10.1371/journal.pone.0184750>> at 9 – citing McNamara, Rosenwax and Holman (2006) 'A method for defining and estimating the palliative care population' *J Pain Symptom Manage* 32(1) at 5-12; see also Palliative Care WA, JSCEOLC Responses to Questions on Notice, 19 December 2017 at 3.

Chapter 1

Data on refractory symptoms

- 1.18. Proponents of legalised assisted suicide suggest that palliative care cannot alleviate the pain of everyone approaching their end of life, and therefore that voluntary euthanasia or physician-assisted suicide should be introduced to address that shortfall. A recurrent question raised in the Committee hearings was whether palliative care could be considered 100 per cent effective for all patients, and if not, could a figure be placed on the number of patients for whom symptoms cannot be managed, referred to as refractory symptoms.
- 1.19. As to whether palliative care could be considered 100 per cent effective for all patients, the common response was that no medical treatment is ever 100 per cent effective for all patients, including palliative care.²⁸
- 1.20. Placing a figure on the number of people experiencing refractory symptoms at the end of life was an issue contested slightly more than the issue of whether or not palliative care is 100 per cent effective for all patients at end of life. Proponents of assisted suicide placed the figure at 5 per cent,²⁹ or between 5 and 10 per cent,³⁰ and even a guess as high as 30 per cent.³¹
- 1.21. A more conservative figure of 2 per cent was consistently given by palliative care specialists and those involved in palliative care service delivery.³²
- 1.22. Conflicting interpretation of data on the incidence of refractory symptoms from the Palliative Care Outcomes Collaboration (PCOC) contributed to the disparity between the 2 per cent figure given by palliative care specialists, and the 5-10 per cent suggested by assisted suicide proponents.

28 See Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, JSCEOLC Transcript, 13 December 2017, Session 1 at 16; Mrs Buchanan, Committee Member, Palliative Care Nurses Australia, JSCEOLC Transcript, 14 December 2017, Session 2 at 10; Dr Campbell, President, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 8; Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Transcript, 27 February 2018, Session 5 at 3; Mr Teale, Chief Executive, Council on the Ageing WA (Inc), JSCEOLC Transcript, 2 March 2018, Session 5 at 2; and Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 28 February 2018, Session 2 at 4.

29 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 7.

30 Dr Lugg, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 26 February 2018, Session 4 at 3.

31 Dr Hennessy, Head of Anaesthesia Department, Sir Charles Gairdner Hospital, JSCEOLC Transcript, 30 April 2018, Session 1 at 3.

32 See Dr Campbell, President, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 8; Dr McNulty, Palliative Care Medical Specialist, JSCEOLC Transcript, 27 February 2017, Session 5 at 3 and Prof Evans, Chief Advisor, Public Policy, Silver Chain Group, JSCEOLC Transcript, 15 December 2017, Session 3 at 11. Dr Khorshid, while not placing a percentage figure, also suggested to the Committee that 'The number of people for whom palliative care is inadequate is very, very small. We acknowledge that there are some, but it is very small': Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, Session 1, 18 May 2018 at 14.

- 1.23. PCOC is a national program that uses standard clinical assessment tools across all states in Australia to measure and benchmark patient outcomes in palliative care. In interpreting this data collected by PCOC, there are some important things that must be considered.
- 1.24. Firstly, data submission to PCOC is not mandatory and only 14 specialist services, out of 22 specialist services in Western Australia, submit data to PCOC.³³ The Health Department warned that while the PCOC data is very valuable and important, it should not be assumed that it is representative of all services in Western Australia.³⁴ Further, the Symptom Distress Scores used to collect the data were designed for patient use, but also allowed for proxy ratings which is not a psychometrically valid technique for data collection and results obtained will differ.³⁵
- 1.25. Secondly, assessment of pain symptoms is also very dependent upon the individual patient and their specific goals of care. The data does not take into account whether some patients chose not to take medication for pain relief. For example, there may be certain side effects that the patient may wish to avoid, or the patient may have religious convictions or other reasons for refusing pain relief medication.³⁶ Symptom assessment scales also do not consider the complex and highly individual nature of people's experiences of pain. For example, if a patient has complex psychosocial or existential distress, this can escalate a patient's physical pain symptoms.³⁷ If a patient's psychological and spiritual suffering has not been addressed, that makes the assessment of that patient's physical pain symptoms far more complex and cannot simply be attributed to a failure of palliative care to relieve physical pain.
- 1.26. Thirdly, whether patients are receiving adequate pain management is also dependent on whether there are enough specialist pain physicians and palliative care physicians available to meet patient demand. For example, accounts from patients were given to the Committee on a site visit to Sir Charles Gairdner Hospital that pain management was not being delivered particularly effectively and this was attributed to understaffing.³⁸ Symptoms should not be deemed refractory if the cause of the unrelieved symptoms is

33 Ms Bolleter, Program Manager, Palliative Care, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 4.

34 Ibid at 5.

35 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group and Consultant Physician, Palliative Care Service, Sir Charles Gairdner Hospital, JSCEOLC Additional Answers to Questions on Notice, undated email.

36 Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, JSCEOLC Transcript, 13 December 2017, Session 1 at 19; Dr Campbell, President, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 8 and Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Transcript, 27 February 2018, Session 5 at 3.

37 Dr McNulty, Palliative Care Medical Specialist, Silver Chain, JSCEOLC Transcript, 27 February 2018, Session 5 at 5.

38 Hon Dr Sally Talbot, Committee Member, and Dr Hennessy, Head of Anaesthesia Department, Sir Charles Gairdner Hospital, JSCEOLC Transcript, 30 April 2018, Session 1 at 10.

Chapter 1

inadequate access to and provision of palliative care or failure to provide best practice therapies.³⁹

- 1.27. To suggest that the figure of 2 per cent is representative of a failure of palliative care to manage physical pain symptoms fails to take these important considerations into account.
- 1.28. Furthermore, PCOC is a voluntary program and is primarily used for two purposes—research and benchmarking, that is, the comparison between one service and another. The validity of PCOC data across specialist palliative care more generally, and whether the data can be considered applicable across all palliative care services in Western Australia is therefore questionable.⁴⁰ If, however, it is accepted that the data is useful for benchmarking, Mr Richard Egan of Defend Human Life! suggests that the service provider with the lowest figures for unmanaged pain symptoms should be used as a ‘gold standard’ to determine best practice.⁴¹ This would be the best use of the data, rather than to extrapolate an average figure for unmanaged pain symptoms across the entire palliative care sector.
- 1.29. It also does not follow that if the physical pain symptoms of some patients cannot be relieved by palliative care therapies that this necessitates the legalisation of assisted dying. Data collected from Oregon, where physician-assisted suicide has been legalised, has shown that physical pain is rarely ever cited as the reason for the request for assisted suicide. The Oregon Health Authority’s *Sixth Annual Report on Oregon’s Death with Dignity Act, 2004*, cites the reasons given by those people who have died under Oregon’s assisted suicide law as being:
- A steady loss of autonomy (91.4 per cent)
 - Less able to engage in activities making life enjoyable (89.7 per cent)
 - Loss of dignity (77 per cent)
 - Loss of control of bodily functions, such as incontinence and vomiting (46.8 per cent)
 - Physical or emotional burden on family, friends, or caregivers (42.2 per cent)
 - Inadequate pain control (26.3 per cent)

39 Radruch et al (2013) ‘The Prague charter: urging governments to relieve suffering and ensure the right to palliative care’ *Palliative Medicine* 27 at 101-102, cited in Australia and New Zealand Specialist Palliative Medicine (ANZSPM) Guidance Document on Palliative Sedation Therapy, provided to the JSCEOLC as Supplementary Information by Dr Allison Parr, Director, Medical Services, St John of God Health Care, Palliative Medicine Consultant, 18 July 2017, at 1.

40 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Transcript, 27 February 2018, Session 5 at 4.

41 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 2.

- 1.30. Earlier annual reports noted that ‘Patients discussing concern about inadequate pain control with their physicians were not necessarily experiencing pain.’⁴² Very similar statistics are also found in the latest 2016 Oregon Health Authority Report.⁴³
- 1.31. The experience in the Northern Territory also evidences similar reasons for patients accessing euthanasia while the *Rights of the Terminally Ill Act 1995* (NT) was in operation there. Kissane noted that ‘fatigue, frailty, depression and other symptoms,’ and not pain, were the prominent concerns of those patients who received euthanasia at that time.⁴⁴
- 1.32. Breitbart et al also found no significant association between desire for hastened death and either the presence or absence of pain or pain intensity. The authors suggest that this finding may reflect the quality of pain management practiced by the study institution, or alternatively, that these results may simply confirm previous research that found little or no relationship between pain and desire for hastened death or interest in assisted suicide.⁴⁵ Other research also supports the conclusion that most patients requesting death do so not based on physical symptoms such as pain but rather based on depression and other forms of psychological distress.⁴⁶ The reasons someone requests assisted dying are complex and multifactorial. Psychological, existential and social motives are more striking features of requests to die than physical symptoms.⁴⁷
- 1.33. Whether assisted suicide should be legalised in Western Australia by trying to determine an exact figure for the number of people who experience refractory symptoms in end of life care is not necessary, since the rejection of euthanasia is not dependent on the perfecting of palliative care. As Dr van Gend has noted, ‘We cannot ease all suffering in dying any more than we can ease all suffering in childbirth, even though we have made

42 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5, at 2-3.

43 See Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 3. Nurses working in hospices in Oregon report that pain and pain control rated tenth in major drivers of desire for voluntary assisted dying (VAD) among hospice patients after desire to control the circumstances of death, the wish to die at home, loss of independence or fear of such loss, and loss of dignity or fear of such loss: Ganzini et al (2002) ‘Experiences of Oregon Nurses and Social Workers with Hospice Patients Who Requested Assistance with Suicide’ *New Engl J of Med* 347 at 582-588, cited by Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 3. See also Blank et al (2017) ‘Characterizing 18 Years of the Death With Dignity Act in Oregon,’ *JAMA Oncol* 3(10) 1403-1406.

44 Kissane, Street and Nitschke (1998) ‘Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia’ *The Lancet* 352 at 1097-102, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 11.

45 Breitbart et al (2000) ‘Depression, Hopelessness and Desire for Hastened Death in Terminally Ill Patients with Cancer,’ *JAMA* 284, 2907-2911 at 2910.

46 Golden and Zoanni (2010) ‘Killing Us Softly: The Dangers of Legalizing Assisted Suicide’ *Disability and Health Journal* 3(1), 16-30, at 23. See also Pearlman et al (2005) ‘Motivations for Physician-assisted Suicide – Patient and Family Voices’ *Journal of General Internal Medicine* 20(3), 234-39 referenced by Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 3.

47 Sprung et al (2018) ‘Physician-Assisted Suicide and Euthanasia: Emerging Issues from a Global Perspective’ *Journal of Palliative Care* sagepub.com/journalsPermissions.nav DOI: 10.1177/0825859718777325 at 3.

Chapter 1

enormous progress... Rejection of euthanasia is not dependent on perfecting palliative care for all patients.⁴⁸

- 1.34. The Professionalism and Human Rights Committee of the American College of Physicians put it another way:

The suffering of dying patients may be great and is caused by somatic symptoms, such as pain and nausea; psychological conditions, such as depression or anxiety; interpersonal suffering due to dependency or unresolved conflict; or existential suffering based in hopelessness, indignity, or the belief that one's life has ended in a biographical sense but has not yet ended biologically. For some patients, a sense of control over the manner and timing of death brings comfort. However, is it reasonable to ask medicine to relieve all human suffering? Just as medicine cannot eliminate death, medicine cannot relieve all human suffering.⁴⁹

- 1.35. As Dr Megan Best articulated the issue:

It is not about a failure of medicine. As I said, we have better palliative care than ever before. In my own career, there has been an exponential improvement in palliative care. So at this time where we can do so much for people who are dying, we have the loudest call for assisted death. I think it is about autonomy—people wanting to be able to control their death.⁵⁰

A comment on the Committee's inquiry into palliative care

- 1.36. The Committee was asked by the Houses to assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care.
- 1.37. The Committee has helpfully acknowledged the importance of access to specialist palliative care, the unhelpfulness of inconsistent data collection, the insufficient number of palliative care workers in Western Australia and the gap in care for those deemed not unwell enough to qualify for an inpatient hospice service. Of particular importance the

48 Dr van Gend, "“Unproductive burdens” still have a right to live,' *The Australian*, 25 March 2011, quoted by Mr Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices, included in JSCEOLC Response to Questions on Notice, 17 April 2018 at 3.

49 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) at 577.

50 Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 2 at 4.

Committee has recognised the need for greater community awareness of palliative care and made recommendations to assess the accessibility issue and improve education to health practitioners and the community.

- 1.38. It is regrettable, however, that the Committee has separated its reporting on palliative care from its reporting on lawful options at end of life. Medical treatment, including palliative care, is indeed a lawful option at end of life.
- 1.39. In addition it is unfortunate that the Committee has not rigorously engaged with the recommendations put to it by Western Australia’s peak body for palliative care.⁵¹
- 1.40. It is most regrettable that the Committee has not tested the veracity of its conclusion that too many Western Australians experience profound suffering as they die, even with access to the best quality palliative care available. There is no doubt that some Western Australians experience profound suffering as they die. This can occur when palliative care is not accessed. However, this can also occur in some instances when less than optimal palliative care is delivered.
- 1.41. These scenarios were plainly articulated to the Committee by Senior Palliative Care Specialist Professor Doug Bridge when he recounted several cases:

A terminal patient—I do not quite like that word, but a man or a woman who is about to die—presented to the Southern Cross Hospital after hours. The patient was seen by emergency telehealth—that is by videoconferencing. The decision was made to admit the patient, but there was no doctor with admitting rights, so the patient was transferred to Merredin 109 kilometres away. Merredin had no admitting doctors so the patient was sent to Northam, 270 km from home. Northam had no beds, so the patient was transferred to Perth. The patient died alone in the ED in Perth 360 kilometres from home. Bad luck; tough; it cannot be helped—really? Can we not do better than that?

...

When I started doing this in 1983, there were no textbooks, no courses, no qualifications, no-one to turn to. Silver Chain said to me, “We’re about to start home care in Claremont. Occasionally, we will have a difficult patient we can’t look after. You’re a nice, kind physician in Fremantle Hospital. Would you take them in and look after them?” I naively said, “Yes, I’ll give it a go.” Shortly afterwards, my intern rang me on Saturday morning, “Doug, I can’t stop this guy’s pain. What

51 Ms Lana Glogowski, Executive Officer, Palliative Care WA, Letter to JSCEOLC, 18 May 2018.

Chapter 1

should I do?" I said, "Give him some morphine." He said, "I have" so I said I would be there in five minutes. I came into the room, saw the ampoule and said, "What's this, David?" It was morphine sulphate, 30 milligrams. That is a big dose. I asked what he had done with it, and he said he had given it intravenously ... He had given him 20 ampoules of 30 milligrams in the last hour and he still wanted pain control. If you did not trust me, you would say this is rubbish; that is enough to kill an elephant. How could he give a man a massive, massive, massive overdose, intravenously? Highly dangerous! I had no idea. I was despairing. Now there is lots of research and knowledge and I would say, "This is easy, David; stop the morphine. He has opioid-induced hyperalgesia syndrome. The morphine backfires in the cell and makes it worse. Stop the morphine and give him methadone and ketamine. He'll be right in a few hours."⁵²

- 1.42. The Committee's hearings and submissions include multiple stories of Western Australians who suffered at end of life. It is important that these stories are heard. It is equally important that those stories are not misconstrued as evidence of the practice of palliative care being incapable of palliating the suffering of patients generally. Evidence of poorly practised palliative care is not evidence as to the efficacy of palliative care when practised properly. Patients with the most difficult cases need access to expertly practised specialist palliative care.

Finding 1

Specialist palliative care is a relatively new discipline within the medical profession.

Finding 2

Palliative care is poorly understood within the Western Australian community.

Finding 3

The provision of quality palliative care affirms a patient's right to choose their therapy, decline futile treatment, choose their place of dying, receive the best possible relief of symptoms and to refuse to prolong the dying process.

52 Prof Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Sciences; WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 4-5 (emphasis added).

Finding 4

Medical treatment, including palliative care is an end of life choice currently available in Western Australia, however:

- a) Patients with non-malignant diseases are under-represented in palliative care in WA; and
- b) access to good quality palliative care across the State is, in any event, currently highly variable.

Finding 5

Data from the Palliative Care Outcomes Collaboration (PCOC) can be useful in comparing one service provider with another but it is not, nor is it intended to be, an academically rigorous tool to assess palliative care generally.

Recommendation 1

The Minister for Health should consult with the Palliative Care Outcomes Collaboration (PCOC) and service providers to determine a data collection methodology that would set the lowest figures for unmanaged pain symptoms as the aspirational standard for every service provider.

Recommendation 2

The Minister for Health should consult with palliative care service providers to ascertain the current deficit in capacity preventing equitable provision of specialist palliative care across Western Australia.

Recommendation 3

The Minister for Health should assess the recommendations made by Western Australia's peak body for palliative care and report to Parliament with a plan to:

- a) utilise co-design workshops;
- b) progress the Compassionate Communities model;
- c) introduce shared care models;
- d) increase the capacity of the Silver Chain Hospice Care Service model of care;
- e) build the capacity of existing outpatient clinics to facilitate Advance Care Planning; and
- f) increase the availability and flexibility of Telehealth.

Refusal of Nutrition and Hydration

- 1.43. Voluntary refusal of food and fluids occurs frequently as a normal part of the natural dying process,⁵³ and as such is often a scenario in which palliative care therapies will be offered, hence the term voluntary palliated starvation. It is legally and ethically possible

53 Mr Cockayne, General Manager, Health Care WA, Silver Chain Group, JSCEOLC Transcript, 15 December 2017, Session 3 at 16.

Chapter 1

to provide palliative care throughout this process since the palliative care is provided with the intent of relieving suffering due to pain or other reasons associated with dehydration and malnutrition.⁵⁴ Providing pain relief to someone who is not swallowing is routinely done in palliative care.⁵⁵

- 1.44. Dr Best gave evidence that the suggestion that patients are starved to death in palliative care units is a misunderstanding of the normal metabolic changes which occur at the end of life. Patients stop feeling hungry and indeed do not gain weight even if force fed, which is not done as it increases the discomfort of the patient (furthermore, forcing the patient to eat and drink would also breach their right to inviolability, which is considered further below).⁵⁶ All patients at the end of life will lose their appetite and lose either the ability to swallow safely or the interest to do so.⁵⁷ Often the refusal of food and fluids is a sign to medical practitioners that a patient is probably going to die fairly soon.⁵⁸
- 1.45. Two Australian legal academics, Professors Lindy Willmott and Ben White, suggest that voluntary palliated starvation is a practice which is occurring more frequently in Australia because of the lack of options that patients have as they approach the end of their lives.⁵⁹ This statement was not supported in evidence given to the Committee from specialists in palliative care.
- 1.46. To voluntarily choose to stop eating and drinking, outside of the end stages of the natural dying process, is a choice that exists in Western Australia.⁶⁰ However, it is a choice that is very rarely made. In the clinical experience of the palliative care specialists who gave evidence to the committee, none had experienced a patient choosing to voluntarily refuse nutrition and hydration to bring about that patient's death.⁶¹ Where patients had

54 Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 24.

55 Dr Koh, Chair, Royal Australian College of General Practitioners, JSCEOLC Transcript, 15 December 2017, Session 1 at 11-12.

56 Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 1 at 2; see also Dr Koh, Chair, Royal Australian College of General Practitioners, JSCEOLC Transcript, 15 December 2017, Session 1 at 11.

57 Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 18 May 2018, Session 2 at 19.

58 Dr Koh, Chair, Royal Australian College of General Practitioners, JSCEOLC Transcript, 15 December 2017, Session 1 at 12.

59 Prof Willmott and Prof White, Directors, Australian Centre for Health Law Research, and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560 at 4.

60 Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 27.

61 The Department of Health recommended that the best people to seek evidence from on this issue were individual health service providers and/or Palliative Care Physicians through the WA Palliative Medicine Specialists Group (Department of Health, JSCEOLC Response to Questions on Notice, undated at 5). See Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 19; Dr McNulty, Palliative Care Medical Specialist, Silver Chain, JSCEOLC Transcript, 27 February

spoken about the option, or had started to refuse nutrition and hydration, they then decided that they did not actually want to go through with it.⁶² Requests were not common, but were considered a good prompt by the palliative care professionals to talk to the person about their wishes and possibly commence the advance care planning process with them.⁶³

- 1.47. Though rare, such requests for voluntary palliated starvation are ethically supported since the right to refuse treatment, or in this case nutrition and hydration, is based on a right to inviolability—a right not to be touched without one’s informed consent. It is not a right to die or a right to be killed. At most, people have a negative content right to be allowed to die, not any right to positive assistance to achieve that outcome.⁶⁴ The important legal principle here is the patient’s right to refuse treatment.⁶⁵ To prevent someone of sound mind from refusing nutrition and hydration would involve the forceful introduction of nutrition and hydration through medical treatment, against the wishes of the individual.
- 1.48. The State Coroner of Western Australia did not consider a death by palliative starvation as a suicide, or a death brought about by an act of self-destruction being an intentional act by a person knowing the probably consequences of their actions. The refusal of hydration and nutrition was not considered by the Coroner as an act of suicide since a person of sound mind can decide not to keep eating and drinking, and was regarded as a decision to allow a natural illness to progress.⁶⁶ Though not expecting to see starvation or dehydration on a death certificate in end of life cases, the Chief Registrar did note that it is quite common to see inanition on the death certificates of those who have died

2018, Session 5 at 7; Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Transcript, 27 February 2018, Session 5 at 8; and Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, JSCEOLC Transcript, 28 February 2018, Session 1 at 12 and 13.

62 See Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 19; Dr McNulty, Palliative Care Medical Specialist, Silver Chain, JSCEOLC Transcript, 27 February 2018, Session 5 at 7; Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, JSCEOLC Transcript, 28 February 2018, Session 1 at 12.

63 Dr Campbell, President, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 10; Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, JSCEOLC Transcript, 28 February 2018, Session 1 at 12 and 13; Ms Brady, Executive Manager, Mission, Catholic Homes WA, JSCEOLC Transcript, 28 February 2018, Session 1 at 12.

64 Boudreau and Somerville (2013) ‘Euthanasia is not medical treatment’ *British Medical Bulletin* 106, 45–66 at 60.

65 Prof Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Sciences; WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 11.

66 Ms Fogliani, State Coroner of Western Australia, JSCEOLC Transcript, 1 March 2018, Session 1 at 11. This was also reflected in the evidence of Ms Wagland, General Manager, Community, Brightwater Care Group, JSCEOLC Transcript, 1 March 2018, Session 2 at 6.

Chapter 1

suffering from dementia, as a person starving themselves to death is a known consequence of dementia.⁶⁷

- 1.49. Professor Michael Francis Quinlan, Consultant General Physician and Professor of Medicine at the University of Notre Dame Australia (UNDA) and former Clinical Professor of Medicine at the University of Western Australia (UWA), also distinguished the refusal of hydration and nutrition from a suicide attempt since it is voluntary and it is reversible if the patient so chooses it.⁶⁸
- 1.50. Contrary to the opinion given by Mr Andrew Denton of Go Gentle Australia, who suggested that palliated starvation and dehydration is a ‘slow and painful’ means of hastening death and ‘long, slow, and psychologically painful for the person going through it, their family and the medical team caring for them,’⁶⁹ evidence given to the Committee by medical professionals indicated that it can be ‘a moderately peaceful way to die as long as good associated palliative care is also given,’⁷⁰ and that ‘when a person stops eating and drinking...they actually enter into a peaceful state, where the ketones and other chemicals from fasting allow the mind to be clear and relaxed.’⁷¹
- 1.51. Evidence was also given to the Committee that a peer reviewed study conducted in Oregon, comparing the deaths of 102 patients who had voluntarily stopped eating or drinking until they died with the deaths of 55 patients who had died from physician-assisted suicide, concluded that the deaths of those who had voluntarily stopped eating or drinking were considered more peaceful and more comfortable than those by assisted suicide.⁷² Dr Rodney Syme, despite being a vocal proponent of euthanasia, wrote in his book *A Good Death: An Argument for Voluntary Euthanasia* (2008), that he was surprised to find how peaceful death by voluntary palliated starvation is, and that it is a choice legally available to patients, but one that is simply too slow.⁷³

Finding 6

Loss of hunger and thirst occurs frequently as a normal part of the natural dying process.

67 Mr Cooper, Principal Registrar, Coroner’s Court of Western Australia, JSCEOLC Transcript, 1 March 2018, Session 1 at 12.

68 Prof Quinlan, Consultant General Physician, JSCEOLC Transcript, 1 March 2018, Session 4 at 5.

69 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 6 and 10.

70 Prof Quinlan, Consultant General Physician, JSCEOLC Transcript, 1 March 2018, Session 4 at 5-6.

71 Prof Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Sciences; WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 5.

72 Ibid at 6.

73 Dr Syme, *A Good Death: An Argument for Voluntary Euthanasia* (2008) – referred to by Prof Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Sciences; WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 6.

Finding 7

Refusal of nutrition and hydration is an end of life choice currently available in Western Australia, however it is significantly distinguishable from assisted suicide as it is based on the right to inviolability and is in any case reversible.

Refusal of Medical Treatment

- 1.52. A patient has the right to refuse medical treatment including in order not to prolong the dying process. This current end of life option should not be conflated with assisted suicide.
- 1.53. An example of an emphysema patient given by Doctors for Assisted Dying Choice in their submission to the Committee is actually an example of refusal of medical treatment, accompanied by good medical care:

when the time came she removed her oxygen and was fitted with a subcutaneous catheter through which was administered standard sedation. By midnight she was unconscious and by 11.30am the next day she took her last breath aged 74.⁷⁴

- 1.54. This patient's death was caused by her underlying condition (emphysema). The patient was entitled to refuse medical treatment (prescribed continuous oxygen). The patient was also entitled to give informed consent to palliative sedation to manage her symptoms and reduce pain and suffering associated with the emphysema.
- 1.55. The Doctors for Assisted Dying Choice example is almost identical to an example given by Professor Bridge:

This man was about 70. He had advanced lung cancer. He was dying. He was kept alive by a breathing machine for some days. He said one day, "I've had enough. Just turn me off." I spoke to him at some length. I spoke to his family. We had long conversations. We agreed it was okay. So in the morning, peacefully, with the family present, he was given extra sedation, he was relaxed and unconscious, the mask was taken off, and he died peacefully a few minutes later ... I do not think we need to change the law to allow it to happen. We need to educate doctors and nurses that it is okay.⁷⁵

- 1.56. Professor Kirsten Auret, Academic in Palliative Care at the University of Western Australia, suggests that '[i]n old terminology, that may have been called passive

74 Doctors for Assisted Dying Choice, JSCEOLC Submission 402 at 9.

75 Prof Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Sciences; WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 7.

Chapter 1

euthanasia, allowing that to happen, where now we would call that good medical practice.⁷⁶

- 1.57. A palliative care physician, Dr Best explained in evidence to the Committee that treatment initially aimed at cure may become futile in a life-threatening illness; that is, it stops working, or is so burdensome, due to distressing side effects like vomiting, that any benefit from the treatment is no longer worthwhile. The treatment may be no longer prolonging life so much as prolonging the process of dying. At this time a decision may be made with the patient to stop such a treatment. This practice is not euthanasia, because the intention is not to kill the patient but to allow the underlying disease to take its natural course and full supported care will remain in place so the patient is kept comfortable. In the same way, ‘taking someone off life support’ is not euthanasia. It is not flicking the switch that kills the patient, it is the underlying disease that does it.⁷⁷
- 1.58. Patients are not always aware that this choice is available to them. Dr Keiron Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, gave the following example:

I had someone who came in the other day who is on a lot of heart medicines. He came in and said, “I want to die.” In actual fact when we explored it, he had not ever realised that he could stop this whole host of heart medicines that he was on, including intravenous medicines and subcutaneous. So when he realised that, when we talked it through with him, it was this huge relief to him that he could stop them.⁷⁸

- 1.59. Dr Best also gave evidence that many people are not aware of the choice to refuse futile medical treatment which leads to the prolonging of suffering:

*We have a lot of people in the community who do not realise that they actually have a choice to stop treatment which is not aimed at cure because of the burden of side effects. In my own practice, time and time again I have seen people who did not realise that they could stop treatment if they wanted to and be more comfortable, and rather than spend their time in hospital spend their time at home with the dog. Even looking at the book of stories of suffering from *Go Gentle—I think it was called *The Damage Done*—there are examples in that of people who suffered because they continued with treatment which they had the opportunity to stop but continued partly because they felt it was aimed**

76 Prof Auret, Academic in Palliative Care, University of Western Australia, JSCEOLC Transcript, 1 March 2018, Session 3 at 5-6 (emphasis added).

77 Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 2 at 2.

78 Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 18 May 2018, Session 2 at 27.

*at cure, and sometimes because family members are scared of losing the person who is dying and may urge them to continue with chemotherapy which is ultimately futile in purpose.*⁷⁹

- 1.60. In her evidence to the Committee, Ms Janet Wagland, General Manager of Brightwater Care Group, gave evidence that people with Huntington's disease regularly forgo the placement of a PEG to allow artificial nutrition and hydration. This is considered an important patient choice:

*The people from the Huntington's community, when you have those conversations, to them it gives them something real to be making choices that they know will have an improved longer term outcome for them depending on what they see as improved. If they would prefer to have a PEG inserted and be fed through central means, and they feel that that gives them longer with their families, for them, that is an improved outcome. For those who do not want to go through the suffering of really not being able to contribute and interact with their environment, which is often what the end result is, they will choose to not have the PEG inserted.*⁸⁰

- 1.61. White, Willmott and Savulescu note that palliative care may be lawfully provided to a patient as they approach death to manage their pain and symptoms.⁸¹ They refer to the decision in *Brightwater Care Group (Inc) v Rossiter*, which makes clear that this position does not change just because the death is occurring due to a refusal of treatment:

There are a number of general principles which can be confidently stated in relation to this issue. The first is that the legal rights and obligations relating to the provision of palliative care are unaffected by the circumstance that the occasion for the provision of that care comes about as a consequence of Mr Rossiter's withdrawal of consent to the continuing provision of other medical treatment, namely, the provision of nutrition and hydration. Put another way, Dr Benstead's rights and obligations with respect to the provision of palliative care to Mr Rossiter if and when he directs Brightwater to discontinue the provision of

79 Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2017, Session 2 at 6.

80 Ms Wagland, General Manager, Community, Brightwater Care Group, JSCEOLC Transcript, 1 March 2018, Session 2 at 8.

81 White, Willmott and Savulescu (2014) 'Voluntary palliated starvation: A lawful and ethical way to die?' (2014) 22 *Journal of Law and Medicine* 276-386 at 382, provided by Prof Willmott and Prof White, Directors, Australian Centre for Health Law Research, and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, in JSCEOLC Submission 560.

Chapter 1

*nutrition and hydration are no different to the obligations which attend the treatment of any other patient who may be approaching death.*⁸²

- 1.62. Similarly, it would be lawful (as well as good and acceptable medical practice) to relieve the suffering of a person dying from a valid refusal of blood transfusion, such as a Jehovah's Witness. It is the fact of the suffering that is relevant, not its origin.⁸³
- 1.63. Mr Denton suggests that '[i]n allowing someone the legal right to refuse life-sustaining treatment we have already accepted the principle that a dying person has a right to hasten their own death.'⁸⁴ However, like the voluntary refusal of nutrition and hydration, a right to refuse treatment is based on the right to inviolability—a right not to be touched without one's informed consent. It is not a right to die or a right to be killed. At most, people have a negative content right to be allowed to die, not any right to positive assistance to achieve that outcome.⁸⁵ Again, the important legal principle here is what is the patient's right—the patient always has the right to decline treatment.⁸⁶
- 1.64. Assisted suicide is said to be different from the refusal of medical treatment, both in its nature and its intention. Death is the sole intended and inevitable outcome of assisted suicide. It is not due to any natural cause, even in those with a terminal illness, but is artificially induced so that a new and otherwise impossible cause of death has been substituted for the one which was to be expected. From both ethical and legal viewpoints, making a person die is different from letting a person die when it is medically proper to do so.⁸⁷
- 1.65. Medical ethics and law strongly support a patient's right to refuse treatment, including life sustaining treatment. The intent is to avoid or withdraw treatment that the patient

82 *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84 at [52].

83 White, Willmott and Savulescu (2014) 'Voluntary palliated starvation: A lawful and ethical way to die?' (2014) 22 *Journal of Law and Medicine* 276-386 at 382, provided by Prof Willmott and Prof White, Directors, Australian Centre for Health Law Research, and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, in JSCEOLC Submission 560. It is noted here that despite the *Rossiter* judgment clearly expounding the law on refusal or withdrawal of medical treatment, Mr Rossiter did not choose to have his PEG tube withdrawn and died from natural causes: Prof Quinlan, Consultant General Physician, JSCEOLC Transcript, 1 March 2018, Session 4 at 6.

84 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 10.

85 Boudreau and Somerville (2013) 'Euthanasia is not medical treatment,' *British Medical Bulletin* 106, 45-66 at 60. See also Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576.

86 Prof Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Sciences; WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 11.

87 Pollard and Winton (1993) 'Why doctors and nurses must not kill patients' *MJA* 158, 426-429 at 426.

judges to be inconsistent with his or her goals and preferences. Death follows naturally, after the refusal, as a result of the underlying disease.⁸⁸

Finding 8

Refusal of medical treatment is an end of life choice currently available in Western Australia, however it is significantly distinguishable from assisted suicide as it is based on the right to inviolability and is in any case reversible.

Palliative Sedation

Palliative sedation therapy and terminal sedation—terminology that can confuse

- 1.66. At the outset it is important to clarify the terminology used to describe ‘palliative sedation’ and to clear up confusion caused by the use of the term ‘terminal sedation.’ It was brought to the Committee’s attention that even in specialist fields people do not always refer to exactly the same thing when using those terms.⁸⁹
- 1.67. ‘Palliative sedation’ is the provision of sedatives in the terminal phase of life and is not the termination of that person’s life. Palliative sedation is not done with the intent of bringing about the end of someone’s life, but is administered in order to relieve the patient from the suffering of refractory symptoms.⁹⁰
- 1.68. The submission from Doctors for Assisted Dying Choice raised a local case: ‘[i]n 2016 a Perth doctor... became the subject of a police murder investigation after she described her management of a dying elderly woman suffering with end stage lung disease using terminal sedation.’⁹¹ The doctor defended her claimed actions by stating that the patient was in the end stages of her disease, was suffering from extreme breathlessness, and had previously attempted suicide.⁹²
- 1.69. It should be noted that the doctor was not a palliative care specialist. Silver Chain noted in their evidence to the Committee that where a patient’s symptoms become

88 Snyder, Sulmasy and Mueller (2017) ‘Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,’ Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576 at 577. This was supported in evidence given to the Committee by Mr Belcher, CEO Braemar Presbyterian Care, JSCEOLC Transcript, 27 February 2018, Session 2 at 10; and Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Transcript, 27 February 2018, Session 5 at 13.

89 Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, JSCEOLC Transcript, 28 February 2018, Session 1 at 13.

90 See Dr Koh, Chair, Royal Australian College of General Practitioners, JSCEOLC Transcript, 15 December 2017, Session 1 at 14; Dr Campbell, President, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 10 and 11 and Palliative Care Nurses Australia, Jane Phillips, President, JSCEOLC Response to Questions on Notice, 29 January 2018 at 3, 4 and 5.

91 Doctors for Assisted Dying Choice, JSCEOLC Submission 402 at 7.

92 Dr Alida Lancée, ‘Sometimes one needs to stand up for what’s right,’ in *The Damage Done* (2016), Go Gentle Australia at 128-130.

Chapter 1

unmanageable in a community palliative care setting, they will refer or transfer the patient to a specialist palliative care unit.⁹³

- 1.70. It would also appear that the doctor's claimed action does not fit within accepted palliative sedation practice as described by Palliative Care Victoria:

Achieving the effective management of pain and other symptoms is a high priority in the care of people with a life limiting illness and people who are dying. Where these symptoms are not readily alleviated by general health and care services, a referral to access the specialised expertise of palliative care services should be made. ...a small minority of patients experience refractory symptoms such as agitated delirium, difficulties breathing, pain and convulsions. Refractory symptoms are defined as: "pain or other symptoms for which all possible treatment has failed, or it is estimated that no methods are available for palliation within the time frame and the risk-benefit ratio that the patient can tolerate." A patient with refractory (unrelieved) distress "must have received skilled multidimensional management directed at the physical, psychological and existential dimensions of the symptom before a symptom is considered refractory." Prudent application of palliative sedation therapy may be used in the care of selected palliative care patients with otherwise refractory distress. [T]he level of sedation used should be the lowest necessary to provide adequate relief of suffering: "The doses of medications should be increased or reduced gradually to a level at which suffering is palliated with a minimum suppression of the consciousness levels and undesirable effects, with documentation of the reason for changes and response to such manoeuvres." Only under exceptional circumstances is deep and continuous sedation required from initiation of palliative sedation therapy.⁹⁴

- 1.71. The doctor's claimed action also appears to be contrary to the practice advocated by Palliative Care WA, which is that:

Terminal sedation is sedation designed to relieve extreme distress in a person who is imminently dying, usually the last hours or days of life. Sedation should be appropriately used for the control of specific symptoms once all other alternatives have been considered and found to be ineffective or inapplicable. The most common refractory

93 Prof Evans, Chief Advisor, Public Policy, Silver Chain Group, JSCEOLC Transcript, 14 December 2017, Session 3 at 12.

94 Palliative Care Victoria (2015) *Submission to the Legal and Social Issues Committee Inquiry into End of Life Choices*, Submission 236 at 14-15, as quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5, at 2 (emphasis added).

symptoms requiring sedation are reported as delirium, which is acute confusion often characterised by agitation (54%) and breathlessness (30%) ... a systematic review by Maltoni and colleagues ... found no evidence that terminal sedation led to hastened death. The palliative care approach advocates managing the dying person's symptoms in the terminal phase in order to relieve suffering and maintain dignity.⁹⁵

- 1.72. Much evidence was heard by the Committee that palliative sedation does not hasten death. Palliative sedation occurs in patients at the end of their life; death is not hastened as it is already occurring due to the underlying medical condition and the research evidence supports this.⁹⁶
- 1.73. Dr Timothy Koh, Chair of the Royal Australian College General Practitioners (RACGP), described the clear distinction between palliative sedation and assisted suicide in this way:

In practice, we are just treating the symptoms, so this is not setting it up as a sort of way of committing euthanasia as far as I can see, basically. There is probably a distinction between those two things, I think. We are really looking at the patient and the needs of the patient and treating those needs but not with the intent of bringing about the end of someone's life.⁹⁷

Palliative sedation does not hasten death

- 1.74. Palliative sedation is not considered to hasten death; in fact the opposite may be true—that is, that if someone's distressing symptoms at end of life are not treated, that in itself can hasten death. In other words, having uncontrolled pain or agitation can hasten death and shorten life.⁹⁸ Dr Elissa Campbell, President of Palliative Care WA, gave evidence to the Committee of an Australian study from a palliative care unit that looked at doses of sedating medications and opioid medications in people in the palliative care unit who died. There was no evidence that the doses of the medication were related to the life expectancy of the people in the hospice. She concludes that the use of these medications, in good quality palliative care, does not hasten death.⁹⁹

95 Palliative Care WA, JSCEOLC Response to Questions on Notice, 19 December 2017 at 8.

96 Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 29.

97 Dr Koh, Chair, Royal Australian College of General Practitioners, JSCEOLC Transcript, 15 December 2017, Session 1 at 13.

98 Dr Campbell, President, Palliative Care WA, JSCEOLC Transcript, 14 December 2017, Session 4 at 10.

99 Ibid at 11. See also Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, JSCEOLC Transcript, 28 February 2018, Session 1 at 14 and her comments on the Maltoni study.

Chapter 1

- 1.75. As to whether palliative sedation medications should be recorded as a cause of, or contributing to, death on the death certificate, Dr Anil Tandon, Chairman of the WA Palliative Medicine Specialists Group, advised:

In the care of a person dying from an irreversible medical condition, the use of sedating or pain-relieving medications are part of standard medical practice and should not be included as a cause of or contributing to the death on the death certificate. Such an inclusion would not be factually correct and would cause undue distress to the family and caregivers of the deceased person. We do not record the medication as the cause or a contributing factor to the death because the disease is the cause and the medications have not contributed to the death, they have only eased the symptoms prior to the death ... If there is doubt as to the contribution of pain relief medication to the death of a person, that death should be reported to the Coroner. If, however, the doctor is of the opinion that the pain relief medications were given for a clinically appropriate indication and at clinically appropriate doses, then they would not be the cause of death.¹⁰⁰

- 1.76. Dr Omar Khorshid, President of the Western Australia branch of the Australian Medical Association (AMA(WA)), also confirmed that palliative sedation medications would rarely, if ever, be recorded as contributing to the death, because it is the disease that led to the death.¹⁰¹
- 1.77. Dr Tandon went on to state that in the practice of caring for people with irreversible conditions who are expected to die, the only difference between patients who have received sedating or pain-relieving medications and those who have not is the degree of pain and other distress, not the timing of their death, and he notes that this has been confirmed in numerous settings by independent researchers.¹⁰² Dr Tandon also provided a collection of studies from research undertaken over the past 20 years into the use of pain medicines and sedatives at the end of life which have demonstrated repeatedly that the use of these medications does not hasten death, including a landmark study published in 2010 which demonstrated in a select group of patients with lung cancer, that their survival was actually longer with palliative care than without.¹⁰³
- 1.78. Dr Mary McNulty, Palliative Care Medical Specialist, put it succinctly in her evidence to the Committee that '[t]he sedation will not take my life any more quickly; it is just that

100 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 1.

101 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 28 February 2018, Session 2 at 6

102 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 2.

103 See Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Transcript, 27 February 2018, Session 5 at 6.

the nature of how I die will change.¹⁰⁴ This is also in line with what is taught in medical schools, where the idea of proportionality is very firmly placed within the definition of palliative sedation taught to students, and that unconsciousness may be the aim of palliative sedation and that the patient will die during that period of unconsciousness.¹⁰⁵

- 1.79. The criticism of palliative sedation raised by Dr Peter Beahan in evidence to the Committee was that it is not always possible to determine whether a patient who has received terminal sedation still suffers with physical or psychological pain, but Dr Beahan did not present any peer reviewed evidence to support this claim and admitted that ‘we do not really know because the patients cannot tell us.’¹⁰⁶ He went on to state that ‘the risk of continued suffering would be more likely with lighter levels of sedation. Heavier sedation may be more effective, but also more likely to shorten life.’¹⁰⁷
- 1.80. Lighter levels of palliative sedation that do not address the distress and refractory symptoms experienced by the patient would be considered poor palliative sedation. Further, Dr Beahan’s evidence that using heavier sedation to adequately address these symptoms is more likely to shorten life is not supported by evidence provided to the Committee from palliative care specialists above, and indeed there is extensive research to the contrary. It should also be noted that neither Dr Beahan, nor his colleagues who gave evidence alongside him to the Committee on behalf of Doctors for Assisted Dying Choice, have any medical experience in the practice of palliative sedation.¹⁰⁸
- 1.81. Dr Alida Lancée asserted to the Committee that ‘there is no evidence that sedating someone actually stops their suffering,’ and referred to the Cochrane review and the conclusion drawn that there is insufficient evidence about the efficacy of terminal sedation in terms of a person’s quality of life or symptom control.¹⁰⁹ However, a proper and full consideration of the Cochrane review and the conclusions drawn by that review reveal that the review concluded ‘No studies measured quality of life or participant well being, which was the primary outcome of the review’ and that ‘Further studies that specifically measure the efficacy and quality of life in sedated people... and quantify adverse effects are required.’¹¹⁰ The conclusion that there is a lack of studies demonstrating that palliative sedation relieves a patient’s suffering,

104 Dr McNulty, Palliative Care Medical Specialist, Silver Chain, JSCEOLC Transcript, 27 February 2018, Session 5 at 17.

105 Prof Auret, Academic in Palliative Care, University of Western Australia, JSCEOLC Transcript, 1 March 2018, Session 3 at 4.

106 Dr Beahan, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 26 February 2018, Session 4 at 6.

107 Ibid.

108 See JSCEOLC Transcript, 26 February 2018, Session 4, at 7.

109 Dr Lancée, Medical Practitioner, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 2 March 2018, Session 3 at 5.

110 Beller et al (2015) ‘Palliative pharmacological sedation for terminally ill adults (Review)’ Cochrane Database of Systematic Reviews 1 CD010206 DOI 10.1002/14651858 at 3.

Chapter 1

the actual conclusion drawn by the Cochrane review, is very different from the assertion made by Dr Lancée that there is no evidence that sedating someone actually stops their suffering, and the unsupported inference that therefore patients undergoing palliative sedation treatment are still suffering.

Palliative sedation is a conventional medical practice in care for the dying

- 1.82. Another criticism made of palliative sedation by proponents of euthanasia is that the medical practice of palliative sedation is a dangerous and unregulated practice, which allows some doctors to euthanise patients ‘behind closed doors’.¹¹¹ Indeed the submission of Mr Ian Wood referred to palliative sedation as ‘terminal sedation’ and questioned whether it constitutes ‘slow euthanasia’ in current palliative care service provision in Australia.¹¹² However later in the same submission, when referring to the conclusions drawn by the Quebec Parliamentary Inquiry 2012 and the findings with regard to the incidence of those ‘euthanised without consent’ in Belgium, Mr Wood writes:

*It is false to say that many patients are euthanised without their consent. These patients receive continuous palliative sedation when they are unable to express consent, when they are dying, and when the doctor and family believe that it is the best way to ease their suffering.*¹¹³

- 1.83. It would appear therefore that for some proponents what is considered ‘slow euthanasia’ and a dangerous and unregulated practice when it occurs in Australia, is considered standard ‘palliative sedation’ when practiced in a country where euthanasia has been legalised. This once again highlights the power and the danger of terminology being conflated in this debate.
- 1.84. The same inconsistency is evident in the Go Gentle Australia submission made by Mr Denton. In discussing the rates of ‘life-terminating acts without explicit request’ (LAWER) in Belgium and the Netherlands, which are frequently cited by opponents of euthanasia as evidence of abuse in those countries, Mr Denton suggests that the rates in these countries may not even be as high as the statistics indicate since in Belgium ‘as in the Netherlands, more specific research into LAWER deaths... further clarified that physicians were, in fact, describing standard clinical management practices of dying patients in the last days and hours of life. These findings raised questions about whether these acts are truly equivalent to non-voluntary termination of life.’¹¹⁴ And yet, earlier in

111 Dr Alida Lancée in JSCEOLC Transcript, 2 March 2018, Session 3 at 4.

112 Mr Wood, Christians Supporting Choice for Voluntary Euthanasia, JSCEOLC Submission 25 at 11.

113 Ibid at 14.

114 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 6.Part E 17.

his submission Mr Denton describes the ‘widely practised’ treatment of ‘terminal sedation’ in Australia as the:

*practice of drugging dying patients into a coma in order to alleviate suffering [that] is “not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it” ...Doctors sign certificates every day where death was the result of sedation and withholding hydration. Who would know if the doctrine of double effect is shielding abuse or cover up? No one is examining, or vouching for, the doctors’ intentions, yet we are told that this system is safer than one where doctors actions are guided by regulations and held accountable by law.*¹¹⁵

- 1.85. So yet again, what is ‘standard clinical management practice in caring for dying patients in their last days and hours,’ and does not necessitate reporting in one jurisdiction is a dangerous, unregulated and unreported practice in another jurisdiction. The only difference, seemingly, being the legal status of euthanasia in those countries.
- 1.86. The inconsistency by these proponents, none of whom are palliative care specialists, only creates confusion. Their evidence obscures what is a standard medical practice in palliative care in Australia and contradicts the breadth of evidence provided to the Committee on the practice of palliative sedation as it occurs in Western Australia. Evidence provided to the Committee included international guidelines for the use of palliative sedation with clear recommended clinical actions that have been adopted by palliative care bodies in Australia.¹¹⁶ Evidence was also given to the Committee that palliative sedation therapies are medical decisions that are always made in partnership between the patient and their doctor, or with the patient’s substitute decision-maker where the consent of the patient cannot be obtained.¹¹⁷
- 1.87. In practice, opioids are titrated, either up or down, according to the response of the patient and the titration process can be either gradual, such as once a week, or as often

115 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 9.

116 See the international guidelines on palliative care contained in Cherny and Radbruch (2009) ‘European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care’ *Palliat Med* 23(7) 581-93 – provided to the Committee by Palliative Care Nurses Australia Inc, Jane Phillips, President, JSCEOLC Response to Questions on Notice, 29 January 2018 at 3; and the Australia and New Zealand Specialist Palliative Medicine (ANZSPM) Guidance Document on Palliative Sedation Therapy, provided to the JSCEOLC as Supplementary Information by Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, 18 July 2017 at 2.

117 See Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 3; Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 26 and Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 29.

Chapter 1

as several times in one day if clinically appropriate. Low doses should be used initially if the pain is not severe or if there are concerns about the ability of the patient to tolerate any potential adverse effects. In all cases, the intention of the titration process is to minimise the duration that a patient is in distress.¹¹⁸ Not only are the medications specially titrated according to the response of the patient, the medications are also reversible.¹¹⁹

The doctrine of double effect is not relied on in palliative sedation

- 1.88. Confusion is also extended by proponents of assisted suicide to the application of the doctrine of double effect as it was expounded by Devlin J in *R v Adams*.¹²⁰ It is argued that palliative sedation involves the hastening of the death of the patient, and that it is a legal medical practice only because of the application of the doctrine of double effect—that the death of the patient was not intended by the medical practitioner, that the medical practitioner’s intent was to relieve the suffering of the patient.¹²¹
- 1.89. However, the experience of the hospice and palliative care movement over the past three decades has shown that the safe and effective use of morphine, and other opioids, and sedatives in pain and symptom control need not bring cause of death into question.¹²² Again, many studies have proven that palliative sedation does not hasten or cause death. There is no clinical scientific evidence that morphine causes death and the respiratory depressant effects of morphine have been shown to be minimal.¹²³ This was

118 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 2. See also St John of God Health Care, JSCEOLC Response to Questions on Notice, undated, at 1 and Dr Parr, Director Medical Services, St John of God Health Care and Palliative Medicine Consultant, JSCEOLC Transcript, 28 February 2018, Session 1 at 15.

119 See the discussion with Dr Hennessy in JSCEOLC Transcript, 30 April 2018, Session 1 at 9 regarding how to reverse the effects of opioids and other drugs and the statements made by Dr Tandon regarding the practice of using high doses of medications to stabilise a patient’s symptoms, and then for those drugs to be ceased and for the patient to resume an active life within the limits of their medical condition in WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 1.

120 *R v Adams* [1957] Crim LR 365. See Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 2 at 11 for a summary of the ethical principle and its application to medical practice.

121 See White and Willmott (2012) ‘How should Australia regulate voluntary euthanasia and assisted suicide?’ *Journal of Law and Medicine* 20, 410-438, and White, Willmott and Ashby (2011) ‘Palliative care, double effect and the law in Australia’ *Internal Medicine Journal* 41(6) 485-492, both provided by Prof Willmott and Prof White, Directors, Australian Centre for Health Law Research, and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, in JSCEOLC Submission 560.

122 White, Willmott and Ashby (2011) ‘Palliative care, double effect and the law in Australia,’ *Internal Medicine Journal* 41(6) 485-492 at 486-7.

123 *Ibid* at 487, citing DuBose and Berde (1997) ‘Respiratory effects of opioids’ *IASP News* at 3-5. The authors also refer to two clinical observational studies which show no evidence of shortened survival resulting from opioid or sedative use in the last days of life: Good, Ravenscroft, Cavenagh (2005) ‘Effects of opioids and sedatives on survival in an Australian inpatient palliative care population’ *Intern Med J* 39, 512-17 and Sykes and Thorns (2003) ‘Sedative use in the last week of life and the implications for end-of-life decision making’ *Arch Int Med* 163, 341-4.

supported by clinical practice evidence provided to the Committee by various medical practitioners and palliative care specialists.¹²⁴ In fact, in evidence to the Committee, high profile advocate of assisted suicide, Dr Phillip Nitschke, stated that morphine is an extremely variable drug in its effect on individuals and it is very difficult to provide someone with a lethal dose.¹²⁵

- 1.90. Quality palliative care should not need to rely upon the medical ethical principle known as the doctrine of double effect as a justification for the administration of opioids or sedatives, as studies have shown that there is no association between the doses of opioids and sedatives on the last day of life and survival.¹²⁶ Emerging evidence shows that sedating medications, when used appropriately, do not hasten death and therefore the application of the doctrine of double effect does not come into play at all.¹²⁷ The conclusion of the 2009 Maltoni study was that ‘Palliative sedation therapy does not

124 See Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, who states ‘if you are using morphine appropriately to manage their symptoms, then the morphine is not what kills them,’ in JSCEOLC Transcript, 13 December 2017, Session 2 at 12. See also Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, who states ‘if you are using medications in a skilled way, actually the evidence from the literature is that the doctrine of double effect does not really come into play, because what we are doing is titrating medication according to need, and then we are bringing about relief of symptoms and relief of distress, and dying may happen alongside that,’ in JSCEOLC Transcript, 28 February 2018, Session 1 at 17; Prof Quinlan, Consultant General Physician, states ‘It was very popular about 30 or 40 years ago to discuss the principle of double effect... I make it clear that it is not a legal principle; it is an ethical principle and, consequently, with better knowledge, better scientific knowledge, better experience, the day-to-day application of double effect is not commonly done,’ in JSCEOLC Transcript, 1 March 2018, Session 4 at 4 and Dr Dunjey, General Practitioner, in answer to the question ‘Do you think that medical practitioners rely on the doctrine of double effect when administering pain-relieving or sedating medications at the end of life?’ stated ‘The short answer is no. The question poses... a dilemma which... is not there and does not need to be there,’ in JSCEOLC Transcript, 2 March 2018, Session 1 at 2; and Jane Phillips, President of Palliative Care Nurses Australia, who wrote ‘To qualify the principle of double effect in everyday clinical practice, palliative care interventions based on evidence-based clinical practice guidelines and the individual characteristics of the patient and made by clinicians with appropriate qualifications and skills are highly unlikely to result in death. The most common foreseen but unintended effects of palliative care interventions are non-life threatening medication side effects, such as nausea, which is likely when a person first begins taking opioids for pain relief,’ JSCEOLC Response to Questions on Notice, 29 January 2018 at 4; and Dr McNulty, Palliative Care Medical Specialist, Silver Chain, who stated ‘We are very certain that the drugs we use do not hasten death, which is why we do not believe that we need the principle of double effect, because we are not doing anything to hasten death,’ in JSCEOLC Transcript, 27 February 2018, Session 5 at 6.

125 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 11.

126 Palliative Care WA, JSCEOLC Response to Questions on Notice, 19 December 2017 at 9.

127 See Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 2 at 19; Dr Best, Palliative Care Physician, JSCEOLC Transcript, 1 May 2018, Session 1 at 3-4.

Chapter 1

shorten life when used to relieve refractory symptoms and does not need the doctrine of double effect to justify its use from an ethical point of view.¹²⁸

- 1.91. Dr Tandon put this most clearly in a written response to a series of question put to him by the Committee:

At the outset, it must be reiterated once again that reference to the doctrine of double effect is erroneous and based on outdated medical knowledge and the incorrect interpretation of this information. An expanding evidence base has repeatedly confirmed that the appropriate use of sedating or pain-relieving medications does not hasten death. Peer-reviewed evidence has been provided to the Joint Select Committee to this effect. Having stated the above, in our opinion current law in Western Australia adequately protects doctors who act appropriately within the limits of their scope of clinical practice.¹²⁹

The morphine myth

- 1.92. So why then do proponents continue to refer to the doctrine of double effect? For example, Professor White, in his evidence to the Committee, stated:

We would say—and I expect you have heard this evidence before—in conversations with some medical colleagues, they say that it need not hasten death, but there are other medical colleagues who have reached the view that in some instances where a patient is close to death there is a prospect of that happening. There are, I guess, different views clinically on it. A relevant consideration from our perspective, putting aside whether or not it does in fact hasten death, is whether a perception that it does can exist.¹³⁰

- 1.93. The ‘morphine myth,’ that palliative sedation hastens death, is perpetuated by euthanasia proponents to draw an equivalence between palliative sedation and assisted suicide—that there is essentially no difference between a doctor relieving the patient’s suffering through sedation, which may also have the unintended consequence of hastening death, and the actions of a doctor who relieves a patient’s suffering through

128 Maltoni et al (2009) ‘Palliative sedation therapy does not hasten death: results from a prospective multicenter study’ *Annals of Oncology* 20(7) 1163-1169, cited by Dr Anil Tandon, Chairman, WA Palliative Medicine Specialists Group, Supplementary Information Provided to the Committee.

129 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 1.

130 Prof White, Director, Australian Centre for Health Law Research, JSCEOLC Transcript, 26 February 2018, Session 2 at 3.

the administration of a lethal medication with the intent to cause the death of that patient.

- 1.94. The Committee received evidence from palliative care specialists that the myth exists both among the general public, and among medical practitioners. Dr Bradley said:

I get that every single day at work. The families go, "Oh, you're going to set up the pump." It is kind of done in inverted commas, almost, as if they assume that because we are talking about providing appropriate levels of pain relief for the patient, sedation if they need it, that that is us as doctors ending their life. We spend a lot of our time on a day-to-day basis explaining that that is not at all what we are doing, that we are not hastening death.¹³¹

- 1.95. Professor Forbes also held a similar view:

I absolutely agree with you that the public does have a misperception here. I actually think it is a very dangerous misperception because it devalues life. It devalues the relationship with the physician as healer. If we lose that, we find it very difficult to do our work. Every therapeutic complication will end up being adjudicated by lawyers and destroy the medical system as we know it, let alone the relationship between patients and doctors.¹³²

- 1.96. In their own personal views, both Dr Bradley and Professor Forbes agreed that the morphine myth is a view also held by some medical practitioners.¹³³

131 Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 18 May 2018, Session 2 at 20-21. See also the comments made by Dr Best, Palliative Care Physician and Academic, with regard to subcutaneous injections of palliative medications, morphine and otherwise, and the perceptions of family members and others who witness it – 'It is just human nature. You see an injection, someone stops breathing. It is understandable that someone might think that they were connected, but most of the drugs we would use at the very end of life with someone whose body was slowing down, generally I think it would be very surprising if they had time to actually take effect, because at the end of life in palliative care we put a little needle under the skin. We do not put it straight into the vein because just under the skin, a subcut needle, is much more comfortable for the patient. It takes a longer time for those drugs to absorb. I think it is a visual thing that I understand people deciding, but in fact it is very unlikely that a subcut injection would cause an immediate stopping of breathing,' JSCEOLC Transcript, Session 2, 1 May 2018 at 9.

132 Prof Forbes, Acting Chief Medical Officer, Department of Health, JSCEOLC Transcript, 18 May 2018, Session 2 at 21.

133 Avant Mutual confirm that this is the case in some instances, noting that 'some practitioners express concern about providing increasing pain relief and sedation in the terminal phase of illness because of the concern that they may be subject to prosecution. The doctrine of double effect is often not well understood,' Avant Mutual, JSCEOLC Submission 545 at 2.

Chapter 1

- 1.97. In fact, the morphine myth and the doctrine of double effect may even act as a deterrent to the provision of good symptom control.¹³⁴ Some physicians may withhold pain medication because of ungrounded concerns that higher doses may accelerate death through respiratory suppression, or that the patient may become addicted to the medication:¹³⁵

*Although a review of the medical literature reveals that the risk of respiratory depression from opioid analgesic is more myth than fact and that there is little evidence that the use of medication to control pain hastens death, the belief in the double effect of pain medication remains widespread. Applying the principle of double effect to end-of-life issues perpetuates this myth and results in the under-treatment of physical suffering at the end of life.*¹³⁶

- 1.98. The morphine myth, and a misunderstanding of the application of the doctrine of double effect in palliative sedation, has also led some doctors to erroneously admit to intentionally hastening their patients' deaths, as Dr Tandon explains:

It is widely recognised that in many cases doctors who admit to intentionally hastening their patients' deaths have misunderstood the application of the principle of double effect and the legislative framework within which they practice. As has been documented even in Australia, some medical practitioners equate the use of appropriate doses of morphine at the end of life with euthanasia, because they mistakenly think that morphine hastens death. As we have already seen, this is not the case. The Committee makes reference to studies that suggest some doctors already admit to intentionally hastening death even though it is currently against the law. We believe that most times this is a misunderstanding of the use of opioids and sedating

134 Sykes and Thorn (2003) 'The use of opioids and sedatives at the end of life' *The Lancet Oncology* 4(5) 312-318, cited by Dr Tandon in Supplementary Information provided to the Committee; Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, also confirmed that she had seen underdosing or undermanaging of pain due to misconceptions held about sedatives in medical practice outside of palliative care: JSCEOLC Transcript, 18 May 2018, Session 2 at 21.

135 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576. See also Janet Hardy (2000) 'Sedation in terminally ill patients' Letter, *The Lancet*, 356 (9245) 1886-7, cited in Go Gentle Australia JSCEOLC Submission 539 at 29.

136 Fohr SA (1998) 'The double effect of pain medication: separating myth from reality' *J Palliat Med* 1(4) 315-28, cited by Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Supplementary Information; See also Dr Best's comment that 'The morphine myth has been around for years, and we do not seem to be able to squash it. That is a shame because it makes people scared to use what is really an excellent treatment for pain,' Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 2 at 1.

*medication. However, it does indicate that some doctors are prepared to act outside the law. If this is the case, then we question how will changing the law make vulnerable people safer?*¹³⁷

- 1.99. If the morphine myth and confusion or fear around the application of the doctrine of double effect is leading to poor management of patient symptoms, it does not follow that assisted suicide must be introduced.

*Under-dosing is a widely recognised problem and leads to much unnecessary suffering and distress for patients and their loved ones. In our opinion, under-dosing occurs not because of uncertainty regarding the law but because of a lack of medical training and erroneous, outdated teaching. Under-dosing is not because of an incorrectly used ethical principle but because of inadequate knowledge on the part of the doctor.*¹³⁸

- 1.100. What is required is greater communication between specialist palliative care services and community level expertise. Specialist services frequently provide advice to general practitioners and others who provide palliative care about dosing, adjustments, safety and drug interactions.¹³⁹ Under-dosing is not a failure of palliative care—it is bad palliative care. It is the improvement of palliative care that must be a priority for the Government of Western Australia, and not the legalisation of assisted suicide.

Finding 9

Palliative sedation, when competently administered, is a legal and ethical end of life choice currently available in Western Australia.

Finding 10

An expanding evidence base has repeatedly confirmed that the appropriate use of sedating or pain-relieving medications does not hasten death.

Finding 11

Palliative sedation does not hasten death.

Finding 12

Under-dosing and failure to make a specialist referral are problems that lead to unnecessary suffering and distress for patients and loved ones.

137 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 4.

138 Ibid at 2.

139 Prof Forbes, Acting Chief Medical Officer, Department of Health, JSCEOLC Transcript, 18 May 2018, Session 2 at 21.

Chapter 1

Finding 13

Under-dosing and failure to make a specialist referral occur because of a lack of medical training and, in some cases, outdated teaching.

Recommendation 4

The Minister for Health should facilitate and monitor an improved communication protocol, and if necessary an improved communication pathway, between medical practitioners and specialist palliative care services.

Recommendation 5

The Minister for Health should develop and roll out a community awareness program about specialist palliative care services.

Recommendation 6

The Minister for Health should consult with palliative care specialists about mechanisms to improve the training and continuous professional education of all health practitioners about specialist palliative care services.

Suicide and the Distinction between Palliative Care and Assisted Suicide

- 1.101. While the final end of life choice, of suicide, is a choice available to Western Australians due to their inherent liberty, it is not a choice encouraged or promoted by the State. Indeed suicide prevention policies and programs have enjoyed long-standing bi-partisan support in Western Australia. Consequently, proponents of assisted suicide are regularly left needing to distance suicide from assisted suicide.
- 1.102. The suggestion is made by assisted suicide proponents that voluntary euthanasia and physician-assisted suicide sit on the spectrum of end-of-life care, alongside palliative care, advanced care directives and the refusal and withdrawal of treatment.¹⁴⁰ However, the choices available to Western Australians at end of life, including palliative care therapies, and the refusal of nutrition and hydration, refusal of medical treatment and palliative sedation have a number of things in common which make them distinct from assisted suicide.
- 1.103. Whilst palliative care is not curative, it also does not have the aim of ending a patient's life. Nothing undertaken in palliative care therapies is undertaken to hasten death.¹⁴¹

140 Mr Denton, Go Gentle Australia, JSCEOLC Response to Questions on Notice, 13 May 2018 at 8.

141 Prof Evans, Chief Advisor, Public Policy, Silver Chain Group, JSCEOLC Transcript, 14 December 2017, Session 3 at 14.

The cause of death of each of these treatment choices will continue to be the underlying disease or condition suffered by the patient.¹⁴²

- 1.104. Assisted suicide, on the other hand, intends to shorten life and death is caused by the administration of lethal medications, and therefore should remain distinct from the field of palliative care.¹⁴³ The European Association for Palliative Care defines euthanasia as ‘a physician (or other person) intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request,’ and defines physician-assisted suicide as ‘a physician intentionally helping a person to terminate their life by providing drugs for self-administration, at that person’s voluntary and competent request’.¹⁴⁴
- 1.105. Proponents and opponents alike agree that the suffering of the patient must be relieved, but disagree on the means by which to achieve this goal. Those opposed to assisted suicide hold the view that killing the patient is not a supportable means to reach the desired goal of relieving suffering. Rather, they suggest that ‘we must kill the pain and suffering, not the person with the pain and suffering.’¹⁴⁵
- 1.106. A critical distinction between assisted suicide and the palliative care choices available to Western Australians at end of life is that the current choices available to patients are all reversible. Palliative care, refusal of hydration and nutrition, refusal of medical treatment and palliative sedation are all reversible. If the intention is to cause the death of the patient, as it is in voluntary euthanasia and physician-assisted suicide, the process kills the patient.¹⁴⁶
- 1.107. What the above discussion about current end of life choices available to Western Australians reveals is that assisted suicide is not a step on the continuum of good end-of-life practices, as it is radically different as the intent is no longer to care but to kill.

142 Mr Cockayne, General Manager, Health Care WA, Silver Chain Group, JSCEOLC Transcript, 14 December 2017, Session 3 at 16.

143 Dr Tandon, Chairman, WA Palliative Medicine Specialists Group, JSCEOLC Response to Questions on Notice, 29 April 2018 at 4.

144 Radbruch L et al (2015) ‘Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care’ *Palliative Medicine* <<http://www.eapcnet.eu/LinkClick.aspx?fileticket=28Vb60In9SQ%3D>> quoted in Palliative Care Nurses Australia, Jane Phillips, President, JSCEOLC Answers to Questions on Notice, 29 January 2018 at 7.

145 Sprung et al (2018) ‘Physician-Assisted Suicide and Euthanasia: Emerging Issues from a Global Perspective’ *Journal of Palliative Care* sagepub.com/journalsPermissions.nav DOI: 10.1177/0825859718777325 at 4.

146 Dr Dunjey, Convenor, Medicine With Morality, JSCEOLC Transcript, 2 March 2018, Session 1 at 3.

Chapter 1

Finding 14

A critical distinction between assisted suicide and the palliative care choices available to Western Australians at end of life is that the current choices available to patients are all reversible.

Chapter 2

The Risks of Legalised Assisted Suicide— Casualties Guaranteed

But the stakes go up when you are saying that someone is going to die.

Dr Nathan Gibson, Chief Psychiatrist of Western Australia, 14 December 2017

There is only one person left, usually, to tell what happened, and that is the person who is under investigation. That is a real problem... at the end of the day it is one person's say-so... The patient, of course, is deceased.

Miss Amanda Forrester, Director of Public Prosecutions (WA), 27 February 2018

Autonomy, Self-Determination and Choice—The Basis of Calls for Assisted Suicide

- 2.1. Calls for the legalisation of assisted suicide in Western Australia, and elsewhere, are based on the social theories of independence and individualism, and values of autonomy, self-determination and choice. Calls for 'choice' were echoed in the submissions made to the Committee,¹⁴⁷ in evidence given to the Committee in public hearings,¹⁴⁸ and indeed among Committee members.¹⁴⁹

However:

Advocates of assisted death assume that it is possible to distinguish between euthanasia requests that are a mis-expression of an

147 For example, see Willmott and White (2017) 'Assisted Dying in Australia: A Values-based Model for Reform,' in *Tensions and Traumas in Health Law* submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A; and Motor Neurone Disease Association (WA) (MNDAWA), JSCEOLC Response to Questions on Notice, undated at 9.

148 See comments made by Mr Teale, Chief Executive, Council on the Ageing (WA), JSCEOLC Transcript, 2 March 2018, Session 5 at 8 regarding the ability to make an 'informed choice' and the comments made by Mrs Trendall, Senior Citizen, JSEOLC Transcript, 7 March 2018, Session 1 at 3, that '[e]ach individual is an independent person and as long as their choice of an end does not in any way impose on any other person, I do not see that there need be any controversy.'

149 See Hon Dr Sally Talbot, Committee Member, JSCEOLC Transcript, 14 December 2017, Session 3 at 15, where the Honourable Member states 'I think the evidence that you have given us is very evocative in terms of emphasising the point about the choice of people who are dying. It seems to me, without wishing to put words into your mouth, that it may be that certain people choose to opt for voluntary assisted dying as one of their options as part of the ways of expanding their choice.'

Chapter 2

*underlying, unresolved need, and those that reflect a personal philosophy of choice, despite optimal care. The stakes are high. Interviewees gave examples of patients who had earlier demanded euthanasia but who then went on to find meaning through the natural dying process. Similarly, there were examples of patients who had contemplated suicide, or survived the attempt, but who valued the life they went on to live. The enemy, in the end, is a simplistic view.*¹⁵⁰

- 2.2. In the words of Mr Dwight Randal, President of the Coalition for the Defence of Human Life:

*It is more than personal if it requires governments to revise laws to allow certain types of homicide and suicide. It is more than personal if it requires doctors to assist in the killing. It is more than personal if it desensitises medical staff to the preciousness of human life...It is more than personal if it creates an atmosphere in which other weak or unwanted people feel pressured to choose to die.*¹⁵¹

- 2.3. Archbishop Timothy Costelloe, Catholic Archbishop of Perth, also saw an important distinction between personal autonomy and absolute personal autonomy since we all exist as persons in society:

*We do not exist as completely isolated, autonomous people, whose decisions have no impact on anybody else. So I think our rights have to be balanced by our responsibilities to the society of which we are a part and to which we have certain obligations. We are not talking about a private and personal decision when we are talking about euthanasia or voluntary assisted dying; we are talking about a decision which, fundamentally, alters a foundational principle upon which our society has been built. So no matter how private the decision might be in one sense that a person might take to seek euthanasia or assisted dying, inevitably, because of the web of relationships that are part of being human, it has impacts beyond the person... and their family.*¹⁵²

- 2.4. Mr Christopher Harkness also expressed his concern that ‘the debates in our culture about euthanasia take a populist and superficial stance that fails to consider the

150 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 252.

151 Mr Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices, included in JSCEOLC Response to Questions on Notice, 17 April 2018 at p8 – quoting Andrew Lansdown (2017) ‘If people were dogs and other false arguments for euthanasia,’ *Life Ministries*, 18 January 2017 <<http://www.lifeministries.org.au/pamphlets/if-people-were-dogs-and-other-false-arguments-for-euthanasia/>>

152 Archbishop Costelloe, Catholic Archbishop of Perth, JSCEOLC Transcript, 8 March 2018, Session 6 at 2-3.

implications for both the individual and society at large. The debate sometimes fails to progress beyond the notion of the rights of the individual to have a dignified death.¹⁵³

- 2.5. In Chapter 2 of this Report, the discussion moves beyond the philosophical justifications for legalised assisted suicide around autonomy and self-determination and considers the practical realities of the revision of laws to allow for doctors to kill, or assist in the killing of their patients in certain circumstances. This Chapter seeks to address the following questions:
- 2.6. How do we assess whether an individual is competent to make the autonomous choice of assisted suicide? And, how do we determine that an individual's request for assisted suicide is not affected by demoralisation?
- How do we ascertain whether an individual's consent is informed and voluntary?
 - Does assisted suicide present an issue for disability discrimination?
 - Does assisted suicide conflict with suicide prevention programs already in operation in Western Australia?
 - Is the medical professional best placed to implement assisted suicide laws?
 - Does legalised euthanasia actually guarantee a good death?

Finding 15

Calls for the legalisation of assisted suicide are based on social theories of independence and individualism and values of autonomy, self-determination and choice.

Finding 16

There is a distinction between personal autonomy and absolute personal autonomy.

Assessment of Competency

- 2.7. Willmott and White's recommendation that 'assisted dying' be permitted is underpinned by the value of autonomy, though they recognise that a person must be competent to exercise that autonomous choice.¹⁵⁴ Determining whether a patient is competent to exercise the choice of assisted suicide then becomes central.

Optional referral for psychiatric assessment

- 2.8. Proponents of assisted suicide assert that the consulting doctor is capable of assessing patient competence, and that psychiatric consultation is only needed when either of the assessing doctor is uncertain about the patient's competence or mental state. A

153 Christopher Harkness, JSCEOLC Submission 266 at 3.

154 Willmott and White (2017) 'Assisted Dying in Australia: A Values-based Model for Reform' in *Tensions and Traumas in Health Law* at 501, provided in Profs Willmott and White, Directors, Australian Centre for Health Law Research, and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

Chapter 2

mandated psychiatric assessment is said to belittle the individual's autonomy, and mandating psychiatric assessment would limit access to assisted suicide since access to psychiatric opinion is limited.¹⁵⁵ General practitioners are considered best placed to assess the patient's mental state and decision making capacity, due to their longitudinal relationship with the patient and the routine use of this assessment in all health care decisions that patients make.¹⁵⁶ This view presupposes that a decision on assisted suicide is comparable to all other health care decisions.

- 2.9. In the Go Gentle Australia submission to the Committee, Mr Denton notes '[w]hat is essential for the purpose of assessing a patient's eligibility for physician assisted dying is not so much 'depression' as the presence of 'adequate decision-making capacity'. There are specific criteria and guidelines for making this kind of assessment and doctors (not just psychiatrists and psychologists) are competent to make these kinds of judgments.'¹⁵⁷ In support of this statement, Mr Denton cites Joshua M. Baruth and Maria I Lapid, 'Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal.'¹⁵⁸
- 2.10. A closer reading and examination of this article shows that while Mr Denton correctly recites that there are 'specific criteria and guidelines' for assessing capacity (the authors refer to the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) as one instrument to assist clinicians in evaluating decisional capacity), the authors also state:

*Importantly, it has been shown that physicians often fail to correctly recognise incapacity, sometimes as much as 58 per cent of the times, which further highlights the importance of using formal assessments like the MacCAT-T as well as consulting relatives and other members of the health care team.*¹⁵⁹

- 2.11. And further:

Additionally, the impact of a decision should be considered. For example, vastly different outcomes result from refusing a life saving treatment that could result in death and refusing a low-risk treatment

155 Doctors for Assisted Dying Choice, JSCEOLC Submission 402 at 4.

156 Ibid at 11. See also Mr Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 2; Mr Walker, Vice President, Dying with Dignity WA, JSCEOLC Transcript, 13 April 2018, Session 5 at 5; Dr Hennessy, Head of Anaesthesia Department, Sir Charles Gairdner Hospital, JSCEOLC Transcript, 30 April 2018, Session 1 at 11; Prof Willmott, Director, Australian Centre for Health Law Research, JSCEOLC Transcript, 26 February 2018, Session 2 at 19; Dying With Dignity (WA), JSCEOLC Submission 565 at 23; Prof Kamien, Medical Practitioner/Emeritus Professor of General Practice, UWA; Doctors for Assisted Dying Choice, JSCEOLC Transcript, 2 March 2018, Session 3 at 10-11.

157 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 6. Part E 41.

158 Baruth and Lapid (2017) 'Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal,' *AMA Journal of Ethics* 19(5) 416-425.

159 Baruth and Lapid (2017) at 420.

*that may or may not have negative consequences. Accordingly, with decisions involving greater risk, a physician should consider more than a single, objective assessment of capacity and incorporate more information based on prior decisions or what others consider a reasonable decision.*¹⁶⁰

2.12. The authors conclude:

*It is not appropriate to let a prior or current psychiatric diagnosis solely determine decisional capacity. However, if a patient is currently suffering from a mood disorder, is potentially suicidal, or has any other condition that could potentially compromise his or her capacity, the patient should be referred to a psychiatrist for a formal consultation.*¹⁶¹

2.13. This closer reading of the Baruth article reveals that the assessment of capacity by doctors can be supported by assessment tools, but that the assessment of capacity is very complex, particularly in decisions involving greater risk to the patient. This inconvenient truth is not addressed by proponents.

2.14. The assurance given by those who do not see a need for mandatory psychiatric assessment is that if the doctor has any doubts about capacity or any other thing in a patient's request, they can then refer them for psychiatric examination.¹⁶² This 'optional referral' model was adopted in the Victorian legislation, which provides for approved training for capacity assessment and specialist referral where a doctor is 'unable to determine whether the person has decision-making capacity in relation to voluntary assisted dying as required by the eligibility criteria, for example, due to a past or current mental illness of the person.' Mr Denton suggests that 'such legislation will improve the capacity to detect mental illness in the terminally ill. Clinicians will be more vigilant in determining if it is present and, if detected, patients will be referred for psychiatric assessment and, if appropriate, care.'¹⁶³

2.15. However the actual evidence from those jurisdictions with optional referral for psychiatric assessment is very different to this optimistic opinion. What has happened in these jurisdictions is that gatekeeping medical practitioners very seldom refer and this results in persons with treatable clinical depression being wrongfully assisted to suicide.¹⁶⁴

2.16. In Oregon, research by Ganzini found that '[a]mong terminally ill Oregonians who participated in our study and received a prescription for a lethal drug, one in six had

¹⁶⁰ Ibid at 421 (emphasis added).

¹⁶¹ Ibid at 421-2.

¹⁶² Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 12.

¹⁶³ Mr Denton, JSCEOLC Response to Questions on Notice, 13 May 2018 at 5.

¹⁶⁴ Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 4.

Chapter 2

clinical depression.¹⁶⁵ Depression is supposed to be screened for under Oregon's enabling legislation. However, in 2016 less than one in twenty five (3.75 per cent) who died under the Oregon law were referred by the prescribing doctor for a psychiatric evaluation before writing a script for a lethal substance.¹⁶⁶ As to the efficacy of a single psychiatric visit to assess capacity, another study by Ganzini found that out of 321 psychiatrists in Oregon, only 6 per cent were very confident that in a single evaluation they could adequately determine whether a psychiatric disorder was impairing the judgment of a patient requesting assisted suicide.¹⁶⁷ In light of this, it would be improper to suggest or assert that the optional referral system in Oregon safeguards against the assisted suicide of patients whose capacity is impaired by depression or other mental health considerations.

- 2.17. A similar experience is also found in other jurisdictions with optional referral for psychiatric assessment. In the Netherlands the rates of psychiatric assessment before euthanasia plummeted from 25 per cent in 1998 to 0 per cent in 2010.¹⁶⁸ In Washington state, examination of Department of Health reports reveals that only 4 per cent of patients were referred for psychiatric evaluations.¹⁶⁹
- 2.18. The optional referral model also presupposes a longitudinal relationship between general practitioner and patient. Doctors for Assisted Dying Choice suggest that general practitioners are considered best placed to assess the patient's mental state and decision making capacity due to their longitudinal relationship with the patient.¹⁷⁰ This assertion fails to take into account that a patient may seek assisted suicide from a doctor with

165 Ganzini et al (2008) 'Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey,' *BMJ* 337:a1682, quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 4-5.

166 Oregon Public Health Division (2017) *Oregon Death With Dignity Act: Data Summary 2016*, Table 1, 'Characteristics and end-of-life care of 1,127 DWDA patients who have died from ingesting a lethal dose of medication as of January 23, 2016 [sic = 2017], by year, Oregon, 1998-2016,' at 9 – cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 5.

167 Ganzini et al (1996) 'Attitudes of Oregon psychiatrists toward physician-assisted suicide,' *Am J of Psych* 153, 1469-75, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 5.

168 Leiva RA (2010) 'Death, suffering and euthanasia,' *Canadian Family Physician* 56(6), 528-530, cited by Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 6.

169 Emanuel et al (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe,' *JAMA* 316(1), 79-90 at 86, citing Washington State Department of Health, *Death With Dignity Act Reports, 2009-2015*
<<http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct>>

170 Doctors for Assisted Dying Choice, JSCEOLC Submission 402 at 11. See also Mr Marshall Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 2; Mr Walker, Vice President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 5; Dr Hennessy, Head of Anaesthesia Department, Sir Charles Gairdner Hospital, JSCEOLC Transcript, 30 April 2018, Session 1 at 11; Prof Willmott, Director, Australian Centre for Health Law Research, JSCEOLC Transcript, 26 February 2018, Session 2 at 19; Dying With Dignity (WA), JSCEOLC Submission 565 at 23; Prof Kamien, Medical Practitioner/Emeritus Professor of General Practice, UWA, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 2 March 2018, Session 3 at 10-11.

whom they do not have a longitudinal relationship, nor is it likely that both assessing doctors will hold a longitudinal relationship with the patient.

- 2.19. The risks of not requiring a psychiatric capacity assessment were identified in a Committee hearing, in discussion between Hon Nick Goiran MLC and Dr Roger Paterson, Doctors for Assisted Dying Choice:

Hon NICK GOIRAN: Are there any risks of not requiring a psychiatric capacity assessment?

Dr PATERSON: There is a theoretical risk. Dr Lisa Miller gave a very good account in her submission to the inquiry of a case where on a superficial level one could take the patient's wish for an early death at face value, but on further exploration and expert treatment that wish turned out to be not needed, fortunately. So you may argue that on occasion a psychiatric opinion may be necessary. We would certainly propose that that should happen, but not mandatory; really leave it up to the GPs who are best placed to make that assessment or referral on when necessary. The GPs know the patients over many, many years in many situations. A psychiatrist coming in cold, as it were, would have to start again. GPs are really well placed to make an assessment of cognitive capacity and psychiatric capacity, and if they are suspicious of any impairment they would refer on. I think psychiatrists would be able and willing to get involved at that stage.

Hon NICK GOIRAN: It is an interesting point. In that Miller case you referred to, wasn't the problem that it was not picked up early and it was not until the expert was involved that there was able to be the right treatment provided? So if the GP misses it at first instance and there is not a mandatory requirement to go to a psychiatrist, the opportunity is lost?

Dr PATERSON: Yes. As I say, it is a theoretical problem—in this case a very real practical problem; an actual problem.

Hon NICK GOIRAN: It was an actual problem in the Miller case.

Dr PATERSON: You could be extra, extra, extra careful and insist on a psychiatrist getting involved, but no jurisdiction has that around the world and I can see why; it just would not work.¹⁷¹

¹⁷¹ Dr Paterson, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 26 February 2018, Session 4 at 9-10.

Chapter 2

Mandatory psychiatric assessment

- 2.20. With regard to the assessment of ‘the potential existence of mental illness in an end of life decision’, Dr Nathan Gibson, Chief Psychiatrist of Western Australia, recommends ‘that any assessment:’

- a. Be mandatory*
- b. Be multiphasic*
- c. Be undertaken over a period of time*
- d. Require extensive third-party corroboration*
- e. Be subject to assessment by multiple credentialed practitioners in any single, individual case*
- f. Be vetted, to exclude inadequate treatment, support or carer resourcing¹⁷²*

- 2.21. Dr Gibson advised that a psychiatrist should provide the clinical assessment of capacity for assisted suicide. The analogy drawn by the Chief Psychiatrist is that, under the *Mental Health Act 2014* (WA), for an individual to be made involuntary he or she must be seen by a psychiatrist. The consequence of holding that person involuntarily is considered so serious that they must be seen by a psychiatrist to determine capacity. Dr Gibson states ‘What I would not like to see is a watered down version that would not apply the same rigour to individuals seeking to end their life.’¹⁷³

- 2.22. With regard to the assessment of a patient’s capacity by a general practitioner, Dr Gibson goes on to state:

*In the situation where a GP is treating mental illness, assisting with the palliative care and making potential capacity assessments that are not leading to the potential death of the person, that may be reasonable. But the stakes go up when you are saying that someone is going to die. I do not think it is reasonable to have a GP make that capacity assessment at that point.*¹⁷⁴

172 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Submission 655 at 4-5.

173 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 14 December 2017, Session 5 at 12. Dr Gibson also restated this position in a later Committee hearing, see JSCEOLC Transcript, 28 February 2018, Session 3 at 3.

174 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 14 December 2017, Session 5 at 13 (emphasis added).

- 2.23. Dr Gibson recognises that he errs on the side of caution in recommending mandatory assessment, but explains his position in this way:

*I plump on the side that we are better to take a rigorous approach and ensure that we do not miss out on those individuals who may have difficult and challenging presentations of mental illness so that those individuals are absolutely able to access the treatment and care that they need. There are logistic issues, I understand, but I am not sure that it would necessarily significantly delay the process for individuals who had capacity who were seeking to access legislation. So, I am really looking at a “first do no harm” to that cohort that really need that assessment. Whether you plump on a psychiatrist or a medical practitioner, if you plump on the side of a medical practitioner, there may be some situations in which someone has a mental illness that is not picked up and not treated, so there may be some cases there. It depends where you actually put the weighting, and I am weighting on the side of a more cautious approach. As I said, I do not think I am out of step with many of my colleagues in that regard. I think there is a multitude of different views. I guess I am trying to make a case for the protection of individuals with mental illness, access to treatment for individuals with mental illness and that in the whole picture there are the rights of people seeking, if the legislation comes in, voluntary assisted dying. There are also the rights of people who may be unwell who need the rigour of assessment.*¹⁷⁵

- 2.24. When we consider the complexities involved in assessment of capacity (below), it is clear that Dr Gibson’s caution is not misplaced.
- 2.25. It should also be noted that while the WA branch of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) expressed concern about resourcing and access issues associated with mandatory psychiatric assessment, the WA branch did not go so far as the RANZCP Victorian branch who gave evidence to the Victorian Inquiry that optional referral for psychiatric assessment was preferable. The WA branch considered specialist capacity assessment by other specialists, for instance, palliative care specialists and geriatricians, to be of significance. They note that ‘[f]or such a difficult area... most medical practitioners would want to seek a specialist capacity assessment... Around end of life choices, obviously, there would have to be a degree of scrutiny of that because it is such a difficult and permanent decision.’¹⁷⁶ RANZCP(WA) did not defer capacity

175 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 28 February 2018, Session 3 at 8 (emphasis added).

176 Dr Moore, Branch Chair, Royal Australian and New Zealand College of Psychiatrists (WA), JCEOLC Transcript, 28 February 2018, Session 5 at 3 and 4.

Chapter 2

assessment to general practitioners and still saw specialist assessment to be of importance.

- 2.26. Further in their submission, RANZCP(WA) state 'Given the serious medico-legal implications, [assessments of mental health diagnoses or cognitive impairment] are necessarily detailed and often require collection of extensive background history, liaison with family/carers and health professionals.' RANZCP(WA) suggest that 'due to the often rapidly changing manifestations of mental illness, proper assessments are best undertaken by clinicians with the benefit of extended interactions over a significant period of time with the individual in question.'¹⁷⁷ They also note that '[t]raumatic brain injury, addictions, dementia and delirium may all confound assessments of capacity and non-psychiatrically trained doctors "are not well placed to recognise the presence of these conditions in the medically ill population."¹⁷⁸

The complexities involved in the assessment of capacity

- 2.27. The reasons behind a preference for specialist assessment of capacity are various and relate to the complexity involved in assessing a patient's capacity, particularly in the context of assisted suicide.
- 2.28. Dr Gibson notes that:

While individuals with mental illness must be afforded the same rights as other individuals within society, they are implicitly vulnerable in the potential context of seeking end of life because of issues of stigma, the inherent nature of mental illness (the complexity of determining remedial drivers and the influences on these), and the complexity of determining capacity.

It is inherently complex to determine the influences on drivers to seek end of life in an individual with mental illness.

It cannot be assumed that decision making regarding end of life for an individual with mental illness is linear, simple or obvious.¹⁷⁹

- 2.29. In his submission to the Committee, the Chief Psychiatrist identifies a number of factors that contribute to the complexity of assessing capacity:
- Capacity is decision specific
 - Capacity is fluctuant, and can change over time

177 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 6.

178 Ibid, quoting Ryan C (2012) 'Playing the Ferryman: Psychiatry's role in end-of-life decision-making,' *ANZJ of Psych* 46(10) at 932-5.

179 Dr Gibson, Chief Psychiatrist of Western Australia, Submission 655 at 4 (emphasis added).

- The assessment of capacity in a clinical setting cannot be a ‘tick-box,’ but involves a robust interpersonal assessment as well as consideration of the specific criteria
- Ability to assess capacity is a variable skill across medical practitioners
- Where an individual has significant, fluctuating mental illness, the clarification of decision-making capacity can be a significant ongoing challenge; Capacity is complex in individuals with mental illness¹⁸⁰

2.30. Dr Gibson also testified to the difficulty of assessing capacity, and that someone who *appears* to have capacity may actually be lacking capacity:

*The example of that [where someone lacks capacity or the psychiatrist has uncertainty about the individual's capacity] is where you see someone - it is not an uncommon scenario—and they appear to have capacity. But when you go and speak to their family, it is very clear that what they have said to you is entirely problematic and they do not have capacity, based on what they have been doing. What they have been saying does not reflect what they have been doing. Sometimes if you just do a one-off assessment with the person, you could be tricked, not because the person is trying to trick you; you just do not get the full story. That is why I think if there is any doubt, you should do it again. Certainly, if someone does not have capacity, you should do it again as well.*¹⁸¹

2.31. RANZCP(WA) also note that:

*People suffering from mental disorders may manifest significant fluctuations in their cognitive function over short periods of time and may also vary in decision-making capacity depending on the matter being addressed... For a person with co-existing physical and mental illnesses, ensuring adequate decision-making capacity in the context of PAS may therefore pose significant challenges.*¹⁸²

2.32. The issue of co-morbidity as a complicating factor in the assessment of capacity has also been raised in peer-reviewed literature. Ryan, a Consultation-Liaison Psychiatrist from the Department of Psychiatry, Westmead, notes that ‘Sadness and despair are normal

180 Ibid at 3-4 (emphasis added). That capacity assessment is a difficult area medically, since capacity can fluctuate and change, was also acknowledged by Mrs Wallace, Delegate of Justice Jeremy Curthoys, State Administrative Tribunal of WA, JSCEOLC Transcript, 28 February 2018, Session 6 at 5-6.

181 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 14 December 2017, Session 5 at 15.

182 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 6 (emphasis added).

Chapter 2

responses to the news that one is gravely ill. However, as many as one in five seriously ill people go beyond this normal response to develop major depression. Major depression is far more than a disorder of emotion; its effects on reason and the intellect may be just as profound.¹⁸³ Further:

*Unfortunately, the diagnosis of major depression in the gravely ill is very difficult. Low spirits are to be expected in serious illness, and many of the other features of major depression (such as weight loss and sleep disturbance) are also common in physical illnesses. The difficulty of diagnosis is reflected in studies that reveal that non-psychiatrically trained doctors miss up to half of cases of major depression in the medically ill.*¹⁸⁴

- 2.33. The risk of undiagnosed mental illness was also identified by the New York Task Force on Life and the Law in a 1997 supplementary report:

*Many individuals who contemplate suicide — including those who are terminally ill — suffer from treatable mental disorders, most commonly clinical depression. Yet, physicians routinely fail to diagnose and treat these disorders, particularly among patients at the end of life. As such, if assisted suicide is legalised, many requests based on mental illness are likely to be granted, even though they do not reflect a competent, settled decision to die.*¹⁸⁵

- 2.34. The difficulties faced by patients with co-morbidity was also addressed in evidence given to the Committee. Dr Best noted that the incidence of depression is high in terminally ill patients, and up to 80 per cent of depressed patients with cancer are not diagnosed or treated.¹⁸⁶ Dr Khorshid of the AMA(WA) noted that:

[T]he discussion around diagnosis of depression and other mental illnesses that are co- morbid with terminal illnesses is very difficult for the average doctor and very difficult for a palliative care physician or any non-psychiatrist, and, in fact, is probably difficult for psychiatrists as well. Our strong recommendation is that a psychiatric assessment be completed for everybody accessing this option, partly around

183 Ryan CJ (1996) 'Depression, decisions and the desire to die' *Med J Aus* (1996) 165(8) at 411.

184 Ibid (emphasis added) – citing the following studies: Feldman, Mayou and Hawton et al. (1987) 'Psychiatric disorder in medical patients,' *QJM* 63, 405-412; Nielson and Williams (1980) 'Depression in ambulatory medical patients: Prevalence by self-report questionnaire and recognition by nonpsychiatric physicians' *Arch Gen Psychiatry* 37, 999-1004 and Clarke and Smith (1995) 'Consultation-liaison psychiatry in general medical units,' *Aust NZ J Psych* 29, 424-432.

185 New York Task Force on Life and the Law (1997) *Supplementary Report to When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context (1994)* at 4-5; quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 10.

186 Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 2 at 3.

*competence...but mainly to exclude significant mental illness. We know those rates of mental illness are extremely high in this population and we would not countenance access to euthanasia because someone is depressed. We feel that would be an inhumane treatment.*¹⁸⁷

- 2.35. General data around liaison psychiatry suggests that around 40 per cent of people in a general hospital setting may be experiencing some degree of significant mental health comorbidity along with their physical health morbidity. Comorbid depression with cancer or other advanced illnesses is common.¹⁸⁸
- 2.36. The impact of failure to identify psychiatric comorbidity in terminal patients is illustrated in a Palliative Care Australia article in which Professor Gregory Crawford shares the difficulty he has encountered in identifying psychiatric illness in a patient suffering from a terminal condition:

One of the motivators was that I looked after a 15-year-old girl who had a malignancy who looked like she was dying. I was working as the clinical head of palliative care at a hospital in Adelaide, and she was referred to us on the basis that she only had weeks to live. She had difficult pain to manage and other symptoms that led to her becoming more and more withdrawn.

I was slow to recognise that she was depressed and I found it hard to find advice and support about to manage it.

I looked in the literature and talked to psychiatrists and other colleagues. I ended up changing her antidepressants and she made a miraculous improvement, both physically and psychologically. She improved and lived for another 12 months. She had serious, progressive disease but her physical function and her ability to interact and live improved. She went off on a holiday, achieved some other things on her wish list and made lots of other nice memories for her family.

She died at home, supported by our palliative care service and her GP, and we had support from the paediatric palliative care service.

It showed me that sometimes the symptoms of impending death and the symptoms of advanced depression can look very much the same. I felt a bit like I had failed, having taken so long to recognise her depression and then act on it, which made me determined to learn more

187 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 7.

188 Dr Miller, Clinician, Consultant Liaison Psychiatrist in Cancer and Palliative Care, JSCEOLC Transcript, 13 December 2017, Session 4 at 4-5.

Chapter 2

about depression in this context. It drove me to try and understand more about psychological illness.

There has been a large amount of research in this area, but it is still very difficult to really determine what is a normal reaction to what is happening, like sadness, and what is an abnormal reaction, like a major depressive illness.

...

The implications of not diagnosing are that patients have increasing suffering and may not be getting the best treatment. They may be losing an opportunity to have more time or meaningful interaction with people around them. For their families, this can be a very large trauma; to not understand why somebody has turned their back on them or why they might be rejecting relationships, being overwhelmingly sad, or wanting to die precipitously. When triggered by depression, those responses can be quite challenging.¹⁸⁹

- 2.37. Professor Crawford notes that the implications of not diagnosing a mental illness in a terminal patient are that the patient will have increased suffering and may not be receiving the best treatment. Were assisted suicide to be legalised in Western Australia, the implications for the patient would also include an early and unnatural death.

Demoralisation and the wish to hasten death

- 2.38. In any event, reducing the need for psychiatric consultation to the issue of competency ignores the relevance of other psychological factors that go into the request for assisted suicide.¹⁹⁰ RANZCP(WA) note in their submission that there is a significant body of literature around the wish to hasten death, which should be taken into account in any discussion of this important and complex area.¹⁹¹
- 2.39. RANZCP(WA) emphasise the need for better supported consultation-liaison psychiatry with psychiatrists who specialise in the treatment of mental illness in the context of physical illness:

In situations where a patient has a terminal condition causing suffering, there is a risk that symptoms of mental ill health may be mistaken by a

189 Heather Wiseman (2017) 'Distinguishing between sadness and depression at the end of life: a significant challenge tackled by a leader in palliative care,' *Palliative Care WA*, 29 August 2017 – interview with Prof Gregory Crawford.

190 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1) 16-30 at 23-24, citing Hendin and Foley (2008) 'Physician assisted suicide: a medical perspective,' *Michigan Law Review* 106, 1613-1640.

191 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 2.

*doctor not trained in psychiatry for an 'understandable' reaction to their condition. Furthermore, treatment for mental health issues can help to relieve the experience of physical pain, due to the interaction of biological and psychological systems.*¹⁹²

- 2.40. As cited earlier, advocates of assisted suicide assume that it is possible to distinguish between euthanasia requests that are a mis-expression of an underlying, unresolved need, and those that reflect a personal philosophy of choice, despite optimal care. The evidence given to the Committee with regard to the complexity of consultation-liaison psychiatry indicates otherwise.
- 2.41. Dr Lisa Miller, Clinician and Consultant Liaison Psychiatrist in Cancer and Palliative Care, gave evidence to the Committee that the expression of a wish for hastened death must be distinguished from specifically a desire to end life, or the desire to pursue assisted suicide as a mechanism of ending life.¹⁹³ The case study she presented clearly illustrates the risk assisted suicide represents for patients affected by a mental illness such as depression, but also the condition of demoralisation:

I have a single clinic. It is the only specifically funded cancer liaison psychiatry clinic in Western Australia. It had a month waitlist, but the urgency of the situation meant that I made specific time to be able to see this fellow within two days of receiving that contact.

I then met with him and with his wife and he certainly appeared very low in mood. I asked him to tell me a bit more about his experience. He described his discomfort on swallowing. He had lost a substantial amount of weight, approximately 10 kilograms, over the course [of] his treatment. He felt that this was unendurable for him. He really felt that there was no point in continuing to live if life meant living like this.

So as a process of taking an individualised history from him, finding out a little bit more about him as a person, the things that were important to him, he was able to actually articulate that there was a range of physical symptoms that were contributing to his significant distress, particularly that pain was making it very difficult for him to eat. He felt that if continued treatment meant that he would continue to need to experience this burden, that that was clearly not an option for him. But he actually also was very much wanting to be helped at the same time,

¹⁹² Ibid at 4.

¹⁹³ Dr Miller, Clinician, Consultant Liaison Psychiatrist in Cancer and Palliative Care, JSCEOLC Transcript, 13 December 2017, Session 4 at 2.

Chapter 2

so I certainly did feel that he was suffering from a major depressive disorder.

I also felt that he was suffering, because I am a palliative medicine specialist by training as well, that he had severe mucositis—so inflammation of the very sensitive mucosal linings that can happen with chemo and radiotherapy for head and neck cancers—and that his substantial weight loss and the associated malnutrition that he had developed was also likely to be a feature contributing both to his low mood, his fatigue, and also to his inability to actually improve his nutrition. Once people slip into starvation syndrome, it is very difficult for them to restore their own nutrition. So in the process of speaking with him and with his wife, he was agreeable to me starting an antidepressant medication that I know to be tolerable for people who are undergoing cancer treatment. It comes in a particular soluble form that makes it less difficult for people who are having trouble swallowing.

We organised for some specialist palliative care input, but also I was able to talk to the radiation oncology registrar through optimising some of his medication so that he could tolerate those in a form that was manageable for him, as opposed to trying to swallow tablets.

In addition, I was able to organise a dietitian referral to work on some supplements to improve his diet. Ultimately, we actually did organise an inpatient hospital admission for some nasogastric feeding to improve his nutrition. Within two weeks, he was already exhibiting substantial improvement in his depression, his symptom control was better and he was feeling that he was sleeping better and, as a result, he was managing his emotions during the day a little better.

I was then able to follow him up and advocate on his behalf, on seeing him on a number of occasions over the next two months as he completed his treatment. Six weeks ago I saw him, big smile on his face, and he said, “Lisa, I’ve just been told my cancer is cured. I’m the best I’ve felt in 10 years. I know I still have a way to go in regaining some of my weight, but I’m back at work. I’m really looking forward to Christmas with my family.”

So, I bring this case because I think a nuanced assessment of an individual’s expression of their suffering that actually then drills down into the biological aspects of that, the psychological aspects of that, the social aspects of that, the spiritual aspects in terms of people’s sense of loss of meaning, loss of role functioning, loss of purpose et cetera, is

*actually really crucial, both in terms of reducing their burden of suffering—I am a doctor and that is my role—but also very important for the experience of his family.*¹⁹⁴

- 2.42. Dr Miller refers to the work of Monforte-Royo et al,¹⁹⁵ whose research suggests that an expressed wish to hasten death is generally a response to multidimensional suffering, and it is acknowledged as a phenomenon that tends to vary over time. It depends on the stage of circumstances in which an individual person might find themselves, and is reflective of a range of domains—physical, psychological, social, existential and spiritual. The wish for hastened death can hold different meanings for different individuals and it can serve functions other than to communicate a genuine wish to die. Dr Miller concludes that as such, there is a very important need to individualise the assessment and to hear the story of the person patient in order to understand what underpins that expression of that wish.¹⁹⁶
- 2.43. Demoralisation as a diagnostic entity is an important consideration in the assisted suicide debate. It acknowledges that there are factors unique to each patient—outside of a diagnosis of clinical depression—that may influence a patient’s request for assisted death. For example, the Professionalism and Human Rights Committee of the American College of Physicians identify loneliness as having a mortality risk similar to that of smoking, yet the health implications of loneliness are underappreciated.¹⁹⁷

In the case study offered by Dr Miller, the patient was diagnosed as suffering from depression, but was also demoralised:

He was depressed and he was demoralised. I am sorry; I know that is a bit of a muddy distinction. He certainly met a full set of criteria for a major depressive episode, which is why I treated him with an antidepressant, which he responded very well to, but there were also features of demoralisation that related to the fact that he was having difficulty swallowing, could not sleep very well, had pain et cetera, and the sense of isolation that that created for him as well, so we were able

194 Dr Miller, JSCEOLC Transcript, 13 December 2017, Session 4 at 2-3.

195 Monforte Royo et al (2012) ‘What Lies Behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients’ *PLoS ONE* 7(5), e37117 doi:10.1371/journal.pone.0037117.

196 Dr Miller, Clinician, Consultant Liaison Psychiatrist in Cancer and Palliative Care, JSCEOLC Transcript, 13 December 2017, Session 4 at 2.

197 Snyder, Sulmasy and Mueller (2017) ‘Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,’ Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576, citing Gerst-Emerson and Jayawardhana (2015) ‘Loneliness as a public health issue: the impact of loneliness on health care utilisation among older adults,’ *Am J Public Health* 105, 1013-9.

Chapter 2

*to actually address features so that both his demoralisation and his depression were responsive.*¹⁹⁸

- 2.44. Access to consultation-liaison psychiatry in the context of legalised assisted suicide in this state would be of great concern. As Dr Miller noted in explaining her case study, she has the only specifically funded cancer liaison psychiatry clinic in Western Australia, and she has a month-long waitlist. St John of God Health Care also noted that rapid access to psychological and psychiatric services is limited outside the context of inpatient specialist palliative care. They note that in the absence of adequately addressing psychological distress, requests for assisted dying may be more likely.¹⁹⁹ Likewise, RANZCP(WA) state:

*Adequate support for consultation-liaison services is essential in ensuring people with chronic and terminal illnesses are able to alleviate or manage psychological suffering. It is arguable that patients are currently able to fully exercise choice regarding end of life care where such services are unavailable or poorly understood.*²⁰⁰

- 2.45. Monforte-Royo et al conclude that the results of their study into the wish to hasten death highlight the importance of analysing the meaning which patients in the advanced stages of an illness attribute to their suffering and its consequences, which renders them highly vulnerable.²⁰¹ The introduction of legalised assisted suicide in Western Australia would present an unacceptable risk to patients in an advanced stage of their illness whose wish for hastened death is not assessed and addressed by a specialised consultation-liaison psychiatrist, but is instead taken as a competent request for assisted suicide at face value.

Finding 17

The stakes are high when an individual is given responsibility to distinguish between euthanasia requests that are a mis-expression of an underlying unresolved need, and those that reflect a personal philosophy of choice, despite optimal care.

Finding 18

An assisted suicide regime with an optional referral for psychiatric capacity assessment does not safeguard against the assisted suicide of patients whose capacity is impaired by depression or other mental health considerations, in part because the ability to assess capacity is variable across medical practitioners.

198 Dr Miller, Clinician, Consultant Liaison Psychiatrist in Cancer and Palliative Care, JSCEOLC Transcript, 13 December 2017, Session 4 at 5.

199 St John of God Health Care, JSCEOLC Response to Questions on Notice, undated, at 4.

200 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 4-5.

201 Monforte Royo et al (2012) 'What Lies Behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients,' *PLoS ONE* 7(5), e37117 doi:10.1371/journal.pone.0037117 at 14-15.

Finding 19

It is inherently complex to determine the influences on drivers to seek end of life in an individual with mental illness.

Finding 20

A single psychiatric visit to assess capacity is inadequate to determine whether a psychiatric disorder is impairing the judgment of a patient seeking assisted suicide.

Finding 21

Diagnosing demoralisation is as important as diagnosing depression and other conditions when seeking to alleviate and manage psychological suffering.

Finding 22

Access to consultation-liaison psychiatry in Western Australia is poor.

Recommendation 7

The Minister for Health should develop a plan to increase the number of consultation-liaison psychiatrists in Western Australia.

Finding 23

The introduction of a legalised assisted suicide regime in Western Australia would present a grave risk to patients, especially those in an advanced stage of their illness whose wish for hastened death has not been assessed and addressed by a specialised consultation-liaison psychiatrist.

Mandatory psychiatric assessment cannot eliminate error in capacity assessment

- 2.46. Mandatory psychiatric assessment of patients does not, however, eliminate error in capacity assessment since the assessment criteria for mental illness will have subjective weighting and analysis based on the skill and experience level of the individual clinician. Furthermore, it is not uncommon for clinicians to disagree on the nature of an individual's mental illness.²⁰² Parker notes, in a study of 94 capacity decisions by the Queensland Guardianship and Administrative Tribunal involving evidence from more than one health professional expert, 27 (28.7 per cent) demonstrated disagreement between the experts concerning capacity. This was not a disagreement over the level of capacity, but a disagreement about the possession of capacity.²⁰³
- 2.47. Dr Gibson also gave evidence to the Committee that two specialist practitioners, such as psychiatrists and geriatricians, could disagree on an assessment of capacity, and this

202 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Submission 655 at 3.

203 Parker M (2008) 'Patient competence and professional incompetence: Disagreements in capacity assessments in one Australian jurisdiction, and their educational implications' 16 *JLM* 25.

Chapter 2

disagreement was more likely to occur in the 'borderline cases.'²⁰⁴ He suggests that 'It is not necessarily about erring; it is about complexity of that grey zone.'²⁰⁵ He goes on to note that:

That is where it is, again, a stakes issue, because some depression can be difficult to diagnose in certain cohorts, especially in someone who is on lots of medications, in someone who is perhaps in pain; it can be tricky to diagnose depression. You might have two psychiatrists who have different opinions on that as well. It is not an easy, lay-down misère diagnosis.²⁰⁶

- 2.48. Professor PE Mullen also refers to her own failure, as a leading forensic psychiatrist, to identify depression in her patients:

I have, on more occasions than I care to recall, failed professionally to recognise depression because I have been caught up in, and dazzled by, the tragedy of my patient's life. I have accepted their wish for death as a rational and proper desire only to have seen their desires melt away with their depression when... less involved colleagues treated the process in which the patients were trapped.²⁰⁷

- 2.49. Dr Miller gave evidence to the Committee that psychiatric assessment of capacity for the purposes of assisted suicide would be problematic:

Certainly, with the nature of assessment of decision-making in my business, particularly because I look after people with primary brain tumours, it is important to understand that decision-making exists on a continuum, but people move backwards and forwards along that continuum depending on the nature perhaps of their tumour, the side effects of treatments that they might be experiencing, the progression of the underlying disease process, and the response to treatments. The notion that it is a black and white sort of idea does not map to the reality of what I see. But I can see that it would also be very difficult, if I were in a position to be someone who is undertaking assessments, the due diligence that would be required for such an assessment in terms of getting a sense of all the issues that might be impacting on that person's level of their expressed wish, and then trying to determine what needs have been met and what needs are not met, and at what point does my

204 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 28 February 2018, Session 3 at 2-3.

205 Ibid.

206 Ibid at 6.

207 Zalberg JR and Buchanan JD (1997) 'Clinical issues in euthanasia' *MJA* 166 at 151, quoting PE Mullen (1995) 'Euthanasia: an impoverished construction of life and death' *J Law Med* 3, 121-128.

assessment become one of a therapeutic intervention. What happens if that person says, "Can I come back and see you to discuss this later?" In terms of resource implications, I think we probably need to be aware of those as broader issues, and certainly access to specialist liaison psychiatry and, indeed, to specialist palliative medicine does vary around the state.²⁰⁸

- 2.50. This reflects the concerns of Kissane, who writes that:

This assessment role [psychiatric assessment in assisted suicide applications] may be perceived as adversarial and not conducive to the development of a therapeutic alliance, upon which successful counselling must depend. Duty of care requires an appropriate trial of proper treatment, with thorough attention to diagnosis, choice and dose of medication, length and variation of therapy, and second opinion if the clinician is unfamiliar with the clinical circumstances present.²⁰⁹

- 2.51. Concern was also expressed by RANZCP(WA) about the resource implications and their fear that mandatory psychiatric assessment of capacity in assisted suicide applications would take psychiatrists away from already needed basic palliative care.²¹⁰ In their submission to the Committee, RANZCP(WA) note that

Additionally, due to resourcing and access issues, consultation-liaison psychiatry services are currently not able to see many patients with a therapeutic need for psychiatric assessment at the end of life (to enable detection and treatment of mental health comorbidities which may impact on their burden of suffering and thus on their desire to pursue PAS). It would be very concerning to see a situation by which current critically stretched services are expected to absorb the significant burden of complex medico-legal assessments, when earlier access to therapeutic intervention may have removed the need for this.

...

The WA Branch is very concerned that the introduction of PAS legislation may mean that the scarce existing resources in consultation-liaison and palliative care are diverted from providing timely service to people with treatable illness into providing the medico-legal assessments. The

208 Dr Miller, Clinician, Consultant Liaison Psychiatrist in Cancer and Palliative Care, JSCEOLC Transcript, 13 December 2017, Session 4 at 3-4 (emphasis added).

209 Kissane DW (2000) 'The Challenge of Informed Consent,' *Journal of Pain and Symptom Management* 19(6) at 473.

210 Dr Moore, Branch Chair, Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Transcript, 28 February 2018, Session 5 at 5.

Chapter 2

*impact of the administrative burden that was imposed by the implementation of the Mental Health Act 2014 has been felt across mental health services and the WA Branch would recommend that this situation be avoided.*²¹¹

- 2.52. The experience in the Northern Territory under the operation of the *Rights of the Terminally Ill Act 1995* (NT) (ROTI Act) also reveals that mandatory psychiatric assessment does not safeguard vulnerable patients. The mandatory system in the Northern Territory signally failed to adequately identify depression, demoralisation or other psychiatric issues which may have been treatable in all four cases of persons euthanised under that regime. The Northern Territory experience evidences that compulsory referral to a psychiatrist, who may have never seen the person before, for a single brief assessment of whether the person's decision making capacity about assisted suicide is affected by depression or other psychiatric factors is clearly an inadequate safeguard and will not make assisted suicide 'safe.'²¹² Using psychologists or psychiatrists as gatekeepers only to establish a patient's capacity to make a decision for assisted suicide contributes to pro forma, meaningless consultations.²¹³
- 2.53. It is clear that no assisted suicide legislation, even with mandatory psychiatric assessment requirements, can safeguard against the assisted suicide of a person suffering from a treatable mental illness and, if for no other reason, assisted suicide should not be legalised in Western Australia.

Finding 24

Mandatory psychiatric assessment cannot eliminate error in capacity assessments.

Finding 25

No assisted suicide regime, even with mandatory psychiatric assessment, can safeguard against the assisted suicide of a person suffering from a treatable mental illness.

Voluntary and Informed Consent

- 2.54. There are three elements for a valid consent to or refusal of medical treatment, being (a) the capacity of the person, (b) the knowledge of what is about to take place with the treatment, and, also very importantly, (c) the voluntariness of that decision.²¹⁴

211 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 7 and 9 (emphasis added).

212 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 13.

213 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1), 16-30 at 24, quoting Hendin and Foley (2008) 'Physician assisted suicide: a medical perspective,' *Michigan Law Review* 106, 1613-1640.

214 Assoc Prof Blake, UWA, JSCEOLC Transcript, 26 February 2018, Session 3 at 12.

Informed consent

- 2.55. The importance of informed consent in medical decision making was highlighted by Associate Professor Meredith Blake, Legal Researcher at the University of Western Australia, in evidence given to the Committee. Associate Professor Blake suggested that an assisted suicide model in Western Australia might require the delivery and communication and taking in of certain amounts of information that would not be required in relation to a minor or standard medical procedure.²¹⁵ This suggestion is understandable given the stakes are self-evidently so much higher for the patient.
- 2.56. Peled et al note that patient autonomy is violated if options that potentially lead to a different choice are not provided.²¹⁶ They suggest that autonomy concerns in relation to assisted suicide are not merely theoretical and that site studies have shown that less than one half of clinic outpatients surveyed in Oregon knew that life support could be withdrawn or that pain can be aggressively managed by increasing medication doses. Also in Oregon, physicians surveyed from 1997 to 1999 reported that 30 per cent of patients who initially sought physician-assisted dying (PAD) received interventions that later altered their desire for PAD. Patients who received substantive interventions (control of pain or other symptoms; antidepressant trial; or referral to palliative care, hospice, mental health, social work, or chaplaincy) were three times more likely to change their minds about PAD than those who did not.²¹⁷
- 2.57. Dr Koh, Chair of the RACGP, gave evidence to the Committee that when asked by patients for euthanasia to be given to them, a broader discussion around the end of life could then be had and that many patients, while of sound mind, do not understand the journey of palliative care and of end of life.²¹⁸ The autonomy of patients requesting assisted suicide in Western Australia will be violated if assisted suicide is sought in the absence of knowledge of other quality end of life care options available to them. Evidence was given to the Committee that not only is the general community not aware of the breadth of available palliative care options, many health professionals are also hold that same lack of awareness.²¹⁹ If the patient is not aware of their full palliative care options, and

215 Ibid.

216 Peled et al (2017) 'Enhancing Informed Consent for Physician Aid in Dying: Potential Role of Handout on Possible Benefits of Palliative Care' *American Society of Clinical Oncology* <<https://doi.org/10.1200/JOP.2017.021105>> at 2.

217 Ibid at 3, citing Ganzini et al (2000) 'Physicians' experiences with the Oregon Death with Dignity Act,' *N Engl J Med* 342, 557-563.

218 Dr Koh, Chair, Royal Australian College of General Practitioners (WA), JSCEOLC Transcript, 14 December 2018, Session 1 at 15.

219 Palliative Care WA, JSCEOLC Responses to Questions on Notice, at 3; Silver Chain, JSCEOLC Response to Questions on Notice, at 2; Dr Bradley, Palliative Care Clinical Lead, WA Cancer and Palliative Care Network, Department of Health, JSCEOLC Transcript, 13 December 2017, Session 1 at 21; Ms Calcutt, Project Officer, Palliative Care WA, JSCEOLC Transcript, 9 April 2018, Session 3 at 8; Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 3; Mrs Buchanan, Committee Member, Palliative Care Nurses Australia, JSCEOLC Transcript, 14 December 2017, Session 2 at 5; Dr Campbell, President, Palliative Care WA, JSCEOLC Transcript,

Chapter 2

the consulting doctor is not aware of these options either, it cannot be said that the patient's request for assisted suicide is informed.

- 2.58. Whilst knowledge is a core component of informed consent, access to the known options is just as important to ensure the knowledge is more than merely theoretical. Informed consent to assisted suicide cannot be obtained unless good palliative care is actually available to the patient. A failure to appropriately control a patient's pain or to provide access to palliative care can result in requests for euthanasia which cannot properly be termed voluntary.²²⁰ It is arguable that the euthanasia of at least one of the patients under the Northern Territory's ROTI Act could not be termed voluntary. With reference to the patient suffering from mycosis fungoides, Kissane notes that the voluntariness of her choice for euthanasia was influenced by her not being informed of the availability of effective treatment for depression nor being given the opportunity to have her suffering alleviated.²²¹ Arguably the lack of specialist palliative care in the Northern Territory at the time of the operation of the ROTI Act could also be said to influence the voluntariness of all of the requests for euthanasia made during that period. Indeed the same issues arise here in Western Australia, where the Committee has heard evidence that up to 60 per cent of Western Australians do not have access to the palliative care that they require.²²²
- 2.59. Whether informed consent is given by a patient is also dependent on a patient's mental condition. It is suggested that demoralised patients may also not be capable of making a truly informed decision in giving medical consent.²²³ Chochinov et al note that:

Although concurrent depression does not necessarily imply that a desire for death is implicitly "irrational," the reasoning processes of depressed patients are characteristically biased by negative mental sets that may affect their capacity to make well-considered life-and-death decisions. Furthermore, demoralisation and a lack of assertiveness may render the

14 December 2017, Session 4 at 8 and 13-14; Mrs Matthews, Individual Submitter, JSCEOLC Transcript, 27 February 2018, Session 3 at 9; Prof Doug Bridge, Senior Palliative Care Specialist, UWA Faculty of Medicine and Health Sciences and WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 1.

220 Strinic V (2015) 'Arguments in Support and Against Euthanasia,' *British Journal of Medicine and Medical Research* 9 at 4 – cited in Quinlan M (2016) "'Such is Life': Euthanasia and capital punishment in Australia: consistency or contradiction?' *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* 6(1) at 12.

221 Kissane DW (2000) 'The Challenge of Informed Consent,' *Journal of Pain and Symptom Management* 19(6) 473-4 at 473.

222 Palliative Care WA, JSCEOLC Response to Questions on Notice, 19 December 2017 at 3, citing Palliative Care Outcomes Collaboration (PCOC) data (2017) Australian Health Services Research Institute, University of Wollongong.

223 Kissane DW (2002) 'Deadly days in Darwin,' in *The Case Against Assisted Suicide*, Foley & Hendin (eds), Johns Hopkins University Press, at 192-209, quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 12.

*depressed terminally ill patient more vulnerable to the suggestions of others, thereby increasing the potential for abuse.*²²⁴

- 2.60. Undue influence and the abuse of vulnerable patients is further considered below.

Finding 26

A valid consent to medical treatment is dependent on the:

- a) capacity of the patient;
- b) patient's knowledge of the treatment options; and
- c) the voluntariness of the decision.

Undue influence

- 2.61. Although someone may have capacity, they may still be unduly influenced so as to make a decision which is not made voluntarily or of their own free will. Mr Cameron Eastwood, a Western Australian legal practitioner, explained in his evidence to the Committee that undue influence is a legal construct that can be defined as the improper use by someone of an ascendancy over another person, to derive benefit for themselves or a third party by coercing actions from overborne person that are not free, voluntary acts. The nature of the relationship between the parties (one of ascendancy by one person over the other) is the foundation of the influence. Risk factors of undue influence include older age, family conflict, isolation, physical disability, mental disorder, recent bereavement and language difficulties.²²⁵
- 2.62. In relation to undue influence in medical decision making, Lord Donaldson MR of the English Court of Appeal, Civil Division, stated the matter to be considered as follows:

A special problem may arise if at the time the decision is made the patient has been subjected to the influence of some third party. This is by no means to say that the patient is not entitled to receive and indeed invite advice and assistance from others in reaching a decision, particularly from members of the family. But the doctors have to consider whether the decision is really that of the patient. It is wholly acceptable that the patient should have been persuaded by others of the merits of such a decision and have decided accordingly. It matters not how strong the persuasion was, so long as it did not overbear the independence of the patient's decision. The real question in each such case is "Does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer

224 Chochinov et al (1995) 'Desire for death in the terminally ill' *The American Journal of Psychiatry* 152(8) 1185-91.

225 Mr Eastwood, Legal Practitioner, JSCEOLC Response to Questions on Notice, 20 April 2018 at 3.

Chapter 2

think and decide for himself?" In other words "Is it a decision expressed in form only, not in reality?"

When considering the effect of outside influences, two aspects can be of crucial importance. First, the strength of the will of the patient. One who is very tired, in pain or depressed will be much less able to resist having his will overborne than one who is rested, free from pain and cheerful. Second, the relationship of the "persuader" to the patient may be of crucial importance. The influence of parents on their children or of one spouse on the other can be, but is by no means necessarily, much stronger than would be the case in other relationships. Persuasion based upon religious belief can also be much more compelling and the fact that arguments based upon religious beliefs are being deployed by someone in a very close relationship with the patient will give them added force and should alert the doctors to the possibility - no more - that the patient's capacity or will to decide has been overborne. In other words the patient may not mean what he says.²²⁶

- 2.63. The possibility that a patient may be influenced by their family to seek assisted suicide is not far-fetched. 'Cries for help' also come from families, who often suffer deeply when a relative has a life-threatening illness, and the incidence of depression in families correlates with its incidence in patients. 'Can't it all end? Isn't there an easier way?' are commonly heard pleas from family members of patients.²²⁷ In a study of relatives and acquaintances of more than 3000 patients who had died, about a quarter of respondents had wished for the patient's earlier death, but only 3.6 per cent of the patients had specifically discussed the issue of euthanasia.²²⁸
- 2.64. It is also possible that a medical adviser may exert undue influence on a patient. Stewart and Lynch also discuss the application of undue influence to cases involving a medical adviser influencing a patient to consent to or withhold consent from a medical procedure. They consider the case of *Centre for Reproductive Medicine v Mrs U*,²²⁹ which involved a claim by a widow that her late husband's withdrawal of consent for the posthumous use of his sperm for IVF had been unduly influenced by a nurse at the clinic and conclude that, notwithstanding the decision in that case, undue influence by a medical adviser may emerge as a factor in the validity of consents to medical treatment.

Why Mrs U is both different and important is that it concerns the influence emanating not from a third party but from the health

226 Lord Donaldson MR in *Re T* [1992] EWCA Civ 18 (30 July 1992) at 31-32 (emphasis added).

227 Zalberg JR and Buchanan JD (1997) 'Clinical issues in euthanasia,' *MJA* 166 150 at 150.

228 Seale C and Addington-Hall J (1994) 'Euthanasia: why people want to die earlier,' *Soc Sci Med* 39, 647-654.

229 Unreported, High Court of Justice, Family Division, The President, 25 January 2002.

professional directly. The Court of Appeal's reluctance to extend the equitable rules traditionally governing property transactions is understandable. But in acknowledging that they 'may have a part to play', the Court presents the possibility that patients may subsequently claim that their consent to or refusal of treatment was unduly influenced by a doctor. Although Mrs U maintains the strict test as to what that influence must amount to, it is not difficult to imagine that in many medical cases a weakened patient simply trusts the doctor's opinion and accedes to what is recommended.

Although the findings in Mrs U seem to foreclose the possibility that undue influence will acquire any immediate significance in the law of consent and the liability of doctors for treatment, they do not entirely dismiss the extension of the concept into that domain.²³⁰

- 2.65. Some proponents of assisted suicide do not see the undue influence of a medical practitioner as an issue. In evidence to the Committee, in relation to the prohibition in the Victorian legislation against doctors raising the issue of 'voluntary assisted dying' with their patients, Dr Brian Hennessy stated 'My opinion is that doctors should be able to raise it with the patient, but the Victorian legislation was never going to get through two houses of Parliament without that phrase, so I think that was political pragmatism.'²³¹

- 2.66. Dr Richard Lugg, Doctors for Assisted Dying Choice also wanted:

to place on the record our view our view that this is an important reason why a ban on doctors raising the option of VAD is not actually in the best interests of patients with unbearable suffering at the end of life. In any event, as doctors, I think we would consider it an unconscionable interference in the doctor–patient relationship. All treatment options should be on the table when doctors and patients are talking, and we think there should be no such ban.²³²

- 2.67. However, in a Committee hearing Mr John McGrath, Committee member said:

That is a good point that you make. A lot of people have made that point to us—that physicians or GPs should not be encouraging people in any way at all; it should be the person's decision if they really come to that point in their life or they are close to passing. I do not think society would

230 Cameron Stewart and Andrew Lynch (2003) 'Undue influence, consent and medical treatment,' *Journal of the Royal Society of Medicine* 96, 598-601.

231 Dr Hennessy, Head of Anaesthesia Department, Sir Charles Gairdner Hospital, JSCEOLC Transcript, 30 April 2018, Session 1 at 14.

232 Dr Lugg, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 26 February 2018, Session 4 at 5.

Chapter 2

*want GPs out there advertising that you can do this or telling their patients that this is an option for them.*²³³

- 2.68. The issue of medical practitioner influence was also identified by the Professionalism and Human Rights Committee of the American College of Physicians, in their statement that:

*Physicians can influence patients, even in ways physicians may not appreciate. Patients seeking physician assisted suicide may seek validation to end their lives. Indeed, studies have shown that socially isolated, vulnerable persons seek social support and contact through visits with their physicians. Physicians may influence patients based on their own fears of death and disability.*²³⁴

- 2.69. Countertransference was explained to the Committee by Dr Miller, where she states:

*Countertransference came originally from the psychoanalytic literature and relates to the feelings that an individual generates. The context was as a therapist towards the person, in essence. There is a transference from the person to the therapist, and a countertransference back in the other direction... Sometimes, people with challenging needs might generate a strong response either at an emotional level or even expressed at a behavioural level in people around them, where it generates a strong response. Sometimes, although it is not the classical meaning of the word, we sometimes talk about countertransference of health professionals towards challenging patients.*²³⁵

- 2.70. The danger of this countertransference, or this projection of health care worker emotions and meanings on to the patient's experience was also identified by Magnusson in *Angels of Death: Exploring the Euthanasia Underground*:

Kerry points out that the danger for nurses who have worked extensively in HIV and have witnessed terrible deaths is to project their own emotions and meanings on to the patient's experience, to agree with the patient's sense of suffering and futility in a way that legitimates and encourages suicidal ideation. 'I often hear nurses saying things like: 'I

233 Mr John McGrath, Committee Member, to Mr Byl, Private Citizen, JSCEOLC Transcript, 1 May 2018, Session 6 at 4.

234 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576, citing Gerst-Emerson and Jayawardhana (2015) 'Loneliness as a public health issue: the impact of loneliness on health care utilisation among older adults,' *Am J Public Health* 105, 1013-9 and Miles SH (1994) 'Physicians and their patients' suicides,' *JAMA* 271, 1786-8.

235 Dr Miller, Clinician, Consultant Liaison Psychiatrist in Cancer and Palliative Care, JSCEOLC Transcript, 13 December 2017, Session 4 at 6.

don't know why they're hanging around, I don't know why they don't just give up." The danger is in the thinking: "Yes it is terrible, I've seen a hundred people die that way; yes—die!", instead of listening to what the person is saying which may be about "I'm frightened of something, I'm scared of suffering."²³⁶

2.71. And further:

Healthcare workers may project their own sense of horror and repulsion, in subtle ways, on to the patient, thereby reinforcing patients' sense of futility. This raises difficult issues. Being a sounding board, and providing 'emotional accompaniment' are a part of caregiving, and these benefits could hardly come from an emotionally remote carer. But risks may arise when care workers are themselves burned out, or fail to recognise the fragility of their patients and the extent of their influence over them.²³⁷

Finding 27

Countertransference and/or undue influence from a medical practitioner would be two dangerous risks in any assisted suicide regime.

Undue influence and elder abuse

2.72. As already noted, the risk factors for undue influence include older age, family conflict, isolation, physical disability, mental disorder, recent bereavement and language difficulties.²³⁸ In light of these risk factors, and the epidemic of elder abuse that is only now coming to light in Western Australia, it would be unconscionable for the Western Australian Parliament to legalise assisted suicide.

2.73. The Legislative Council of Western Australian established a Select Committee on Elder Abuse on 13 September 2017. Its terms of reference are:

- a) *determine an appropriate definition of elder abuse;*
- b) *identify its prevalence;*
- c) *identify the forms of elder abuse, including but not limited to neglect;*
- d) *identify the risk factors;*
- e) *assess and review the legislative and policy frameworks;*

236 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 92-93.

237 Ibid at 251-2.

238 Mr Eastwood, Legal Practitioner, JSCEOLC Response to Questions on Notice, 20 April 2018 at 3.

Chapter 2

- f) *assess and review service delivery and agency responses;*
- g) *the capacity of the Western Australia Police to identify and respond to allegations of elder abuse;*
- h) *identify initiatives to empower older persons to better protect themselves from risks of elder abuse as they age;*
- i) *consider new proposals or initiatives which may enhance existing strategies for safeguarding older persons who may be vulnerable to abuse; and*
- j) *consider any other relevant matter.*

- 2.74. The Select Committee on Elder Abuse recently made public the paper *Elder Abuse Protocol: Guidelines for Action* (2017), published by the Western Australian Alliance for the Prevention of Elder Abuse (APEA). The World Health Organisation (WHO) definition of 'elder abuse' is adopted in the Guidelines, which is defined as 'a single act, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.'²³⁹
- 2.75. The Guidelines note that the WHO estimates that 15.7 per cent of people 60 years and older in the community may have experienced abuse. This means that potentially over 75,000 older Western Australians are affected. The Guidelines note that this number may be a lot higher for people in 'at-risk' categories, including older people with physical or mental incapacity and people living in institutional settings. Figures of reported elder abuse are likely to underestimate prevalence due to the fact that only a small fraction of cases are reported.²⁴⁰
- 2.76. Evidence was heard by the Select Committee on Elder Abuse in a public hearing with Dr Helen McGowan, of the Older Adult Mental Health Sub-Network, that it is much more difficult to quantify psychological and mental abuse, than the financial abuse of older adults. Dr McGowan also noted that an older age Western Australian is much more likely to experience elder abuse if that person is chronically ill. Of particular note was her evidence that the capacity of general practitioners to identify elder abuse in their patients is 'incredibly variable.'²⁴¹

239 World Health Organization (2002) 'The Toronto Declaration of the Global Prevention of Elder Abuse,' at 3, cited in WA Alliance for the Prevention of Elder Abuse (APEA) (2017) *Elder Abuse Protocol: Guidelines for Action* at 4.

240 WA Alliance for the Prevention of Elder Abuse (APEA) (2017) *Elder Abuse Protocol: Guidelines for Action* at 5.

241 Dr Helen McGowan, Psychiatrist of Old Age and Clinical Co-Lead, WA Mental Health Network, Older Adult Mental Health Sub-Network, Select Committee on Elder Abuse Transcript, 21 May 2018, Session 1 at 10.

- 2.77. Evidence was also heard from Mr Michael Bowyer, Principal Legal Officer of the Public Trustee, that the prosecution of elder abuse cases is a real issue in that 'it is very difficult when your best witness cannot give evidence.'²⁴²
- 2.78. Case study evidence was given to the Select Committee on Elder Abuse by Advocare, a community based advocacy organisation for older adults and people with disabilities. One such case study involved an elderly man diagnosed with terminal cancer and dementia who, with the support of his family (other than his son), had declined futile treatment and had accepted palliative care support in the home. Services were set up for the man but his son, who had a history of issues associated with mental ill-health and drug and alcohol abuse, prevented these palliative care services from access to the home.²⁴³
- 2.79. A Senior Rights Victoria summary of case law and best practice on undue influence in the financial abuse of elders reveals that undue influence can be easily missed and may be difficult to identify.²⁴⁴ A recent parliamentary report on elder abuse in New South Wales also referenced the failure of professionals to identify undue influence and so unwittingly facilitate elder abuse.²⁴⁵ The NSW report further noted that undue influence by one family member over another is commonly facilitated by legal professionals because of their failure to detect when an older person is struggling to manage their financial affairs, that is, when they lack financial capacity.²⁴⁶
- 2.80. It is also worth noting here that in cases of undue influence in matters of financial elder abuse, courts can apply the remedy of rescission. However, what remedy will there be for older Western Australians for whom undue influence has affected their decision to undergo assisted suicide?
- 2.81. Mr Eastwood suggests that an increase in these types of abusive behaviour will occur, with regard to the published research into the increasing prevalence of elder abuse, the

242 Mr Michael Bowyer, Principal Legal Officer, Office of the Public Trustee, Select Committee on Elder Abuse Transcript, 26 March 2018, Session 2 at 15.

243 Advocare Inc (2018) 'Advocare Elder Abuse recent case studies demonstrating the complex nature of Elder Abuse,' Select Committee on Elder Abuse, Western Australia, Advocare tabled paper (2), 12 March 2018.

244 Senior Rights Victoria, <<https://assetsforcare.seniorsrights.org.au/relationship-breaks-down/equity/undue-influence-unconscionable-dealing/>> referred to by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 23.

245 NSW Legislative Council, General Purpose Standing Committee No. 2, Elder Abuse in New South Wales, June 2016, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 23.

246 NSW Legislative Council, General Purpose Standing Committee No. 2, Elder Abuse in New South Wales, June 2016, at 80, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 23-24.

Chapter 2

proportional ageing of the population and an increased incidence of dementia in our elderly population.²⁴⁷

- 2.82. Professors White and Willmott identify the elderly as a vulnerable group, but claim that there is no evidence that such persons have been at increased risk in countries with assisted suicide.²⁴⁸ In response to this assertion, Ms Marina Re, Chief Executive Officer of IdentityWA, writes

Clearly there is no such evidence of those at risk of family coercion or those with disability where no such data has been gathered against these measures. In examining Oregon Health Authority's (OHA) most recent report for 2017, the following observations are offered: For those at risk of family coercion, Oregon [Dying With Dignity Act] requires that the patient needs to be known by doctor. This could be a means to detect possible coercion through witnessing family dynamics. However, the OHA 2017 report shows that the median length of the patient-doctor relationship is just 10 weeks, and in some cases only one week. It is noted that the doctors complete the documentation: a standardised box-ticking exercise for demographic information that reduces responses to generic categories which cannot penetrate the depth patients' subjective experiences and motivations. One possible measure for family coercion would be the sense of "being a burden," which the OHA 2017 report shows to be 55%. It is noted that this ranks above "concern about pain" (21%) as the reason for accessing the DWDA. [Professors White and Willmott] identify the elderly as a vulnerable group. Their claim that there is no evidence to support an increased risk to them is refuted in the OHA 2017 report which shows that the median age is 72 years. Elder abuse is a real and burgeoning problem in Australia. We submit that euthanasia or assisted suicide will not improve this problem.²⁴⁹

- 2.83. The vulnerability of a frail, elderly or ill person to subtle coercion and undue influence was recognised by Sir James Hannen in the 1885 case of *Wingrove v Wingrove*:

The coercion may of course be of different kinds, it may be in the grossest form, such as actual confinement or violence, or a person in the last days or hours of life may have become so weak and feeble, that a

247 Mr Eastwood, Legal Practitioner, JSCEOLC Transcript, 8 March 2018, Session 1 at 2.

248 Willmott and White (2017) 'Assisted Dying in Australia: A Values-based Model for Reform,' in *Tensions and Traumas in Health Law* at 496-7, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

249 Ms Marina Re, Chief Executive Officer, IdentityWA, JSCEOLC Response to Questions on Notice, 10 April 2018 at 2-3.

*very little pressure will be sufficient to bring about the desired result, and it may even be that the mere talking to him at that stage of illness and pressing something upon him may so fatigue the brain, that the sick person may be induced, for quiteness' sake, to do anything. This would equally be coercion, though not actual violence.*²⁵⁰

- 2.84. Mr Richard Egan, Defend Human Life!, argues that in light of this statement by Justice Hannen, simply requiring a physician to tick a box stating that the person requesting assisted suicide is doing so voluntarily is no guarantee that the physician has the competence or has undertaken the extensive and careful inquiries necessary to establish that the person is not subject to undue influence or subtle pressure (albeit unwittingly) from family, friends or society to request assisted suicide so as not to burden others. He argues that no jurisdiction that has legalised assisted suicide has even made any serious effort to establish a genuinely safe framework in this regard.²⁵¹
- 2.85. Associate Professor Blake gave evidence to the Committee that 'safeguards' could be included in assisted suicide legislation to ensure voluntary and informed consent, but the weakness of such procedural 'tick a box' safeguards is evident in the following comment by Associate Professor Blake in a Committee hearing:

*We can have safeguards. We can have ways of best practice and ways of demonstrating that, with this evidence, we can feel comfortable that this person has the capacity to make this decision, has received all the appropriate information and understood it, and has made this decision free of undue influence. That is all we can do, really, because we cannot climb into somebody else's head.*²⁵²

- 2.86. That the safeguards against coercion or undue influence are the doctors themselves, rather than prescriptive 'safeguards' or 'best practice' models is clear in an exchange between Mr Marshall Perron, assisted suicide advocate, and Hon Nick Goiran MLC in a Committee hearing:

Mr PERRON: I believe that the duress question, which is in virtually all legislation, including the Northern Territory legislation, is one of the criteria that is assessed by two doctors in almost all cases of safeguards, and I believe that considering these are not short meetings between doctor and patient, I think that the demeanour of the patient could be

250 Sir James Hannen in *Wingrove v Wingrove* [1885] 11 PD 81, quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 24.

251 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 24.

252 Assoc Prof Blake, UWA, JSCEOLC Transcript, 26 February 2018, Session 3 at 13.

Chapter 2

assessed by doctors reasonably, particularly two of them, including the question of whether they are acting under coercion.

Hon NICK GOIRAN: So the safeguards are the doctors?

Mr PERRON: In this case, yes.

Hon NICK GOIRAN: Should those doctors have had some rapport with the patient?

*Mr PERRON: Not necessarily.*²⁵³

- 2.87. And yet, Dr Khorshid of the AMA(WA) also notes that medical practitioners:

*are not skilled in legal decisions, we are not skilled in knowing what underlying motivations there might be behind a decision to proceed with euthanasia, we are not skilled at knowing whether coercion is occurring, we are not skilled at knowing the impact of a will on a family when we are talking about these complex decisions at end of life... this is such a high stakes decision, it would be unconscionable to get it wrong or to put in a structure that was ripe for abuse or that just did not achieve the outcomes that they were all hoping for.*²⁵⁴

- 2.88. Elder law expert Ms Margaret Dore goes one step further than Mr Egan, to suggest that a legislative assisted suicide scheme officially sanctions the abuse of vulnerable adults. Data from Oregon shows that in 2016 nearly one out every two (48.7 per cent) patients who died after taking prescribed lethal medication cited concerns about being a ‘burden on family/caregivers’ as a reason for the request.²⁵⁵ Ms Dore states:

In both Washington and Oregon, the official reporting forms include a check-the-box question with seven possible “concerns” that contributed to the lethal dose request. These concerns include the patient's feeling that he was a “burden.” The prescribing doctor is instructed: “Please check ‘yes,’ ‘no,’ or ‘don’t know’ depending on whether or not you believe that a concern contributed to the request.”

In other states, a person being described as a “burden” is a warning sign of abuse. For example, Sarah Scott of Idaho Adult Protection Services describes the following “warning sign:” “Suspect behavior by the

253 Mr Marshall Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 7.

254 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 6.

255 Oregon Public Health Division (2017) ‘Oregon Death With Dignity Act: Data Summary 2016, Table 1. Characteristics and end-of-life care of 1,127 DWDA patients who have died from ingesting a lethal dose of medication as of January 23, 2016 [sic = 2017], by year,’ Oregon, 1998-2016 at 10, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 22.

caregiver... [d]escribes the vulnerable adult as a burden or nuisance.” The recommendation is that when such “warning signs” exist, a report should be made to law enforcement and/or to the local adult protective services provider.

Washington and Oregon, by contrast, instruct its doctors to check a “burden” box. Washington and Oregon promote the idea that its citizens are burdens, which justifies the prescription of lethal drugs to kill them. Washington’s and Oregon’s Acts do not promote patient “control,” but officially sanctioned abuse of vulnerable adults.²⁵⁶

- 2.89. Concerns about pressure on the elderly to seek assisted suicide have been widely expressed in the assisted suicide debate in Australia. Former Labor Prime Minister Kevin Rudd expressed his concern in this way:

What I am deeply worried about is one simple practical question, which is: at the point at which an older person concludes that they are sick, they are very sick, and that they have become a burden on their families or their community, the pressure now transfers to them in terms of making a decision about their life’s future. And I cannot have any confidence that, and I do not believe, we should place that burden on people in their later years.²⁵⁷

- 2.90. Similar concerns were also expressed by another former Labor Prime Minister Paul Keating:

it is “commonplace” for patients to tell doctors in front of their loved ones that they have no wish to be a burden on their families. Once this bill is passed the expectations of patients and families will change. The culture of dying, despite certain and intense resistance, will gradually permeate into our medical, health, social and institutional arrangements. It stands for everything a truly civil society should stand against. A change of this kind will affect our entire community not just a small number of dying patients. It is fatuous to assert that patients will not feel under pressure once this bill becomes law to nominate themselves for termination.²⁵⁸

256 Dore MK (2010) “Death With Dignity”: A Recipe for Elder Abuse and Homicide (Albeit Not by Name)’ *Marquette Elder’s Advisor* 11(2) quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 21-22.

257 Kevin Rudd quoted in John Ferguson and Troy Bramston, ‘Victoria’s euthanasia bill confronts new hurdle,’ *The Australian*, 24 October 2017.

258 Paul Keating, ‘Voluntary euthanasia is a threshold moment for Australia, and one we should not cross,’ *Sydney Morning Herald*, 19 October 2017.

Chapter 2

- 2.91. Hon Paul Keating also quotes Dr Michael Gannon, the then President of the Australian Medical Association, who said:

*Once you legislate this you cross the Rubicon. The cause for euthanasia has been made in a very emotional way and this is the latest expression of individual autonomy as an underlying principle. But the sick, the elderly, the disabled, the chronically ill and the dying must never be made to feel they are a burden.*²⁵⁹

- 2.92. The legalisation of assisted suicide itself implies pressure, since society thereby proclaims that suicide is a recommended measure in certain situations.²⁶⁰

- 2.93. And yet, ageist stereotypes and discrimination still exist, and of most concern, are found in the statements made by proponents of assisted dying. During the debate over the Northern Territory's ROTI Act, Mr Bill Hayden urged doctors to support euthanasia as a right and a duty. He made the following comment to the College of Physicians: 'There is a point when the succeeding generations deserve to be disencumbered of some unproductive burdens.' This comment that 'unproductive burdens' should do the right thing by society was supported by the then South Australian Governor, Mr Mark Oliphant.²⁶¹

- 2.94. The danger of a defeatist view on elder abuse was starkly outlined to the Committee by this evidence from a proponent of assisted suicide,

*I find that an interesting thing in view of the current abuse of the elderly. My personal feeling is that the elderly, if they are being abused or coerced, would in fact be so disillusioned, particularly if this were family members, that they would actually welcome an end to their life.*²⁶²

- 2.95. It is a sad state of affairs in Western Australia that the legalisation of assisted suicide is considered a solution for those members of our community suffering from elder abuse.

- 2.96. It is this ageism, the structural devaluation of older people within a society, that heightens the risk of elder abuse.²⁶³ The APEA Guidelines submitted to the Select Committee on Elder Abuse also acknowledge that ageist stereotypes and discrimination

259 Ibid, quoting Dr Gannon, (then) AMA President.

260 Stahle F (2017) 'Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,' *Journal of Ethics in Mental Health* 10 at 5.

261 Quoted by Mr Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices, included in JSCEOLC Response to Questions on Notice, 17 April 2018 at 8.

262 Mrs Trendall, Senior Citizen, JSCEOLC Transcript, 7 March 2018, Session 1 at 2.

263 Jane Mussared, Chief Executive of the Council on the Ageing SA, 'Stopping elder abuse requires community wide effort,' 15 June 2018 <<https://indaily.com.au/opinion/2018/06/15/stopping-elder-abuse-requires-community-wide-effort>>

may lead to negative attitudes and discriminatory policies and practices by individuals and institutions.²⁶⁴ It would be unconscionable for the Western Australian Parliament to introduce an assisted suicide regime that entrenches existing discrimination against vulnerable older Western Australians. Laws should protect those who are most vulnerable in our community. Assisted suicide is a recipe for elder abuse.

Finding 28

Elder abuse is a real and burgeoning problem in Western Australia.

Finding 29

The capacity of medical practitioners to identify elder abuse in their patients is incredibly variable in Western Australia.

Finding 30

Redress can be difficult in some elder abuse cases when the best witness lacks capacity to give evidence.

Finding 31

Redress in any assisted suicide case is an impossibility.

Finding 32

The presence of undue influence can be difficult to identify and is easily missed.

Finding 33

The introduction of a legalised assisted suicide regime in Western Australia would be a recipe for elder abuse.

Recommendation 8

The Minister for Seniors and Ageing should develop and roll out a comprehensive plan to tackle elder abuse in Western Australia.

Assisted Suicide and Disability Discrimination

2.97. There is a focus by some assisted suicide proponents to ensure that people with a disability are not discriminated against in their ability to access assisted suicide regimes:

we note that individuals without disabilities are able to end their suffering through suicide. But this option may not be open to some individuals who have a physical disability that prevents them from doing so. Prohibiting assisted dying can thus be seen as offending the value of equality through discrimination on the basis of physical

264 WA Alliance for the Prevention of Elder Abuse (APEA) (2017) *Elder Abuse Protocol: Guidelines for Action* at 17.

Chapter 2

*disability...having a disability should not of itself prevent a person from receiving assistance under assisted dying legislation. That is, if the person satisfies the eligibility requirement of 'medical condition', he or she should not be regarded as ineligible because that medical condition results from a disability.*²⁶⁵

- 2.98. Removal of time limits to require a particular proximity to death has been suggested to allow persons with a medical condition, such as quadriplegia who require artificial nutrition and hydration to survive.²⁶⁶ This position is based on the view that disability may be regarded as 'abhorrent' by the individual, and equates to a loss of dignity:

Illnesses and diseases have different medical trajectories. Some illnesses or diseases may mean that a person is deprived of independence because he or she needs assistance from others for all aspects of living. Some individuals may find it undignified to continue to live in circumstances where they must rely on others to, eg, feed them, bathe them and assist them with toileting, and may prefer to end their lives rather than continue to live in this fashion. A competent person who forms that view should have the right to end her or his life.

...

*Relevant to this argument is that illness and disease can result in individuals having to rely on others for all aspects of their lives, and living in a way that they regard as abhorrent. The loss of dignity may be a significant factor in deciding that life has become unacceptable, and voluntary euthanasia or assisted suicide would enable such a person to bring life to an end, and should be permitted.*²⁶⁷

- 2.99. Such quality of life arguments are described by Fabian Stahle as

[A] mechanism... employed that excuses the mortal deed by reducing the human dignity and integrity of the patient. The action is justified by

265 Willmott and White (2017) 'Assisted Dying in Australia: A Values-based Model for Reform' in *Tensions and Traumas in Health Law* at 494, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

266 Willmott and White (2017) 'Assisted Dying in Australia: A Values-based Model for Reform' in *Tensions and Traumas in Health Law* at 504, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

267 White and Willmott (2012) 'How should Australia regulate voluntary euthanasia and assisted suicide?' *Journal of Law and Medicine* 20, 410-438 at 418 and 422, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560.

*claiming that the patient's quality of life is so low that death is a better alternative. The inference is that it is not a life worth living, anyway. This way of emphasizing the sick person's limitations and reduced possibilities for an independent life is tantamount to dehumanization. It is the degradation of a human being into a sub-human object with a lower protection value, in order to make it easier to participate in the person's death.*²⁶⁸

- 2.100. Statements in support of assisted suicide for people with disabilities stand in direct contrast with those statements made by several prominent people living with disability on this issue:

*Whilst supporters of assisted suicide claim that the opposition of disabled people is irrelevant because these bills are only intended for terminally ill people, the top five reasons given by those using the Oregon assisted suicide law all relate to the experience of disability: "loss of autonomy" (91%), "less able to engage in activities" (89%), "loss of dignity" (81%), "loss of control of bodily functions" (50%) and "feelings of being a burden" (40%). Assisted suicide laws are at their core, about disability.*²⁶⁹

*Euthanasia concerns me greatly, especially because I have a disability. If legalised, people like myself will be vulnerable, especially as time goes on. People with disabilities or incurable illnesses will have to choose whether or not they want to be a burden on other people. Euthanasia will become normalised in our society and people like myself would be conditioned and pushed towards it. People who do not want to die will die. An ethical threshold is crossed if we legalise euthanasia. There will be people who society will say, "Their lives are worth living." And there will be those who society will believe are better off dead. Allowing people to legally end their life has consequences for our entire society.*²⁷⁰

This fear of disability typically underlies assisted suicide. Janet Good, an assisted suicide advocate who worked with Jack Kevorkian, was clear about this: "Pain is not the main reason we want to die. It's the indignity. It's the inability to get out of bed or get onto the toilet. . . [People]. . . say, 'I can't stand my mother - my husband—wiping my

268 Stahle F (2017) 'Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,' *Journal of Ethics in Mental Health* 10 at 6.

269 Carr L (2017) 'It's about people like me: disabled and dead against euthanasia,' <<https://www.mercatornet.com/careful/view/its-about-people-like-me-disabled-and-dead-againsteuthanasia/20276>> quoted in Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 5.

270 Mr Byl, Private Citizen, JSCEOLC Transcript, 1 May 2018, Session 6 at 2.

Chapter 2

butt". But as many thousands of people with disabilities who rely on personal assistance have learned, needing help is not undignified, and death is not better than reliance on assistance. Have we gotten to the point that we will abet suicides because people need help using the toilet?²⁷¹

You have to see that at the very heart of [the New Zealand End of Life Choices Bill] is a primal fear of becoming disabled. To put it in the words of Baroness Jane Campbell (a disabled peer) "...society's view of terminal illness and [of] disability I think can be summed up in one word. That word is fear: fear of loss of opportunity; fear of denial of self determination; fear of loss of control; fear of pain; fear of hardship; fear of being a burden to others." Does that attitude of fear and diminution of disability that runs through society and is utterly embedded in the words of this bill offend me? Absolutely, and to the marrow of my bones ... And let's be very, very clear that there can be no protection, there can be no "safeguards," in a bill that starts with the implicit proposition that it is better to be dead than disabled. That's choice?²⁷²

People make all sorts of assumptions about the quality of my life and my levels of independence. They're almost always wrong.

I've lost count of the number of times I've been told, "I just don't think I could live like you," or "I wouldn't have the courage in your situation," or, my favourite one to overhear (and I've overheard it more than once), "You'd just bloody top yourself, wouldn't you?" What we as a society think we know about what it means to live as a disabled person comes from cultural representations of disability seen through a nondisabled lens. And we, as people with disability, rarely get to tell our own stories.

Also, social attitudes towards disabled people come from a medical profession that takes a deficit view of disability. This is my major concern with legalising assisted death; that it will give doctors more control over our lives. As a disabled person who has had a lot to do with the medical profession, I can tell you that this is the space in which I've experienced some of the very worst disability prejudice and discrimination. Doctors

271 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide' *Disability and Health Journal* 3(1) 16-30 at 18.

272 Wendi Wicks, Not Dead Yet, 11 June 2018, Submission Against the New Zealand End of Life Choices Bill <<http://notdeadyet.org/2018/06/wendi-wicks-hard-hitting-oral-testimony-against-nz-end-of-life-choices-bill.html>>

might know about our biology, but it doesn't mean they know about our lives.

Media reports on assisted dying feed these misconceptions. ABC News reported this week on the case of Barbara Harling, a Queensland woman with motor neurone disease who said that she would consider moving to Tasmania if the Voluntary Assisted Dying Bill had passed. Harling is quoted as saying: "Well, let's put it this way. I can use my left hand, my right hand is just about useless. If I can't use my left hand to wipe my bottom, then I can do nothing else for myself. That means someone has to do everything for me. I couldn't bear to live like that."

The thing is, a lot of people do live like that. I know many, many people who depend on personal assistants for all of their daily living tasks, some of them requiring 24 hour care. Having to rely on someone else to wipe your bum may not be something anyone aspires to, but I'm quite sure it's never killed anyone.

Perhaps our discomfort with this kind of thing is why we don't hear the counter view in reports about assisted dying. Often we hear supporters of euthanasia and assisted suicide talk about wanting to avoid the pain and suffering that often comes with imminent death. But more often, we hear stories like Barbara Harling's, which are more about wanting to avoid a loss of autonomy and independence.²⁷³

- 2.101. Vulnerable communities and individuals raise strong concerns that legalisation of assisted suicide leads to attitudinal changes, subtle biases about quality of life, and judgments that some lives are not worth living.²⁷⁴ In relation to the construct of 'dignity,' Mr Randal of the Coalition for the Defence of Human Life writes

We believe that the process of dying should never be characterised as "undignified." Natural death usually involves loss of appetite, fatigue, increased sleep, physical weakness, confusion, disorientation, social withdrawal, laboured breathing, loss of bodily control and so forth. This progressive decline is to be expected and nurses and doctors know how to deal compassionately with it. This is not an "undignified" death, any more than a woman giving birth to a child is undignified, or a person forced to wear a colostomy bag is undignified, or a quadriplegic

273 Stella Young, 'Disability - a fate worse than death?' *ABC Ramp Up*, 18 Oct 2013 <<http://www.abc.net.au/rampup/articles/2013/10/18/3872088.htm>>

274 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576.

Chapter 2

*requiring someone to look after his/her bodily needs is undignified. On the contrary, caring for the terminally ill through the final stages of their lives demonstrates our society's care, compassion, commitment and respect for the dying. It is our view that deliberately killing a human being with a lethal injection, or by any other means—is truly undignified.*²⁷⁵

- 2.102. Mrs Esther Humble, a speech pathologist working with people with disability, also raised a significant concern about the message that the legalisation of assisted suicide sends in relation to dignity, disability and quality of life, and the impact on social perception of disability:

*My third concern is that if laws such as this are implemented, the perceptions of society of disability will worsen. I read some submissions by some senior citizens who do not have terminal illness, but are requesting euthanasia to be an option to them because they are concerned about the unknown; they are concerned that if in the future, "I lose my mental or physical abilities, if I become dependent on others, cannot control my bodily fluids, then I would please not like to live anymore." However, essentially they are saying that it is untenable for them to live in a way that people with disability often live every day. This sends a message to society that living in such a way, as is often the lifestyle for people with disabilities, is a poor quality of life, cannot be enjoyed and is not worth living. I think this sends a very negative message to people with disabilities who live like this, many who claim to have a good quality of life.*²⁷⁶

- 2.103. Professors Willmott and White, proponents of assisted suicide, argue that the state has an interest in preserving the life of a healthy and well person, but that this interest falls away when a person has a medical condition that will cause their death.²⁷⁷ Ms Re of IdentityWA responds:

This statement seems to assume that, at a particular point, the state should "lose interest" in the preservation of persons who have been diagnosed with a terminal medical condition. The statement is framed in such a way as to assume that the value of persons who have been

275 Mr Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices, submitted in JSCEOLC Response to Questions on Notice, 17 April 2018 at 3.

276 Mrs Humble, Private Citizen, JSCEOLC Transcript, 5 April 2018, Session 2 at 2-3.

277 Willmott and White (2017) 'Assisted Dying in Australia: A Values-based Model for Reform' in *Tensions and Traumas in Health Law* at 502-3, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

diagnosed with a terminal medical condition is somehow less than those who do not have such a condition.

We believe that such a statement is contrary to much of what is held as central both in the caring professions, and in our WA society more broadly... Our experience is far from [Professors Willmott and White's] suggestion that life nearing its end is somehow less valuable. On the contrary, our experience has been that life becomes all the more precious. This has left us with the view that non-abandonment and considerate care is one of the hallmarks of the success of our work, and indeed of our society.

The state certainly has an interest in this. If it did not, why would so much energy, effort, attention, and funding be put towards the question of what constitutes best practice end of life care?²⁷⁸

- 2.104. Any legalisation of assisted suicide would also occur 'within the context of a health care system and a society pervaded with prejudice and discrimination against people with disabilities.' Already, this prejudice and discrimination play out in life-threatening ways, including pressure by hospital staff on people with disabilities who are nowhere near death to sign 'Do Not Resuscitate' orders and reject life-sustaining treatment.²⁷⁹ Evidence was given to the Committee about the discrimination and inequity of access to health care that people with disabilities experience in this State. Mrs Gaye Matthews, the mother of, and carer for, Carissa Matthews who lived with a disability, said 'I very much feel that if we had just left Carissa in hospital, they would have suspended treatment.'²⁸⁰ Ms Re also gave evidence that

We have had occasions that people in our care have been unwell—for example, had a really bad cough or bronchitis or whatever—and have been taken to an emergency department, and this has happened more than once. Then there has been a discussion that the treatment would be a course of antibiotics and did we want the person to be treated. I guess when that happens, the question is really: why would that discussion need to take place in the first place? If that was an able-bodied person, if that was someone fit and healthy and whatever else, there would be no question about that. That does not happen all the time, but it does happen. Gaye's comment about the way that people

278 Ms Re, Chief Executive Officer, IdentityWA, JSCEOLC Response to Questions on Notice, 10 April 2018 at 1.

279 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1) 16-30 at 18, quoting Longmore P. 'The resistance: the disability rights movement and assisted suicide,' in Longmore P, ed. *Why I burned my book and other essays on disability* (2003) Philadelphia: Temple University Press at 175-203.

280 Mrs Matthews, Individual Submitter, JSCEOLC Transcript, 27 February 2018, Session 3 at 5.

Chapter 2

*are viewed in terms of the quality of their existence and how they are valued as individuals is something that is of great concern to us. People with disabilities, particularly people with severe disabilities, both intellectual and physical disabilities, most certainly are devalued by our society and there can be, on occasion, a different set of rules that apply.*²⁸¹

- 2.105. Mrs Matthews also gave evidence to the Committee that ‘Sadly we had to fight/demand palliative care which was far more than the “just take her home” response of the consultant in the hospital.’²⁸²
- 2.106. In light of the inequitable access to health care in Western Australia, including inequitable access to palliative care services, it is clear that assisted suicide would not promote choice for people living with disabilities in this State:

[People with disabilities] already experience a lot of difficulty in accessing basic healthcare and community services. Should it be that euthanasia is an easier option for them to access than basic health care, that would be very, very wrong. That is a concern by disability advocates such as Craig Wallace, who says that until people with disability are able to access the same level of community services and health care and have access to the same choices of health care, then euthanasia is a poor choice that should not be offered. Would it be right to have easier access to euthanasia than to proper dental care? That would be wrong, and also these things put people with disability at higher risk of experiencing suffering considered to be intolerable. It is how society relates to them.

...

*Also, we do know that people with disability experience high levels of abuse and all these factors can lead to them becoming more vulnerable, I would say, to choosing an option which might be because there are limited options rather than because that is the best option for them.*²⁸³

- 2.107. The idea that the availability of assisted suicide presents a choice for those who would like it is challenged by disability rights advocates, who suggest that inequitable access to health care for disabled people renders that choice illusory:

[T]he idea of choice ... is a sad shabby figment. You need to keep in mind that choice - an underpinning of [assisted suicide legislation] - will be, to

281 Ms Re, Chief Executive Officer, IdentityWA, JSCEOLC Transcript, 27 February 2018, Session 3 at 6.

282 Mrs Matthews, Individual Submitter, JSCEOLC Response to Questions on Notice, undated.

283 Mrs Humble, Private Citizen, JSCEOLC Transcript, 5 April 2018, Session 2 at 1-2.

*disabled people, like the choice poorer people have in supermarkets- a choice with fewer options; a choice with more illusions than equality.*²⁸⁴

- 2.108. Assisted suicide proposals usually would require two doctors to agree to a person's request for a prescription for a lethal dose to be used to end the person's life. To do so the doctors essentially need to agree that the person would 'be better off dead' or at least that it is reasonable for a person in that position to consider that he or she would be better off dead.²⁸⁵ Legalised assisted suicide therefore threatens to create a 'two-tiered system' where non-disabled individuals who express suicidal wishes will receive suicide prevention services, while individuals with disabilities will receive lethal prescriptions, resulting in 'death to the socially devalued group.'²⁸⁶
- 2.109. As outlined earlier in this Report, doctors are also less likely to identify depression in people with disability, simply by assuming that it is normal for a person with a disability to show signs of depression such as sadness and a lack of hope. Doctors may also easily miss the particular vulnerability of a person living with disability to overt or subtle coercion from family or caregivers who reinforce a feeling that the person is a burden, 'too much trouble' or that 'life is too hard.'²⁸⁷
- 2.110. The risk that assisted suicide presents to people with disability in the context of this approach by health professionals, particularly following an initial diagnosis of a condition that may involve a considerable level of disability, is made clear in the following account:

This approach poses a severe risk to people following an initial acquisition or diagnosis of a condition that may involve a considerable level of disability. Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in our lives. However, the adaptation usually takes considerably longer than the mere fifteen-day waiting period [generally] required by assisted suicide proposals. People with new diagnoses of terminal illness appear to go through similar stages. In that early period before one learns the truth about how good one's quality of life can be, it would be all too easy, if assisted suicide is legal, to make the final choice, one that is irrevocable. Dr Richard Radtke, a well-known retired academic oceanographer in Hawaii, provides one such example. Dr Radtke has had a very disabling form of muscular sclerosis for over 25 years. In the period after his

284 Wendi Wicks, Not Dead Yet, Submission Against the New Zealand End of Life Choices Bill, 11 June 2018 <<http://notdeadyet.org/2018/06/wendi-wicks-hard-hitting-oral-testimony-against-nz-end-of-life-choices-bill.html>>

285 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 27.

286 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide' *Disability and Health Journal* 3(1) 16-30 at 18.

287 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 29.

Chapter 2

*diagnosis, doctors often classified him as terminally ill. He experienced severe depression for two years. Had assisted suicide been legal, he acknowledges that he would have chosen it and died long ago. Today, still with an extremely limiting disability, he has retired from a successful academic career, is a happily married father, remains the president of a charitable foundation, and is grateful for the length and varied experiences of his life. How many such individuals is our society prepared to sacrifice as the collateral damage from the legalization of assisted suicide?*²⁸⁸

- 2.111. The State Government's interest in preserving the life of all its citizens, regardless of their medical condition or disability, should be a priority of the highest order. The Government should make active and sustained efforts to provide equitable access for disabled people to quality health care in Western Australia, including the highest standard of palliative care, which is currently lacking. Any Government initiative should support people living with disabilities in Western Australia to be able to make choices in their living with the care and health services that they need.

Finding 34

Assisted suicide laws are, at their core, about disability.

Finding 35

Assisted suicide laws enshrine a negative message about living with a disability.

Finding 36

There can be no protection or safeguard in any law that begins with the implicit proposition that it is better for some people to be dead than disabled.

Finding 37

People with disabilities experience discrimination and inequity of access to health care in Western Australia.

Recommendation 9

The Minister for Disability Services should develop a plan, in consultation with people with disabilities, carers, the Minister for Health and health practitioners, to deliver equitable access to health care in Western Australia.

288 Ibid, citing M Golden, 'Why assisted suicide must not be legalized,' Disability Rights Education and Defense Fund <<https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/>>

Finding 38

An assisted suicide regime threatens to create a two-tiered system where individuals without a disability who express that they wish to end their life are referred to suicide prevention services, while individuals with disabilities who express that they wish to end their life are referred for lethal prescriptions.

Assisted Suicide and Suicide Prevention**An artificial distinction between ‘rational’ suicide and suicide generally**

- 2.112. Proponents of assisted suicide, or what they would prefer termed ‘assisted dying,’ construct a distinction between rational suicide (assisted suicide) and suicide generally. ‘Assisted deaths’ are said to be a choice between two different ways of dying, unlike general suicide, where the choice is between living and dying.²⁸⁹
- 2.113. Dr Elizabeth Moore, Chair of the RANZCP, drew a distinction between the two in evidence to the Committee: ‘When a person is not expected to live for a certain amount of time, that they have unbearable pain or suffering, I think this is a very different scenario from actually saying that the person wants to suicide in the parlance that we are now talking about suicide prevention.’²⁹⁰
- 2.114. The irony of this distinction was raised by former Attorney General Hon Michael Mischin in the Legislative Council in debate about the terms of reference of the Joint Select Committee on End of Life Choices. He argued:

It is ironic when it is suggested that somehow the issue of suicide generally is entirely different from the issue of a medical diagnosis leading to a desire to put oneself out of one’s misery because, in every case reported in the newspaper of late in which this issue has been raised and people have talked about their experiences and why they would like to be able to be assisted to kill themselves, a little line is routinely put at the bottom of the article that states: if you or anyone else is considering suicide, please contact X helpline. It is not by any means a totally different issue; it is germane to this issue. It is an issue that I think members of the community concerned about where the lines are drawn would need us to ensure that this committee, if it does express a wide variety of views, will look into and decide on.’²⁹¹

289 Mr Wood, Christians Supporting Choice for Voluntary Euthanasia, JSCEOLC Transcript, 13 April 2018, Session 3 at 2.

290 Dr Moore, Branch Chair, Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Transcript, 28 February 2018, Session 5 at 6.

291 Hon Michael Mischin, *Hansard*, Legislative Council, 22 August 2017 at 3079.

Chapter 2

2.115. The RANZCP(WA) also recommended ensuring that support for carers and suicide prevention programs for older adults are adequately resourced and ironically considered that additional resources may be needed to provide support during the assisted suicide debate in Western Australia.²⁹²

2.116. In evidence given to the Committee, Dr Best articulated it in this way:

*When most people want to hasten death, we call it a psychiatric emergency and we worry about the rising rate of suicide in our country. Why are the terminally ill treated differently? Why isn't this a psychiatric emergency? The legalisation of euthanasia sends a message to our society that suicide is a legitimate solution for trouble in life.*²⁹³

2.117. Boudreau and Somerville suggest that to create a distinction between persons with a terminal illness and persons without a terminal illness is artificial and dishonours the terminal phase of a person's life:

*It is also pertinent to point out that Canada continues to fund and promote programs that aim to prevent suicide. If suicide is conferred the status of a right or is held to be acceptable medical treatment it would be difficult to reconcile this situation with the presence of programs that aim to actively thwart it. Some resolve this dilemma by trying to banish the word 'suicide' from the debate, in favor of the phrase 'assisted dying.' Marcia Angell, erstwhile editor of the NEJM and a fervent proponent of PAS, endorses the notion that 'assisted dying' can be distinguished from 'typical suicide.' The latter is described as being undertaken by someone with a normal life expectancy, whereas the former is carried out in someone 'who is near death from natural causes anyway.' They are going to die anyway, so what does it matter?! We believe that this reasoning is rather disingenuous and that it can result in a dishonouring of that segment remaining in someone's life, whether this is measured in minutes or months, and could deprive them of something as ephemeral as dreams and hopes. It certainly negates the idea of dying as our last great act of living.*²⁹⁴

292 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 10.

293 Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 2 at 3.

294 Boudreau and Somerville (2013) 'Euthanasia is not medical treatment,' *British Medical Bulletin* 106, 45-66 at 62.

- 2.118. The Professionalism and Human Rights Committee of the American College of Physicians also very recently articulated that '[l]egalized physician-assisted suicide medicalises suicide.'²⁹⁵

Conflict with existing suicide prevention programs

- 2.119. As already noted, Hon Michael Mischin MLC identified the presence of suicide prevention information in news articles in which assisted suicide is discussed. The World Health Organisation warns news media to '[a]void language which sensationalizes or normalizes suicide, or presents it as a solution to problems' and '[a]void explicit description of the method used in a completed or attempted suicide.'²⁹⁶ Dr Best also recognised the conflict with suicide prevention strategies in her statement that the legalisation of euthanasia sends a message to our society that suicide is a legitimate solution for trouble in life (above). It follows that proponents of assisted suicide are out of step with World Health Organisation policies on suicide prevention.
- 2.120. Concern about the conflict between legalised assisted suicide and suicide prevention programs was a theme consistently raised in Committee evidence. Rev Dr Joseph Parkinson of the LJ Goody Bioethics Centre asks 'If all suicides are tragic, how can some suicides be considered good—and indeed, authorised by the State?'²⁹⁷ Mr Paul Byl, a private citizen who gave evidence to the Committee about living with a disability, states 'Either society recognises that all life is valuable or we will not be able to find a good, fixed, unchallengeable reason to stop anyone from committing suicide.'²⁹⁸
- 2.121. In a response to the Committee's Questions on Notice, Ms Re gave detailed consideration to the question of autonomy and suicide raised by Professors Willmott and White in their own evidence to the Committee, and the contradiction that arises between suicide prevention programs and assisted suicide:

In keeping with the social theory of individualism, [Professors Willmott and White] extend the definition of autonomy to self-determination which they hold involves having a person's will respected and acted upon. In other words, a person determines that what they want is suicide, and therefore they shall have it. Our position sees no conflict in "respecting" a person's will to suicide in the sense that this will is acknowledged. That is a basic premise of accompaniment. However,

295 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576.

296 World Health Organisation (2008) *Preventing Suicide: A Resource for Media Professionals*, Geneva, at 6, 7 and 8, cited in R Doerflinger, (2017) 'The Effect of Legalizing Assisted Suicide on Palliative Care and Suicide Rates: A Response to Compassion and Choices,' *On Point* 13 at 6.

297 Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 6.

298 Mr Byl, Private Citizen, JSCEOLC Transcript, 1 May 2018, Session 6 at 2.

Chapter 2

*[the Professors] erroneously equate the expression of autonomy (or self-determination) with its fulfilment, as in a person's will is to be "acted upon." Some pages later, [they] at least recognise that autonomy cannot be "unfettered," and that it is constrained by inter alia the value of life. We argue that this is the principle on which suicide prevention programs are based. The contradiction between these programs and assisted suicide is therefore readily apparent.*²⁹⁹

- 2.122. Rev Ashley Saunders, National Director of FamilyVoice Australia, suggests '[w]e cannot afford to send mixed messages about the value of life or about suicide. So in a sense giving in to a person, whether older or younger, when they are for one reason or another suffering and desiring to end their life, in my view is bad policy and actually is counterproductive.'³⁰⁰ The inherent conflict in public policy between assisted suicide and suicide prevention was also raised by Mr Randal of the Coalition for the Defence of Human Life.³⁰¹
- 2.123. Assisted suicide legislation creates 'an instrumental scale to determine who can be assisted with suicide and who is provided treatment for suicidal ideation.'³⁰² Mr Egan of Defend Human Life! articulates the issue in this way

If you look at your state's suicide prevention study or framework ... the target is to tell everybody that there is a better way, that there is hope. An assisted suicide scheme wants to bracket off a whole category of people and say suicide prevention for most Western Australians, and suicide facilitation, by law, for some other Western Australians. How are you making that distinction? Of course, the broader your assisted suicide law that is passed, the more that distinction is sort of harder to sustain, and the messages that are then sent out to the community.

...

Members tried to press the Minister for Health on this in the Victorian Parliament: What is Lifeline going to be told? If someone calls up saying, "I'm feeling suicidal," do they first ask, "Well could I check whether you

299 Ms Re, Chief Executive Officer, IdentityWA, JSCEOLC Response to Questions on Notice, 10 April 2018 at 1-2.

300 Rev Saunders, National Director, FamilyVoice Australia, JSCEOLC Transcript, 9 March 2018, Session 3 at 4.

301 Mr Randal, President, Coalition for the Defence of Human Life, JSCEOLC Response to Questions on Notice, 17 April 2018 at 2.

302 'ACUF Senior Policy Fellow, and Senior Policy Fellow for the Centre for Human Dignity, Julie Hocker Testifies at the New York Assembly, New York Assembly Committee on Health, Public Hearing on Bill 2383-A,' 3 May 2018 – cited in Prof Margaret Somerville, Professor of Bioethics, University of Notre Dame Sydney, Supplementary Information provided to the JSCEOLC, 8 May 2018.

have a diagnosis of a terminal illness that gives you less than six months to live; yes or no? If the answer is yes, let me refer you to the Western Australian government assisted suicide facilitation line.” ... Members of Parliament did try to probe this question in Victoria, but were certainly not to my mind given satisfactory answers, because we would be introducing a double standard.³⁰³

- 2.124. It would be more logical and intellectually honest for a proponent of assisted suicide to take the position of Dr Nitschke, Exit International, or the position of Mr Silvan Luley and Mr Ludwig Minelli of Dignitas, Switzerland, that assisted suicide should be available for all:

So all people qualify...including the depressed, the elderly bereaved, the troubled teen...we should not erect artificial barriers in the way of subgroups who don't meet our criteria.³⁰⁴

It is logic, from our point of view and our experience, because, quite simply, people who have a real choice and are professionally accompanied and are professionally counselled if they are a patient—it does not matter whether they are in a life crisis or whether they have terminal cancer—when they know they can turn to someone, maybe a physician, maybe an organisation like Dignitas, when they know they can talk openly about it... and get advice, then they are much less at risk to turn to violent methods. So the best—it might sound provocative, but our experience is that the best suicide prevention and suicide attempt prevention that you can have is if you give as far as possible access to assisted dying, because people then know they can access professional help and have a choice and thus they do not have to turn to violent methods.³⁰⁵

- 2.125. In a study by Jones and Paton, comparing trends in suicide rates in US states that have legalised assisted suicide compared against those that have not, found that legalising assisted suicide was associated with a 6.3 per cent increase in total suicides (i.e. including assisted suicides). This effect was larger (14.5 per cent) in the over 65s age group. While not considered a significant increase, the introduction of legalised assisted suicide was

303 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 6 and 7.

304 Philip Nitschke in an interview with Kathryn Jean Lopez in the *National Review*, 5 June 2001 and quoted in *Hansard*, Standing Committee on Legal and Constitutional Affairs, 14 April 2008 at 43.

305 Mr Luley, Board Member, Dignitas, Switzerland, JSCEOLC Transcript, 8 March 2018, Session 5 at 7 (emphasis added).

Chapter 2

certainly not associated with a decline in non-assisted suicide rates.³⁰⁶ The hypothesis that the legalisation of assisted suicide will reduce suicide rates does not hold.

- 2.126. In 2012, the age-adjusted suicide rate among Oregonians was 17.7 per 100,000, 42 per cent higher than the national average. The rate of suicide among Oregonians has been increasing since 2000. Suicide rates among adults aged 45-64 years rose more than 50 per cent from 18.1 per 100,000 in 2000 to 28.7 per 100,000 in 2012; the rate increased more among females than among males. This suicide rate data did not account for physician-assisted suicides under Oregon's *Death With Dignity Act*.³⁰⁷
- 2.127. The Coalition for the Defence of Human Life suggest that these figures indicate that the legalisation of assisted suicide sends the message that suicide is an appropriate and acceptable response to suffering, and normalises this most tragic of actions.³⁰⁸

The assisted suicide of Dr David Goodall

- 2.128. The highly publicised assisted suicide of Dr David Goodall earlier this year raised some very concerning issues. Dr Goodall was quoted in news media as stating:

*My feeling is that an old person like myself should have full citizenship rights including the right of assisted suicide. Once a person is past the stage of middle life, one has paid back to society the debts that have been paid out. One should feel free to use the rest of his life as one chooses. If one chooses to kill oneself then that's fair enough. I don't think anyone else should interfere.*³⁰⁹

- 2.129. His assisted suicide in Switzerland came after repeated failed suicide attempts in the 12 months prior to his death.³¹⁰
- 2.130. Dr Nitschke urged the Western Australian Parliament to consider the Swiss assisted suicide model that 'allows for a person to say, "Look, I've reached the end of my very productive life and now is the time to die. In other words, it's my right to have access to the best drugs."³¹¹
- 2.131. In contrast to the position of Dr Nitschke, Dr Michael Gannon (the then President of the AMA) expressed concern that the suicide of someone who is aged 100 was being

306 Jones and Paton (2015) 'How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide?' *Southern Medical Journal* 108 (2015) 599-604.

307 Shen and Millet (2015) *Suicides in Oregon: Trends and Associated Factors 2003-2012*, Oregon Health Authority, Portland, Oregon, at 3 and 7.

308 Mr Randal, President, Coalition for the Defence of Human Life, JSCEOLC Response to Questions on Notice, 17 April 2018 at 1.

309 Charlotte Hamlyn, '104-year-old academic David Goodall to travel to Switzerland for voluntary euthanasia' *ABC News*, 1 May 2018.

310 *Ibid.*

311 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 3.

celebrated and wondered ‘What is the age at which we no longer celebrate people continuing with life?’³¹² Dr Gannon also expressed concern with the reasoning Dr Goodall had expressed around his decision:

*People like Dr Goodall make a decision based on nothing more than they’ve decided there’s nothing more to live for. I think that’s a dangerous line to cross. I have serious concerns about a community where we make arbitrary decisions about whose life is valuable enough to continue and whose should be ended under the law. A society should aspire to look after people who are struggling and to make sure that their lives are worth living. We should aspire to better end-of-life care. We should aspire to better palliative care.*³¹³

- 2.132. It is also important to note that Dr Goodall had recently experienced ageism in his workplace. The ABC reported in 2016 that after having worked for nearly two decades at the Edith Cowan University, Goodall was told to leave amid concerns about his well-being. The incident gained international media attention, with Goodall, then 102, calling it ageism in the workplace, and saying ‘It’s depressed me; it shows the effect of age. The question would not have arisen if I were not an old man.’³¹⁴
- 2.133. After feeling that he was too old to actively participate in society, Dr Goodall was then farewelled by the Premier of Western Australia with the words ‘He’s a very, very old man and he’s obviously had enough. I feel for him and his circumstance and I wish him all the best in his last journey.’³¹⁵
- 2.134. Calls for access to assisted suicide for the elderly were also made in evidence to the Committee. Ms Patricia Marshall, a private citizen and retired public servant, stated

The questions of loss of self-autonomy and human dignity, conscious awareness of physical or mental deterioration and the realisation that meaningful participation in life has come to an end are very important considerations for the elderly and should be included in any discussion of end-of-life choices. The process of ageing brings an increasing awareness of one’s own deterioration and detachment from what is perceived as a complete life. It is only when this process is directly experienced that it can be fully understood; therefore, it is necessary for those making decisions to change the law to take some advice from

312 Philip Oltermann, ‘David Goodall, Australia’s oldest scientist, ends his own life aged 104’ *The Guardian*, 10 May 2018.

313 Charlotte Hamlyn and Brianna Shepherd, ‘David Goodall ends his life at 104 with a final powerful statement on euthanasia’ *ABC News*, 11 May 2018.

314 Lindsey Bever, ‘David Goodall, 104, just took his own life, after making a powerful statement about assisted death’ *The Washington Post*, 10 May 2018.

315 Dylan Caporn, ‘First-class for final journey’ *West Australian*, 3 May 2018 at 7.

Chapter 2

those who may choose a voluntary and dignified end to their life when they perceive it to be complete.

...

[Y]ou get to an age where you have not got many more years left and you start to think, "I've done everything useful in my life that I'm ever going to do and I'm eking out the rest of my life on whatever small amount of capital I have been able to accumulate." Then there is ill health, and I think one does perceive one's own mental capacity deteriorating. When you start to think, "How much longer am I going to go on?" and then, "What will end when I can no longer control my bodily functions, my finances, my social life?"³¹⁶

- 2.135. Finding where to draw the line at who would be eligible to access assisted suicide proved more difficult however. Dr Goodall suggested access to people past the stage of middle life:

Once one is past the stage of middle life, one has paid back to society the debts that have been paid out. One should be free to use the rest of his life as one chooses. If one chooses to kill oneself then that's fair enough. I don't think anyone else should interfere.³¹⁷

- 2.136. In evidence to the Committee, Mrs Kathleen Trendall, a senior citizen, suggested 'perhaps people over 90.'³¹⁸
- 2.137. In response to the question 'Do you think there is a stage where you may not have that capacity [to voluntarily consent to assisted suicide]?' Mrs Marshall relied 'You might not, but of course, that is the point at which you have to go, isn't it?'³¹⁹
- 2.138. In contrast to the comments made by Dr Gannon (above) that 'A society should aspire to look after people who are struggling and to make sure that their lives are worth living. We should aspire to better end-of-life care. We should aspire to better palliative care,' the following exchange took place

Hon Dr SALLY TALBOT: I wondered if I could just ask you two other quick things. Sometimes when people talk about that trajectory into old age—advanced old age—it is described as a kind of increasing misery. So, you lose all your friends, you have just talked about your money dwindling;

316 Mrs Marshall, Retired Public Servant, Albany resident, JSCEOLC Transcript, 7 March 2018, Session 1 at 1 and 3.

317 Charlotte Hamlyn, 'Academic David Goodall turns 104 and his birthday wish is to die in peace' *ABC News*, 4 April 2018.

318 Mrs Trendall, Senior Citizen, JSCEOLC Transcript, 7 March 2018, Session 1 at 2.

319 Mrs Marshall, Retired Public Servant, JSCEOLC Transcript, 7 March 2018, Session 1 at 4.

there is not much to live for. So the people who do not agree with you would say, "It is up to society to remove the misery. If we remove the misery, then these people won't want to die." Do you have any comments about that?

Mrs MARSHALL: Why? Why would you want to do that?

Mrs TRENDALL: I could not see society improving the financial position of very elderly people.

*Mrs MARSHALL: Quite the reverse!*³²⁰

Older age suicide

- 2.139. Calls for access to assisted suicide for the elderly are regularly joined with concerns about older adult suicide rates in the Australian population. For example, dying with dignity state that:

*It is also worthwhile noting Mr Denton's reference to data provided by the National Coronial Information System on the numbers and methods relating to elderly Australians taking their lives. These show "the dark reality" facing too many older Australians... On average, two octogenarians a week are killing themselves in this country. The most common method used is hanging.*³²¹

- 2.140. However, concern was raised by RANZCP in evidence to the Committee that:

*Australia's oldest citizens, those aged 80 and above, are the age group most likely to die as a result of suicide (ABS, 2012). This has led to a misconception that suicide in older people is largely driven by suffering associated with chronic, debilitating or terminal illness, whereas the aetiology of suicide is complex and usually multifactorial.*³²²

- 2.141. RANZCP assert that it is imperative that the implementation of physician-assisted suicide be accompanied by stringent safeguards to ensure that older people considering suicide are not given access to assisted suicide, as well as an expansion of suicide prevention programs to target older persons.³²³ They also gave evidence that there is a need for specialist older adult mental health expertise and services and that '[a] physician assisted

320 Mrs Trendall, Senior Citizen, and Mrs Marshall, Retired Public Servant and Senior Citizen, JSCEOLC Transcript, 7 March 2018, Session 1 at 5.

321 Dying with Dignity (WA), JSCEOLC Submission 565 at 14.

322 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 5.

323 Ibid.

Chapter 2

suicide framework must take into consideration the under-diagnosis and under-treatment of depression and suicidality in older people.³²⁴

- 2.142. Rosenwax and McNamara have also identified that persons aged over 84 years are a group in the Australian population who are the least well-served by specialist palliative care.³²⁵

On becoming a society accepting of suicide

- 2.143. Just as assisted suicide for the terminally ill is logically extended to the assisted suicide of the elderly who are 'tired of life,' as in the case of Dr Goodall, the acceptance of assisted suicide also changes the perception of suicide generally so that it is no longer seen as tragic, but as an understandable solution to a person's problems. This sentiment was reflected in the comments of Mrs Trendall in relation to the suicide of older people suffering elder abuse: 'My personal feeling is that the elderly, if they are being abused or coerced, would in fact be so disillusioned, particularly if this were family members, that they would actually welcome an end to their life.'³²⁶
- 2.144. It is also evidenced in this discussion had in a Committee hearing:

Mr J.E. McGRATH: Further to that, if someone was in a relationship where they had a relationship that was not working and it was very stressful on one of the partners and it was affecting them mentally and they decided, "I don't think I need to be here anymore," do you think they should be given the right to end it?

Mr IRELAND: If the circumstance was simply what you have articulated, my answer would probably be no. These days, one can remove oneself from a relationship that is not working. As I said to you before, divorce back then was pretty well unheard of, or frowned upon at least. Today, relationships break up more often than they stay together—or as often as they stay together. I can understand someone who is in a relationship and who is being battered, being physically and mentally abused by their partner, wanting to take their own life—yes. But if it was merely a breakdown of the relationship in terms of two people finding it uncomfortable or intolerable to live with one another but there is no physical abuse and no mental abuse, then no, I would not agree with that at all.

324 Ibid.

325 Rosenwax and McNamara (2006) 'Who receives specialist palliative care in Western Australia – and who misses out,' *Palliat Med* 20(4) 439-45.

326 Mrs Trendall, Senior Citizen, JSCEOLC Transcript, 7 March 2018, Session 1 at 2.

Hon NICK GOIRAN: *But if there is physical abuse, it would be okay?*

Mr IRELAND: *Sorry?*

Hon NICK GOIRAN: *If there was physical abuse in a relationship, then it would be okay?*

Mr IRELAND: *I think if it was severe physical abuse, yes. I can understand women who are being physically abused by their partners, unless they see a way out of the relationship and unless they find opportunities to move out of the relationship without fear, I can understand someone taking their own life if they were being severely physically abused, yes.*

Mr R.R. WHITBY: *You are not suggesting, though, that the state sanction that?*

Mr IRELAND: *No, I am not suggesting that at all. All I am suggesting is that I can understand someone taking their life, but I understand it would be impossible to legislate for that. You have to place yourself in the shoes of the individual. Each one of us in that situation—if you are a male or a female, living in a situation where you are being battered or being abused sexually or physically and you found no way out of it, I could understand someone wanting to take their own life. Good grief! I think it would be, in some cases, a natural extension for some people who cannot find their way out of it.³²⁷*

- 2.145. Dr Khorshid also gave evidence to the Committee of an anecdote shared at an AMA symposium conducted by AMA(WA) on the issue of assisted suicide, and attended by Professor Theo Boer, formerly a proponent of suicide from the Netherlands. Dr Khorshid reported that:

suicide is seen more and more in Dutch society as a reasonable way out of whatever your existential suffering is. [Professor Boer] gave a specific example of a suicide of a woman—he did not mention how it happened—in a particular area in the Netherlands in a big town. The paper in that town had a six-page spread on this young woman, from his point of view, almost celebrating the fact that she had taken this courageous decision to end her life through whatever suffering it was. I do not think he gave us the exact reason that she ended her life. That is just an example of how rather than regarding suicide as a tragedy,

³²⁷ Mr Ireland, JSCEOLC Transcript, Session 3, 30 April 2018, pp5-6 (emphasis added).

Chapter 2

*which is our normal response, it was being seen as a reasonable option to get you out of the situation that you are in.*³²⁸

- 2.146. These comments reflect what had earlier been described by Mr Randall as the ‘certain logic that if the state sanctions suicide in some form or another, then, as the law has an educative function, suicide will be seen by the public as an acceptable thing to do in certain situations such as terrible pain, terminal illness and deep depression.’³²⁹ That logic, Mr Randall suggested, leads inevitably to a question:

*If a person in intractable pain can receive state-sanctioned assistance to kill themselves, then why can't a person who experiences similar pain, or who is deeply distressed, determine to take measures to end their own life?*³³⁰

- 2.147. Suicide should never be considered an acceptable solution for challenging situations, or even extreme hardship, in an individual’s life. Suicide is always a tragic occurrence, hence our justified investment in suicide prevention programs.

Western Australian Coronial data on suicides

- 2.148. Some proponents of assisted suicide assert that some suicides occur because palliative care is not an adequate treatment option for those people. Comment was made by the Committee Chair that ‘Submissions received by the Committee indicate that there are people in the community for whom palliative care is not an adequate treatment option, and they choose to take their own lives.’³³¹
- 2.149. Coronial data was provided to the Committee on the suicides of 199 Western Australians from 2012 to 2017. Closer and proper consideration of the Coronial data supplied to the Committee does not support this statement.
- 2.150. Evidence that these individuals suicided because palliative care was not an adequate treatment option for them is not supported by the data. There is no reference in the data to the failure of palliative care, or whether these individuals either had accessed or even had access to palliative care services. The Coroner’s Report states:

In some cases, the deceased suffered from both mental and physical conditions which may have contributed to their intentional self-harm. In some instances, it was difficult to determine if the mental or the physical condition made a more significant contribution to their intentional self-

328 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 9-10.

329 Mr Randal, President, Coalition for the Defence of Human Life, JSCEOLC Response to Questions on Notice, 17 April 2018 at 2.

330 Ibid.

331 Ms Sanderson, JSCEOLC Chair, JSCEOLC Transcript, 13 December 2017, Session 1 at 17.

harm based on the information provided within the attached documentation.

*In addition, it should be noted that the inclusion of the reference to the deceased's physical condition is not standardised across coronial documentation. As such, in some cases, it was difficult to ascertain the extent to which the deceased's condition influenced their motivation to self-harm.*³³²

- 2.151. The Coronial report initially identified 240 cases of 'Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions in Western Australia' over the five year period between 2012 and 2017. This number was reduced by the Coroner's office to 199, as 41 of those cases were revealed by manual review of the data to show no evidence of the deceased being diagnosed with a terminal or debilitating physical condition.
- 2.152. Of the 199 cases, review of the data suggests that in 42 of the cases the individual could be classed as suffering from a terminal condition, while 157 would be classified as debilitating conditions. Of the 42 cases where the individual's case may have been terminal, the limited information provided in these cases indicates that 27 of these cases were advanced, or in the terminal stages of that illness. Others may also have involved advanced or terminal illness, however, this cannot be ascertained from the limited data provided in the Coronial report. For example, in Case 134 the deceased was an adult male who suffered from a number of medical conditions, including bowel cancer which had been surgically treated earlier that year. In the weeks prior to his death, the deceased was suffering pain following recent colon surgery, which involved the removal of a colostomy bag. The deceased was being treated with medication for pain management, but remained anxious and depressed about his symptoms. For the purposes of examining the Coronial data, Case 134 has been included in the 42 cases of terminal conditions because of the diagnosis of bowel cancer, which can be a terminal condition. However, there is nothing in the report to suggest that this was a terminal condition in Case 134, or that the deceased was suffering from an advanced stage of that disease. In a similar way, in Case 198 the deceased was an older male who had a medical history of hypertension, prostate cancer, atypical pneumonia, cystoscopy and asthma. The deceased had experienced a recent decline in his eyesight which rendered him unable to watch television or see telephone numbers, and he had recently handed in his driving licence. For the purposes of examining the Coronial data, Case 198 is included in the 42 cases involving a terminal illness because the deceased's medical history included prostate cancer which can be a terminal illness. However once again, there is nothing in

332 Coronial Report CR17-61.1, 'Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions in Western Australia 2012-2017,' at 3, provided by Gary Cooper, Principal Registrar, Coroner's Court of Western Australia, JSCEOLC Response to Questions on Notice, 24 May 2018.

Chapter 2

the report to suggest that this was a terminal condition in Case 198, or that the deceased was suffering from an advanced stage of that disease.

- 2.153. Further, any suggestion that the debilitating conditions reported in the data evidence a need for legalised assisted suicide in Western Australia can only be done if one fails to consider the data in detail. Of what appears to be 157 cases that are non-terminal, some of the conditions in those cases include diabetes, ongoing pain from workplace and vehicle accidents, 'elbow pain' (Case 87), 'long term arthritis' (Case 107), 'recurrent back pain but was otherwise healthy' (Case 181), 'generally well but had begun to suffer incontinence and difficulty walking' (Case 236) and 'significant eye problems his whole life, but was otherwise well' (Case 239). These conditions are not indicative of 'people in the community for whom palliative care is not an adequate treatment option, and they choose to take their own lives.'
- 2.154. The incidence of mental conditions in those classified as suffering from a debilitating condition was also very high. 99 of the 157 cases evidenced some level of mental ill-health, including depression, suicidal ideation or previous suicide attempts, anxiety disorder or bipolar disorder. Further, information provided in the data also suggests, as the Coroner's report states, that 'it [is] difficult to ascertain the extent to which the deceased's condition influenced their motivation to self-harm.'³³³ For example, information provided in the cases included financial and relationship problems, experience of sexual abuse as a child, imprisonment, criminal charges, unemployment, social isolation and a history of drug and alcohol abuse.
- 2.155. The multifactorial nature of suicide is also evident in the 42 cases that may be classed as terminal. Fifteen of those cases included information relating to current or past mental ill-health (including diagnosis and treatment of depression) or previous suicide attempts. Equally, it is not possible to draw an inference of good mental health from the absence of information in the Coronial data on the mental state of the other 27 individuals who may have had an advanced terminal condition. To suggest that palliative care was not an adequate treatment option and therefore that they chose to take their own lives fails to take into account the full set of circumstances operating in that person's life at the time of their death. For example, Case 92, was an 'older male who died as a result of a self-inflicted gunshot wound.' He had 'progressive terminal cancer and was in constant pain and discomfort. He lived alone in a makeshift residence.'³³⁴ Case 205 had 'end stage alcoholic liver disease and Zieve's syndrome' and 'two days before his death the

333 Coronial Report CR17-61.1, 'Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions in Western Australia 2012-2017,' at 3, provided by Gary Cooper, Principal Registrar, Coroner's Court of Western Australia, JSCEOLC Response to Questions on Notice, 24 May 2018 at 4.

334 Coronial Report CR17-61.1, 'Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions in Western Australia 2012-2017,' at 3, provided by Gary Cooper, Principal Registrar, Coroner's Court of Western Australia, JSCEOLC Response to Questions on Notice, 24 May 2018, Case 92.

deceased was evicted from his home and was conveyed to hospital after ambulance officers responded to a mental health alert.³³⁵

- 2.156. It should be noted that of the 42 cases that may be classed as terminal, seven of these cases referred to the individual having been a member of a euthanasia organisation, or having researched euthanasia prior to their death.³³⁶ Of these seven deaths, there is no information provided in the Coronial data whether these individuals had received palliative care, whether these individuals had access to the palliative care services they needed, or whether palliative care they had received was an inadequate treatment option for them.
- 2.157. It is agreed that these are 'brutal, lonely deaths that leave ineradicable scars in the families and first responders left to pick up the pieces.'³³⁷ However, this data provided by the WA Coroner does not support the assertion that 'the prohibition of peaceful, doctor-assisted death drives some terminally ill individuals to suicide using violent and undignified means.'³³⁸
- 2.158. In light of the complexity that the Coronial data reveals, any suggestion that nothing could be done in any of these 199 cases other than the offering of assisted suicide is an appalling and defeatist proposition.
- 2.159. In the words of Rev Peter Abetz, WA State Director of the Australian Christian Lobby, 'I think we can do much, much better as a community than just to offer a less messy suicide.'³³⁹

Finding 39

An assisted suicide regime in Western Australia would send a message that suicide is a legitimate solution in certain circumstances.

335 Coronial Report CR17-61.1, 'Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions in Western Australia 2012-2017,' at 3, provided by Gary Cooper, Principal Registrar, Coroner's Court of Western Australia, JSCEOLC Response to Questions on Notice, 24 May 2018, Case 205.

336 Cases 25, 59, 71, 83, 98, 147 and 204 in Coronial Report CR17-61.1, 'Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions in Western Australia 2012-2017,' at 3, provided by Gary Cooper, Principal Registrar, Coroner's Court of Western Australia, JSCEOLC Response to Questions on Notice, 24 May 2018.

337 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 6.

338 Mr Francis, Dying for Choice Submission 642 at 12.

339 Rev Abetz, WA State Director, Australian Christian Lobby, JSCEOLC Transcript, 9 March 2018, Session 2 at 8.

Chapter 2

Finding 40

Some proponents of assisted suicide endeavour to resolve the dilemma of inconsistency on suicide prevention by banishing the word 'suicide' from the debate in favour of the phrase 'assisted dying.'

Finding 41

The highly publicised case of Dr David Goodall involved circumstances of overt ageism, troubling signs of suicide celebration and a seeming absence of any suicide prevention measures at work.

Finding 42

The suicide rates in people aged 80 and above is a particular concern in Western Australia.

Finding 43

The reason for older age suicide is complex and usually multifactorial, and should not be confused with the misconception that such suicides are driven by suffering associated with chronic, debilitating or terminal illness.

Recommendation 10

The Minister for Mental Health, in consultation with the Minister for Seniors and Ageing, should expand suicide prevention programs to further target older Western Australians.

Recommendation 11

The Minister for Mental Health should direct the Mental Health Commission to conduct an urgent review, outside and separate to any other general review processes underway, into the effectiveness of Western Australia's current suicide prevention strategies and programs in light of the Dr David Goodall case.

Finding 44

Coronial data identified the suicide of 199 Western Australians with a terminal or debilitating condition between 2012 and 2017. Examination of the data reveals that 42 may be capable of being classified as suffering from a terminal condition and 157 with a debilitating one. Of the 42 cases, 27 can be identified as being in the advanced or terminal stage of illness. Of the 157 cases, 99 evidenced some level of mental ill-health.

Finding 45

A close and proper examination of the coronial data of suicides between 2012 and 2017 does not support the assertion that individuals suicide because palliative care is not an adequate treatment option, but rather confirms the multifactorial nature of suicide.

Assisted Suicide and the Medical Profession

Assisted suicide fundamentally alters the role of the medical profession

- 2.160. The World Medical Association, in its Resolution on Euthanasia:

*reaffirms its strong belief that euthanasia is in conflict with basic ethical principles of medical practice, and strongly encourages all national medical associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions.*³⁴⁰

- 2.161. The American College of Physicians also state that the practice of assisted suicide:

*is problematic given the nature of the patient-physician relationship, affects trust in the relationship as well as in the profession, and fundamentally alters the medical profession's role in society... Control over the manner and timing of a person's death has not been and should not be a goal of medicine.*³⁴¹

- 2.162. Indeed, the American College of Physicians question whether assisted suicide is a type of control over suffering and the dying process that is even within the goals and scope of medicine.³⁴²

- 2.163. Mrs Suzanne Greenwood, Chief Executive of Catholic Health Australia said, in evidence to the Committee:

*On... the question of clinical erosion, it is very much that the role of the clinician is to assist and help a person. To come to the conclusion that assisting and helping a person to remove their pain is to remove the person is just something that is not palatable to us.*³⁴³

- 2.164. Mr Tim Hammond, former Federal Labor MP, expressed the change this way:

340 World Medical Association (2017) *WMA Resolution on Euthanasia* <<https://www.wma.net/policies-post/wma-resolution-on-euthanasia/>> quoted in Mr Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices included in JSCEOLC Response to Questions on Notice, 17 April 2018 at 1-2.

341 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576, quoted in Rev Dr Parkinson, Director, LJ Goody Bioethics Centre, JSCEOLC Submission 53 at 7.

342 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576.

343 Mrs Greenwood, Chief Executive, Catholic Health Australia, JSCEOLC Transcript, 28 February 2018, Session 1 at 8.

Chapter 2

And as legislators, let's be very clear-eyed in what we would be doing if we were to vote for such a law. As Paul Keating has said—“(it) means permitting physicians to intentionally kill patients or assisting patients in killing themselves.”³⁴⁴

- 2.165. Offence is taken by proponents of euthanasia to the use of the word ‘killing’ when applied to the administration of assisted suicide by a medical practitioner. Their preference is for terms such as voluntary assisted euthanasia or assisted death. That the line drawn between assisted death and killing is a tenuous one is revealed in the following exchange between Dr Roger Hunt, a palliative care practitioner and advocate of assisted suicide, and Professor Margaret Somerville, provided in evidence to the Committee:

I was speaking here in Australia several years ago and I said that we cannot have doctors killing people. A friend of mine who is also palliative physician and one of the rare ones who approves of euthanasia, Dr Roger Hunt, jumped up in the audience and said, “Margo, would you stop using that word ‘killing’? It is not killing.” I said, “What is it?” and he said, “It’s VAE.” I asked him what that stood for and he said voluntary assisted euthanasia. I went on in the speech and I made the suggestion that if we do it, let us keep it out of medicine, and who should it be, and I said lawyers. Roger rose to his feet and yelled out across the audience and said, “Margo, are you crazy? You would have lawyers killing people?” So when it was lawyers, it was seen as what it was; when it was doctors, it was not. That is because people find it very hard to believe that a doctor would do anything that was not ethical and entirely within their own, and just their own, best interests. We know that from what is called the “therapeutic misconception syndrome” in research—medical research. Even when you give a full explanation that this research will be of no benefit to you, when you go back and interview those people who were in the research study, they say things such as, “I really think this has helped me,” and you have already told them that it is not going to do that. So people trust doctors, and that trust is enormously important. You have to have trust in the medical institution, and that is also involved here.³⁴⁵

- 2.166. The conflict between a doctor’s duty to protect the welfare of their patient and the practice of assisted suicide is clearly explained by Dr William Toffler, Professor Emeritus

344 Tim Hammond, ‘Euthanasia and why I’m against it’ *PerthNow*, 3 December 2017.

345 Prof Somerville, Professor of Bioethics, University of Notre Dame Sydney, JSCEOLC Transcript, 1 May 2018, Session 8 at 5.

of the Department of Family Medicine, Oregon Health and Science University in the following statement:

My job as a doctor is to alleviate their suffering, it's not to be a vending machine when they make a good 'rational' argument that they'd be better off dead. It's like being a lawyer for the defence and a lawyer for the prosecution in the same courtroom. Am I arguing for their health and wellbeing, to extend life as long as is reasonable, or am I advocating for their early demise because after all they are going to die anyhow? And then by the way, if you don't think that's a conflict of interest, I am also the judge to decide which argument is the best. And if you are not bothered by that, I am also the executioner. There are about 200 doctors in the State of Oregon who believe they can keep all that conflict of interest straight. It's a delusion.³⁴⁶

The medicalisation of death

- 2.167. It can be argued that making physicians the arbiters of assisted suicide is a return to paternalism and not a power physicians should want, that in fact the legalisation of assisted suicide does not empower the patient, but rather empowers the physician.³⁴⁷
- 2.168. The Professionalism and Human Rights Committee of the American College of Physicians write that:

The suffering of dying patients may be great and is caused by somatic symptoms, such as pain and nausea; psychological conditions, such as depression or anxiety; interpersonal suffering due to dependency or unresolved conflict; or existential suffering based in hopelessness, indignity, or the belief that one's life has ended in a biographical sense but has not yet ended biologically. For some patients, a sense of control over the manner and timing of death brings comfort. However, is it reasonable to ask medicine to relieve all human suffering? Just as medicine cannot eliminate death, medicine cannot relieve all human suffering.

...

346 Dr William L Toffler, Professor Emeritus, Department of Family Medicine, Oregon Health and Science University, interviewed in Kevin Dunn (2018) *Fatal Flaws: Legalizing Assisted Death*.

347 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576.

Chapter 2

*Society's goal should be to make dying less, not more, medical. Physician-assisted suicide is neither a therapy nor a solution to difficult questions raised at the end of life.*³⁴⁸

- 2.169. That this power would be placed in the hands of medical professionals was also evident in the concerns expressed to the Committee by palliative care service provider Silver Chain, who were clear that assisted suicide is not a part of palliative care provision and that were it to be considered so, patients would fear the intentional ending of their life if assisted suicide were part of Silver Chain's care service:

Hon NICK GOIRAN: So are you concerned that if Silver Chain were to provide assisted suicide, it would put off clients from accessing Silver Chain in the first place?

*Mr COCKAYNE: For a part of the community it may, you know. If Silver Chain was providing that service directly, then some people may connect dots and infer that actually that is what you might do, irrespective of what my wishes are.*³⁴⁹

- 2.170. Similar concerns were expressed by Dr Alison Parr, Director of Medical Services, St John of God Health Care and Palliative Care Consultant:

*I think one of the big challenges with palliative care is the fear. When people initially hear about a referral to palliative care, for example, we spend a lot of time with those first contacts with patients and families just actually providing reassurance about what we are there to do. For some people, there is a fear that actually what we are there to do is end their life. To be able to currently say to them, "Look, we're here and we're all about living, actually. Until you die, it is not about assisting you to die and we're not about to do anything that is likely to shorten your life" often helps to build trust and allows people to open up in their most vulnerable times and talk very openly about their thoughts and fears. I guess there is potential in that situation to not be able to offer that level of reassurance and for people then to be even more wary of accessing services that might help them. That would potentially be a concern.*³⁵⁰

348 Ibid at 577 and 578.

349 Mr Cockayne, General Manager, Health Care WA, Silver Chain Group, JSCEOLC Transcript, 15 December 2017, Session 3 at 14.

350 Dr Parr, Director, Medical Services, St John of God Health Care and Palliative Medicine Consultant, JSCEOLC Transcript, 28 February 2018, Session 1 at 8.

The false assertion that assisted suicide is only about patients and not their doctors

- 2.171. To counter the awkwardness that legalised assisted suicide medicalises death, proponents assert that assisted suicide has nothing to do with doctors, and has everything to do with the autonomous patient. This assertion is seen in Go Gentle Australia's submission to the Committee, where Mr Denton writes that '[o]nly one person is being asked to make a life and death decision. Not the doctor. The person who is dying,' in support of a physician-assisted suicide model like that recently adopted in Victoria.³⁵¹ He states:

This is not a law for doctors, even though, importantly, a law like this will protect doctors in a way they are currently not protected, should they assist a patient to die. This is a law for patients and I think in this conversation, the patient's voice, the patient's right to have a choice, the patient's right to determine that inevitable and most crucial thing in life, which is how we die, is overlooked and too often we look at this with the framework of: how do doctors feel about it? And part of what I have been trying to do over the last three years is tip the balance back to, "Wait a minute, this is actually about how we die, not about how doctors feel about how we die."³⁵²

- 2.172. Dr Syme also gave evidence to the Committee about the centrality of the patient in the control offered by patient-administered lethal medication:

I am absolutely convinced that self-administration is the appropriate thing for a number of reasons, but principally because that places control over the end of life firmly and totally in the hands of the individual... What is more, I would suggest to you that the responsibility for this action should lie with the individual. I as a doctor—my responsibility is to try to help you to go as far with your life as I possibly can. But if you feel you can go no further, I have a responsibility to help you to have a peaceful death. If you want to end your life, that is your responsibility. If you want to end your life, it is your responsibility to take that action if you are physically capable of doing so. It is not proper, in my opinion, for you to think that you can pass that responsibility to me. It is the greatest safeguard that you can have in legislation to put the onus on the individual if they want to end their own life because of their

351 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 43.

352 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 6.

Chapter 2

*intolerable suffering, and that is their responsibility and the safeguard is that they have to do it themselves.*³⁵³

- 2.173. As did Mr Murray Hindle, President of Dying with Dignity (WA):

*a drug that the individual can get after meeting the criteria and then take it themselves is by far the best option. It then takes away “the doctor’s a killer” sort of attitude that seems to be rife, and the person is able to do it themselves. Even if a doctor does help, he is really only facilitating the person to take their own life. I suppose it depends on how you look at it, but giving an assistance, handing a person the drug or at least giving it to them because they cannot handle it themselves, I really do not see that as killing them.*³⁵⁴

- 2.174. Stahle suggests that this is a deliberate transference of responsibility for the act onto the patient in order to lower the threshold to allow legalisation:

*In an assisted suicide, it is also the patient himself/herself who has to take the death drug. By way of this arrangement, one is able to transfer the responsibility for the act to the patient. This effectively lowers the threshold for legalization. It becomes more palatable for the doctor than to give a lethal injection, and the doctor does not even need (in Oregon) [and under the Victorian legislation] to be present when the patient takes the death drug... That the doctor “only” prescribes the poison and the patient himself/herself takes it is an example of diffusing responsibility. One can argue that the prescription in itself is harmless. However, with the prescription, a deadly substance is made available and the patient is recommended to use it. Furthermore, the physician consults with another physician. That is presented as a safety measure for the patient, but at the same time it means that they together take the decision to approve the patient’s request, which is another example of diffusing responsibility. All the parties involved can then distance themselves from their personal moral responsibility. In Oregon, they are also completely exonerated from all legal responsibility through the “good faith” rule that protects all the participants.*³⁵⁵

- 2.175. Mr Denton’s assertion that it is only the patient who makes a life and death decision is contradicted by Dr Nitschke, a fellow assisted suicide proponent, who in evidence to the

353 Dr Syme, Medical Practitioner and Vice President of Dying With Dignity Victoria, JSCEOLC Transcript, 13 April 2018, Session 4 at 10.

354 Mr Hindle, President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 6.

355 Stahle F (2017) ‘Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,’ *Journal of Ethics in Mental Health* 10 at 5-6.

Committee stated that '[i]nvariably it comes back down to the medical profession who act as judge here and effectively decide if a person gets the right to die, whether they qualified to die or not. That is not a position that fits very comfortably with many medical professionals.'³⁵⁶

- 2.176. Mr Perron's criticism that 'it is all about access to the keys to the medicine cabinet. In that cabinet the government keeps the means to die a peaceful, tranquil death, but the law says you are not allowed to have any,'³⁵⁷ is ironically answered by Dr Syme, who states that '[the doctor] is critically important to the individual's being fully informed and is the key to a dignified death.'³⁵⁸
- 2.177. Furthermore, directly contradicting his own assertion that assisted suicide has nothing to do with doctors, in his submission Mr Denton writes that 'the second major safeguard [of legislated assisted suicide] is the conservatism of the medical profession.'³⁵⁹ On the one hand, assisted dying has nothing to do with doctors, but on the other hand, the doctor is central to the safeguarding against abuse. This anomaly is considered further later in this Report in the section entitled "*A safeguard is only as good as the doctor enforcing it.*"

The question of whether assisted suicide should be administered by a profession outside of the medical profession

- 2.178. Since the introduction of assisted suicide would fundamentally alter the role of the medical profession and with it the doctor-patient relationship, it has been suggested that an entirely separate group of professional people should be trained to administer the program.³⁶⁰ The AMA note that there is a lot of sympathy within parts of the medical profession for the idea that someone else other than medical professionals should be administering assisted suicide because the act of assisted suicide is not considered to be a medical act.³⁶¹ This was also confirmed by Mr John McGrath, Committee member, who said that this idea was raised in discussion he had with a surgeon who confirmed that many doctors do not want to be involved in assisted suicide and would prefer for the program to operate outside the medical profession.³⁶²

356 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 2.

357 Mr Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 1.

358 Syme R (2008) *A good death: An argument for voluntary euthanasia*, Carlton, Victoria: Melbourne University Publishing at 30.

359 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 41.

360 See Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 2 at 5 and Prof Somerville, Professor of Bioethics, University of Notre Dame Sydney, JSCEOLC Transcript, 1 May 2018, Session 8 at 3.

361 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 7.

362 Mr John McGrath, Committee member, JSCEOLC Transcript, 18 May 2018, Session 1 at 23.

Chapter 2

- 2.179. Assisted suicide is outsourced to private organisations in the Netherlands and Switzerland. However, such transparency would prove too great a hurdle for proponents of the legalisation of assisted suicide:

It could all be managed privately, as it is being done already—to a large degree—in the Netherlands, Switzerland and the United States by the death lobby. But, if in the initial stages such an arrangement would have been advocated, it would have given rise to invincible resistance to the euthanasia movement. No, in its propaganda this movement needs to take advantage of the positive reputation of the medical profession and the idea of it being healthcare.³⁶³

- 2.180. Boudreau and Somerville also identify the advantage proponents derive from aligning assisted suicide with the medical profession:

The pro-euthanasia lobby derives advantages by aligning itself tightly with medicine and physicians. The history of physician involvement in capital punishment is illustrative of this strategy. Juries in the USA, who had seen horrific footage of convicted murderers being executed in the ‘electric chair,’ became reluctant to convict persons accused of capital offences or to vote for a death sentence for felons convicted of a capital offence. Most physicians and the American Medical Association adamantly opposed medicine’s involvement in administering capital punishment by lethal injections. Nevertheless, some physicians participated. By virtue of their involvement and in concocting a method of execution that makes a convicted criminal appear serene during final moments, enhanced acceptability was conferred on the procedure. It has been suggested that ‘the law turned to medicine to rescue the death penalty.’³⁶⁴

The low number of doctors likely to participate in an assisted suicide program

- 2.181. AMA(WA) recommend that consideration should be given to the number of doctors who would realistically be involved in assisted suicide, were it to be introduced. In a survey of its members conducted in 2016, 62 per cent said they would not provide physician-assisted suicide, while 25 per cent believed that they would. However the AMA note that in practice, this second figure is even lower. They refer to statistics in Canada which indicate that approximately 1 per cent of doctors have taken up the practice of assisting suicide. The AMA suggest that ‘[t]his has major implications for access to doctors

363 Stahle F (2017) ‘Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,’ *Journal of Ethics in Mental Health* 10 at 13.

364 Boudreau and Somerville (2013) ‘Euthanasia is not medical treatment,’ *British Medical Bulletin* 106, 45-66 at 49-50.

providing assisted dying, potentially increasing disparity of treatment for those in lower resourced settings.³⁶⁵

- 2.182. It is also reported that in Oregon and Washington state very few physicians participate in physician-assisted suicide. Data on the practice of physician-assisted suicide in Oregon in 2015 reveals that the 218 prescriptions written under the legalised program in that State were written by 106 physicians, representing 1 per cent of actively licensed physicians.³⁶⁶
- 2.183. In relation to psychiatric assessment of patients requesting assisted suicide, research shows that while some 64 per cent of British psychiatrists agreed that psychiatric assessments are important in the physician-assisted suicide context, only 35 per cent would be willing to carry out such assessments. A pilot survey of RANZCP WA branch members indicated a similar trend.³⁶⁷
- 2.184. The major implications for access to doctors providing assisted dying, and the increasing disparity of treatment for those in lower resourced settings, is a very real issue and was the case in the Northern Territory when assisted suicide legislation was in operation there. This was identified by Dying With Dignity WA in their oral evidence to the Committee,³⁶⁸ and in their submission where they state that:

Western Australia, a truly vast State with a population highly centralised in a few locations, most especially Perth, has particular needs and difficulties that are not the same as those in Victoria, or even in NSW, and accordingly special consideration needs to be given to the needs of people living in remote and regional areas, many of whom are indigenous and suffer from various hardships, and in particular the law to be introduced needs to cater for the limited availability of specialist care to such persons.

...

Nor should there be a requirement that routinely one of the doctors must have specialist qualifications relating to the condition in question... there may be some cases where that would not be feasible or appropriate. It is to be remembered that in remote areas, access to specialists may be difficult and cause considerable delay; and that some

365 AMA(WA), JSCEOLC Submission 685 at 5.

366 Emanuel et al (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe,' *JAMA* 316(1), 79-90 at 83.

367 Royal Australian and New Zealand College of Psychiatrists (WA), JSCEOLC Submission 391 at 8.

368 Mr Walker, Vice President, Dying with Dignity WA, JSCEOLC Transcript, 13 April 2018, Session 5 at 5. See also the comments made by Mr Francis, Dying for Choice, JSCEOLC Transcript, 9 April 2018, Session 1 at 14.

Chapter 2

*doctors may choose not to assist, for personal ethical or religious reasons. Difficulties of these kinds beset the operation of the Northern Territory Act.*³⁶⁹

2.185. Their solution to address this disparity in healthcare resourcing for rural and remote areas is to expand the professions who may assist in a patient's suicide to include nurses as well as doctors, and to limit any requirement for medical specialist involvement. Dying with Dignity's concern that Indigenous Western Australians suffering from 'various hardships' will have limited access to assisted suicide services because of their remote location ignores the existing unaddressed problem of fear that some Indigenous people hold toward the medical profession.

2.186. The evidence of Dr Khorshid stands in direct contrast to the opinions held by Dying with Dignity WA:

*[The AMA] are still concerned that if the medical profession generally is associated with ending people's lives, that may create a further barrier to our Indigenous population accessing medical care. We know that some of their views around death are quite different to those of the western mindset. That is already a barrier to seeking medical care for certain Indigenous members of the community.*³⁷⁰

2.187. It is bad public health policy to prioritise ready access to a new 'end of life choice' like assisted suicide in the knowledge that access to existing choices like specialist palliative care is poor to variable for rural and remote Western Australians.

Finding 46

Governing medical bodies both inside and outside Western Australia discourage medical practitioners from participating in assisted suicide, even if the local law allows it or decriminalises it.

Finding 47

The licencing of medical practitioners to assist in the suicide of their patients alters the role of the medical profession.

Finding 48

There are multiple conflicts of interest for a medical practitioner assisting in the suicide of their patient.

369 Dying with Dignity (WA), JSCEOLC Submission 565 at 6 and 23-24.

370 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 7.

Finding 49

An assisted suicide regime would improperly absolve a medical practitioner of responsibility for giving a lethal injection to their patient or for giving their patients a prescription to poison themselves.

A Safeguard is Only as Good as the Doctor Enforcing it

- 2.188. One of Australia’s most high profile proponents of assisted suicide, Mr Denton suggests that a major safeguard against abuse in the practice of assisted suicide is the conservatism of the medical profession:

*The second major safeguard is the conservatism of the medical profession—the professions’ ethic to help their patients to go as far with their lives as possible while respecting their autonomy, and their concern to protect the vulnerable, which includes suffering, dying people. This conservatism should not be under-estimated.*³⁷¹

- 2.189. Mr Denton also placed emphasis on the trust we hold in the medical profession in evidence to the Committee, stating that ‘[w]e trust our medical profession and we trust them to make complicated judgements every day in our hospital system and in their offices.’³⁷²

- 2.190. Similar sentiments were repeated by Dr Syme in evidence to the Committee:

*I have helped a lot of people at the end of that life and it has always been my fundamental belief, or approach, to try to help people to go as far with their lives as possible. I believe that that will be the attitude of the majority of medical practitioners who become involved in assisted dying. Doctors are a conservative group; they will not want to be helping people with assistance to die without very, very due cause.*³⁷³

- 2.191. Magnusson also suggests that ‘careful screening is surely an essential precondition to rational euthanasia practice.’³⁷⁴

- 2.192. In his evidence to the Committee, however, Mr Denton confirmed that doctors would be less conservative now than they were at the time of the operation of the ROTI Act in the Northern Territory where, as noted above, there were very few medical practitioners willing to euthanise patients, or to even assess cases as the consulting doctor:

371 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 41.

372 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 12.

373 Dr Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, JSCEOLC Transcript, 13 April 2018, Session 4 at 5.

374 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 213.

Chapter 2

Mr DENTON: The Northern Territory cases took place, you may recall, in an extraordinarily heated atmosphere. It is very different from where we are now. Just to give you a sense, that was 1997. That was the first law written in the world. Four people died then under that law before it was repealed. These same kinds of laws are now available to over 100 million people around the world, so the whole thing has moved on a lot further since then. They happened in an atmosphere of extreme heat, where the AMA in the Northern Territory was warning doctors off against helping anybody because they would be liable for legal action. What happened under that law—and you will recall that federal politics came it into (sic.) very quickly; there was enormous media attention—I think was deeply distorted. I do not think doctors acted as they would now and I do not think patients were given the help that they would get now.

Hon NICK GOIRAN: So was the conservative culture of the medical profession that you referred to more conservative then in 1996 or is it more conservative now?

Mr DENTON: I cannot give a definitive answer to that, except to say that I think it is less conservative now, and I do not even say this critically...

...

Hon NICK GOIRAN: I am a little troubled that you say to the committee that the doctors are less conservative now than what they were 20 years ago if the conservative culture is to be the main safeguard.

Mr DENTON: No, you misunderstand me. You are taking the words “not conservative” as meaning reckless. Consultation with a patient, which is what I am advocating, is not being reckless. Consultation with a patient is being a good doctor.³⁷⁵

- 2.193. That a doctor may be less conservative, or more likely to approve an assisted suicide request, than was the case in the Northern Territory in 1997 compromises the proposition that doctor conservatism is a ‘major safeguard,’ especially where the doctor may in fact be biased toward assisted suicide (considered further below).
- 2.194. What is also interesting is Mr Denton’s reliance on the conservatism of the medical profession to safeguard the assisted suicide process on the one hand, and his submission that ‘Doctors sign certificates every day where death was the result of sedation and

375 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 8-9 (emphasis added).

withholding hydration. Who would know if the doctrine of double effect is shielding abuse or cover up?’³⁷⁶ Mr Denton appears to have very little faith in palliative care specialists in their current practice of end of life care, and yet he holds great faith in the medical profession to safeguard vulnerable patients under a legalised assisted suicide program where doctors are permitted to intentionally kill a patient.

- 2.195. A doctor would not have to be acting recklessly for abuse under assisted legislation to occur. Evidence has already been given in this Report that in jurisdictions with optional referral for psychiatric assessment, gatekeeping medical practitioners seldom refer and that this results in persons with treatable clinical depression being wrongfully assisted to commit suicide. Observers in the Netherlands have also concluded that the relevant legal guidelines in that jurisdiction are variously interpreted and definitions of ‘unbearable suffering’ differed considerably between doctors.³⁷⁷ It has been noted that in relation to data from Washington State that error in accurate prognosis in assisted suicide cases has doubled, it is unlikely that medical practitioners have actually become less competent at prognosis. It is more likely that as assisted suicide becomes established, medical practitioners who participate in its operation by prescribing lethal doses of medication pay less attention to a statutory limit regarding expected time until death.³⁷⁸

- 2.196. Furthermore:

Not all doctors are skilled in the management of patients with advanced cancer, are effective communicators, and have a thorough understanding of the relative benefits of pharmaceutical, neurosurgical and anaesthetic approaches to pain control. A particular concern is that some doctors (or health providers) do not realise the limitations of their knowledge. In some instances, they believe that if they cannot fix the problem it cannot be fixed! Whereas it is possible that the problem could be partially alleviated if the patient were to be referred to experts familiar with managing terminally ill patients.

...

For some doctors who are unaware of the other approaches, the next-best alternative is perceived as helping such patients to die. Their compassion and concern for the patient’s well-being inexorably lead to their acceptance of—and, ultimately for some, their practice of—euthanasia rather than resulting in true empathy and the insight to

376 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 9.

377 Zalcborg JR and Buchanan JD (1997) ‘Clinical issues in euthanasia,’ *MJA* 166 150 at 151, citing H Hendin (1994) ‘Seduced by death: doctors, patients and the Dutch cure,’ *Issues Law Med* 10, 123-168.

378 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 15-16, citing Washington State Department of Health, *Death With Dignity Act Reports*, 2009-2015.

Chapter 2

*involve expert professionals in helping to support patients and their families.*³⁷⁹

- 2.197. Mr Denton's high-stakes trust in the medical profession was challenged by Hon Nick Goiran MLC, who suggested that such an extreme level of trust may be misplaced:

*You have said a few times this afternoon or this evening for you that—you use the word “we”—we trust our doctors. I should perhaps disclose to you that before entering Parliament, I was a barrister and solicitor in Western Australia and part of my practice was medical negligence law, so I guess perhaps when you say “we,” as a society there are degrees of trust. Some of us are, perhaps through painful lived experience of our clients, a little less trusting than others.*³⁸⁰

- 2.198. Pollard and Winton's summation is succinct and to the point:

*We have not yet achieved excellence, or even satisfactory competence, in the limited tasks we have set ourselves in medical decision-making. There are still complaints about inattentive, uncommunicative doctors, inadequate pain control and neglectful care. Agreed patient rights are not always adequately observed. Where is the evidence that we would manage decisions any better when error would be tragic and irreversible?*³⁸¹

Doctor bias toward assisted suicide

- 2.199. Mr Denton suggests that the process of determining whether a patient can access assisted suicide is its own safeguard:

*What will happen is this: when a patient presents saying “I want help to die,” the doctor is going to ask, “why?” They're going to look at all that patient's symptoms. They're going to want to know what's going on in that patient's life that's making them feel like they no longer want to live.*³⁸²

- 2.200. Evidence of doctor bias toward assisted suicide indicates that such a process is no safeguard at all, or at best that such a safeguard is only as good as the doctor involved.

379 Zalcberg JR and Buchanan JD (1997) 'Clinical issues in euthanasia' *MJA* 166 150 at 151.

380 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 12.

381 Pollard B and Winton R (1993) 'Why doctors and nurses must not kill patients,' *MJA* 158, 426-429 at 428.

382 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 40.

- 2.201. Dr Syme acknowledges that there is a possibility for bias to be held by the doctor in his statement that '[i]t is essential that one's innate sympathy for a person's suffering does not introduce bias into one's decisions.'³⁸³
- 2.202. In discussing the attitudes held by medical professionals toward euthanasia, Magnusson notes that '[a]t one extreme, some revisionists display what we call the 'Rambo' or 'cowboy' factor: an almost reckless individualism which most readers, we believe, would find disturbing.'³⁸⁴ Magnusson further observes that:

The overwhelming majority of those interviewees who were implicated in 'disturbing' episodes [of illegal euthanasia of a patient] were simultaneously gracious and dedicated professionals who inspired trust, and who genuinely cared about the suffering of their patients. It is difficult not to recall the interview with Richard, an opponent of euthanasia, who said: "I don't idealise doctors. They are fairly ordinary people with many of the same frailties which most people have, although hopefully accustomed to operating within a professional framework."³⁸⁵

- 2.203. Professor Michael Quinlan, Dean of the School of Law Sydney at the University of Notre Dame Australia, notes that the legalisation of assisted suicide will most likely attract participation of medical practitioners who are also advocates of the practice:

[I]f euthanasia were to be legalised, participation by medical practitioners (or others given authority by the State to euthanise) would be voluntary. This in itself may create issues of concern, as advocates for euthanasia may be most attracted to take up that role. Indeed, in the brief period of operation of the NT [ROTI] Act, the euthanasia campaigner Dr Nitschke administered euthanasia to all of those who accessed the procedure. Some such doctors may consciously or unconsciously have a preference for euthanasia. This may result in an actual or, at least, perceived conflict of interest particularly given the fiduciary relationship of trust that exists between a doctor and patient. Quite unlike a hangman or executioner administering a lethal injection, a doctor who administers euthanasia will have a clear doctor-patient fiduciary relationship. Such a doctor may well have been involved in assisting the patient to decide on the course of euthanasia and have facilitated the achievement of that objective. For example, during the brief operation of the NT [ROTI] Act, Dr Nitschke paid for the

383 Syme R (2008) *A good death: An argument for voluntary euthanasia* at 191.

384 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 105.

385 *Ibid* at 208.

Chapter 2

*fees of one of the psychiatrists who signed off on the availability of euthanasia for one of his patients.*³⁸⁶

- 2.204. Evidence to support this concern about doctor bias is also found in Oregon, where a physician member of a pro-assisted suicide lobby group provided the consultation in 58 of 61 consecutive cases of patients receiving physician-assisted suicide in Oregon.³⁸⁷ This evidence raises concerns about the objectivity of the process and the safety of patients, and the influence of bias on the decision-making of these physicians in the assisted suicide process.³⁸⁸

Doctor shopping

- 2.205. Concern about doctor shopping was expressed to the Committee by the AMA(WA):

*In terms of the decision to proceed and an approval process, we are not comfortable with two independent doctors agreeing with each other. We find that to be fundamentally flawed. If an individual wanting to seek euthanasia did not meet the criteria by two particular doctors, they will go and find another two doctors that do agree with them. We know this occurs right now in medicine in Western Australia where if doctors do not give you the answer that you want, you just go find another one. Doctors are good at certain things in medicine, we are okay at other things, but we are not skilled in all of these sorts of decisions.*³⁸⁹

- 2.206. The probability of doctor shopping occurring under a legalised assisted suicide scheme was also addressed by Rev Saunders, an accredited personal injury lawyer specialist, in this exchange with Hon Nick Goiran MLC:

Hon NICK GOIRAN: Would it be common for you in your experience as an accredited personal injury lawyer specialist to have to seek out those medical opinions from time to time?

Rev. SAUNDERS: Yes, in every case.

Hon NICK GOIRAN: If one of the safeguards was to have more than one medical practitioner to provide a diagnosis, how difficult would it be to get two doctors to agree?

386 Quinlan M (2016) “Such is Life”: Euthanasia and capital punishment in Australia: consistency or contradiction?’ *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* 6(1) at 21-22.

387 Hendin and Foley (2008) ‘Physician-assisted suicide in Oregon: a medical perspective,’ *Mich Law Rev* 106, 1613–40.

388 Pereira J (2011) ‘Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,’ *Current Oncology* 18(2) 38-45 at 40.

389 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, Session 1, 18 May 2018 at 6.

Rev. SAUNDERS: Can I say with the greatest of respect to medicolegal practitioners, it would not be very difficult at all. Does it come as a surprise to members of this committee to hear that in every case where you act for a plaintiff you present two or three medical reports that are very favourable to the plaintiff while at the same time in the very same case the defendant will present two or three medical reports that will say something entirely different? That is the reality of medicolegal practise in Australia.

Hon NICK GOIRAN: So you just keep shopping until you get the opinion you want?

Rev. SAUNDERS: I would like to think that we did not, but is that, in terms of the areas of interest of this committee, a realistic danger? In my view, yes.³⁹⁰

2.207. Magnusson also raises the issue of doctor shopping:

Nevertheless, since a treating physician may not wish to perform euthanasia, it is inevitable that terminally ill patients may end up 'shopping' for a doctor prepared to assist them. Quill and colleagues emphasise that 'physician-assisted suicide should be carried out only in the context of a meaningful doctor-patient relationship. Ideally, the physician should have witnessed the patient's previous illness and suffering.' Miles fears that legalisation may 'empower not only physicians with good relationships, but also those with transient, inadequate, or troubled relationships with chronically ill patients.'³⁹¹

2.208. How a legislative scheme for assisted suicide could ensure that assisted suicide was only carried out in the context of a meaningful doctor-patient relationship is not self-evident.

Finding 50

A safeguard in an assisted suicide regime that involves a medical practitioner is only as safe as the practitioner is competent.

Finding 51

A safeguard in an assisted suicide regime that involves a medical practitioner is unable to protect against unconscious incompetence.

390 Rev Saunders, National Director, FamilyVoice Australia, JSCEOLC Transcript, 9 March 2018, Session 3 at 7.

391 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 278-9.

Chapter 2

Finding 52

A safeguard in an assisted suicide regime that involves a medical practitioner is unable to protect against mistake, error or negligence.

Finding 53

Legalisation of assisted suicide will attract participation by medical practitioners who are also advocates of the practice.

Finding 54

Even if the risk of doctor bias toward assisted suicide is the same as doctor bias in general, the consequences are not comparable.

Finding 55

Doctor shopping is a clear danger of an assisted suicide regime, with no solution apparent.

Medical Error in Diagnosis and Prognosis

2.209. Mr Denton suggests that:

*Doctors who object [to ‘voluntary assisted dying’ or assisted suicide] portray it as though they are being asked to ‘kill’ a patient. In reality, what they’re being asked to do is what they already do—make a careful diagnosis that a patient’s condition is terminal, and at its end stages, and their suffering is intolerable, and go through with them their treatment options.*³⁹²

2.210. The requirement for ‘a careful diagnosis that a patient’s condition is terminal and at its end stages’ is no meaningful safeguard when the large body of evidence of medical error in prognosis, and even in diagnosis, are considered.

Error in prognosis

2.211. Much evidence was received by the Committee as to the risk of medical error in prognosis. In relation to the unworkability of a safeguard that requires a time period before death, as is incorporated into the Victorian legislation, Dr Nitschke said:

What period defines a person’s terminal status—is it six months, is it nine months? Oh, well, we have decided to make it even safer by making it six months. Most doctors involved watching that process closely just shrugged at that point, because that is an almost impossible decision to

392 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 43 (emphasis added).

*make. You just have no idea whether a person is going to live for six months or nine months.*³⁹³

- 2.212. The AMA(WA) highlighted the complexity involved in medical decision making:

*Really the point is that everything is far more complex in reality than it sounds when you are writing down rules on a piece of paper. A key example, one that has stuck in my mind, was her example of the most wrong she has got prognosis as a palliative care physician where an individual she talked about was given a few weeks or months to live and is still going strong decades later. We do get prognoses wrong and we need to understand that everything we talk about is grey when we are talking about end-of-life issues.*³⁹⁴

- 2.213. Committee member Mr John McGrath also noted:

*I just want to make a quick comment. I think that is the crux of the whole thing. Obviously, the best doctor in the world does not know when someone is going to die precisely. I know people who have been sent home and they have been told that they have six months to live, and four years later you still seeing them walking around. It is an impossibility for the medical profession to make decisions that can be so accurate.*³⁹⁵

- 2.214. Mr Wayne Belcher OAM, Chief Executive Officer of Braemar Presbyterian Care, also noted:

[W]e have a resident in one of our facilities now who was told by his GP that his prognosis was to die before Christmas 2016. He is still with us. Medicine is not an exact science.

...

*The difficulty for medicine is that it is not an exact science. It is good, and even the advances made in the last 30 or 40 years—I would not want to be around 40 years ago, given the things that are happening today. Some of those advances are great, but prognosticating about the time when the terminal phase of life is upon us—it is not there; it is not a pure science.*³⁹⁶

393 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 12.

394 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 6.

395 Mr McGrath, Committee Member, JSCEOLC Transcript, 13 December 2017, Session 2 at 21.

396 Mr Belcher, CEO Braemar Presbyterian Care, JSCEOLC Transcript, 27 February 2018, Session 2 at 7 and 12.

Chapter 2

- 2.215. Professor Douglas Bridge, Senior Palliative Care Specialist, shared his personal experience in prognostic error:

I did a survey of my own results. I thought, "How good am I at guessing?", so I checked. Forty times I used this thing. One patient had been discharged. I rang up the nursing home and said, "Can you please tell me what day this person died?" They said, "He's still alive," six months later. So 39 of the 40 died in two or three days; one, I felt very embarrassed. I thought he was on the point of death and he woke up and got better, so we cannot always predict death.³⁹⁷

- 2.216. Western Australia's Chief Psychiatrist, Dr Gibson, stated:

It is tricky, because it is also about prognosis. We know that prognosis is flawed. A cancer specialist might say that you have six months and you might last two years. It is the same with things like dementias. A specialist might say you have two to five years to live with this dementia, and someone might live for 10 years. So, there is also that issue of prognosis, I think, which lawmakers have to consider as part of the process.³⁹⁸

- 2.217. In contrast to this evidence, Mr Denton gave the following evidence to the Committee:

I guess the other interesting thing to say is that research shows that there is no perfect science to diagnosis and doctors, by some considerable margin, are over-optimistic in their diagnosis of terminal patients. They give them longer to live than they actually turn out to live. There is a great deal of evidence to support that. If you are talking about doctors making errors in an imperfect science, then, unfortunately, they err on the side that is not most useful to the patient.³⁹⁹

- 2.218. This suggestion from Mr Denton completely contradicts the substantial evidence available that doctors frequently under-estimate the prognosis of their patients, including evidence from jurisdictions where assisted suicide has been legalised. Mr Egan of Defend Human Life! has analysed the reporting data from Oregon and Washington which shows the frequency with which patients accessing assisted suicide in those

397 Prof Bridge, Senior PC Specialist, UWA Faculty of Medicine and Health Sciences; WA Country Health Service, Royal Perth Hospital, JSCEOLC Transcript, 9 March 2018, Session 5 at 12.

398 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 28 February 2018, Session 3 at 11.

399 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 13.

jurisdictions have lived longer than the prognosis given by the consulting doctor, the prognosis of which deemed them eligible to access lethal medications:

[T]he longest duration between initial request and ingestion recorded is 1009 days (that is 2 years and 9 months). And in the most recent year for which data is available, that is 2015, one person ingested lethal medication 517 days after the initial request for the lethal prescription was made.⁴⁰⁰

2.219. Data from the Oregon *Death With Dignity Act* annual reports shows that:

- in every year of full operation of the Act (1999-2015) there is at least one case (almost certainly many more but only the longest duration is reported in the data) where the time between initial request and ingestion was greater than nine months;
- in 14 of the 17 years there was at least one case where the time between initial request and ingestion was greater than one year;
- in 10 of the 17 years there was at least one case where the time between initial request and ingestion was greater than 15 months;
- in 6 of the of the 17 years there was at least one case where the time between initial request and ingestion was greater than 18 months, and
- in 4 of the 17 years there was at least one case where the time between initial request and ingestion was greater than two years.

2.220. Evidently in each of these cases the prognosis of less than six months to live was wildly inaccurate.⁴⁰¹

2.221. Although Washington state's *Death With Dignity Act* specifies that only persons with 'six months or less to live' may request lethal doses of medication from a physician, the data shows that in each year between 5 and 17 per cent of those who die after requesting a lethal dose do so 25 weeks or more later, with one person in 2012 dying nearly 3 years (150 weeks) later, and one person in 2015 dying nearly two years later (95 weeks). Washington physicians who prescribe lethal medication seem to be getting more inaccurate in their prognoses for assisted suicide candidates. In the first three years of

400 Oregon Public Health Division (2016) 'Oregon's Death With Dignity Act: 2015 Data Summary, Table 1. Characteristics and end-of-life care of 991 DWDA patients who have died from ingesting DWDA medications, by year,' Oregon, 1998-2015 at 7, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 14.

401 Data obtained for each year of operation of the *Death With Dignity Act* from the Oregon Health Authority, *Death With Dignity Annual Reports* by Mr Egan, Research Officer, Defend Human Life, JSCEOLC Submission 5 at 14-15.

Chapter 2

the Act's operation (2009-2011) 6.43 per cent of persons who died after ingesting a prescribed lethal dose 25 weeks or more after the initial request. However, this rate of inaccurate prognosis more than doubled to 13.33 per cent over the next four years of the Act's operation (2012-2015).⁴⁰²

- 2.222. Mr Egan also cites many peer-reviewed studies of prognostic accuracy demonstrate the statement made by Mr Denton to be incorrect:

One recent study of prognostic accuracy for brain cancer found that 'All physicians had individual patient survival predictions that were incorrect by as much as 12-18 months, and 14 of 18 physicians had individual predictions that were in error by more than 18 months. Of the 2700 predictions, 1226 (45%) were off by more than 6 months and 488 (18%) were off by more than 12 months.' Of particular relevance to the use of a prognosis of expected death within no longer than 12 months to grant access to assisted suicide is the finding that 'In this study all physicians were unable to accurately predict longer-term survivors. Despite valuable clinical data and predictive scoring techniques, brain and systemic management often led to patient survivals well beyond estimated survivals.'⁴⁰³

*A study published in 2000 in the British Medical Journal found that physicians only made accurate (within 33% margin either way) prognoses in 20% of cases for terminally ill patients. Significantly for the use of a prognosis of not expected to live more than 12 months in allowing access to assisted suicide or euthanasia is the finding that in 17% of cases physicians were overly pessimistic in their prognosis by more than 33% and out by a factor of 2 in 11.3% of cases. In other words, perhaps more than one in ten people given a prognosis of 12 months to live may live for 2 years or more.*⁴⁰⁴

A study on the accuracy of prognoses in oncology found that 'discrimination between patients who would survive for one year and

402 Washington State Department of Health, *Death With Dignity Act Reports, 2009-2015*, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 15-16.

403 Kondziolka D (2014) 'The accuracy of predicting survival in individual patients with cancer,' *Journal of Neurosurgery*, 120(1), 24-30, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 16.

404 Christakis NA (2000) 'Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study,' *BMJ* 320, 469 cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 16.

those who would not was very poor,⁴⁰⁵ and can be described as ‘only slightly better than a random guess.’⁴⁰⁶

- 2.223. The Australian Commission on Safety and Quality in Health Care state in their National Consensus Statement that:

Predicting prognosis and the timing of dying can be difficult. For some patients, it may be difficult to distinguish clinical deterioration that is reversible from deterioration that is irreversible and part of the normal dying process. In such cases, it may be appropriate to consider a trial of treatment for a defined period to assess reversibility of a patient’s deterioration.⁴⁰⁷

- 2.224. Mr Egan suggests that the critical point to note here is that using a 12 months to live criteria for admission to palliative care does not preclude trials of treatment or, of course, unexpected spontaneous recovery. However, using a 12 months to live criteria to prescribe or administer lethal drugs (perhaps as soon as 10 days after such a prognosis is first given) excludes these possibilities.⁴⁰⁸

- 2.225. Golden and Zoanni also state that it is extremely common for medical prognoses of a short life expectancy to be wrong, citing studies that show that only cancer patients show a predictable decline, and even then that this decline is only in the last few weeks of life. These studies show that with every disease other than cancer, prediction is unreliable.⁴⁰⁹ They write:

Prognoses are based on statistical averages, which are nearly useless in determining what will happen to an individual patient. Thus, the potential reach of assisted suicide is extremely broad and could include many people who may be mistakenly diagnosed as terminal but who have many meaningful years of life ahead. This poses considerable danger to people with new or progressive disabilities or diseases, who

405 Mackillop and Quirt (1997) ‘Measuring the accuracy of prognostic judgments in oncology,’ *Journal of Clinical Epidemiology* 50(1) 21-9, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 17-18.

406 White et al (2016) ‘A systematic review of predictions of survival in palliative care: How accurate are clinicians and who are the experts?’ *PLOS One*, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 17-18.

407 Australian Commission on Safety and Quality in Health Care (2015) *National Consensus Statement: essential elements for safe and high-quality end-of-life care* at 17.

408 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 18.

409 Golden and Zoanni (2010) ‘Killing Us Softly: The Dangers of Legalizing Assisted Suicide,’ *Disability and Health Journal* 3(1) 16-30 at 21.

Chapter 2

*may often be misdiagnosed as terminally ill but who, in many cases, outlive these prognoses by years or even decades.*⁴¹⁰

- 2.226. Magnusson, in citing the confronting tactic of euthanasia campaigners to use dying patients for propaganda purposes, refers to a case from New South Wales:

*Perhaps the most confronting tactic of euthanasia campaigners is to use dying patients themselves. In 1999 the New South Wales Voluntary Euthanasia Society produced a shock television commercial featuring June Burns, a dying cancer patient and mother of four, who told viewers 'I feel life is very precious and I've enjoyed every moment of it and I wish I could go on but I can't and I'd like to die with dignity.' Eight months later June was reported to be in remission, her doctors believing she could live for another two years.*⁴¹¹

Error in diagnosis

- 2.227. Evidence was also presented to the Committee on the prevalence of misdiagnosis by medical practitioners. Dr Khorshid informed the Committee that:

*Sometimes you will have a doctor who will say, "You've got a day to live; sort out your affairs," and the patient is still going a year later. We make mistakes, and that is one of the complexities in this area. Somebody thinks they have got a certain period of time but that could be completely wrong—the diagnosis can be wrong, the prognosis can be wrong and strange things happen. That is the reality of dealing with people.*⁴¹²

- 2.228. Avant Mutual, a large medical indemnity insurer, presented evidence to the Committee that in the 2017 financial year, of 16 closed matters in Western Australia where diagnostic error was the primary allegation, approximately one third of those diagnostic error cases were not resolved in the doctor's favour.⁴¹³ In reviewing their national claims data for 2017, there were 33 matters relating to end of life care and around half of those matters related to diagnostic error.⁴¹⁴

- 2.229. Avant Mutual research referred to the Committee also shows that:

Accurate diagnosis is key to understanding a patient's health concern and making appropriate care decisions. However, diagnosis is estimated to be incorrect roughly 10% of the time. Although true incidence data

410 Ibid.

411 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 268.

412 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 28 February 2018, Session 2 at 9.

413 Avant Mutual, JSCEOLC Response to Questions on Notice, 26 March 2018 at 1.

414 Ibid.

are lacking, mounting evidence suggests diagnostic errors result in an alarming rate of patient harm and death.⁴¹⁵

Diagnostic errors are common, appear in every healthcare setting and occur when diagnosing common and unusual conditions. While it is important to acknowledge that some diagnostic errors result from factors outside of a doctor's control, or are simply unavoidable (e.g. an undetectable malignancy, a typical presentation of a disease, incorrect information from a patient), the majority involve a doctor making a cognitive error, usually several types.⁴¹⁶

Our analysis also highlighted the seriousness of injuries seen in diagnostic error claims. In almost half (46%) of all matters where a doctor's actions allegedly resulted in serious permanent physical injury or death, diagnostic error was alleged to be the cause. This rate was higher than all other types of allegation. For general practitioners, the rate was particularly high.⁴¹⁷

2.230. Avant Mutual also cite Dr Walid Jammal, who states:

Making a correct diagnosis remains to me, as a doctor, a quintessential sign of my clinical competency. Yet despite all the technological advances that surround us all, making a correct diagnosis remains a challenging task. I am constantly aware of the possibility of making a diagnostic error. The more experienced I become, the more I realise that there are no shortcuts. Every step of the iterative process involved in reaching a correct diagnosis requires my constant attention. I am constantly learning and adapting. I am learning to listen better to patients. In a complex medical world, I am realising that I am no longer what I was taught to be: a "lone ranger." I am constantly trying to instil team work, trust, and collaboration into the way I work. Examining and understanding the way I think, my cognitive processes, and what factors influence my reasoning, have helped me improve. But most importantly,

415 'Avant research reveals factors underlying diagnostic error claims,' 12 March 2018, Avant article referred to in JSCEOLC Response to Questions on Notice, 26 March 2018 (emphasis added), citing Clinical Excellence Commission (2015) *Diagnostic Error: Learning Resource for Clinicians*, and Graber ML (2013) 'The incidence of diagnostic error in medicine' *BMJ Qual Saf* 22:ii21–ii27.

416 'Avant research reveals factors underlying diagnostic error claims,' 12 March 2018, Avant article referred to in JSCEOLC Response to Questions on Notice, 26 March 2018 (emphasis added), citing Clinical Excellence Commission (2015) *Diagnostic Error: Learning Resource for Clinicians*; National Academies of Sciences, Engineering, and Medicine, Institute of Medicine (2015) *Improving Diagnosis in Health Care*, Washington, DC; and Jammal and Lewis (2017) 'Cognitive bias and failure to diagnose: when you need to "think slow,"' *Medicine Today* 18(9), 65-67.

417 'Avant research reveals factors underlying diagnostic error claims,' 12 March 2018, Avant article referred to in JSCEOLC Response to Questions on Notice, 26 March 2018 (emphasis added).

Chapter 2

*errors I have made have taught me to make the patient the most important part of the team. I have learnt that constantly adapting, communicating, managing expectations, and maintaining a good relationship with the patient are the most crucial part of helping me avoid errors and their associated complaints and claims.*⁴¹⁸

2.231. Mr Peter McClennan, Chief Executive Officer of medical insurance company Best Doctors, suggests that 10 per cent of patient cases in Australia are mis-diagnosed.⁴¹⁹

2.232. The possibility of difference in medical opinion on diagnosis was also identified by Rev Saunders, who confirmed from his experience in his practise of medical negligence and personal injury law that difference in diagnosis would frequently occur:

*Of course, in every case. In every case that went to court you would have competing medical evidence; you would have one doctor saying this and another doctor that. Sometimes it was a difference of interpretation; other times it was even a difference of causation, a difference of diagnosis. So, yes, those differences went from what I might call the “nuanced” differences right through to diametrically opposed diagnoses.*⁴²⁰

2.233. In evidence given to the Committee regarding the end of life care of his wife, who suffered from progressive sub-cranial palsy, and whose request that antibiotics not be administered was not followed by the care facility in which she lived, Mr Bruce Buchanan gave evidence of his own experience of the misdiagnosis of a terminal condition:

I was diagnosed with cancer of the pancreas and I was given five weeks to live. At the point where this came up, I collapsed. The initial signs of cancer of the pancreas are jaundice, blockage of the bile duct and pain. I had jaundice and a blockage of the bile duct, but I did not have any pain. It is common, as it were. I am not a medical person, but from what I know of it, if you have got those symptoms, you have got either kidney stones, cancer of the pancreas or, in one in umpteen many chances, something else, and that is what I had—the something else. In fact, in hospital they said, “Sorry, chum; you’ll be dead in about five weeks. We’re going to send you up to Fiona Stanley to see what we can do for you, but this is it.” I had the slightly unpleasant task of ringing my wife,

418 Dr Walid Jammal, Senior Medical Advisor, Advocacy, Avant Mutual, quoted in ‘Avant research reveals factors underlying diagnostic error claims,’ 12 March 2018, Avant article referred to in JSCEOLC Response to Questions on Notice, 26 March 2018.

419 Alice Uribe, ‘Doctors Mis-Diagnose 1 in 10, says insurer,’ *Australian Financial Review*, 28 August 2017, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 17.

420 Rev Saunders, National Director, FamilyVoice Australia, JSCEOLC Transcript, 9 March 2018, Session 3 at 7.

who was in an aged-care facility because I could not look after her, to say, "Sorry; I won't see you again. I'll be dead before anything happens." Fortunately, when I got to Fiona Stanley, what they firstly do is they unblock your bile duct and you start to get better, and then the cancer of the pancreas should knock you off. The doctor was simply incompetent, and I say that advisedly. We all make mistakes—maybe parliamentarians do not make mistakes! But everybody else does in the world. It was more than that; it was simply incompetence, because he could have easily discovered whether or not I had cancer by a simple needle biopsy of my pancreas, which took about an hour or less, because I had one much later on when I had not died and they said, "We think you've got something else." They said, "We'd better check up to see that your pancreas is all right" and an hour later someone trots in and says, "There's no cancer at all." I had spent all this time expecting to die and telling everyone else that I had cancer and I had not. It was an interesting experience, I can tell you.⁴²¹

- 2.234. Mr Buchanan was diagnosed with pancreatic cancer and spent five months in palliative care before his misdiagnosis was identified after he outlived his prognosis by many months. Mr Buchanan was actually suffering from a chronic inflammatory condition called immunoglobulin 'IgG4' disease which affected his pancreas. His misdiagnosis of advanced terminal pancreatic cancer would have caused Mr Buchanan and his wife extreme distress, and stands as a terrible record of medical practitioner error. However more than that, it is evidence of the risk that Western Australians would be exposed to under any legalised assisted suicide regime, for Mr Buchanan's misdiagnosis would have made him eligible to access assisted suicide.
- 2.235. That patients may be assisted to suicide on the basis of misdiagnosis is not a purely theoretical assertion. Evidence is also available that misdiagnosis *has* occurred in patients who have been euthanised:

Using Nembutal, the drug Nitschke says he "promotes," 70-year-old Gold Coast widow Nancy Crick killed herself in May 2002. Nitschke had been her doctor, publicised her case, told her how to kill herself and helped arrange for her to die surrounded by 21 euthanasia activists. An autopsy later revealed Crick had no trace left of cancer—a fact of which her son said she was not aware.⁴²² Nitschke said whether or not she had cancer was "irrelevant."⁴²³

421 Mr Buchanan, Private Citizen, JSCEOLC Transcript, 1 May 2018, Session 9 at 7.

422 A Bolt, 'At last, we wake up to Dr Death, Philip Nitschke' *Herald Sun*, 6 July 2014.

423 'The troubling death of Nancy Crick' *The Age*, 28 May 2002.

Chapter 2

And:

[I]t was only after the family of retired Italian magistrate Pietro D'Amico, aged 62, insisted on an autopsy that he was found not to have a terminal illness at all, despite being given such a diagnosis by both Italian and Swiss doctors prior to undergoing assisted suicide in Switzerland.⁴²⁴

2.236. Mr Egan concludes that:

Published research on the accuracy of prognoses and diagnoses, as well as data from jurisdictions with a 6 months to live criterion, all point to the reality that under assisted suicide laws some people will die who are not terminally ill (errors in diagnosis), could be cured (wrong advice or reluctant to undergo treatment for reasons that could be overcome with the right help) or having much longer to live than predicted (errors in prognosis).⁴²⁵

Finding 56

There is a large body of evidence of medical error in prognosis.

Finding 57

Any safeguard in an assisted suicide regime is rendered useless in the event of medical error in prognosis.

Finding 58

There is a large body of evidence of medical error in diagnosis.

Finding 59

Any safeguard in an assisted suicide regime is rendered useless in the event of medical error in diagnosis.

There is No Right to Receive Assistance from a Physician to Suicide

2.237. Professors Willmott and White suggest that the since an individual has the right to self-determination, it follows that the individual also has the right to receive assistance to die:

The right of a competent person to make decisions that affect her or his own life is seen as fundamental in a liberal democracy such as Australia... This right of self determination should entitle a competent

424 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 17, citing 'Aided suicide in question after botched diagnosis,' *The Local*, 11 July 2013.

425 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 14.

*person who is informed of her or his medical diagnosis, prognosis, treatment options and consequences of those options to choose the manner in which he or she dies. This right includes the right to ask for someone else to end her or his life, or to receive assistance to die.*⁴²⁶

- 2.238. The flaw in this view is immediately apparent and was raised by Ms Re of IdentityWA in her evidence to the Committee:

In keeping with the social theory of individualism, [Professors Willmott and White] extend the definition of autonomy to self-determination which they hold involves having a person's will respected and acted upon. In other words, a person determines that what they want is suicide, and therefore they shall have it. Our position sees no conflict in "respecting" a person's will to suicide in the sense that this will is acknowledged. That is a basic premise of accompaniment. However, [the Professors] erroneously equate the expression of autonomy (or self-determination) with its fulfilment, as in a person's will is to be "acted upon."

...

*[Professors Willmott and White at page 492 of Chapter 26] fail to consistently apply the principle of autonomy in the pursuit of fulfilling the will. If a person wills to commit suicide, then consistently applied autonomy dictates this is accomplished by the individual. Demanding intervention to fulfil an individual's will to suicide automatically involves a completely separate individual (such as a doctor), and the principle of autonomy no longer applies. This is precisely the issue that Parliament is confronting: on what basis might some instances of the currently legislated homicide be permitted, but not other instances? This explains why suicides are investigated as suspicious deaths.*⁴²⁷

- 2.239. By law, patients in Western Australia have the negative right to refuse nutrition and hydration, and indeed medical treatment, based on the right to inviolability. These rights were confirmed in the judgment of Martin CJ in *Brightwater Care Group (Inc) v Rossiter*.⁴²⁸ In that judgment, the Chief Justice noted that in his Second Reading speech in support of the *Acts Amendment (Consent to Medical Treatment) Act 2008* (WA), which

426 White and Willmott (2012) 'How should Australia regulate voluntary euthanasia and assisted suicide?' *Journal of Law and Medicine* 20, 410-438 at 418, provided in Prof Willmott and Prof White, Directors, Australian Centre for Health Law Research, and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560.

427 Ms Re, Chief Executive Officer, IdentityWA, JSCEOLC Response to Questions on Notice, 10 April 2018 at 1-2.

428 [2009] WASC 229.

Chapter 2

created Advance Health Directives and Enduring Powers of Guardianship in Western Australia, the then Attorney General, Hon Jim McGinty MLA clarified that although a patient, or someone on the patient's behalf, will be entitled to refuse lawful treatment, there will still be no legal entitlement by a patient to demand treatment.⁴²⁹

- 2.240. It follows that the medical profession operate within the bounds of ethical responsibilities, and are not merely providers of a service on demand:

*Only by this balancing of ethical principles can physicians fulfil their duties, including those in more everyday encounters, such as when a physician advises against tests requested by a patient that are not medically indicated, declines to write an illegal prescription, or breaches confidentiality to protect public health. It also undergirds the physician's duty not to engage in futile care (such as care based on requests for non-indicated cardiopulmonary resuscitation or end-of-life treatment of brain-dead patients under an expansive view of patient autonomy). Physicians are members of a profession with ethical responsibilities; they are moral agents, not merely providers of services.*⁴³⁰

- 2.241. The suggestion that there is a patient right to receive assistance to die is entirely false and unfounded in law and medical ethics.

Finding 60

Although a patient, or their substitute decision maker, is entitled to refuse lawful treatment, there is no entitlement at law by a patient to demand treatment.

Finding 61

The proposition that a patient has a right to received assistance to suicide is wrong both at law and in medical ethics.

What Effect does Killing Patients have on Medical Professionals?

- 2.242. Finally, the effect of killing a patient on the wellbeing of the medical practitioner must be considered.
- 2.243. Accounts from practitioners who have engaged in the intentional killing of a patient clearly reveal the toll that action takes on the practitioner:

429 *Brightwater Care Group v Rossiter* [2009] WASC 229, per Martin CJ, para 47 at 16 (emphasis added).

430 Snyder, Sulmasy and Mueller (2017) 'Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper,' Professionalism and Human Rights Committee of the American College of Physicians, *Annals of Int Med* 167(8) 576 at 577.

*Harvey, an unassuming general practitioner, admitted to performing euthanasia 'probably a dozen times' over a number of years. He explains that 'on an ethical level...I support people's right to choose...to end their own life.' As an individual, however, he said, 'I find it very stressful dealing with it'. Harvey believes that 'having assisted people before...there is only a finite [number] of times that you can do it', because it is 'very draining' and 'ugly.'*⁴³¹

*'I get sad', said Gary, 'I get depressed; it's not nice to kill someone, it's not an easy thing to do [although] it does get easier with time—after doing several, that's easier than the first couple.'*⁴³²

'You can never get over the feeling of being executioner—you're turning up at an appointed time; you know that when you leave the room, the person is going to be dead'—Dr Philip Nitschke⁴³³

- 2.244. Dr Best gave evidence to the Committee that Belgian health professionals have reported a great degree of moral distress in having to be involved in the practice of assisted suicide and that to be both practising palliative care and administering euthanasia was extremely difficult with a high psychological cost for that group of doctors.⁴³⁴
- 2.245. A 2011 survey among Dutch physicians found that 86 per cent of physicians dread the emotional burden of performing euthanasia.⁴³⁵ Interviews of physicians who have participated in euthanasia (where the doctor provides a lethal injection) and physician-assisted suicide (where the doctor provides a lethal medication to a patient who self-administers that drug) indicate that the decision to go through with a procedure is neither easy nor straightforward.⁴³⁶
- 2.246. Studies confirm that doctors pay a high psychological price for their involvement in assisted suicide. Stahle notes the work of Dr Kenneth Stevens, from Oregon, who has compiled physicians' experiences from many different sources. Stevens concludes 'that

431 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 106.

432 Ibid at 10.

433 Philip Nitschke quoted in C Henderson, C Ryan and T Aubin, 'A Fight to the Death' *Who*, 23 February 1998 at 35, and cited in Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 174.

434 Dr Best, Palliative Care Physician and Academic, JSCEOLC Transcript, 1 May 2018, Session 2 at 5.

435 Van der Heide and Onwuteaka-Philipsen et al (2012) *Second Evaluation of the Euthanasia Law*, cited in Emanuel et al (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe,' *JAMA* 316(1) 79-90 at 87.

436 Emanuel et al (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe,' *JAMA* 316(1) 79-90 at 87, citing Dobscha, Heintz, Press and Ganzini (2004) 'Oregon physicians' responses to requests for assisted suicide: a qualitative study,' *J Palliat Med* 7(3) 451-461 and Ganzini et al (2001) 'Oregon physicians' attitudes about and experiences with end-of-life care since passage of the Oregon Death with Dignity Act,' *JAMA* 285(18) 2363-2369.

Chapter 2

the emotional and psychological effects on the participating physician can be substantial ... [and] can have significant effects on many participating physicians.’ As one of many examples, he refers to a television program reporting a euthanasia case, in which the Dutch physician who performed euthanasia noted that:

*To kill someone is something far reaching and that is something that nags at your conscience... I wonder what it would be like not to have these cases in my practice. Perhaps I would be a much more cheerful person.*⁴³⁷

2.247. Stahle also notes the comments of Jonquiere, a euthanasia practitioner from the Netherlands, who admits that helping someone to end their life places a heavy burden on the provider of such services. In light of this burden, Jonquiere’s recommendation is that doctors begin with the most obvious cases of suffering. ‘I always refrain from using the term “killing.” You terminate life—and actually, more than that, you terminate the suffering,’ Jonquiere says. ‘Get used to that idea, because it is counter-human a little bit. It never will be a routine action.’⁴³⁸

2.248. The desensitisation of the medical practitioner involved should be of significant concern. The effect of repeated involvement in the intentional killing of a patient is referred to in the Magnusson account of ‘Gary,’ and Jonquiere above. Evidence was given to the Committee on the effect of the practice of assisted suicide on the medical practitioners involved and the result of desensitisation and the risk this presents for vulnerable patients at end of life

It is hardwired into us that we do not kill each other. A doctor particularly, who has been trained to care for people—even Nitschke talks about how he felt after the first people he killed, and he is passionate, he believes he is doing the right thing. There certainly have been doctors in the Netherlands who did some euthanasias and then stopped. It is a very hard thing that we ask doctors to do if we make a law defending euthanasia...A doctor who is repeatedly giving lethal injections to patients and seeing the patients die in front of them becomes inured to that. I am not blaming them if that is the legal system and they do it, but that happens to them. It is not surprising then that in 2015, in the next round of five-year detailed studies, they found that

437 Stahle F (2017) ‘Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,’ *Journal of Ethics in Mental Health* 10 at 7 referring to Stevens KR (2006) ‘Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians’ *Issues Law Med* 21(3) 187-200.

438 Stahle F (2017) ‘Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,’ *Journal of Ethics in Mental Health* 10 at 8.

*there were 431 people killed in the Netherlands by direct action by a doctor with the explicit intention of ending their life—no request.*⁴³⁹

- 2.249. The desensitisation of medical practitioners if assisted suicide were legalised in Western Australia would heighten the other risks to vulnerable patients as already outlined in this Report.

Wounded healers

- 2.250. It was revealed in a 2013 report that doctors reported substantially higher rates of psychological distress and attempted suicide than both the general Australian population and other professionals, with 21 per cent having been diagnosed with or treated for depression.⁴⁴⁰ Dr Michael Gannon, then AMA President, said ‘there would be a very, very small number of doctors who haven’t been touched by the suicide of a colleague, either at medical school or as a doctor.’⁴⁴¹ In her article ‘Wounded healers’, Sharon Verghis asks ‘Is there something unique in the psychological makeup of doctors that puts them at higher risk of mental illness and suicide?’

*Yes, Myers concludes... First, there’s what he calls the “wounded healer” hypothesis of psychoanalyst Carl Jung. People drawn to medicine, Myers says, are often simultaneously the right people and the wrong people for the role. Many, he told LitMed, are “survivors of childhood trauma, loss and family dysfunction. [They] make great doctors but can be vulnerable to psychiatric symptoms either genetically or from their early environment.” The traits that help them excel in their profession—altruism, empathy, sensitivity to the pain of others—can prove to be pitfalls, says Myers. “We look for sensitivity in applicants to medical school and residencies and it is frightening to think that so positive an attribute can be part of the volatile mix that leads to suicide in distressed doctors.” Add to this a tendency to perfectionism.*⁴⁴²

- 2.251. The higher rates of psychological distress and suicide in the medical profession is of serious concern, not only for the wellbeing of medical students and professionals, but also for the conflict this presents in a legalised assisted suicide framework where doctors are to be the ‘safeguards’ against vulnerable patients accessing assisted suicide.
- 2.252. It has been said that there is an urgent need for reform of college exam processes and possible amendments to mandatory reporting laws, along with more doctor-focused

439 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 9.

440 beyondblue, National Mental Health Survey of Doctors and Medical Students, October 2013
<https://www.beyondblue.org.au/docs/default-source/research-project-files/bl1132-report---nmhdmss-full-report_web>

441 Sharon Verghis, ‘Wounded healers,’ *The Australian*, 5 May 2018.

442 Ibid.

Chapter 2

counselling services and hospital-based wellness programs. A comprehensive strategy across prevention, early intervention and crisis intervention for the whole profession is required.⁴⁴³

Finding 62

The emotional and psychological effects on medical practitioners participating in assisted suicide are substantial and consequential.

Finding 63

The desensitisation of medical practitioners by participation in assisted suicide exacerbate the risk that already exists due to doctor bias.

Finding 64

The rate of psychological distress and attempted suicide by medical practitioners is high.

Recommendation 12

The Minister for Mental Health should direct the Mental Health Commission to develop, in consultation with medical practitioners and the Department of Health, a comprehensive mental health strategy for prevention, early intervention and crisis intervention for the whole of the medical profession.

Assisted Suicide Cannot Guarantee a ‘Good Death’

- 2.253. Proponents of assisted suicide suggest that the inability of palliative care to address the refractory symptoms of a small minority of people suffering from a terminal condition in the dying phase necessitates the legalisation of assisted suicide. The suggestion is made that palliative care cannot provide a ‘good death’ for *all* individuals, and that, by contrast, assisted suicide can and is therefore required.
- 2.254. Doctors for Assisted Dying Choice list their criteria for a ‘good death’ as
- *To know when death is coming, and to understand what can be expected*
 - *To be able to retain control of what happens*
 - *To be afforded dignity and privacy*
 - *To have control over pain relief and other symptom control*
 - *To have time to say goodbye, and control over other aspects of timing; and*
 - *To be able to leave when it is time to go, and not to have life prolonged pointlessly⁴⁴⁴*
- 2.255. Doctors for Assisted Dying Choice also assert that members of the medical profession have a duty to respond to patient’s needs since they ‘have the means and skills to provide

443 Recommendations made in Sharon Verghis, ‘Wounded healers,’ *The Australian*, 5 May 2018.

444 Doctors for Assisted Dying Choice, JSCEOLC Submission 402 at 1.

a gentle death' and 'a duty to ensure that the duration of [a patient's] suffering is as short as possible.'⁴⁴⁵ They refer to the use of 'best practice protocols' regarding 'medication that is reliable', and that 'Nembutal solution is the gold standard for oral use and should be made available.'⁴⁴⁶ Similar statements were made in evidence in Committee hearings. Mr Hindle, President of Dying with Dignity (WA) suggested that 'Nembutal is the way to go. I am not aware of anybody who has taken Nembutal who has not succeeded in what they set out to do.'⁴⁴⁷ After criticising the efficacy of palliative sedation (noting here the unsoundness of this criticism—as already considered in Chapter 1—Palliative Sedation), Dr Beahan of Doctors for Assisted Dying Choice states

*By contrast, voluntary assisted dying in those who request it is quick, painless and certain.*⁴⁴⁸

- 2.256. In contrast to these absolute statements, some proponents of assisted suicide did acknowledge that complications with medication do in fact arise in assisted suicide, but sought to minimise or downplay the frequency of this occurrence and the impact on the individual involved:

*[Complications with the use of Nembutal] are rare and I guess you would have heard from Dignitas because they have almost more experience than anyone in the world over the use of that drug. Taken as a drink, orally—that is, by mouth—it is a very effective drug. To say that there have never been complications, though, there is an aphorism in medicine which I remember: never say never, because there are exceptions to everything, and there is always some example somewhere in the world where things did not go according to plan. I am sure that there are—of course, I have read of some—experiences where the drug did not do exactly what it was supposed to do.*⁴⁴⁹

*So there have been instances of people waking up, and one only—I think it is elaborated on later in the article—had some problems associated with it. Sorry; there is another paragraph and I had seen it. But, overall, any incidence of that sort of thing is very low indeed... in Oregon the model is the prescription is there, the patient deals with it themselves, and problems have been very few and far between ... Nothing is perfect, but these articles are highly reassuring, I would suggest, in describing how it happens in Oregon.*⁴⁵⁰

445 Ibid.

446 Ibid at 12.

447 Mr Hindle, President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 7.

448 Dr Beahan, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 26 February 2018, Session 4 at 6.

449 Dr Nitschke, Exit International, JSCEOLC 13 April 2018, Session 1 at 8.

450 Mr Walker, Vice President, Dying with Dignity (WA), JSECOLC 13 April 2018, Session5 at 7-8.

Chapter 2

2.257. Dignitas of Switzerland, also gave evidence that:

For the past 20 years, we have done over 2 500 accompanied suicides and we have a zero fail rate. The thing is, you have to know—you have to have know-how—not necessarily a lot of medical know-how, but you have to have know-how how to handle pentobarbital and what to expect... when you have the know-how, there is a zero fail rate.⁴⁵¹

2.258. Indeed, Dignitas went on to suggest that no complications exist in assisted suicide deaths as all possible problems or complications are thought of in advance and therefore avoided:

Hon NICK GOIRAN: When you say that you have been involved in some many years ago, how many is some?

Mr LULEY: I think it was three or four cases.

Hon NICK GOIRAN: Would you be in a position to tell the committee if there were any complications that you witnessed during those three or four that you are involved in?

Mr LULEY: There were no complications, and this relates to the earlier question on the application, the ingestions of pentobarbital—whether there is a failure rate. There is no failure rate, because we have the know-how to handle the pentobarbital. We know how to handle it and instruct the patients what to do. There is no problem.

Hon NICK GOIRAN: I remember you mentioned earlier that you had worked out a technique to shift the patient to ensure that the drug went into the intestines. How did you find out about this technique?

Mr LULEY: We have a kind of advisory committee which includes lawyers and medical doctors. They are not on the board; it is like an advisory committee of Dignitas. One of them was an elderly medical doctor, and he brought up that idea, and said that it could be possible that there are rare patients with an anomaly in the stomach-intestine connection, pylorus I think it is called called—an anomaly in the stomach. It is rare, but it does exist. He said if ever there is a situation of a patient being comatose, but the effect of the pentobarbital is not taking its effect, we simply shift the body. When we first had a case like that, where it took about one and a half hours and the patient was still lying on the bed and still sleeping—unconscious—we moved the body to one side and within

⁴⁵¹ Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 8 March 2018, Session 5 at 2-3.

a quarter of an hour, the patient passed away. It was an idea by a doctor that it could be that. We tried and realised it worked.

Hon NICK GOIRAN: Yes, okay, so I think, if I understand you, you are saying that this advisory panel and this doctor had given advance thought to a problem that could arise, and had developed a solution before the problem arose.

Mr LULEY: That is correct. I would not be able to say if the problem had arisen earlier before Dignitas was [inaudible] with Exit, whether they earlier on had an issue with that. We had the know-how and we applied it. I think it is probably just a dozen cases of the 2 500, as far as I can see, that our team encountered the issue.⁴⁵²

- 2.259. Meanwhile in another Committee hearing the complications with Nembutal were described this way by Dr Alida Lancée, Doctors for Assisted Dying Choice:

Hon NICK GOIRAN: Dr Lancée, in response to the question from my colleague Mr McGrath you raised nembutal. I note that your submission also refers to it as being the gold standard. What are the complications with nembutal?

Dr LANCÉE: The complications—in terms of—well, the complication would be that it is very bitter and it is very difficult to self-ingest. Complications in terms of whether it has the outcome that the patient wishes, there is a potential that it may lead to a protracted uncertain duration that it takes from ingestion until death, and I think in Oregon there was one person who actually woke up again, so needed to have the injection as a backup to allow them to stop their suffering.⁴⁵³

- 2.260. However, the actual evidence of the incidence rate of complications in Oregon directly contradicts the evidence given by Dr Lancée and others. The suggestion that only one person in Oregon has woken again after the administration of Nembutal, and that they ‘needed to have a further injection as a back up to allow them to stop their suffering’ is incorrect as the reporting data from Oregon outlines quite a different picture:

In 2016 one in nine (8.1%) (sic.) of those for whom information about the circumstances of their deaths is available either had difficulty ingesting or regurgitated the lethal dose... from 2010 reports of complications were only recorded if a physician was present at the time

452 Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 8 March 2018, Session 5 at 5-6, including information provided by the witness to the Committee clarifying the transcript.

453 Dr Lancée, Medical Practitioner, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 2 March 2018, Session 3 at 9.

Chapter 2

*of administration so percentages for complications artificially decline as complications are listed as “unknown” for the majority of cases in which no physician was present.*⁴⁵⁴

- 2.261. The interval from ingestion of lethal drugs to unconsciousness has been as long as one hour while the interval from ingestion to death has ranged from 1 minute to as long as 104 hours (4 days and 8 hours).⁴⁵⁵ In 2005, ‘One patient became unconscious 25 minutes after ingestion, then regained consciousness 65 hours later. This person did not obtain a subsequent prescription, and died 14 days later of the underlying illness (17 days after ingesting the medication).’⁴⁵⁶ This case was patient David Prueitt who, after ingesting the prescribed barbiturates spent three days in a deep coma, then suddenly woke up, asking his wife ‘Honey, what the hell happened? Why am I not dead?’ David survived for another 14 days before dying naturally from his cancer.⁴⁵⁷
- 2.262. Since 2005 five other people have regained consciousness after ingesting the lethal medication:

*‘In 2010, two patients regained consciousness after ingesting medications. One patient regained consciousness 88 hours after ingesting the medication, subsequently dying from underlying illness three months later. The other patient regained consciousness within 24 hours, subsequently dying from underlying illness five days following ingestion. In 2011, two patients regained consciousness after ingesting the medication. One of the patients very briefly regained consciousness after ingesting the prescribed medication and died from underlying illness about 30 hours later. The other patient regained consciousness approximately 14 hours after ingesting the medication and died from underlying illness about 38 hours later.’*⁴⁵⁸

In 2012 ‘one patient ingested the medication but regained consciousness before dying of underlying illness ... The patient regained

454 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 31-21, citing Oregon Public Health Division, ‘Oregon Death With Dignity Act: Data Summary 2016, Table 1. Characteristics and end-of-life care of 1,127 DWDA patients who have died from ingesting a lethal dose of medication as of January 23, 2016 [sic = 2017], by year,’ Oregon, 1998-2016 at 10.

455 Ibid at 11.

456 Oregon Department of Human Services, Office of Disease Prevention and Epidemiology (2006) Eighth Annual Report on Oregon’s Death with Dignity Act at 14.

457 ‘Oregon man wakes up after assisted-suicide attempt,’ Seattle Times, 4 March 2005.

458 Oregon Health Authority, Death With Dignity Act, Year 14 - Table 1, Characteristics and end-of-life care of 596 DWDA patients who died after ingesting a lethal dose of medication as of February 29, 2012, by year, Oregon, 1998-2011, footnote 12 at 6.

*consciousness two days following ingestion, but remained minimally responsive and died six days following ingestion.*⁴⁵⁹

- 2.263. These are the cases we do know about. As Mr Egan points out (above), from 2010 the percentages for complications artificially decline as complications are listed as ‘unknown’ for the majority of cases in which no physician was present. Blank et al also note that information on drug effectiveness and complications was requested on all patients from 1998 to 2010, but that after that only cases where a health care provider was present at the time of death were obtained.⁴⁶⁰ That these patients were left to die alone, at risk of complications without the presence of a medical professional, stands in stark contrast to the assertion of Doctors for Assisted Dying Choice that assisted suicide should be legalised as ‘doctors have a duty to respond to [a] patient’s needs’ and ‘have the means and skills to provide a gentle death’ and a ‘duty to ensure that the duration of this suffering is as short as possible.’⁴⁶¹
- 2.264. Emanuel et al note that ‘There are no flawless medical procedures; all procedures and interventions can have complications. Determining the rate of problems and complications related to euthanasia and PAS has been challenging because of definitions and the lack of witnesses.’⁴⁶² They state that:

*For several years, Oregon reported no complications. Between 1998 and 2015 (average number of deaths per year, 55), Oregon reported absence of data on complications for 43.9% of cases, no complications for 53.4% of cases, and regurgitation of medication in 2.4% of cases as the sole complication. The state reported that between 2005 and 2012, 6 patients (0.7%) regained consciousness after ingesting the lethal medications but paradoxically does not classify this as a complication. The median time between ingestion of barbiturate and death was 25 minutes, but the range extends to 104 hours—more than 4 days. The number of prolonged deaths—those taking longer than a day—is not reported in Oregon.*⁴⁶³

459 Oregon’s Death With Dignity Act—2012 Table 1, Characteristics and end-of-life care of 673 DWDA patients who died after ingesting a lethal dose of medication as of January 14, 2013, by year, Oregon, 1998-2012 at 2.

460 Blanke et al (2017) ‘Characterizing 18 Years of the Death With Dignity Act in Oregon,’ *JAMA Oncol* 3(10) 1403-1406.

461 Dr Alida Lancée, WA State Convenor, Doctors for Assisted Dying Choice, JSCEOLC Submission 402 at 1.

462 Emanuel et al (2016) ‘Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe’ *JAMA* 316(1) 79-90 at 86 (emphasis added).

463 Ibid (emphasis added).

Chapter 2

- 2.265. On the data on patient deaths from Oregon that the interval from ingestion of lethal drugs to death has ranged from 1 minute to as long as 104 hours, evidence was given to the Committee that:

One example of this lack of knowledge is the reported range of time between ingestion and death, which the OHA 2017 Data Summary indicates has been from 1 minute to 104 [hours]. Death is unlikely within 1 minute of taking the sedatives when the patient is sufficiently well to self administer. Likewise, the effect of the short-acting sedatives would have dissipated by (say) 24 hours at best. It is unclear how death occurred. It can however be stated with some measure of certainty that in some of these “death with dignity” instances, people experienced suffering over and above that of their terminal illness.⁴⁶⁴

- 2.266. Evidence of the clinical procedures for assisted suicide was also provided to the Committee:

I have seen also the clinical procedure for, I think, Oregon in the United States, where it is death by lethal injection, and in that circumstance it is a course of three different types of drugs injected over a period of time. It is extremely distressing, actually, just to read the clinical procedure, because it is things like, if there are any carers in the room for the individual, warn them that after this injection the individual may be gasping for breath, may suffer a cardiac arrest. It also contemplates that the timing of death may be up to 24 hours. It is very difficult to kill a human being; there is not a nice easy one-size-fits-all approach.⁴⁶⁵

- 2.267. Evidence of complications also exists from Washington State. In relation to which drug should be used, there is evidence from Washington State that:

The first Seconal alternative turned out to be too harsh, burning patients’ mouths and throats, (p34) causing some to scream in pain. The second drug mix, used 67 times, has led to deaths that stretched out hours in some patients — and up to 31 hours in one case. [Twenty per cent] of the cases were 3 hours or more before death, which we think is too long,” said Robert Wood, a retired HIV/AIDS researcher who volunteers with the advocacy group End of Life Washington, in an email. The longest was 31 hours, the next longest 29 hours, the third longest 16 hours and some 8 hours in length. “Patients and families are told to expect sleep within 10 minutes and death within four hours.

464 Ms Re, Chief Executive Officer, IdentityWA, Response to Questions on Notice, 10 April 2018 at 3.

465 Mrs Greenwood, Chief Executive, Catholic Health Australia, JSCEOLC Transcript, 28 February 2018, Session 1 at 9.

When it takes far longer, family members get worried, even distressed, said Dr. Carol Parrot, a retired anesthesiologist who has prescribed drugs for dozens of aid-in-dying patients in Washington. Doctors recently began using the newest drug mixture and will gather data about its effectiveness.⁴⁶⁶

2.268. Emanuel et al note that:

In Washington state, for 2014 and 2015 combined, the data are less complete. For the 292 reported cases, 1.4% of patients regurgitated the medications, and 1 patient experienced a seizure. It is unclear if any patients in Washington state regained consciousness. Only 66.8% of patients died in less than 90 minutes, while the range extends to 30 hours.⁴⁶⁷

2.269. Emanuel et al also refer to complications in the Netherlands:

A comprehensive 2000 study of problems and complications in 649 Dutch cases (prior to the actual legalization) revealed a higher frequency of problems with [physician-assisted suicide] than with euthanasia. Technical problems with PAS, such as difficulty swallowing, occurred in 9.6% of cases, and complications such as vomiting or seizures occurred in 8.8% of cases. In 1.8% of PAS cases, patients awoke from coma and in 12.3% of cases time to death was longer than anticipated or the patient never became comatose. For euthanasia, 4.5% of cases had technical problems, such as inability to find a vein for injection, and in 3.7% of cases patients had complications such as vomiting, ormyoclonus. In 0.9% cases patients awoke from coma, and in 4.3% of cases time to death was longer than expected or the patient did not become comatose. These data are 16 years old, and 13 years of legalization may have reduced the complication rate.⁴⁶⁸

2.270. The suggestion that 13 years of legalisation in the Netherlands may have reduced the complication rate is not supported by the more recent evidence from Oregon and Washington.

466 JoNel Aleccia 'Docs In Northwest Tweak Aid-In-Dying Drugs To Prevent Prolonged Deaths' *Kaiser Health News*, 21 February 2017 (<https://khn.org/news/docs-in-northwest-tweak-aid-in-dying-drugs-to-prevent-prolonged-deaths/>), quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 33-34.

467 Emanuel et al (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe,' *JAMA* 316(1) 79-90 at 86.

468 Ibid.

Chapter 2

- 2.271. Emanuel et al refer only to complication statistics in Oregon, Washington and the Netherlands and state ‘There are no data from other countries, including Belgium, on problems or complications with euthanasia or PAS.’⁴⁶⁹
- 2.272. What data we do have available to us on complications in assisted suicide practice from Oregon, Washington and the Netherlands directly contradicts the assertions from proponents cited above that complications either do not exist at all or are rare. To those proponents who are intellectually honest enough to acknowledge that complications do occur, but then seek to downplay or minimise the relevance of such complications, law Professor Quinlan’s discussion on the *raison d’être* of assisted suicide is instructive:

*Complications in administering capital punishment by lethal injection are unacceptable. It must however be remembered that the purpose of capital punishment is primarily the death of the convicted criminal. One of the *raison d’être* of euthanasia is different. It is securing a “good death.” This means that complications in administering euthanasia are not only unacceptable; where this is the procedure’s objective, they undermine its foundational purpose. Forty years of capital punishment by lethal injection and the international experience of euthanasia by this means suggest that complications may be inevitable and militate against the legalisation of euthanasia in Australia for this reason.*⁴⁷⁰

- 2.273. Deaths by assisted suicide are not all ‘quick, painless and certain’ as proponents would like us to believe, nor do doctors have the means and skills to *always* provide a ‘gentle death’ or ‘good death’ and a doctor *cannot* ‘ensure that the duration of a patient’s suffering is as short as possible.’

Finding 65

Evidence of complication rates of physician assisted suicides in Oregon until 2010 are troubling. Complication rates after 2010 artificially declined as from this time reports of complications were only recorded if a physician was present at the time of administration.

Finding 66

Evidence of complication rates in Washington are equally troubling with multiple instances of regurgitation, one-third of patients taking in excess of one and a half hours to die, at least one patient suffering a seizure and another taking 30 hours to die.

469 Emanuel et al (2016) ‘Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe’ *JAMA* 316(1) 79-90 at 86.

470 Quinlan M (2016) “‘Such is Life’: Euthanasia and capital punishment in Australia: consistency or contradiction?’ *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* 6(1) at 18 (emphasis added).

Finding 67

Decades of experience in administering capital punishment, euthanasia and assisted suicide indicate complications are inevitable and this alone ought to militate against legalisation in Western Australia.

Trading Lives

2.274. Chapter 2 of this Report has identified many areas of risk in the legalisation of assisted suicide, including:

- The complexity in assessment of competence and that it cannot be ensured that patients suffering from mental illness, including depression and demoralisation, will not be euthanised;
- The risk in determining that a patient has given informed consent;
- The risk that a patient's consent may not be voluntary, but subject to undue influence and the risk this especially poses to patients already vulnerable to elder abuse;
- Increased risk to people living with disabilities, who already suffer discrimination in the health care system;
- An inherent conflict with existing suicide prevention programs;
- Evidence that assisted suicide may deter certain patients from accessing conventional palliative care services;
- Risk to the wellbeing of the medical practitioners involved in the provision of assisted suicide;
- The inevitability of casualties arising from error rates in misdiagnosis and prognosis; and
- Complications involved in the procedure itself.

2.275. Proponents point to studies that have sought to measure vulnerability to risk in assisted suicide, such as the study conducted by Battin et al, who after examining data from Oregon and the Netherlands, concluded that there was no evidence that vulnerable people, except for people with AIDS, are euthanised more disproportionately than others.⁴⁷¹ 'Vulnerable' was defined in the study as individuals who are elderly, female, uninsured, of low education status, poor, physically disabled or chronically ill, younger

471 Battin et al (2007) 'Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups,' *J Med Ethics* 33, 591–7.

Chapter 2

than the age of majority, affected with psychiatric illnesses including depression, or of a racial or ethnic minority. A study of the demographic profile of patients in the United States revealed that those who have received assisted suicide interventions are white, well-educated and well insured.⁴⁷² Arguably these studies have failed to measure vulnerability to risk. These studies can be challenged on the basis that vulnerability to assisted suicide cannot be categorised simply by reference to race, sex, or other socioeconomic status.⁴⁷³ Finlay and George suggest that there are other characteristics, that are individual to each patient and extend beyond the macro-categorisations of demography, such as emotional state, reaction to loss, personality type and the sense of being a burden, that are also important.⁴⁷⁴ Patients are also vulnerable to the level of training and experience that their physicians have in palliative care and to the personal views of their physicians about the topic, as a study has shown that the more physicians know about palliative care, the less they favour assisted suicide.⁴⁷⁵ That an individual is white, well-educated and well insured, also does not mean that that individual would not be susceptible to the risks listed above.

2.276. It cannot be guaranteed that a person suffering from mental illness or demoralisation will not be euthanised. It cannot be guaranteed that a person will have been offered specialist palliative care services in order to make an informed choice to proceed with assisted suicide. It cannot be guaranteed that the consent of every patient requesting assisted suicide is voluntary and free of undue influence. It cannot be guaranteed that a person without a terminal illness, or with a prognosis of many years to live, will not be euthanised. It also cannot be guaranteed that the legalisation of assisted suicide will ensure a 'good death,' free of complications, for all patients. What can be guaranteed is that an assisted suicide regime will always result in casualties.

2.277. Dr Khorshid advised the Committee that:

nowhere are the safeguards perfect because the innate nature of these discussions means that there is always uncertainty. There is uncertainty about prognosis, there is uncertainty about competence, there is uncertainty about family dynamics and, as I mentioned before,

472 Emanuel et al (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe,' *JAMA* 316(1) 79-90 at 87.

473 Pereira J (2011) 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,' *Current Oncology* 18(2), 38-45 at 42.

474 Finlay and George (2011) 'Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups--another perspective on Oregon's data,' *J Med Ethics* 37(3) 171-4.

475 Pereira J (2011) 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,' *Current Oncology* 18(2), 38-45 at 42.

*coercion... Any system that you put in has limitations on how effective it can be at ensuring that rules are being followed.*⁴⁷⁶

2.278. Thus, the question must be asked, how many such individuals is our society prepared to sacrifice as the collateral damage from the legalisation of assisted suicide?⁴⁷⁷

2.279. Mr Egan suggests that the test as to whether to introduce legalised assisted suicide in Western Australia is analogous to the reintroduction of capital punishment:

*Many people hold the view that capital punishment may be justified in a particularly horrific case. However, such people may still reject the reintroduction of capital punishment because they are not convinced that any proposed regime can ensure that not even a single innocent person is put to death wrongly by the State. The same test should be required for any regime claiming a safe approach to assisting the suicide of certain Western Australians.*⁴⁷⁸

*I believe that the proper test for a law permitting assisted suicide or euthanasia is the one that many of you would apply to any proposal to reintroduce capital punishment, perhaps in the light of some horrific new murder, serial killer or rapist... That test is: can we craft a law that will ensure there will not be even one wrongful death? I do not believe we can.*⁴⁷⁹

2.280. The burden of proof is on those advocating for a change in the law to establish that such a profound change would be safe for the whole community.⁴⁸⁰ Proponents of assisted suicide have not met this burden.

2.281. Mr Laurence Van Der Plas, Research Officer for the Association for Reformed Political Action, offered a similar test, applying assisted suicide to the risk matrix used in the fire and rescue service:

When I was a volunteer in the fire and rescue service, one of the things we had was this whole idea that if there is a bushfire, do people stay

476 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, Session 1, 18 May 2018 at 17, paraphrasing evidence given at the recent AMA(WA) Symposium on End of Life Choices by Professor Finlay, Co-Chair, Living and Dying Well.

477 M Golden, 'Why assisted suicide must not be legalized,' Disability Rights Education and Defence Fund,' <<https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/>> quoted in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 29.

478 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 35. See also Dwight Randal, President, Coalition for the Defence of Human Life, JSCEOLC Response to Questions on Notice, 17 April 2018 at 10.

479 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 2.

480 Ibid at 1.

Chapter 2

and defend their homes or do they go? That is the question: what do you do? What you do is you say, "In each situation, whether I stay and defend or whether I go, what is the best outcome and what is the worst outcome?" The best outcome if you stay and defend your house, is that the fire passes your house or you manage to defend it and your house is safe. Whether you go, the best outcome is actually same. The fire passes your house; the fire brigade gets it; it is all good. What is the worse outcome in each state? The worst outcome if you go early, is that your house is burnt up. You are safe, but you lose your house. What is the worst possible outcome if you stay and defend? The worst outcome is you die. On that basis alone people are told: go. At least your life is safe. If you transpose that across to assisted dying, the best possible outcome for every Western Australian if we do not legalise assisted dying is a peaceful death—that is the best possible outcome in both cases. What is the worst possible outcome? The worst possible outcome if we do not allow assisted dying, is that some people may die a painful death. We grant that. What is the worst possible outcome if we do allow assisted dying? The worst possible outcome is that someone who does not need to die inadvertently does. That is what we mean by the risk assessment. Under that matrix, the worst possible outcome is far worse under assisted dying. That is a death that did not have to occur or should not have occurred.⁴⁸¹

- 2.282. In 2010, a report from the Victorian Institute of Forensic Medicine considered the cases of 51 people who died from Nembutal in Australia. The report found that young people and depressed people were more likely to die by Nembutal than terminally ill people in Australia. Dr Nitschke's response to this finding in the Victorian report was that 'There will be some casualties... but this has to be balanced with the growing pool of older people who feel immense well-being from having access to this information.'⁴⁸²
- 2.283. Dr Henry Marsh, a noted British neurosurgeon and champion of assisted suicide, famously said 'Even if a few grannies are bullied into committing suicide, isn't that a price worth paying so that all these other people can die with dignity?'⁴⁸³

481 Mr Van Der Plas, Research Officer, Association for Reformed Political Action, JSCEOLC Transcript, 8 March 2018, Session 3 at 8-9.

482 Julia Medew 'Young people gain access to euthanasia drug,' *Sydney Morning Herald*, 15 February 2010 <<https://www.smh.com.au/lifestyle/health-and-wellness/young-people-gain-access-to-euthanasia-drug-20100215-nzon.html>> (emphasis added).

483 Dr Henry Marsh quoted in 'Henry Marsh: The Do No Harm author on the secrets of brain surgery,' *The Times*, 23 April 2017 <<https://www.thetimes.co.uk/article/i-had-to-tell-the-family-her-death-had-been-avoidable-they-still-thanked-me-hvv6jgnnj>> and quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 2 (emphasis added).

2.284. Mr Egan calls this ‘trading lives:’

[I]f you make a law based on a small number of hard cases, unless you can be sure that the law you craft is only going to apply to that small number of hard cases, then you are essentially trading lives. Some people are going to die prematurely... in order to try to relieve the particular pain or difficulty of other people.⁴⁸⁴

2.285. In evidence to the Committee, Rev Saunders stated that ‘the objective deleterious effects of laws allowing assisting suicide and euthanasia significantly outweigh any perceived subjective benefits.’⁴⁸⁵

2.286. Similarly, ‘[i]f these laws have a deleterious effect on palliative and end-of-life care, and on suicide prevention efforts, in the general population of the states enacting them, the number of people (including seriously ill people) adversely affected by them vastly exceeds the number of patients who actually make use of the “aid in dying” option.’⁴⁸⁶

2.287. Former Prime Minister, Mr Paul Keating stated:

An alarming aspect of the debate is the claim that safeguards can be provided at every step to protect the vulnerable. This claim exposes the bald utopianism of the project—the advocates support a bill to authorise termination of life in the name of compassion, while at the same time claiming they can guarantee protection of the vulnerable, the depressed and the poor. No law and no process can achieve that objective. That is the point.

...

It is true that if this bill fails then some people will endure more pain and this is difficult for legislators to contemplate. It is also true, however, that more people in our community will be put at risk by this bill than will be granted relief as its beneficiaries. This is the salient point... The issue is not how many people will choose to die under this proposed law. It is how many people may die when otherwise they wouldn't.

...

Opposition to this bill is not about religion. It is about the civilisational ethic that should be at the heart of our secular society. The concerns I

484 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 2.

485 Rev Saunders, National Director, FamilyVoice Australia, JSCEOLC Transcript, 9 March 2018, Session 3 at 8.

486 R Doerflinger (2017) ‘The Effect of Legalizing Assisted Suicide on Palliative Care and Suicide Rates: A Response to Compassion and Choices,’ *On Point* 13 at 7.

Chapter 2

*express are shared by people of any religion or no religion. In public life it is the principles that matter. They define the norms and values of a society and in this case the principles concern our view of human life itself. It is a mistake for legislators to act on the deeply held emotional concerns of many when that involves crossing a threshold that will affect the entire society in perpetuity.*⁴⁸⁷

- 2.288. Mr Denton suggests that '[w]hat we are looking to do is create a law which mitigates harm in the community.'⁴⁸⁸ Mr Denton also suggests that to be on the anti-euthanasia side of the debate means to be deliberately ignorant of the suffering of others— 'Opponents to this law make every effort to drown out [the voices of the terminally ill] in this debate. Look straight past them. Pretend their stories never happened,' drowning out the voices of 'the most vulnerable in our society, those most in need of our compassion and protection.'⁴⁸⁹
- 2.289. Assisted suicide laws in Western Australia will not mitigate harm in the community. Assisted suicide laws in this State will expose Western Australians to the very real risk of premature and wrongful death. To support assisted suicide is to be ignorant of the impact that the lifting of the prohibition on one person deliberately killing another would have on Western Australia, particularly on the most vulnerable members of our community, including the terminally ill, the mentally ill, the disabled and the elderly. If that ignorance is not present then such proponents have determined that the trading of lives is acceptable.
- 2.290. Autonomy and choice are important values in any society, but they are not absolutes. The decision for lawmakers is ultimately this:

*You have a choice: to make euthanasia available for the small number of people who want to choose the timing and manner of their own death; or you can choose to protect those people at risk of dying when they do not really want to, if a law is passed. Personally, I do not think that government exists to support the autonomy for the few at the cost of the security of the vulnerable. Mahatma Gandhi said, "The calibre of a society lies in how it treats its most vulnerable members."*⁴⁹⁰

487 Paul Keating, 'Voluntary euthanasia is a threshold moment for Australia, and one we should not cross,' *Sydney Morning Herald*, 19 October 2017.

488 Mr Denton, *Go Gentle Australia*, JSCEOLC Transcript, 13 April 2018, Session 6 at 9-10.

489 Mr Denton, *Go Gentle Australia*, JSCEOLC Submission 539 at p8.

490 Dr Best, *Palliative Care Physician and Academic*, JSCEOLC Transcript, Session 2, 1 May 2018 at 3.

Finding 68

The onus is on those advocating for a change in the law to establish that such a profound change will be safe for the whole community. Anything less results in nothing more than the trading of lives.

Finding 69

The best possible outcome in an assisted suicide regime is that a person who was dying, dies sooner than they would have. The worst possible outcome in an assisted suicide regime is a wrongful death.

Chapter 3

Lessons Learned from Other Jurisdictions

The clinical experience observed during the brief life of the ROTI Act [euthanasia legislation in the Northern Territory] could be regarded as an experiment in which the legislation that supported the practice of euthanasia can be examined for its effectiveness. This [clinical experience] ...demonstrated the inadequacy of provisions of the ROTI Act and suggested that the vulnerable cannot be safely protected by such legislation.

Prof David Kissane AC MD⁴⁹¹

There is no redress for family or friends in the event that a death was hastened and one or more of the eligibility requirements was not met. Obviously one cannot be brought back from the dead.

Marshall Perron, former Chief Minister of the Northern Territory,
who sponsored the Rights of the Terminally Ill Act 1995⁴⁹²

- 3.1. It was asserted to the Committee that 'repeated, independent, peer-reviewed, and exhaustive, reviews have shown no evidence of abuse of the vulnerable overseas.'⁴⁹³
- 3.2. Dr Lancée, Doctors for Assisted Dying Choice, suggests that:

We have the benefit of being able to learn from the experience of other jurisdictions over several decades. We can check the multitude of reports and reviews about the problems they faced and we can feel reassured that none of the dreaded fears of elder abuse, coercion, death-thirsty doctors, slippery slopes or degradation of palliative care have been realised in places where voluntary assisted dying is legal.⁴⁹⁴

491 Professor David W Kissane, MD is an academic psychiatrist, psycho-oncology researcher and author. He is currently the Head of Psychiatry for Monash University in Australia, recently the Chairman of the Department of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center in New York and previously the Foundation Chair of Palliative Medicine at the University of Melbourne. He was also made a Companion of the Order of Australia in January 2018 for his contribution to the field of psycho-oncology and palliative medicine as an educator, researcher, author and clinician. Quote taken from Kissane DW (2000) 'The Challenge of Informed Consent,' *Journal of Pain and Symptom Management* 19(6), 473-4 at 474.

492 Mr Marshall Perron, Private Citizen, JSCEOLC Response to Questions on Notice, undated.

493 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 42.

494 Dr Lancée, Medical Practitioner, JSCEOLC Transcript, Session 6, 5 April 2018 at 7.

Chapter 3

- 3.3. Mr Marshall Perron, former Chief Minister of the Northern Territory, and architect and sponsor of the *Rights of the Terminally Ill Act 1995* (NT) (ROTI Act), writes:

*It has been clearly shown that responsible, safe laws can be drafted that allow willing doctors to respond to requests for early termination of life made by a competent adult. Experience elsewhere demonstrates there are a number of models that work, each of them differing in regard to eligibility, pre-conditions to be met and the form of assistance that can be provided.*⁴⁹⁵

- 3.4. Professors White and Willmott also gave evidence to the Committee that the claim is made by opponents of assisted suicide:

*that the law will inevitably expand over time to allow new and broader groups to have access to assisted dying. But this factual claim doesn't reflect what has happened elsewhere. There have been virtually no changes in the regimes that permit assisted dying overseas.*⁴⁹⁶

- 3.5. Similarly, Mr Denton observed that

*It is not that people don't campaign for or talk about changes, they do and will always do it as part of a democratic society, but the notion that once a law for voluntary assisted dying is passed, it will invariably change is simply not supported by the evidence from overseas jurisdictions.*⁴⁹⁷

- 3.6. Great emphasis was also placed by proponents on the decision of the Supreme Court of Canada in *Carter v Canada (Attorney General)*,⁴⁹⁸ where it was said the Court 'looked at all the available peer-reviewed evidence itself and concluded that there was no evidence that people who were vulnerable were at risk under the assisted dying legislation.'⁴⁹⁹ Speaking about the first instance decision in *Carter*, Mr Stephen Walker, Vice President of Dying with Dignity Western Australia, stated:

But in the end she very clearly comes down on the side of saying that the systems that she has looked at and heard about operate well and

495 Mr Marshall Perron, Private Citizen, JSCEOLC Submission 23 at 5-6.

496 Professors White and Willmott in White, McGee and Willmott (2017) 'As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric,' *The Conversation*, 20 September 2017, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560. Similar assertions were also made to the Committee by Mr Neil Francis, JSCEOLC Transcript, 9 April 2018, Session 1 at 10.

497 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 46.

498 2015 SCC 5.

499 Prof Willmott, Director, Australian Centre for Health Law Research, JSCEOLC Transcript, 26 February 2018, Session 2 at 11.

*that there is virtually no abuse, that there is no coercion or imposition upon elderly people or people who are otherwise vulnerable, that safeguards can and do work, and that, as I would read her, nothing is perfect and we need to maintain vigilance. However, overall, despite the myths that go around, she found that the systems in these various jurisdictions do work very well.*⁵⁰⁰

- 3.7. Four important points need to be made here. The first is that there is peer-reviewed evidence of abuse, including peer-reviewed evidence of the abuse of legalised euthanasia here in Australia while the ROTI Act was operational.⁵⁰¹
- 3.8. Second, in a decision as important as this, to create an exception to the prohibition against the killing of one person by another, the Parliament of Western Australia should take into account all available evidence. Evidence of abuse of the legal limits and the wrongful deaths of individuals in jurisdictions where assisted suicide is legal, whether peer-reviewed or not, should be considered. Whether this evidence should hold any weight will be an assessment made by each Parliamentarian in the decision-making process.
- 3.9. Third, consideration of the decisions made by other jurisdictions who have not legalised assisted suicide should also be made. This Chapter considers those jurisdictions who have rejected the legalisation of assisted suicide, the number of which far outweigh the jurisdictions where assisted suicide is legalised. The *Carter* decision from Canada,⁵⁰² so highly relied upon by proponents of assisted suicide, can also be counter-balanced and outweighed with decisions of the House of Lords in the United Kingdom,⁵⁰³ and the decision of the High Court of Ireland in *Fleming v Ireland & Ors*.⁵⁰⁴
- 3.10. Finally, consideration of the legislation so recently passed in Victoria in the final section of this Chapter, and the criticisms of that legislation by proponents of assisted suicide,

500 Mr Walker, Vice President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 11.

501 See Kissane, Street and Nitschke (1998) 'Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,' *The Lancet* 352(9134) at 1097-1102 and for international jurisdictions see Kim et al (2016) 'Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014,' *JAMA Psychiatry* 73(4) at 362-68; Chambaere et al (2010) 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey,' *CMAJ* 182(9) at 895-901; Pereira J (2011) 'Legalising euthanasia or assisted suicide: the illusion of safeguards and controls,' *Current Oncology* 18(2) at 38-45; Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1) at 16-30 and Hendin and Foley (2008) 'Physician-assisted suicide in Oregon: a medical perspective,' *Mich Law Rev* 106 at 1613-40.

502 *Carter v Canada (Attorney General)* 2012 BCSC 886, upheld in *Carter v Canada (Attorney General)* [2015] 1 SCR 331.

503 Report of the Select Committee on Medical Ethics, House of Lords, Vol 1, Session 1993-1994, 1994 London: HMSO.

504 [2013] IESC 19.

Chapter 3

reveals that extension of eligibility criteria will logically occur following legalisation. The clear and vast evidence from Committee hearings and submissions sustain this conclusion.

The Lived Experience in Australia—The Northern Territory

- 3.11. The WA Chapter of Exit International’s submission to the Committee stated that:

From the experiences in other jurisdictions, we believe that [protecting patients from possible abuse] can be achieved without subjecting ill people to a protracted bureaucratic process in an already stressful and likely painful situation. In this respect we would also like to mention Australia’s first [voluntary euthanasia] legislation, the Northern Territory’s Rights of the Terminally Ill Act... which had adequate provisions to prevent abuse.⁵⁰⁵

- 3.12. Evidence was given to the Committee that the law was not broken in the Northern Territory while the ROTI Act was in operation.⁵⁰⁶ When asked ‘Do you maintain to this day that your actions were lawful?’ Dr Nitschke answered, ‘Yes, I do. I mean, they were lawful under the Northern Territory Rights of the Terminally Ill Act and all of the four people who went through that arduous selection process demonstrated their eligibility.’⁵⁰⁷
- 3.13. Peer reviewed literature, including a journal article co-authored by Dr Nitschke himself, reveals evidence to the contrary—that deaths occurred that were not lawful under the ROTI Act.⁵⁰⁸
- 3.14. Dr Nitschke, founding member of Exit International, writes in that organisation’s submission that ‘As the only doctor to have lawfully provided voluntary euthanasia to four patients in Australia, I suggest that I have unique insights into how a carefully-worded and construed end of life rights law can operate at a practical level.’⁵⁰⁹ He writes, ‘In 1996-97, these safeguards were effective in ensuring that the four of my patients who used the *ROTI Act* in 1996-97 were all terminally ill, of sound mind, had their medical options fully explained, were over 18 years and so on.’⁵¹⁰
- 3.15. Ironically, in contrast to his own statements and in contrast to Exit International’s submission above, Dr Nitschke gave evidence to the Committee that:

505 Exit International (WA), JSCEOLC Submission 100 at 2.

506 Mr Neil Francis, Dying for Choice, JSCEOLC Transcript, 9 April 2018, Session 1 at 14-15.

507 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 5-6.

508 Kissane, Street and Nitschke (1998) ‘Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,’ *The Lancet* 352(9134) at 1097-1102.

509 Exit International, JSCEOLC Submission 141 at 1.

510 Exit International, JSCEOLC Submission 141 at 2.

There were problems. Marshall Perron foresaw some of those problems when he said—I remember asking him and talking to him about it before the vote was taken in the territory Parliament. He said he did not want sick people having to jump through hoops—his words. Of course, what we got in that piece of legislation, that Rights of the Terminally Ill Act, was a piece of legislation that made very sick people jump through hoops. When the law passed, I found myself dragging very sick people—in the first case, Bob Dent—from doctor to doctor to get the signatures necessary to demonstrate eligibility to die. The irony of that was not missed on people like Bob Dent who was so sick, yet he said, “I have to qualify to be eligible to die.” I felt cruel having to drag him around to make him satisfy those onerous restrictions of that law. I saw the need for safeguards, but they were particularly difficult ones to comply with.⁵¹¹

The Rights of the Terminally Ill Act 1995 (NT)

- 3.16. Section 4 of the ROTI Act provided that ‘A patient who, in the course of a terminal illness, is experiencing pain, suffering and/or distress to an extent unacceptable to the patient, may request the patient’s medical practitioner to assist the patient to terminate the patient’s life.’ Section 3 defined a ‘terminal illness’, in relation to a patient, as ‘an illness which, in reasonable medical judgment will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the patient, result in the death of the patient.’
- 3.17. The ROTI Act further provided that a ‘medical practitioner who receives a request’ may, if certain conditions are met, ‘assist the patient to terminate the patient’s life.’ The conditions to be met included that:

The medical practitioner is satisfied, on reasonable grounds, that

- (i) the patient is suffering from an illness that will, in the normal course and without the application of extraordinary measures, result in the death of the patient;*
- (ii) in reasonable medical judgment, there is no medical measure acceptable to the patient that can reasonably be undertaken in the hope of effecting a cure; and*
- (iii) any medical treatment reasonably available to the patient is confined to the relief of pain, suffering and/or distress with the*

511 Dr Nitschke, Exit International, JSCEOLC Transcript 13 April 2018, Session 3 at 2 (emphasis added).

Chapter 3

object of allowing the patient to die a comfortable death; (s7(1)(b));

A second 'medical practitioner who holds prescribed qualifications, or has prescribed experience, in the treatment of the terminal illness from which the patient is suffering' has examined the patient and has confirmed

(i) the first medical practitioner's opinion as to the existence and seriousness of the illness;

(ii) that the patient is likely to die as a result of the illness; and

(iii) the first medical practitioner's prognosis (s7(1)(c)(i) and (iii));

'A qualified psychiatrist' has 'confirmed that the patient is not suffering from a treatable clinical depression in respect of the illness' (s7(1)(c)(ii) and (iv)); and

The illness is causing the patient severe pain or suffering (s7(1)(d))

- 3.18. As will be demonstrated below, the circumstances surrounding the deaths of the four patients euthanised under the ROTI Act show that these deaths occurred outside of the abovementioned eligibility prescriptions and safeguards written into the legislation.

Lack of access to good palliative care

- 3.19. First, Dr Nitschke emphasised in evidence to the Committee that one of the safeguards that should be included in assisted suicide law is that 'the person must have exhausted all palliative care options available to them,' a safeguard taken directly from Part 2 of the ROTI Act.⁵¹²
- 3.20. However, palliative care was—in the words of Dr Nitschke himself—an 'embryonic speciality' in the Northern Territory at the time of the ROTI Act.⁵¹³ That 'palliative care facilities were underdeveloped in the Northern Territory' was also identified by Kissane, Street and Nitschke in 'Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia.'⁵¹⁴ In case 3, the patient may have benefited from radiotherapy or strontium but neither of these was available in the Northern Territory.⁵¹⁵ In Case 5, the patient had an obstruction and was clinically

512 Dr Nitschke, Exit International, JSCEOLC Submission 141 at 1.

513 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 9.

514 Kissane, Street and Nitschke (1998) 'Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,' *The Lancet* 352(9134) 1097-102.

515 Ibid at 1099.

jaundiced.⁵¹⁶ Section 7(1)(e) of the ROTI Act required Dr Nitschke as the ‘medical practitioner who receives a request’ to have ‘informed the patient of the nature of the illness and its likely course, and the medical treatment, including palliative care, counselling and psychiatric support and extraordinary measures for keeping the patient alive, that might be available to the patient.’ However, Kissane reports that ‘when questioned about options like stenting for obstructive jaundice or the management of bowel obstruction,’ Dr Nitschke ‘acknowledged limited experience, not having been involved in the care for the dying before becoming involved with the *ROTI Act*.’⁵¹⁷ This raises doubts as to whether the patient in this case—who was reported by Dr Nitschke to exhibit ‘indecisiveness’ over a two month period about whether or not to request euthanasia—would still have done so if he had been given better symptomatic relief for the jaundice and obstruction.⁵¹⁸

A patient who was not terminally ill was euthanised

- 3.21. In Case 4, there was no medical consensus that the patient’s diagnosed medical condition, mycosis fungoides, was a terminal illness: ‘One oncologist gave the patient’s prognosis as nine months, but a dermatologist and a local oncologist judged that she was not terminally ill. Other practitioners declined to give an opinion. In the end an orthopaedic surgeon certified that the *ROTI* provisions for terminal illness had been complied with.’⁵¹⁹
- 3.22. Professor Quinlan’s legal analysis of the deaths under the ROTI Act is as follows:

Whilst there were no definitive instances of innocent prisoners being executed, over the 196 year history of capital punishment in Australia, in the brief period in which euthanasia was lawful in the Northern Territory, 2 out of the 7 patients who sought euthanasia were provided with inadequate information of their true medical condition and of their treatment options. Unlike the criminal justice system, with its system of judicial appeals, under the NT Act, if a doctor found that the patient did not meet the criteria for access to euthanasia, the patient (or his or her advisers) could approach an unlimited number of other doctors until one could be found who would give the required opinion. This situation arose during the brief operation of the NT Act in Case 4. When there was no consensus that the patient’s condition satisfied the NT Act’s requirements, among oncologists, the patient made an appeal on national television. An orthopaedic surgeon, who had no expertise in her condition as the NT Act required, provided the certification that the

516 Ibid at 1100.

517 Ibid at 1101.

518 Ibid at 1100.

519 Ibid at 1101.

Chapter 3

*patient's condition was terminal and she was euthanised. In Kissane's opinion: 'The voluntariness of her choice for euthanasia was influenced by her not being informed of the availability of effective treatment for depression nor being given the opportunity to have her suffering alleviated.' In Case 5, a patient was jaundiced and suffering from a bowel obstruction but was not advised of the palliative care and medical treatment available. In Kissane's view: 'Given the level of error rate that does occur in medical practice, this experience [of the operation of the NT Act] suggests it would be impossible to safely legislate for doctors to kill.'*⁵²⁰

Evidence of doctor shopping

- 3.23. Dr Nitschke confirmed that 'doctor shopping' was involved in the management of Case 4. He gave evidence to the Committee that:

*ultimately because we needed a Territory specialist, and there are not many, we got Stephen Badley, who was an orthopaedic surgeon, who, out of compassion said, "I cannot possibly stand to see this suffering going on any longer. I will sign it and take the heat," and by hell he took the heat.*⁵²¹

- 3.24. Mr Perron also confirmed that the patient's television appeal 'was successful' and a 'specialist who was not a specialist in the relevant disease [signed] off on it because he felt so bad about this woman's plight.'⁵²² When asked by Hon Nick Goiran in a Committee hearing whether he 'would describe the signing off by the orthopaedic surgeon as a success,' Mr Perron answered:

*it was not necessarily in accordance with the legislation's intent, but no party involved regrets what they did in that circumstance.*⁵²³

Patients with mental illness and undiagnosed demoralisation were euthanised

- 3.25. From the case histories, it is also apparent that Cases 3 and 4 each had depressive symptoms.
- 3.26. In case 3, the patient had received 'counselling and anti-depressant medication for several years.' He spoke of feeling sometimes so suicidal that 'if he had a gun he would

520 Quinlan M (2016) "Such is Life": Euthanasia and capital punishment in Australia: consistency or contradiction?' *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* 6(1) at 8-9, citing David W. Kissane (2000) 'The Challenge of Informed Consent' *Journal of Pain and Symptom Management* 19 at 473.

521 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 6.

522 Mr Marshall Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 9.

523 Ibid.

have used it.’ He had outbursts in which he would ‘yell and scream, as intolerant as hell’ and he ‘wept frequently.’⁵²⁴

3.27. Neither the patient’s adult sons nor the members of the community palliative care team who were caring for him were told he was being assessed for euthanasia. ‘A psychiatrist from another state certified that no treatable clinical depression was present.’⁵²⁵

3.28. In Case 4, the case of non-terminal mycosis fungoides:

*the psychiatrist noted that the patient showed reduced reactivity to her surroundings, lowered mood, hopelessness, resignation about her future, and a desire to die. He judged her depression consistent with her medical condition, adding that side-effects of her antidepressant medication, dozepin, may limit further increase in dose.*⁵²⁶

3.29. Kissane comments that ‘Case 4 was receiving treatment for depression, but no consideration was given to the efficacy of dose, change of medication, or psychotherapeutic management.’ While Dr Nitschke ‘judged this patient as unlikely to respond to further treatment,’ Kissane comments that ‘nonetheless, continued psychiatric care seemed warranted—a psychiatrist can have an active therapeutic role in ameliorating suffering rather than being used only as a gatekeeper to euthanasia.’⁵²⁷

3.30. The patient’s mood appeared to have been ‘normalised’ as a predictable response to her medical condition. Kissane suggests that acceptance that she had an autonomous right to euthanasia (despite the fact that she did not meet the eligibility requirement of a terminal illness) may have prevented this clinician from considering his or her duty under the *Mental Health Act 2007* (Cth) to protect a suicidal patient from endangering herself, the former Act taking precedence over the ROTI Act.⁵²⁸

3.31. Further concerns have been raised regarding Case 5. Dr Nitschke reported that ‘on this occasion the psychiatrist phoned within 20 min, saying that this case was straightforward.’ This assessment took place on the day on which euthanasia was planned. This case involved an elderly, unmarried man who had migrated from England and had no relatives in Australia. Dr Nitschke recalled ‘his sadness over the man’s loneliness and isolation as he administered euthanasia.’ Dr Nitschke has since revealed

524 Kissane, Street and Nitschke (1998) ‘Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,’ *The Lancet* 352(9134) 1097-1102 at 1099.

525 Ibid.

526 Ibid at 1100.

527 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 11, citing Kissane, Street and Nitschke (1998) ‘Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,’ *The Lancet* 352(9134) 1097-1102.

528 Kissane DW (2000) ‘The Challenge of Informed Consent,’ *Journal of Pain and Symptom Management* 19(6) 473-4 at 473.

Chapter 3

in testimony to a Senate committee, that he also personally paid for this psychiatric consultation and that it in fact took less than 20 minutes.⁵²⁹

3.32. Dr Kissane, commenting on the issue of demoralisation, writes:

Review of these patients' stories highlighted for me the importance of demoralization as a significant mental state influencing the choices these patients made. They described the pointlessness of their lives, a loss of any worthwhile hope and meaning. Their thoughts followed a typical pattern of thinking that appeared to be based on pessimism, sometimes exaggeration of their circumstances, all-or-nothing thinking in which only extremes could be thought about, negative self-labelling and they perceived themselves to be trapped in this predicament. Often socially isolated, their hopelessness led to a desire to die, sometimes as a harbinger of depression, but not always with development of a clinical depressive disorder. It is likely that the mental state of demoralization influenced their judgement, narrowing their perspective of available options and choices. Furthermore, demoralized patients may not make a truly informed decision in giving medical consent.⁵³⁰

3.33. In relation to Case 4, Kissane concludes that:

The clinical experience observed during the brief life of the ROTI Act could be regarded as an experiment in which the legislation that supported the practice of euthanasia can be examined for its effectiveness. This patient generated a range of ethical concerns regarding the nature and quality of her medical care. Her story demonstrated the inadequacy of provisions of the ROTI Act and suggested that the vulnerable cannot be safely protected by such legislation.⁵³¹

3.34. It should be noted here that Mr Perron and Dr Nitschke were the only persons whose 'expert' opinions were sought by the Committee on the operation of the ROTI Act. Dr Kissane was also identified to the Committee as an expert in this field,⁵³² however evidence was not sought from him by the Committee.

529 P Nitschke, *Hansard*, Senate Standing Committee on Legal and Constitutional Affairs, *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill* 2008, 14 April 2008 at 42, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 12.

530 Kissane DW (2002) 'Deadly days in Darwin,' in *The Case Against Assisted Suicide*, Foley and Hendin (eds) at 192-209.

531 Kissane DW (2000) 'The Challenge of Informed Consent,' *Journal of Pain and Symptom Management* 19(6), 473-4 at 474.

532 See Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 10.

Dr Nitschke—where is he now?

- 3.35. Apart from being the only medical practitioner to administer euthanasia in Australia under assisted suicide legislation, Dr Nitschke has a long reported history of assisting in the suicides of countless individuals, both in Australia and overseas.
- 3.36. Mrs Judi Taylor advised the ABC that an online forum called Peaceful Pill, run by Exit International (and for which members must pay a fee to access), needlessly facilitated her son's suicide. Mr Lucas Taylor was 26 years old when he committed suicide after following the advice provided to him on the online forum.
- 3.37. Dr Nitschke's response to Mrs Taylor's devastation and criticism was 'If he got the wrong advice she may have had a brain-dead dependent on her hands' and '[t]hat would not be in anyone's interests.'⁵³³ Dr Nitschke has described the deaths of young people like Mr Taylor as a 'casualty' of the need for assisted suicide information to be widely available. As already cited in this Report, Dr Nitschke stated that 'There will be some casualties... but this has to be balanced with the growing pool of older people who feel immense well-being from having access to this information.'⁵³⁴
- 3.38. Dr Nitschke is well known for his strongly held belief that assisted suicide should be available to all, regardless of their mental or physical health:

*I do not believe that telling people that they have a right to life while denying them the means, manner, or information necessary for them to give this life away has any ethical consistency... And someone needs to provide this knowledge, training, or recourse necessary to anyone who wants it, including the depressed, the elderly bereaved, the troubled teen.*⁵³⁵

- 3.39. In September 2014, it was reported that Dr Nitschke was being investigated by police in every Australian state over his possible role in nearly 20 deaths in the previous three years, all of them apparently suicides. One investigation by Victoria Police concerned the death of a 55-year-old Geelong man who allegedly killed himself using a self-administered kit bought through a company affiliated with Exit International. All of the

533 Dr Nitschke, quoted in Stephanie Chalkley-Rhoden, 'Exit International forum coached young man to his death, mother claims,' *ABC News*, 26 July 2014.

534 Julia Medew 'Young people gain access to euthanasia drug' *Sydney Morning Herald*, 15 February 2010 <<https://www.smh.com.au/lifestyle/health-and-wellness/young-people-gain-access-to-euthanasia-drug-20100215-nzon.html>>

535 Philip Nitschke and Fiona Stewart (2005) *Killing Me Softly: Voluntary Euthanasia and the Road to the Peaceful Pill* at 312.

Chapter 3

deaths being investigated involved the use of the two suicide methods promoted by Dr Nitschke—Nembutal or a nitrogen inhalant device.⁵³⁶

- 3.40. Dr Nitschke has been associated with many high-profile deaths, including that of 70-year-old Nancy Crick (as previously mentioned in Chapter 2 in the section entitled *Error in diagnosis*), whose autopsy revealed that she did not have cancer, a fact which Nitschke deemed ‘irrelevant’;⁵³⁷ Syd and Marjorie Croft, a healthy couple in their late 80s;⁵³⁸ 79-year-old Lisette Nigot in Perth who was neither ill nor in pain,⁵³⁹ and Alzheimer’s sufferer Graeme Wylie, whose family friend (and euthanasia supporter) had obtained Nembutal to be administered to him and which was finally administered to him by his wife. The wife and friend involved claimed that Mr Wylie had wanted to end his own life, but a jury found that he lacked the capacity to decide due to his Alzheimer’s disease.⁵⁴⁰ Petrified of going to jail, the family friend who obtained the Nembutal, took her life with the same drug she illegally obtained for Mr Wylie.⁵⁴¹
- 3.41. Dr Nitschke was suspended by the Medical Board of Australia after investigation into his involvement in the death of Perth man Nigel Brayley. Mr Brayley, 45, died in May 2014 after contacting Dr Nitschke and taking the euthanasia drug Nembutal. Mr Brayley was implicated in the deaths of two of his partners and feared being charged with his wife’s murder.⁵⁴² Though he denied that he had breached his professional obligations by assisting in Mr Brayley’s suicide, the Medical Board suspended Dr Nitschke, citing that he presented ‘a serious risk to public health and safety.’⁵⁴³ Dr Nitschke’s response was

536 J Davies, ‘Euthanasia campaigner Nitschke investigated over more deaths,’ *The Age*, 28 September 2014 <<http://www.smh.com.au/national/euthanasia-campaigner-nitschke-investigated-over-more-deaths-20140927-10msng.html>>

537 A Bolt, ‘At last, we wake up to Dr Death, Philip Nitschke,’ *Herald Sun*, 6 July 2014 <<https://www.heraldsun.com.au/news/opinion/andrew-bolt/at-last-we-wake-up-to-dr-death-philip-nitschke/news-story/b106a0996e5132af63dcfa3233d156dc>>

538 ‘Healthy choosing premature death, says Nitschke,’ *The Age*, 16 December 2002 <<https://www.theage.com.au/national/healthy-choosing-premature-death-says-nitschke-20021216-gduxwr.html>>

539 ‘Healthy woman thanks Dr Nitschke, then kills herself,’ *The Sunday Morning Herald*, 26 November 2002 <<https://www.smh.com.au/national/healthy-woman-thanks-dr-nitschke-then-kills-herself-20021126-gdfvde.html>>

540 Angus Hohenboken ‘Manslaughter ruling over euthanasia,’ *The Australian*, 20 June 2008 <<https://www.theaustralian.com.au/news/nation/manslaughter-ruling-over-euthanasia/news-story/58ea4f84aa3bdfbd9e5808cac973f495?sv=c1d2259110d4d688375edce43624700d>>

541 Kim Arlington, ‘Euthanasia advocate Caren Jennings “bullied” in trial’ *The Daily Telegraph*, 21 September 2008 <<https://www.dailytelegraph.com.au/news/nsw/suicide-to-avoid-dying-in-jail/news-story/73d64c27e51a2070a93c4fae258ee4ea?sv=9a5853d7aff43bd0061e2a1ea95c7de3>>

542 ‘Philip Nitschke denies he “went too far” helping depressed Nigel Brayley die,’ *news.com.au* 4 July 2014 <<https://www.news.com.au/national/western-australia/philip-nitschke-denies-he-went-too-far-helping-depressed-nigel-brayley-die/news-story/1aa59a8c9ce52838f294146f20bcfb0?>>

543 Stephanie Chalkley-Rhoden, ‘Exit International forum coached young man to his death, mother claims,’ *ABC News*, 26 July 2014 <<http://www.abc.net.au/news/2014-07-25/euthanasia-forum-coached-young-man-into-taking-his-life-mother/5623408>>

'That's about the most ludicrous thing they've said, that... telling me I'm no longer a practising doctor is going to somehow or other change things.'⁵⁴⁴

- 3.42. Dr Nitschke has developed suicide machines,⁵⁴⁵ advised on recipes for homemade pills to assist in suicide,⁵⁴⁶ and has developed a testing kit to allow people who have purchased Nembutal to test its potency.⁵⁴⁷ In 2006, Exit International published the *Peaceful Pill Handbook*, co-authored by Dr Nitschke. The *Peaceful Pill Handbook* enables readers to compare for themselves the benefits of various options such as Nembutal, Helium and the Exit Bag, prescription drugs, carbon monoxide, cyanide and the DIY peaceful pill.⁵⁴⁸ Although the *Peaceful Pill Handbook* was banned by the Australian Federal Government in February 2007, Exit International conduct workshops on how to bypass the Australian Government's internet filter to order and download it, and continue to revise and sell new editions at its website, on Amazon and for Kindle.⁵⁴⁹
- 3.43. More recently, in commenting on the work of the Last Wish Cooperative in the Netherlands, who claim to distribute a lethal powder to those who wish to commit suicide, Dr Nitschke states in an Exit International Media Release:

*With the wide, legal availability of this new drug, no one will bother with a restrictive euthanasia legislation that requires people close to death to obtain permission from a doctor to die. When the time is right, people craving a peaceful death, will simply take this new drug. No one will bother with the legislative safeguards in new proposed legislation, when this product becomes available.*⁵⁵⁰

- 3.44. Dr Nitschke continues his activities promoting suicide, only in April this year showcasing a 'suicide machine' at an Amsterdam funeral fair, which Dr Nitschke hopes will one day be available as a 3D-printable device.⁵⁵¹

544 'Euthanasia advocate Philip Nitschke suspended by the Medical Board of Australia' *ABC News*, 23 July 2014 <<http://www.abc.net.au/news/2014-07-24/euthanasia-advocate-philip-nitschke-suspended-by-medical-board/5615268>>

545 'Nitschke suicide device out' *Sydney Morning Herald*, 3 December 2002

<<https://www.smh.com.au/national/nitschke-suicide-device-out-20021203-gdfwqf.html>>

546 Philip Nitschke and Fiona Stewart (2005) *Killing Me Softly: Voluntary Euthanasia and the Road to the Peaceful Pill*.

547 'Nitschke unveils new euthanasia aid' *ABC News*, 18 June 2009

<<http://www.abc.net.au/news/2009-06-18/nitschke-unveils-new-euthanasia-aid/1324714>>

548 'The Peacefull Pill handbook' <<https://www.peacefulpillhandbook.com/about-the-handbook/>>

549 Steele and Worswick (2013) 'Destination death: A review of Australian legal regulation around international travel to end life,' *JLM* 21, 415.

550 Exit International Media Release, 'Dutch Euthanasia Drug Breakthrough De-rails WA Legislative Change,' dated 2 September 2017 <<https://exitinternational.net/media/MRWAAug17.pdf>>

551 'Nitschke's 'suicide machine' draws crowds at Amsterdam funeral fair,' *The Guardian*, 15 April 2018; Caroline Overington, 'Philip Nitschke invents suicide capsule with 3D printer,' *The Australian*, 24 November 2017 <<https://www.theaustralian.com.au/news/health-science/philip->

Chapter 3

- 3.45. Dr Nitschke now resides in the Netherlands and remains active in Exit International, and has been affiliated with the Last Wish Cooperative, an organisation that supports access to suicide without the constraints of the participation of the medical profession. This directly contradicts the evidence given to the Committee by Mr Luley of Dignitas (Switzerland), who suggests that ‘...if you want to get rid of Dr Nitschke’s Exit International, you must do what he is doing. People only turn to organisations like Dignitas or Exit International and Philip Nitschke because they are not met at eye level with their wishes, with their fears, with their needs.’⁵⁵² The Netherlands has one of the most widely framed euthanasia laws in the world, and that is where Dr Nitschke has chosen to reside and continues his work assisting the suicides of anyone who seeks it. This was acknowledged by Mr Denton, who gave evidence to the Committee that

*I think regardless of what law you write—this exists even in the Netherlands, which has had the longest and deepest conversation about this of any society on earth—their remains societies, like Dr Nitschke’s Exit in Australia, an organisation about which I have mixed feelings, that supply the means to people, or supply the advice to people to get the means, for people such as you have described, to end their life as they choose on their own terms.*⁵⁵³

- 3.46. The question for the Western Australian Parliament to answer is not a complicated one: Should Dr Nitschke be given a licence to ‘set up shop’ in WA? If the answer is yes, then lawmakers should press ahead with the legalisation of assisted suicide. If the answer is no, then the collective energies and efforts of lawmakers would be better directed to ensuring that every Western Australian in need has access to specialist palliative care, including dignity therapy and consultation-liaison psychiatry.

Finding 70

When assisted suicide was legal in the Northern Territory one patient, diagnosed with mycosis fungoides and receiving treatment for depression, was euthanised on the certification of an orthopaedic surgeon with no expertise in the condition, notwithstanding that a dermatologist and a local oncologist had assessed that the patient was not terminally ill.

[nitschke-invents-suicide-capsule-with-3d-printer/news-story/318561693f3a6eee1e10069df83a3839?login=1](https://www.jseolc.gov.au/news-story/318561693f3a6eee1e10069df83a3839?login=1)

552 Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 8 March 2018, Session 5 at 4.

553 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 11.

Finding 71

When assisted suicide was legal in the Northern Territory one patient was euthanised even though he was jaundiced and suffering from a bowel obstruction and not advised of the palliative care and medical treatment available. The psychiatric certification in that case consisted of a 20-minute consultation paid for by Dr Philip Nitschke on the day the assisted suicide was scheduled.

Finding 72

Doctor shopping took place when assisted suicide was legal in the Northern Territory.

Finding 73

When assisted suicide was legal in the Northern Territory one patient, who had received counselling and anti-depressant medication for several years, was euthanised after a psychiatrist from another State certified that no treatable clinical depression was present, notwithstanding that neither the patient's adult sons nor the members of the community palliative care team who were caring for him were told he was being assessed for assisted suicide.

Finding 74

The clinical experience observed during the period when assisted suicide was legal in the Northern Territory demonstrates the inadequacies of safeguards and this experience alone ought to militate against legalisation in Western Australia.

Recommendation 13

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Northern Territory experience.

The European Experience—The Netherlands

- 3.47. Although it is illegal under Dutch criminal law to assist in suicide or to terminate life upon request, since 1973 Dutch courts have recognised a defence of 'necessity' which permits a doctor to avoid liability by pointing to his or her duty 'to reduce suffering or to respect the personality [autonomy] of the patient.'⁵⁵⁴ Magnusson notes that:

The requirements for the necessity defence have undergone subtle elaboration over the past three decades. In November 2000 the defence was, for the first time, given an explicit statutory basis, following the approval of amendments to the Dutch Penal Code by the Lower House of the Dutch Parliament. These amendments were passed by the Upper House in April 2001. To avoid liability under the Penal Code, doctors will be required to satisfy the 'due care' requirements set out in the

554 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 64.

Chapter 3

Termination of Life on Request and Assisted Suicide (Review Procedures) Act. In addition, the doctor must report the death to the municipal coroner as required under Dutch burial legislation.

Under the due care requirements, it is not necessary for the patient to be suffering physical pain: unbearable mental anguish is sufficient. Similarly, there is no requirement for the patient to be in the terminal phase of an illness, or indeed to be suffering from any (physical) disease at all. A physical disability, or a condition of 'untreatable misery', will suffice. Where the patient's suffering is non-somatic in origin, the new legislation does not explicitly require the treating doctor to arrange for psychiatric review, although this seems implicit in the requirements that the independent doctor must certify that the patient's condition is hopeless and without prospect of improvement. More generally, however, 'due care' does not require depression, or any psychiatric illness, to be excluded.⁵⁵⁵

- 3.48. Professor Willmott gave evidence to the Committee that:

Our understanding is that the Dutch law has not altered since it was first enacted. When it was first enacted, minors, in some circumstances, were entitled to access assistance to die, but that has not been altered in the Netherlands... I understand that there is currently some review in the Netherlands about whether or not they should be reforming the Dutch law around euthanasia, but, as yet, it has not been changed.⁵⁵⁶

- 3.49. Professor Willmott's understanding of the law is incorrect. Until 2001, the Netherlands allowed only adults access to euthanasia or physician-assisted suicide. However, in 2001 the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001* was passed to allow for children aged 12–16 years to be euthanised if consent is provided by their parents, even though this age group is generally not presumed to have capacity. The law even allows physicians to proceed with euthanasia if there is disagreement between the parents. By 2005, the Groningen protocol, which allows euthanasia of newborns and younger children who are expected to have 'no hope of a good quality of life,' was implemented.⁵⁵⁷

- 3.50. The Groningen protocol was developed by a committee of physicians and lawyers at the University Medical Centre Groningen in order to assist with the decision making process

555 Ibid at 64-65.

556 Prof Willmott, Director, Australian Centre for Health Law Research, JSCEOLC Transcript, 26 February 2018, Session 2 at 11.

557 Pereira J (2011) 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,' *Current Oncology* 18(2) 38-45 at 41.

when considering actively ending the life of a newborn, by providing the information required to assess the situation within a legal and medical framework.⁵⁵⁸

- 3.51. Under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*, euthanasia technically remains illegal for patients under the age of 12. The Groningen protocol does not give physicians unassailable legal protection and no black letter law exists in this area. However, courts have so far protected physicians from prosecution so long as they act in accordance with the protocol.⁵⁵⁹
- 3.52. What is important to note is that the active termination of the life of newborns in the Netherlands was occurring prior to the introduction of the Groningen protocol, and without prosecution. A 2005 review study of 22 reported cases of the active ending of the life of a newborn between 1997 and 2004 (prior to the drafting of the Groningen protocol) found that all of these cases had been performed in accordance with ‘good practice’ and confirmed that none of these cases were prosecuted.⁵⁶⁰ Unreported cases of the active ending of life of a newborn during this period were not considered in the study.
- 3.53. As Dr Herbert Hendin explained in congressional testimony, Dutch policies have gradually expanded from assisted suicide to euthanasia for the terminally ill to euthanasia for the chronically ill; to euthanasia for ‘psychological distress;’ and from voluntary euthanasia to involuntary euthanasia, which ‘has been justified as necessitated by the need to make decisions for patients not [medically] competent to choose for themselves.’⁵⁶¹ The idea of allowing death to be a solution to the problem of suffering was first accepted by the courts in 1973, though initially only in very special, limited cases. Stahle explains that this ‘threshold event’ set in motion a development where this idea was expanded further through a series of court rulings and prosecution concessions. The law ‘was adapted to fit the practice instead of vice versa.’⁵⁶²

Extension of the law to include euthanasia for psychiatric illness

- 3.54. Prior to 1994, the Dutch Supreme Court had recognised a defence of ‘necessity’ under narrowly defined circumstances to a charge of performing euthanasia. In the 1994

558 Verhagen and Sauer (2005) ‘The Groningen protocol – euthanasia in severely ill newborns,’ *N Engl J Med* 352(10) 959-62.

559 Lindemann and Verkerk (2008) ‘Ending the Life of a Newborn: the Groningen Protocol,’ *The Hastings Centre Report* 38(1) at 42-51.

560 Verhagen, Brouwer and Sauer (2005) ‘Deliberate termination of life in newborns in the Netherlands; review of all 22 reported cases between 1997 and 2004,’ *Ned Tijdschr Geneesk* 149(4) at 183-8.

561 Hendin H, *Suicide, Assisted Suicide and Euthanasia: Lessons From the Dutch Experience: Hearings Before the Subcommittee on the Constitution of the House Comm. on the Judiciary*, 104th Congress, 2nd Session, 29 April 1996, cited in Golden and Zoanni (2010) ‘Killing Us Softly: The Dangers of Legalizing Assisted Suicide,’ *Disability and Health Journal* 3(1) 16-30 at 27.

562 Stahle F (2017) ‘Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,’ *Journal of Ethics in Mental Health* 10 at 12.

Chapter 3

Chabot case,⁵⁶³ the Court expanded the defence to include assistance of patients whose suffering was not of somatic origin (somatic relating to the physical body, as distinct from the mind).

3.55. JT Smies summarises the *Chabot* case as follows

*Dr. Boudewijn Chabot was a psychiatrist who supplied lethal drugs to a patient who had recently experienced a series of traumatic events that had left her with no desire to live. Although offered treatment for her condition, the patient refused. The Court began by affirming its earlier holdings that euthanasia and assisted suicide can be justified if: the defendant acted in a situation of necessity, that is to say... that confronted with a choice between mutually conflicting duties, he chose to perform the one of greater weight. In particular, a doctor may be in a situation of necessity if he has to choose between the duty to preserve life and the duty as a doctor to do everything possible to relieve the unbearable and hopeless suffering of a patient committed to his care. The prosecution argued that the defence of justification should not be available to doctors who assist with suicides in cases where the suffering is non-somatic and the patient is not in the 'terminal phase.' The Supreme Court rejected this contention, and held that in such cases the justification can be rooted in the autonomy of the patient herself. The Court noted that, 'the wish to die of a person whose suffering is psychic can be based on an autonomous judgment.'*⁵⁶⁴

3.56. Euthanasia is now legally permitted in the Netherlands for dementia patients and for persons with depression or other mental health issues in the complete absence of any physical illness or suffering.⁵⁶⁵ Euthanasia was performed in 2015 for personality disorder with post-traumatic stress disorder and self-mutilation, and obsessive compulsive disorder.⁵⁶⁶

3.57. The rate of euthanasia for psychiatric illness in the Netherlands has also been increasing. A 1997 study estimated that the annual number of cases was between 2 and 5, while in 2013 there were 42 reported cases.⁵⁶⁷ In 2016 there were 60 notifications of euthanasia

563 *Office of Public Prosecutions v Chabot*, Nederlandse Jurisprudentie 1994, nr 656; Tijdschrift voor Gezondheidsrecht 1994-96, nr 74.

564 Smies JT (2003-2004) 'The legalisation of euthanasia in the Netherlands,' *Gonzaga Journal of International Law* 7 at 19-20, quoted by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 7.

565 Regional Euthanasia Review Committees, *Annual report 2010* at 10, 13 and 22-23, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 7.

566 Regionale Toetsingscommissies Euthanasie, Jaarverslag 2015 at 50-52, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 7.

567 Kim et al (2016) 'Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014,' *JAMA Psychiatry* 73(4) 362-368 at 363.

or assisted suicide involving patients with psychiatric disorders (more than four times the cases in 2012 (14 cases)), and 141 notifications involving dementia (more than three times the notifications involving dementia in 2012 (42 cases)). These cases were in the absence of any other condition justifying euthanasia.⁵⁶⁸

- 3.58. A study by Kim et al found that persons receiving euthanasia or physician-assisted suicide in the Netherlands for psychiatric disorders were mostly women with complex and chronic psychiatric, medical and psychosocial histories, and disagreements about patient eligibility among physicians was not unusual. Euthanasia and physician-assisted suicide proceeded with the disagreements unresolved for most cases.⁵⁶⁹

The rise of private organisations involved in offering euthanasia to patients deemed ineligible by their physician

- 3.59. Kim et al note the emergence in 2012 of the ‘End-of-Life Clinic’ (Levenseindekliniek) in Netherlands, who provide euthanasia and physician-assisted suicide (EAS) to patients whose own physician has declined to perform EAS. The End-of-Life Clinic consists of mobile teams made up of a physician and a nurse funded by Right to Die NL (Nederlandse Vereniging voor een Vrijwillig Levenseinde, the Dutch association for a voluntary end of life).⁵⁷⁰
- 3.60. The End-of-Life Clinic are increasingly involved in the assisted suicide of persons suffering from psychiatric illness. End-of-Life Clinic cases represented 1 of 12 cases in 2012, 6 of 32 cases in 2013, and 8 of 16 cases in 2014.⁵⁷¹ By 2016, more than half (37) of the 60 cases of euthanasia for psychiatric disorders in 2016 were carried out by doctors from the End-of-Life Clinic.⁵⁷²

The ‘tired of life’ argument currently underway

- 3.61. Paul Appelbaum, Chair of the World Psychiatric Association’s ethics committee, criticises the risk that euthanasia for psychiatric illness presents, ‘inducing hopelessness among other individuals with similar conditions and removing pressure for an improvement in psychiatric and social services.’⁵⁷³
- 3.62. Theo Boer, ethicist and former supporter of euthanasia in the Netherlands, gave evidence to the AMA(WA) in their recent Symposium on end of life choices that suicide

568 Regionale Toetsingscommissies Euthanasie, Jaarverslag 2016 at 12, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 7.

569 Kim et al (2016) ‘Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014,’ *JAMA Psychiatry* 73(4) 362-368 at 365.

570 Ibid at 363.

571 Ibid at 365.

572 Regionale Toetsingscommissies Euthanasie, Jaarverslag 2016 at 15, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 7.

573 Paul S Appelbaum (2016) ‘Physician-Assisted Death for Patients With Mental Disorders – Reasons for Concern,’ *JAMA Psychiatry* 73(4) 325-326.

Chapter 3

has been normalised in the Netherlands, and as such, there has been an increase in the suicide rate in that country when compared with the similar jurisdiction of Germany, where euthanasia is not legalised.⁵⁷⁴

- 3.63. In October 2016, the Minister for Health and Minister for Justice in the Netherlands began promoting that all elderly people who are ‘tired of living’ should be offered medical assistance to die. In support of the proposal, Health Minister Edith Schipper outlined how beneficial it is for many elderly people to die, as compared to continuing to live.⁵⁷⁵ Legislators in the Netherlands are proposing a ‘Completed Life Bill’ that would allow anybody age 75 years or older to be euthanised, even if they are healthy.⁵⁷⁶
- 3.64. Dr Nitschke gave evidence to the Committee that this is logically where the debate will go in Western Australia, and welcomes the opportunity for such debate:

I want to see a debate held about a ‘tired of life’ argument such as we are seeing here in the Netherlands. Should every person over a certain age be issued with those drugs? That is where the debate will go. I am predicting that. It will happen even in Western Australia and other Australian states, because that is where the debate around the world is heading.⁵⁷⁷

An erosion of medical standards in the care of the terminally ill

- 3.65. Government-sanctioned studies suggest an erosion of medical standards in the care of terminally ill patients in the Netherlands where 50 per cent of Dutch cases of assisted suicide and euthanasia are not reported, more than 50 per cent of Dutch physicians feel free to suggest euthanasia to their patients, and 25 per cent of these physicians admit to ending patients’ lives without their consent (more than 1000 people each year).⁵⁷⁸
- 3.66. Lord McColl of Dulwich, in evidence to the House of Lords, stated:

My first experience of the Dutch euthanasia law occurred when I visited the Netherlands as a member of the Select Committee on Medical

574 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 3-4 and at 8.

575 Stahle F (2017) ‘Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,’ *Journal of Ethics in Mental Health* 10 at 4.

576 Dwight Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices, included in JSCEOLC Response to Questions on Notice, 17 April 2018 at 5.

577 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 8.

578 The Committee to Study the Medical Practice Concerning Euthanasia (1991) *Medical decisions about the end of life*, The Hague, Vols 1 and 2, 1 September 1991; and Hendin, H (2004) ‘Commentary: the case against physician-assisted suicide: for the right to end-of-life care’ *Psychiatric Times* 21(2) <<http://www.psychiatrictimes.com/geriatric-psychiatry/commentary-case-against-physician-assisted-suicide-right-end-life-care>> cited in Golden and Zoanni (2010) ‘Killing Us Softly: The Dangers of Legalizing Assisted Suicide,’ *Disability and Health Journal* 3(1) 16-30 at 27.

*Ethics, chaired by the noble Lord, Lord Walton of Detchant. The Dutch doctors told us: “We agonised over our first case of euthanasia all day, but the second case was much easier and the third was a piece of cake.” We found that rather chilling.*⁵⁷⁹

- 3.67. Boudewijn Chabot, the psycho-geriatrician and prominent euthanasia supporter involved in the *Chabot* case in 1994 which saw Dutch law extended to allow euthanasia for psychiatric illness, said very recently that things are ‘getting out of hand... look at the rapid increase... The financial gutting of the healthcare sector has particularly harmed the quality of life of these types of patients. It’s logical to conclude that euthanasia is going to skyrocket.’⁵⁸⁰
- 3.68. Of physicians in the Netherlands, 15 per cent have expressed concern that economic pressures may prompt them to consider euthanasia for some of their patients, with a case already cited of a dying patient who was euthanised to free a hospital bed.⁵⁸¹

The Regional Euthanasia Review Committees and their permissive findings

- 3.69. Not only is the continual extension of the law in the Netherlands of concern, there has also been an increasing tolerance toward transgressions of the law with almost all decisions by the Regional Euthanasia Review Committees (RTE) finding in favour of the medical practitioner that due care criteria have been met, even in the most grievous of cases. These cases reveal an increasing tolerance toward transgressions of the law and a change in societal values toward assisted suicide after legalisation.
- 3.70. In the first four years after the euthanasia law came into effect in the Netherlands, 16 cases (0.21 per cent of all notified cases) were sent to the judicial authorities, few were investigated, and none were prosecuted. In one case, a counsellor who provided advice to a non-terminally ill person on how to suicide was acquitted.⁵⁸²
- 3.71. Only one of 110 psychiatric EAS cases reported to the RTE during 2011 to 2014 did not meet the due care criteria. Four of the 5306 EAS cases (0.1 per cent) in 2014 were judged as not meeting the due care criteria.⁵⁸³ Such a statistic could be cited as evidence of the success of the Dutch laws and the adherence of medical practitioners to due care criteria.

579 Lord McColl of Dulwich, *Hansard*, House of Lords, 6 May 1998, Vol 589 cc707-26 (emphasis added).

580 Boudewijn Chabot quoted by Dwight Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices, included in JSCEOLC Response to Questions on Notice, 17 April 2018 at 5.

581 George, Finlay and Jeffrey (2005) ‘Legalised euthanasia will violate the rights of vulnerable patients’ *BMJ* 331, 684–5, referenced in Pereira J (2011) ‘Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,’ *Current Oncology* 18(2), 38-45 at 42.

582 Pereira J (2011) ‘Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,’ *Current Oncology* 18(2), 38-45 at 40.

583 Kim et al (2016) ‘Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014’ *JAMA Psychiatry* 73(4) 362-368 at 367.

Chapter 3

However, the retrospective oversight system in the Netherlands generally defers to the judgments of the physicians who perform and report euthanasia and physician-assisted suicide.⁵⁸⁴ Further consideration of the cases involved reveals that the review process favours medical practitioners and like the Dutch laws themselves, the approach of the RTE has broadened the scope of acceptable practice on a case by case basis.

- 3.72. Among all 110 psychiatric cases reported to the RTE, the RTE found that the due care criteria were not met in only one patient, a woman (case 2014-01) in her 80s with chronic depression who sought help from the End-of-Life Clinic. The clinic physician met with her twice (the first time was 3 weeks before her death), and the patient was not alone on both occasions, with family members present. The physician was not a psychiatrist, did not consult psychiatrists, was unaware of the Dutch Psychiatric Association Guidelines, and yet 'had not a single doubt' about the patient's prognosis. The consultant in the case, a general practitioner, agreed with the physician that all due care criteria were met.⁵⁸⁵
- 3.73. In another case, the RTE was critical yet judged that the physician acted with due care. The patient (case 2013-27) had attempted suicide, which led to a broken thigh. The patient refused all treatments and requested EAS. The RTE was 'puzzled' by the fact that this physician 'complied with the patient's [EAS] wish almost at once' and criticised the physician for prematurely opting for the EAS evaluation because the RTE could 'not exclude the possibility that the patient might yet have accepted treatment.' However, the RTE ultimately decided that the case met the due care criteria 'at the moment' the euthanasia was implemented.⁵⁸⁶
- 3.74. What of those cases where a finding against the medical practitioner was made, where it was held that due care criteria had not been met? In case 15 of the *2011 Annual Report*, the RTE conclude that the attending physician failed to achieve an accurate diagnosis of the woman's back pain and only prescribed limited pain relief medication. Consequently it could not be said that the woman's pain was definitively unrelievable. Of course the woman can get no relief from this finding of error on the part of the doctor, who failed her and then euthanised her, as she is already dead by euthanasia.⁵⁸⁷ The same lack of remedy applies to the two cases of people with dementia who were euthanised in 2012 in relation to which the Review Committees found 'not to have been handled with due care.'⁵⁸⁸ In Case 2015-01 the RTE found a lack of due care before euthanasia was carried

584 Ibid.

585 Ibid at 366.

586 Ibid.

587 Regional Euthanasia Review Committees, *Annual report 2011* at 17 cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 26.

588 Regional Euthanasia Review Committees, *Annual report 2012* at 13 cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 26.

out on a woman with a history of stomach pains from an undiagnosed cause, who was reluctant to be examined by a geriatrician. No further action was taken on this case.⁵⁸⁹

- 3.75. Criminal investigations into five cases of euthanasia in the Netherlands have been launched since March 2018, after a sharp rise in the number of physician-assisted deaths.⁵⁹⁰ Two deaths being examined by the prosecutor in the Noord-Holland province involve a doctor employed by the End-of-Life Clinic. It is claimed that a 67-year-old woman, who lacked the capacity to express her own will because of Alzheimer's, was euthanised in May 2017 despite the physician being unable to ascertain whether the request for death was voluntary and deliberate. In a second case, an 84-year-old woman was euthanised in June 2017 after claiming her life was 'hopeless' because of several physical illnesses. It has been suggested that this was not sufficiently proven to be case.
- 3.76. The public prosecutor in Oost-Nederland is also investigating the euthanasia of a 72-year-old woman in April 2017 who had metastasised cancer but lapsed into a coma, which circumstance the RTE determined left the physician unable to ascertain that the decision for euthanasia was voluntary and well-considered. In the fourth case, which is being investigated in The Hague, a euthanasia request from an 84-year-old woman was granted in February 2017 after the patient complained that her freedom of movement had been 'very much restricted' by pulmonary emphysema. It has been claimed the physician concluded too easily that the suffering of the patient was hopeless.⁵⁹¹
- 3.77. The fifth case involves the euthanasia of an elderly woman suffering from Alzheimer's disease who was physically restrained by family while euthanasia was administered by a physician. In Case 2016-85 the RTE found that the doctor involved had not acted with due diligence in administering euthanasia to a woman with Alzheimer's disease. The woman had made a general reference in a living will to wanting euthanasia 'whenever I think the time is right.' Later, the patient said several times in response to being asked if she wanted to die: 'But not just now, it's not so bad yet!' At the time the doctor euthanised the patient she was unable to voluntarily request euthanasia as she had lost capacity. The doctor gave evidence to the RTE that she was fulfilling a written request the patient had made for euthanasia years before and that since the patient was not competent, nothing the woman said during her euthanasia procedure was relevant. The

589 Regionale Toetsingscommissies Euthanasie, Jaarverslag 2015 at 28-31, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 27.

590 Daniel Boffey, 'Dutch prosecutors to investigate euthanasia cases after sharp rise,' *The Guardian*, 12 March 2018; Maria Cheng, 'Dutch probe 'appalling' euthanasia of dementia patient,' *Medical Xpress*, 20 April 2018.

591 Daniel Boffey, 'Dutch prosecutors to investigate euthanasia cases after sharp rise,' *The Guardian*, 12 March 2018.

Chapter 3

RTE found that even if the patient had said at that moment ‘I don’t want to die,’ the doctor would have continued.⁵⁹²

- 3.78. In Case 2016-85, the doctor had put medication into the patient’s coffee to reduce her consciousness deliberately so as to avoid her resisting being given the euthanasia drugs. Nonetheless she struggled against the administration of an intravenous lethal injection and was physically restrained by family members while the doctor completed the administration of the lethal drugs. The RTE found that given the clear signs that the patient was struggling to protest her death, the doctor should have stopped. On the morning of the euthanasia, when her family was present, the patient was even making plans to go out to eat with them.⁵⁹³
- 3.79. The outcome in these five cases remains to be seen. Whatever the outcome it will be of no comfort to the respective patients.

‘Don’t go there’

- 3.80. In reviewing the Dutch experience, Dr Khorshid of the AMA(WA) gave the following evidence to the Committee:

probably the most poignant individual comment from the whole symposium was that of Theo Boer. When Dr Noonan asked him what was his advice to AMA WA in this debate, he said that if he looked in the bottom of his heart, he would say, “Don’t go there.” This is the position of somebody who has been a supporter and who is an ethicist and has thought a lot about it and had a lot of experience, but he has seen, I guess, a liberal model and the damage that has done to his society. That is not necessarily a widely held view in the Netherlands. I know there would be a lot of very strong supporters of what happens in the Netherlands. But someone who has thought about it deeply and been deeply involved has said to us, be very, very careful, and I think we should heed that message.⁵⁹⁴

- 3.81. The evidence considered in this section on the Dutch experience, from government, peer-reviewed and wider sources, should give the Western Australian Parliament pause before considering the legalisation of assisted suicide in Australia. Proponents suggest that there is no evidence of abuse in this jurisdiction, but that is plainly false. This

592 Regionale Toetsingscommissies Euthanasie, Jaarverslag 2016, p. 54-58 <<https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2016/april/12/jaarverslag-2016/RTEjv2016.pdf>>; Regional Euthanasia Review Committees Annual Report 2016 https://english.euthanasiecommissie.nl/binaries/euthanasiecommissie-en/documents/publications/annual-reports/2002/annual-reports/annual-reports/RTE_annual_report_2016.pdf>

593 Ibid.

594 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 8.

evidence shows that we should heed Professor Theo Boer's expert advice and reject the legalisation of assisted suicide in this State.

Finding 75

In 1973, Dutch courts interpreted a defence of necessity to permit a doctor to avoid liability for euthanasia and assisted suicide by pointing to his or her duty to reduce suffering or to respect the autonomy of the patient.

Finding 76

After 1973, Dutch courts elaborated on their interpretation of a doctor's defence of necessity, incrementally increasing the scope of practice of euthanasia in the Netherlands, including for psychiatric illness, albeit restricted to adults only.

Finding 77

In 2001 the Netherlands passed statutory law to fit the existing practice of euthanasia but extended it to allow for children as young as 12 to be euthanised subject to parental consent (even in the presence of disagreement between parents).

Finding 78

In 2005, the Netherlands endorsed the Groningen Protocol to further extend the practice of euthanasia to younger children, including newborns.

Finding 79

Consistent with the Northern Territory experience, assisted suicide in the Netherlands takes place notwithstanding disagreement amongst physicians about patient eligibility.

Finding 80

Doctor shopping in the Netherlands has now become commercialised by the emergence of at least one private organisation who will provide assisted suicide to patients whose own physician has declined.

Finding 81

The latest frontier in the Netherlands is a debate on whether assisted suicide should be extended to those who are 'tired of life.'

Finding 82

In the Netherlands in 2011, the Regional Euthanasia Review Committee found that the attending physician failed to accurately diagnose the patient's back pain.

Finding 83

In the Netherlands in 2012, the Regional Euthanasia Review Committee found that two cases of patients with dementia were not handled with due care.

Chapter 3

Finding 84

In the Netherlands in 2013, an assisted suicide took place of a patient who had a broken thigh following an attempted suicide.

Finding 85

In the Netherlands in 2014, the assisted suicide of a woman over 80 years of age with chronic depression took place on the certification of a physician who was not a psychiatrist, who did not consult psychiatrists and was unaware of the Dutch Psychiatric Association Guidelines.

Finding 86

In the Netherlands in 2015, the Regional Euthanasia Review Committee found a lack of due care on a euthanasia carried out on a woman with a history of stomach pains from an undiagnosed cause.

Finding 87

In the Netherlands in March 2018, criminal investigations were confirmed as having been launched into four cases of euthanasia in 2017.

Finding 88

The defence of necessity also exists in Western Australian common law. It has, however, been expressly excluded as a defence to both homicide and euthanasia.

Finding 89

The experience observed of assisted suicide in the Netherlands demonstrates an incremental extension in the practice of assisted suicide, the commercialisation of doctor shopping, and the reality that no redress is available when safeguards inevitably fail.

Recommendation 14

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Netherlands experience.

The European Experience—Belgium

Amendment of the law to extend euthanasia to children

- 3.82. In May 2002, the Belgian parliament approved a law on euthanasia, hereafter referred to as the Euthanasia Act 2002.⁵⁹⁵ This Act allowed for the euthanasia of patients in ‘constant and unbearable physical or mental suffering that cannot be alleviated.’ Minors

595 Actes parlementaires du Sénat de Belgique 2001–2002, Bruxelles, 2002; number 2–244/26.

were included in the original proposals but removed from the final legislation in the face of political opposition.⁵⁹⁶

- 3.83. In February 2014 Belgium amended its law to extend the right to request euthanasia to terminally ill children. Belgium is the only jurisdiction to have legislatively removed all reference to an age restriction (in the Netherlands, by comparison, children must, in theory by statute law, be over the age of 12). This amendment permits children of any age to request euthanasia provided that they understand the consequences of their decision as verified and certified by a child psychiatrist or psychologist. The child must be in a 'medically futile condition of constant and unbearable physical suffering that cannot be alleviated and that will result in death in the short term' and, although no age restriction is given, the child must also display the 'capacity of discernment' and be 'conscious at the moment of making the request.'⁵⁹⁷
- 3.84. It was noted at the time of the amendment's passage that 'for a society, like Belgium, which tolerates euthanasia in certain defined circumstances already, to deny children with capacity the same opportunities to end their suffering humanely, to the same extent as their older contemporaries, must surely be as unjust as it is discriminatory.'⁵⁹⁸

Euthanasia for psychiatric illness

- 3.85. Like the Netherlands, Belgium also allows euthanasia for people diagnosed with mental illness. A 2015 report investigating the deaths of 100 people by euthanasia for mental illness found that women are more vulnerable to being killed for their poor mental health in Belgium. Of the 100 cases, 11 patients were under 30 years of age (with the average age of death in the cohort being 47 years). The conditions for which requests were considered included: depression, bipolar, schizophrenia, Asperger's syndrome (19 cases); post-traumatic stress disorder; complicated grief; eating disorders; obsessive-compulsive disorders; anxiety; and attention deficit hyperactivity disorder.

*In total, 48 of the 100 patients' euthanasia requests were accepted (48%), because [the psychiatrist], in discussion with the patients' other practitioners and families, considered the requests to be based on reasons that were sufficiently tangible and reasonable, and because all legal requirements had been fulfilled.*⁵⁹⁹

596 Chandrika Narayan, 'First child dies by euthanasia in Belgium,' *CNN*, 17 September 2016.

597 Euthanasia Act 2002, section 3§1.

598 Samanta J (2015) 'Children and euthanasia: Belgium's controversial new law,' *Diversity and Equality in Health and Care* 12(1) 4-5.

599 Thienpont et al (2015) 'Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study,' *BMJ Open* 5:e007454, quoted in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 9.

Chapter 3

- 3.86. A total of 124 people were killed by euthanasia in Belgium in 2014 and 2015 for mental and behavioural disorders, including depression (41); dementia (36); borderline personality disorder (14); bipolar disorder (9); obsessive-compulsive disorder (5); personality disorder (3); post-traumatic stress disorder (1); psychosis (1); schizoaffective disorder (1); and anorexia (1).⁶⁰⁰ This figure of 124 people euthanised for mental and behavioural disorders in Belgium in 2014 and 2015 represents 3.1 per cent of all euthanasia cases in Belgium in that time period (3,950 total cases).⁶⁰¹
- 3.87. Euthanasia was even approved for a 24-year-old woman in Belgium, known as Laura, on the sole grounds of her mental suffering based on suicidal ideation.⁶⁰² Where euthanasia for ‘unbearable psychological suffering’ is legal, psychiatrists are tasked both with preventing suicide, and acting as gatekeepers to euthanasia.⁶⁰³ The approval of euthanasia for suicidal ideation is of deep concern. Dr Paul Appelbaum, Chair of the World Psychiatric Association’s ethics committee, asks ‘Will psychiatrists conclude from the legalisation of assisted death that it is acceptable to give up on treating some patients?’⁶⁰⁴
- 3.88. Mr Charles Lane suggests that some doctors already have given up on treating their patients. He cites the example of Tine Nys in Belgium. In 2009, 37-year-old Ms Nys became distraught after a romantic breakup and began seeking the assistance of a doctor to euthanise her. Ms Nys had a history of mental illness, including a teenage suicide attempt, but had been doing well more recently. In February 2010 she received a diagnosis of autism, and two months later was administered with a lethal injection.⁶⁰⁵
- 3.89. Belgian mental health professionals, ethicists and physicians have published a call to ban euthanasia for the mentally ill. As of 10 July 2018, the ‘Review Belgian Euthanasia Law for Psychic Suffering’ (REBEL) petition contained the signatures of 252 Belgian clinicians against the practice.⁶⁰⁶

600 Federale Controle- en Evaluatiecommissie Euthanasie, Zevende verslag aan de Wetgevende Kamers (2014 – 2015), 7 Oct 2016 at 8 and 38, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 8-9.

601 Dwight Randal, President, Coalition for the Defence of Human Life, JSCEOLC Response to Questions on Notice, 17 April 2018 at 2.

602 ‘Healthy Woman Will Die By Doctor-Assisted Euthanasia Over Suicidal Thoughts,’ *Inquisitor*, 24 June 2015, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 8.

603 Jamie Hale, ‘We’re told we are a burden. No wonder disabled people fear assisted suicide,’ *The Guardian*, 1 June 2018.

604 Paul S Appelbaum (2016) ‘Physician-Assisted Death for Patients With Mental Disorders – Reasons for Concern,’ *JAMA Psychiatry* 73(4) 325-326.

605 Charles Lane, ‘Doctors Decided Man With Autism Couldn’t Be Treated So They Euthanised Him,’ *LifeNews*, 19 June 2018.

606 ‘Review Belgian Euthanasia Law for Psychic Suffering,’ (REBEL) <<https://www.rebelpsy.be>>

Polypathology

- 3.90. Section 3.1 of Belgium’s Act on Euthanasia prescribes that the patient be ‘in a medically futile condition... resulting from a serious incurable disorder caused by illness or accident.’ The evidence from Belgium is that this phrase is capable of very broad application and a new category of ‘polypathology’ has arisen for which patients can request euthanasia. In 2015 there were 299 cases of reported euthanasia for non-terminal conditions (14.8 per cent of all cases). These cases included 107 cases of ‘polypathology’ where death was not expected soon and there was no particular major illness or disorder, as well as 57 cases of mental or behavioural disorders. Additionally there was one case of euthanasia for a congenital abnormality or chromosomal disorder.⁶⁰⁷
- 3.91. The Euthanasia Evaluation and Control Commission describes ‘polypathology’ as including situations where mobility difficulties, increasing deafness or loss of vision have led to loneliness, social isolation or a decreased ability to engage in various activities as sufficient justification for euthanasia. Urinary or fecal incontinence, described as a loss of dignity, is also mentioned in this context.⁶⁰⁸
- 3.92. Belgium’s euthanasia law has been broadly interpreted to allow for the euthanasia of a victim of sexual abuse, the euthanasia of a patient suffering from gender dysphoria and even the preliminary approval of euthanasia for an inmate as an alternative to life imprisonment:

In late 2012 a 44 year old woman known as Ann G was euthanased by her psychiatrist on the grounds of unbearable psychological suffering. She had been treated for anorexia since her teenage years by psychiatrist Walter Vandereycken. In 2008 she publicly accused Vandereycken of sexual abusing her under the guise of therapy. In October 2012 he admitted to years of sexual abuse of several of his patients. Following this admission Ann G spoke of some temporary relief from “the cancer in her head” but subsequently persisted in her request for euthanasia.⁶⁰⁹

On 30 September 2013 Nathan Verhelst was euthanased on the grounds of unhappiness following a sex change operation. Nathan (previously known as Nancy) had been rejected by a family who hated girls. Commenting on the euthanasia Nathan’s mother said: “When I saw

607 Federale Controle- en Evaluatiecommissie Euthanasie, Zevende verslag aan de Wetgevende Kamers (2014 – 2015), 7 Oct 2016 at 10, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 19.

608 Ibid at 28, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 20.

609 ‘Patiënte van psychiater Vandereycken krijgt euthanasia’ *De standard*, 28 January 2013, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 20.

Chapter 3

*'Nancy' for the first time, my dream was shattered. She was so ugly. I had a phantom birth. Her death does not bother me.*⁶¹⁰ *The doctors who approved and carried out euthanasia on Nathan Verhelst effectively affirmed the rejection Nathan had experienced since childhood.*⁶¹¹

*On 15 September 2014 the Brussels Court of Appeal decided that Frank Van Den Bleeken, who has been detained since the 1980s as a mentally impaired man accused of rape and murder, could legally request euthanasia as an alternative to life in prison.*⁶¹² *His euthanasia was scheduled for 11 January 2015 but was halted after the doctors treating him decided not to go ahead with it.*⁶¹³

- 3.93. It has also been considered in Belgium whether euthanasia should be available to a man who had requested euthanasia on the grounds of his sexual attraction to men:

*In June 2016 the BBC interviewed a 39 year old Belgian man, known as 'Sebastien,' who was in the process of being assessed for euthanasia on the grounds of his sexual attraction to men which he said he had never accepted and found unbearable. The outcome of his assessment has not been reported. However, Gilles Genicot, a member of Belgium's Federal Euthanasia Evaluation and Control Commission, commented "It's more likely he has psychological problems relating to his sexuality. I cannot find a trace of actual psychic illness here. But what you cannot do is purely rule out the option of euthanasia for such patients. They can fall within the scope of the law once every reasonable treatment has been tried unsuccessfully and three doctors come to the conclusion that no other option remains."*⁶¹⁴

- 3.94. It is also alarming to note that the Belgian Society of Intensive Care have endorsed doctors' participation in actively shortening the dying process using sedatives 'in the absence of discomfort.'⁶¹⁵

610 Bruno Waterfield 'Mother of sex change Belgian: "I don't care about his euthanasia death,"' *The Telegraph* 2 October 2013, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 20.

611 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 20.

612 'Belgian murderer Van Den Bleeken wins "right to die,"' *BBC News Europe* 15 September 2014, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 21.

613 'Belgian rapist Van Den Bleeken refused "right to die,"' *BBC News Europe* 6 January 2015, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 21.

614 Jonathan Blake 'Man seeks euthanasia to end his sexuality struggle,' *BBC News* 9 June 2016, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 20-21.

615 Sprung et al (2018) 'Physician-Assisted Suicide and Euthanasia: Emerging Issues from a Global Perspective' *Journal of Palliative Care* sagepub.com/journalsPermissions.nav DOI:

Use of life-ending drugs without explicit request

- 3.95. In a 2010 study, Chambaere et al studied the incidence of the use of life-ending drugs without an explicit request from the patient and note that this occurred in 1.8 per cent of all deaths in Flanders in the study period.⁶¹⁶ In cases where the decision to administer euthanasia was not discussed with the patient, the physician specified that the reason it was not discussed with the patient was because the patient was comatose (70.1 per cent of cases) or had dementia (21.1 per cent of cases). Physicians specified that the decision had not been discussed with the patient because the decision was in the patient's best interest (17 per cent) or because discussion would have been harmful (8.2 per cent). Compared with voluntary euthanasia or assisted suicide explicitly requested, pain and the patient's wish for ending life were more often reasons for carrying out euthanasia or assisted suicide, whereas family burden and the consideration that life was not to be needlessly prolonged were more often reasons for using life-ending drugs without explicit patient request (or non-voluntary euthanasia).⁶¹⁷
- 3.96. Mr Denton takes issue with the characterisation of 'the use of life-ending drugs without explicit patient request' as non-voluntary euthanasia. He suggests that the data is influenced by the possibility that many of these actions could have been the administration of palliative sedation to a patient at end of life, a standard palliative care practice.⁶¹⁸ This is not supported by evidence from the report itself, where it clearly states that life-ending drugs were administered to kill the patient without the patient's explicit consent. Palliative sedation does not involve the administration of life-ending drugs to kill the patient, as has already been outlined earlier in this Report.
- 3.97. Chambaere et al note that voluntary euthanasia and assisted suicide were typically performed in younger patients, patients with cancer and patients dying at home which was consistent with findings from other studies. They found that the use of life-ending drugs without explicit patient request occurred predominantly in hospital settings and among patients 80 years of age or older who were in a coma or had dementia, with the authors concluding that this cohort of people could be described as 'vulnerable' patient groups at risk of life-ending without request.⁶¹⁹ Nurses were more often involved in the administration of the drugs when there was no explicit request from the patient than in cases of voluntary euthanasia or assisted suicide.⁶²⁰

10.1177/0825859718777325 4 – citing Vincent et al (2014) "“Piece” of mind: end of life in the intensive care unit statement of the Belgian Society of Intensive Care Medicine,' *J Crit Care* 29(1) 174-5.

616 Chambaere et al (2010) 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey,' *CMAJ* 182(9) 895-901.

617 Ibid.

618 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 6. Part E 17.

619 Chambaere et al (2010) 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey,' *CMAJ* 182(9) 895-901.

620 Ibid.

Chapter 3

- 3.98. The authors note that the use of life-ending drugs without a patient's explicit request occurred more often in Flanders, Belgium, than in other countries, including the Netherlands. They suggest that Flemish physicians have been shown to be more open to this practice than physicians elsewhere, suggesting a larger degree of paternalistic attitudes. The authors note that the occurrence of this practice has not increased since legalisation, and that the rate has in fact dropped slightly, in line with a similar reduction in the Netherlands. They conclude however that although legalisation of euthanasia seems to have had an impact, more efforts are needed to further reduce the occurrence of life-ending drug use without an explicit request from the patient in Belgium.⁶²¹

Euthanasia and palliative care in Belgium

- 3.99. Requests by the Belgian palliative care community at the time of drafting the Belgian euthanasia laws to include an obligatory palliative care consultation ('palliative filter') were denied. From 2002 to 2007 in Belgium, a palliative care physician was consulted (as a second opinion) in only 12 per cent of all cases of euthanasia. Palliative care physicians and teams were not involved in the care of more than 65 per cent of cases receiving euthanasia. Moreover, the rates of palliative care involvement have been decreasing. In 2002, palliative care teams were consulted in 19 per cent of euthanasia cases, but by 2007 such involvement had declined to 9 per cent of cases. Pereira suggests that this finding contradicts claims that legalisation in Belgium has been accompanied by significant improvements in palliative care.⁶²²
- 3.100. Pereira notes that a network of physicians trained to provide the consultation role when euthanasia is sought in Belgium has been established, and is known as the Life End Information Forum (leif). Their role includes ensuring that the person is informed of all options, including palliative care. However, Pereira notes that most leif physicians have simply followed a 24-hour theoretical course, of which 3 hours are related to palliative care, which is hardly sufficient to enable a leif member to provide the adequate advice on a patient's complex palliative care needs.⁶²³

Finding 90

Similar to the Netherlands, Belgium allows assisted suicide for patients diagnosed with a mental illness.

Finding 91

The abuse of practice in Belgium, including approval on the grounds of suicidal ideation, has led to at least 252 Belgian clinicians calling for a review of the law on assisted suicide.

621 Ibid.

622 Pereira J (2011) 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,' *Current Oncology* 18(2) 38-45.

623 Pereira J (2011) 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,' *Current Oncology* 18(2) 38-45.

Finding 92

In Belgium in 2012, a 44-year-old woman was euthanised by her psychiatrist on the grounds of unbearable psychological suffering notwithstanding her history of sexual abuse by a psychiatrist under the guise of therapy.

Finding 93

In Belgium in 2013, an adult male who had undergone gender reassignment surgery was euthanised on the grounds of unhappiness, notwithstanding that the patient's family had rejected him from birth due to his female biology.

Finding 94

Belgian physicians the subject of a peer-reviewed study in 2010 confirmed the use of life-ending drugs without an explicit request from the patient, including because they considered discussion would have been harmful or because they considered the decision was in the patient's best interest.

Finding 95

The experience observed of assisted suicide in Belgium demonstrates an extension in the law and practice of assisted suicide, the inadequacies of safeguards and the undeniable reality that no redress is available to patients after the event.

Recommendation 15

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Belgian experience.

The European Experience—Switzerland

- 3.101. The Committee sought out the opinions and experience of Mr Minelli, founder of Dignitas, Switzerland, and Mr Luley, Dignitas Board Member. Mr Minelli and Mr Luley were in fact some of the few people called upon by the Committee to give evidence in two separate hearings.
- 3.102. Dignitas operates under a unique legalisation model. Jurisdictions with legalised assisted suicide usually have prescribed safeguards in place, restricting eligibility and requiring consultations with physicians. In Switzerland, however, the penal code allows for a person to assist another to suicide by omission. The *Swiss Criminal Code 1937* Article 115 reads:

Inciting and assisting suicide—Any person who for selfish motives incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty.

Chapter 3

- 3.103. Prosecution can only occur where selfish motive can be proved, or where doubt is raised as to a person's competence to make an autonomous choice to suicide.
- 3.104. In the absence of legislation, the practice of assisted suicide in Switzerland is unregulated and has been extended from the terminally ill to the very ill facing extreme suffering, to the elderly suffering the effects of old age or a combination of illnesses and to those who are physically healthy.⁶²⁴
- 3.105. Mr Luley confirmed that by law, assisted suicide can be offered to anyone:

Hon NICK GOIRAN: That is very helpful. So there have never been any restrictions in Switzerland with regard to access to this. I think it is the case that some people have sought assisted suicide, or accompanied suicide, in Switzerland but been refused. Is that true?

Mr LULEY: Yes, because it is in the free decision of a medical practitioner—a physician—to decide whether he wants to give access to assisted dying; whether he wants to write a prescription for the pentobarbital or not. As you can guess, every medical doctor, when a perfectly healthy person and a mentally healthy person would come and would say, "I want to have an accompanied suicide," and the doctor would say, "What's wrong with you? You probably are in a life crisis. You certainly need treatment, but you don't need an assisted suicide. Let's talk about this first and see how we can improve your quality of life so you can get back on track." No Swiss doctor would ever write a prescription for [indistinct]. Theoretically, by law—just theoretically—the doctor could do so. He might get into conflict with the professional board of medical doctors, he might get into conflict with some, let us say, ethics committees or whatever, but based simply on the law a doctor could do so, but it would be against any logic to do that. It is the same for us as an organisation. It might sound provocative to you, but we at Dignitas could do an accompanied suicide for someone who is perfectly healthy, who has no medical diagnosis whatsoever. The law would allow that, but it is understood that no—as long as the person of course has mental capacity—that is always the base; that is understood—but nobody would ever do that.⁶²⁵

624 Andreas Brunner, Zurich chief public prosecutor, quoted by Clare O'Dea in 'Finding a place for assisted suicide in society,' 9 July 2012 <http://www.swissinfo.ch/eng/dying-with-dignity_finding-a-place-for-assisted-suicide-in-society/32986262>

625 Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 9 April 2018, Session 2 at 4-5 (emphasis added).

- 3.106. Mr Luley suggested that the person must be ‘unhealthy’ in some way in order to be assisted to suicide in Switzerland, meaning that ‘there must be some sort of medical diagnosis, a certain severeness of suffering... Whether it is physical or mental health suffering, it does not matter. Both have the right to access assisted dying in Switzerland.’⁶²⁶
- 3.107. Mr Luley was asked by Hon Nick Goiran if there had ever been a case of an accompanied suicide of a healthy person by Dignitas, to which Mr Luley gave the reply ‘Never, ever.’⁶²⁷ This is intriguing since Italian magistrate Pietro d’Amico was euthanised in Switzerland after a wrong diagnosis from Italian and Swiss doctors. An autopsy conducted at the request of the deceased’s family revealed that he was not suffering from a life-threatening illness at the time of his death.⁶²⁸
- 3.108. That ‘suffering’ is also widely interpreted in Switzerland is clear in a statement made by Dr Nitschke to the Committee. Referring to the case of Dr Goodall, Dr Nitschke urged the Committee to consider endorsing the Swiss model here in Western Australia:

*I would urge the Western Australian Parliament to consider [the Swiss legislative model, which] allows for a person to say, “Look, I’ve reached the end of my very productive life and now is the time to die. In other words, it’s my right to have access to the best drugs.” In Switzerland [Dr Goodall] will get the best drugs. Now we are trying to work out the logistics of trying to get this very important person through the very difficult journey, of course, some many thousands of kilometres away. Unfortunately, the only option left in a country like Australia is that a person will have to go and die in a strange place.*⁶²⁹

Dignitas—helping people suicide

- 3.109. Mr Luley’s evidence that Dignitas would never assist in the suicide of a healthy person, despite the fact that this would be permitted under Swiss law, is contradicted by his own statement to the Committee that:

Dignitas is a human rights organisation with a human rights approach which puts the focus on where there is a right to life, there must also be a right to end your life when you want it for whatever reason... if you give the right to an extension of life and the right to end your life when you want to end it, then you automatically have to in a way include helping people who want to end their life out of good reason in a

626 Ibid at 5.

627 Ibid.

628 Mr Richard Egan, Defend Human Life!, JSCEOLC Submission 5 at 17, citing ‘Aided suicide in question after botched diagnosis,’ *The Local*, 11 July 2013.

629 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 3.

Chapter 3

*professional manner, to make sure that these people would not turn to violent methods, like jumping from a high building or going in front of a train.*⁶³⁰

- 3.110. Mr Luley goes further to suggest that a very open assisted suicide law that can be widely interpreted to include anyone, where ‘it does not matter whether they are in a life crisis or whether they have terminal cancer,’ is the best model for suicide prevention:

*In Oregon, the suicide rate has gone up—not much, but it has risen. Here in Switzerland, it has been decreasing. It is logic, from our point of view and our experience, because, quite simply, people who have a real choice and are professionally accompanied and are professionally counselled if they are a patient—it does not matter whether they are in a life crisis or whether they have terminal cancer—when they know they can turn to someone, maybe a physician, maybe an organisation like Dignitas, when they know they can talk openly about it, without [inaudible] and get advice, then they are much less at risk to turn to violent methods. So the best—it might sound provocative, but our experience is that the best suicide prevention and suicide attempt prevention that you can have is if you give as far as possible access to assisted dying, because people then know they can access professional help and have a choice and thus they do not have to turn to violent methods.*⁶³¹

- 3.111. Mr Luley’s words may be interpreted to mean that the suicides of these people were avoided because they were reassured by their ability to access assisted suicide through organisations such as Dignitas in Switzerland, and therefore did not turn to violent methods. That is, since they could be ‘professionally accompanied’ by an organisation like Dignitas, and ‘professionally counselled’ about suicide, they did not turn to suicide as they knew that assisted suicide would be an option for them if the time came.
- 3.112. An alternative interpretation of his words is, however, also open, particularly when read in the context of other statements made to the Committee and historically by Mr Minelli and Mr Luley. This is, that suicide by violent methods has decreased in Switzerland as people turn to organisations like Dignitas for assistance:

But here in Switzerland, where we definitely have a more progressive legal situation, which gives them more open-minded, more liberal and

630 Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 8 March 2018, Session 5 at 2.

631 Ibid at 7 (emphasis added).

*more people access to assisted dying, here the number of violent suicides, has decreased and, yes, the data is available publicly.*⁶³²

- 3.113. In a 2010 article in *The Atlantic*, Mr Luley is quoted as saying:

Suicide is not bad... There's nothing wrong with wanting to end your life. Sometimes life is great, sometimes life is shit. I have the right to say that I'm pissed off with my life, and I want to end it.

...

*Dignitas exists to prevent [failed suicide attempts], to see to it that those wishing to kill themselves may do so without fear of pain or failure. The fact that people lack legal access to a death like this is the group's organising principle.*⁶³³

- 3.114. Mr Minelli is also quoted as saying that suicide is 'the last human right' and is outspoken in his desire to do away with anything that might restrict the practice of assisted suicide. In an interview with the BBC, he went so far as to call assisted suicide 'a marvellous possibility given to a human being' to escape their suffering.⁶³⁴
- 3.115. It is very difficult to see how the 'professional accompaniment' and 'professional counselling' of Dignitas, in light of these statements by Mr Minelli and Mr Luley, could be said to deter people from suicide.
- 3.116. The 2015 Swiss suicide rate of 10.7 per 100,000 (male 15.5, female 6.0) published by the World Health Organisation reveals that the Swiss suicide rate is similar to the rates of neighbouring countries France and Austria, and is higher than that of Germany where the rate is 9.1 per 100,000 (male 13.9 and female 4.5).⁶³⁵
- 3.117. The raw, or non-standardised, Swiss suicide rate is somewhat higher. In 2014, 1,029 people committed non-assisted suicide (754 men and 275 women) for a rate of 12.5 per 100,000 (18.5 male, 6.6 female). This statistic does not include the 742 assisted suicides in that same year (320 men and 422 women).⁶³⁶

632 Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 9 April 2018, Session 2 at 3.

633 Falconer, Bruce 'Death Becomes Him' (2010) *The Atlantic*, March Issue
<<https://www.theatlantic.com/magazine/archive/2010/03/death-becomes-him/307916/>>

634 Ibid.

635 World Health Organization (2015) 'Suicide rate estimates, age-standardized Estimates by country' <<http://apps.who.int/gho/data/node.main.MHSUICIDEASDR?lang=en>>

636 Federal Statistical Office (2014) 'Cause of death statistics 2014: Assisted suicide and suicide in Switzerland,'
<<https://www.bfs.admin.ch/bfs/en/home/statistics/health.assetdetail.3902308.html>> and
Federal Statistical Office (2014) 'Switzerland's population 2014,'
<<https://www.bfs.admin.ch/bfs/en/home/statistics/population.assetdetail.349851.html>>

Chapter 3

- 3.118. The sheer volume of suicides (both assisted and non-assisted) ought to be of great concern.

Helium experimentation in Dignitas assisted suicides

- 3.119. Also of significant concern was evidence to the Committee that Dignitas experimented with helium as a means of death in the assisted suicides of a number of people when the organisation was unable to obtain lethal prescriptions from doctors at one stage.
- 3.120. Suicide organisations in Switzerland who only provide assisted suicide to Swiss residents often obtain lethal prescriptions from doctors who have known their patients for years and are intimately familiar with the details of their medical histories. Dignitas, whose clients are largely foreign, is unable to do so: the consulting physician does not typically have a long history with the person requesting assistance, and the physicians are compelled to make hurried decisions once the person has flown into the country. In 2007 this practice drew harsh criticism in the international press and in response, Zurich's chief physicians increased the requirement to two doctors' appointments. According to a report, Mr Minelli:

viewed it as a personal attack, and his response was as swift as it was extreme: a series of four 'demonstration' deaths using helium gas. The suicides gave Minelli the opportunity to experiment with new methods and served as a not-so-subtle reminder that, if necessary, he could continue on even without doctors and their sodium pentobarbital.⁶³⁷

- 3.121. Dignitas' experimentation was raised in evidence with Mr Minelli and Mr Luley in a Committee hearing by Hon Nick Goiran MLC:

Hon NICK GOIRAN: If it is such a good method, why do you not keep using it now?

Mr LULEY: Because it is very technical with—well, I do not want to talk about it now, because this is all public. You research it yourself, then you will realise how effective and how efficient and how easy it is. But it is a very technical method, and pentobarbital is a much simpler method, and more aesthetic. If you want to take this way with helium, you must work with a hood, or with a bag over your head, and so on and so on; you need the gas. Think of Europe, where we had the thinking with some older people, going back to the German Deutsches Reich—the Nazis—triggering ideas of that. We do not want to touch that. It works. No doubt about it, it works very well, but it is better not to use that method,

637 Falconer, Bruce 'Death Becomes Him' (2010) *The Atlantic*, March Issue
<<https://www.theatlantic.com/magazine/archive/2010/03/death-becomes-him/307916/>>

*not for medical or technical reasons [inaudible] with having perspective.*⁶³⁸

- 3.122. In 2010, Mr Minelli shared details of the helium experimentation with journalist Bruce Falconer, and confirmed that he was pleased with the result:

*I think it is the best method... But it is not nice to see... Muscles are agitated. Eyes open and close. Arms and legs twitch without coordination. And if you are not well informed, you might mistake this for a terrible struggle against death, which it is not. It's just the same as when you cut the head off a chicken.*⁶³⁹

- 3.123. Mr Minelli was never prosecuted for these deaths, as presumably the four people who died by helium experimentation had consented to assisted suicide by that method.

- 3.124. More recently, Mr Minelli defended a charge of profiteering. It was alleged that in 2010 Mr Minelli had charged a mother and daughter around 10,000 Swiss francs each for assisted suicide, instead of the usual cost of some 5,000 to 6,000 Swiss francs. In a second case, Mr Minelli was alleged to have taken advantage of an 80-year-old woman who was sick but not terminally ill. He approached four doctors before finally finding one who was willing to assist the woman to suicide. Prosecutors argued that his persistence in the second case was based on the fact that the woman had promised him a donation of 100,000 Swiss francs to Dignitas on her death. They also alleged that she had given Mr Minelli power of attorney, allowing him to transfer 46,000 Swiss francs to a Dignitas account when she died.⁶⁴⁰ Prosecutors also alleged that Mr Minelli had not honoured her request to have her ashes buried beside her husband in Germany, but had disposed of them in lake Zurich.⁶⁴¹ The charges of profiteering against Mr Minelli failed. With the high standard of proof in criminal cases, and the fact that the best witness was unavailable, it is no surprise that prosecutions were unsuccessful. This demonstrates the inherent difficulty in testing the integrity of a safeguard after the event. Meanwhile, redress for a victim is an impossibility after the event.

- 3.125. In light of the experience regarding Swiss assisted suicide law and its practice by Dignitas, the WA Parliament should reject the advice of Dr Nitschke. A Swiss model of assisted suicide should not be adopted in Western Australia.

638 Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 9 April 2018, Session 2 at 10.

639 Falconer, Bruce 'Death Becomes Him' (2010) *The Atlantic*, March Issue
<<https://www.theatlantic.com/magazine/archive/2010/03/death-becomes-him/307916/>>

640 'Head of Swiss assisted suicide group Dignitas in court on profiteering charges,' *The Local*, 18 May 2018.

641 Justin Huggler, 'Founder of Swiss assisted suicide organisation on trial for profiteering from his clients,' *The Telegraph*, 18 May 2018.

Chapter 3

Finding 96

Assisted suicide in Switzerland is based on a penal code that allows, by omission, for a person to assist another to suicide.

Finding 97

At least four assisted suicides in Switzerland have occurred while practitioners experimented with the use of helium, which results in agitated muscles, eyes opening and closing, and arms and legs twitching without coordination.

Finding 98

In Switzerland in April 2013, a retired Italian magistrate, aged 62, was assisted to suicide on the basis of a terminal illness diagnosed by Italian and Swiss doctors only for an autopsy to find no terminal illness.

Finding 99

The experience observed of assisted suicide in Switzerland underscores the inherent difficulty in testing the integrity of safeguards after the event whilst re-confirming the impossibility for redress by the victim after the event.

Recommendation 16

The Government and the Parliament of Western Australia should reject the advice of Dr Nitschke and rule out introducing an assisted suicide regime based on the Swiss model.

The North American Experience—Canada

- 3.126. In evidence to the Committee, Mr Walker of Dying with Dignity (WA) asserted that the Canadian model of legalised assisted suicide is workable, and one that should be considered for introduction here in Western Australia:

*Canada is surely a most useful parallel for us to consider; it is by no means a harebrained scheme. It has been adopted. It is working and we suggest it is the best model to follow.*⁶⁴²

- 3.127. A legislative assisted suicide model was introduced in Canada following the Supreme Court ruling in *Carter v Canada (Attorney General)*,⁶⁴³ which held that the current blanket prohibition on assisted suicide breached the right to life. This decision overturned the existing law made in the 1993 decision of the Court in *Rodriguez v Canada* in which the Court had held that the prohibition of assisted suicide in the Criminal Code was not contrary to the Canadian Charter of Rights and Freedoms. The court's 2015 reasoning

642 Mr Walker, Vice President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 4.

643 [2015] 1 SCR 133.

included that, where suicide is legally permitted but ‘assisted dying’ is not, some individuals may die earlier than they would if ‘assisted dying’ were permitted—that is, they may suicide before they would request assisted suicide because they fear losing the physical capacity to suicide unassisted and being trapped with no way out.⁶⁴⁴

Expansion of the model

- 3.128. It is interesting that Dying with Dignity WA recommend the Canadian model for adoption here in Western Australia, commending it as ‘the best model to follow,’ whilst implicitly criticising the model as more conservative than the Supreme Court’s determination allowed for in the *Carter* decision. Mr Walker states that ‘more litigation is going on in Canada now, seeking to challenge the conservative nature of the Canadian Act.’⁶⁴⁵
- 3.129. In June 2016, a Bill C-14 was passed in Canada’s Parliament to legalise and regulate assisted suicide in that country, or what is termed ‘Medical Assistance in Dying’ (MAID). The legislation specifies that a person must be facing a ‘reasonably foreseeable natural death,’ however within one year of Bill C-14’s passage through Parliament, the Supreme Court of Ontario had issued an interpretation of this provision that expanded the application of assisted suicide to cover people who are not terminally ill but who have an irreversible, deteriorating chronic illness, even if that condition will not of itself cause death.⁶⁴⁶
- 3.130. Calls are also being made for the scope of the law to be extended to include the assisted deaths of children and teenagers. A survey by the Canadian Pediatric Surveillance Program observed that 118 pediatricians confirmed that they had had exploratory conversations with children, teenagers and parents about assisted dying for minors.⁶⁴⁷ In December 2016, only months after the C-14 Bill was passed, Health Canada had commissioned a committee of experts to consider the extension of the current laws to include mature minors.⁶⁴⁸ A Canada Health media release stated:

On behalf of the Government of Canada, Minister of Health Jane Philpott and Minister of Justice and Attorney General of Canada Jody Wilson-Raybould are pleased to announce that they have engaged the

644 Willmott and White (2017) ‘Assisted Dying in Australia: A Values-based Model for Reform,’ in *Tensions and Traumas in Health Law* at 489-90, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

645 Mr Walker, Vice President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 4.

646 *AB v Canada (Attorney General)* 2017 ONSC 3758, 19 June 2017, cited by Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 13-14.

647 Aaron Derfel ‘Physician-assisted deaths have jumped 282% in one year: commission,’ *Montreal Gazette*, 26 October 2017.

648 Charles Lewis ‘How crazy is it to encourage the mentally ill to kill themselves?’ in *National Post*, 14 June 2018.

Chapter 3

*Council of Canadian Academies (CCA) to conduct independent reviews related to specific types of requests for medical assistance in dying. The three reviews will focus on requests by mature minors, advance requests, and requests where mental illness is the sole underlying medical condition.*⁶⁴⁹

- 3.131. In 2017, a 27-year-old Canadian man named Adam Maier-Clayton took his own life. He suffered from mental illness and had written about wanting a legal way to end his suffering and his life in a Globe essay months before his death. Mr André Picard, *The Globe and Mail's* health reporter, wrote a column that urged lawmakers to heed to Mr Maier-Clayton's wish in honour of his tragic death:

*Other Canadians who want to avail themselves of assisted death shouldn't have to wait either for legislation to catch up with the court ruling and public sentiment. Most people accept that if someone's dying anyhow, it's OK to hasten their death, especially if they're old. But cases such as Mr. Maier-Clayton's make us distinctly uncomfortable. He was young, healthy-looking and not suffering from any obvious physical illness. We should not discriminate or deny people rights because it makes us queasy or because of our prejudices. This case reminds us just how severe mental illness can be.*⁶⁵⁰

- 3.132. In a survey study released in September 2017, an overwhelming majority of Quebec caregivers said they favour extending medical aid in dying to those afflicted with Alzheimer's disease or dementia (Canadian law presently requires that the patient who makes the request must do so 'in a free and informed manner,' thereby excluding those with dementia.) The survey by Université de Sherbrooke epidemiologist Professor Gina Bravo found that 91 per cent of respondents support the idea of assisted dying for individuals suffering from dementia who are at the terminal state of their illness, showing signs of distress and who have an advance written directive. Furthermore, 72 per cent said they were for assisted dying even for Alzheimer's patients who did not sign a written directive before their illness.⁶⁵¹
- 3.133. Calls are also being made in Canada for 'death on demand.' Dr Yves Roberts, an advocate for the introduction of assisted suicide legislation in Canada, has published an open letter expressing shock over the developments in the two years since the passage of the C-14 Bill, and the calls now being made for death on demand based on the argument that it is

649 Health Canada, Government of Canada, 'Government of Canada Initiates Studies Related to Medical Assistance in Dying,' News Release, 13 December 2016 (emphasis added).

650 André Picard 'The mentally ill must be part of the assisted dying debate,' *The Globe and Mail*, 17 April 2017.

651 Aaron Derfel 'Most caregivers favour assisted dying for Alzheimer's patients: survey,' *Montreal Gazette*, 21 September 2017.

discriminatory to require certain conditions to be fulfilled before a doctor can approve the assisted suicide of a patient.⁶⁵²

3.134. In February 2018, less than two years after the passing of the C-14 Bill, the Superior Court of Justice Division Court of Ontario ruled on the constitutionality of the ‘Effective Referral Provisions’ of the Human Rights Policy and MAID Policy of the College of Physicians and Surgeons of Ontario. The Effective Referral Provisions require physicians who are unwilling to provide, amongst other matters, MAID to their patients, on moral or religious grounds to provide an effective referral to another health care provider. The ruling forces objecting physicians to refer patients to a physician who will help kill the patient and effectively states ‘that if doctors are unwilling to perform legal actions, they should find another job.’⁶⁵³ Forced referral was unprecedented in any other jurisdiction with legalised assisted suicide. There is also evidence that Canadian hospices are being bullied into hosting euthanasia, with a recent edict by the Fraser Health Authority in British Columbia ordering (non-religious) healthcare facilities, including hospices, to participate in assisted suicide, which is an infringement on the conscience rights of the medical staff employed at these facilities.⁶⁵⁴

3.135. Canadian bioethicists at the University of Montreal, Ms Julie Allard and Dr Marie-Chantal Fortin, have recently published an article promoting organ donation through the Medical Assistance in Dying program in Canada:

*MAID (medical aid in dying) has the potential to provide additional organs available for transplantation. Accepting to procure organ donation after MAID is a way to respect the autonomy of patients, for whom organ donation is an important value. Organ donation after MAID would be ethically acceptable if the patient who has offered to donate is competent and not under any external pressure to choose MAID or organ donation.*⁶⁵⁵

3.136. Allard and Fortin acknowledge that there might be some ethical complications. Patients might feel that they are a burden and could only be useful if they were to give their

652 Yves Roberts MD, Secretary, College des medecines du Quebec, ‘Towards death a la carte?’ 10 May 2017 <https://collectifmedecins.org/en/dr-roberts-regrets/#_ftn1>, referred to in evidence by Professor Somerville, Professor of Bioethics, University of Notre Dame Sydney, JSCEOLC Transcript, 1 May 2018, Session 8 at 3.

653 Dwight Randal, President, Coalition for the Defence of Human Life, Presentation to the Select Committee on End of Life Choices, included in JSCEOLC Response to Questions on Notice, 17 April 2018 at 6.

654 Ibid.

655 Allard and Fortin (2016) ‘Organ donation after medical assistance in dying or cessation of life-sustaining treatment requested by conscious patients: the Canadian context,’ *Journal of Medical Ethics* doi:10.1136/medethics-2016-103460.

Chapter 3

organs. This would constitute a subtle form of coercion. However, Allard and Fortin are confident that this can be overcome:

*It will be difficult to disentangle patients' motivations for requesting MAID, but the complete separation of the two decisional processes should help to ensure that the MAID request is motivated by unbearable suffering, as required by law, and not by the feeling that one's value is limited to one's organs.*⁶⁵⁶

- 3.137. Prisoners are also now permitted to access assisted suicide under the MAID legislation in Canada. As at March 2018, one prisoner had already been killed under the legislation, and Correctional Services Canada (CSC) confirmed that it had received eight requests for MAID. CSC is now permitted to organise MAID, or assisted suicide, for a prisoner in a community hospital and also in a penitentiary regional hospital or treatment centre in exceptional circumstances and at the request of the inmate.⁶⁵⁷ Correctional Investigator Dr Ivan Zinger criticised the possibility of inmates being euthanised in a prison in a letter to CSC, suggesting that a prohibition on MAID within prisons would protect the integrity of the system now and in the future, when eligibility for assisted death could expand to prisoners suffering from acute psychiatric illnesses.⁶⁵⁸

Problems with implementation of the current model

- 3.138. Calls for expansion aside, there is nothing to indicate that the current legislative model in Canada is workable. Dr Gordon Gubitz, an assisted suicide provider from Canada, gave evidence to the AMA(WA) Symposium on End of Life Choices recently here in Perth, with Dr Khorshid later telling the Committee that:

*in sharing his personal experiences, [Dr Gubitz] was able to make it clear to us that the processes were not terribly robust in Canada... they have work to do before they have a system that they would promote to other countries as being good.*⁶⁵⁹

- 3.139. Issues around process, infrastructure, funding and reporting in Canada were identified by Dr Khorshid in evidence to the Committee.⁶⁶⁰
- 3.140. Concern has also been raised over the rate at which assisted suicide is increasing in Canada, where deaths through 'Medical Aid in Dying' increase from 167 cases in 2015-2016, to 638 cases in 2016-2017—an increase of 282 per cent.⁶⁶¹ Derfel suggests that

656 Ibid.

657 Michael Cook, 'Euthanasia performed on Canadian prisoner,' *BioEdge*, 4 March 2018.

658 Ibid.

659 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 17.

660 Ibid at 4.

661 Aaron Derfel, 'Physician-assisted deaths have jumped 282% in one year: commission,' *Montreal Gazette*, 26 October 2017.

this increase highlights the growing popularity of assisted suicide in Quebec, but also raises questions about whether the rules are being followed properly.⁶⁶²

- 3.141. Whether the rules are being followed in Canada is not a hypothetical question, as the province of Quebec illustrates. Before the passage of Bill C-14 federally, assisted suicide legislation was passed in the Canadian province of Quebec on 5 June 2014.⁶⁶³ This measure was challenged by the Canadian federal government, but in December 2015 the Quebec Court of Appeal confirmed that the legislation would stand in light of the Canadian Supreme Court's *Carter* decision.⁶⁶⁴
- 3.142. In the first nine months following the passage of the Act in Quebec, the Commission sur les soins de fin de vie (CSFV), or End of Life Commission, found that one of the requirements of the legislation was not met in 21 cases of physician-assisted dying. Among the requirements not met, the main concerned the independence of the second doctor (18 cases). The others related to end-of-life criteria (two cases) and to the attainment of a serious and incurable illness (one case), as defined by Quebec law.⁶⁶⁵
- 3.143. In response to these breaches of the legislative requirements, the Minister for Health and Social Services stated:

*These data demonstrate the vital work done by the Commission on end-of-life care. The vast majority of physician-assisted dying, 85%, was administered in accordance with the requirements of the Act and we must remain vigilant with respect to the conditions of administration. The figures presented in this report reflect the first few months of application of the Act, which is, in a way, a period of learning and adaptation for the actors concerned. Over the next few months, we will strive to resolve the adjustment difficulties and we will ensure that each stakeholder understands the requirements of the Act.*⁶⁶⁶

- 3.144. This strive to resolve 'adjustment difficulties' and to 'ensure that each stakeholder understands the requirements of the Act' did not produce results.
- 3.145. In the second year of the Quebec Act's operation, the Commission was unable to conclude compliance with the legislative requirements in 3 per cent of the case reports provided to the Commission (19 case reports), due to incomplete information provided

662 Ibid.

663 Bill 52, also known as 'An Act respecting end-of-life care,' National Assembly, Quebec.

664 [2015] 1 SCR 133.

665 Office of the Minister of Health and Social Services, 'Minister Gaetan Barrett releases the Commission's first report on end of life care,' Media Release, Quebec, 27 October 2016 <<https://www.newswire.ca/fr/news-releases/le-ministre-gaetan-barrette-rend-public-le-premier-rapport-de-la-commission-sur-les-soins-de-fin-de-vie-598891241.html>>

666 Ibid (emphasis added).

Chapter 3

by the attending physician in those reports. The Commission also concluded that in 31 cases of physician-assisted death, the legislative requirements were not met in this twelve month period. Again, among the requirements not met, the main one in 20 cases concerned the independence of the second doctor. In seven cases, the doctor who administered euthanasia failed to have a conversation with the patient to verify that the request was free and informed, that suffering was persistent and to verify the consistency of the wish to die. In one case in this 12-month period the patient did not have a serious and incurable illness.⁶⁶⁷

- 3.146. It seems that the Minister of Health and Social Services has now given up trying to ensure compliance with the Act with regard to the most frequent compliance problem in Quebec, that is, the lack of an independent second doctor:

Since February 2017, the [End of Life] Commission has adapted its assessment of this criterion in the light of ongoing work in partnership with the MSSS [Ministère de santé et services sociaux (Ministry of Health and Social Services)] and the CMQ [Collège des Médecins du Québec (College of Physicians of Quebec)]. These cases would now be considered compliant, as long as the other criteria are met.⁶⁶⁸

- 3.147. The province of Quebec illustrates clear breaches of the legislative requirements in that jurisdiction, and a seeming lack of will on the part of the government to ensure compliance.

- 3.148. Meanwhile, evidence was also given by Dr Gubitzi in his practice of assisted suicide in Canada, that some of the patients who requested his assistance had not received any palliative care.⁶⁶⁹ Dr Craig Sinclair, Research Fellow at UWA, gave evidence to the Committee that he was:

supportive of the rights-based approach that is taken in Canada and established in Carter v Canada. I believe that an approach grounded in the principles of autonomy and equality of access to assisted dying would be preferential. Within such an approach, the safeguarding that

667 Office of the Minister of Health and Social Services, 'Minister Gaetan Barrette tables Commission Report on End-of-Life care,' Media Release, Quebec, 26 October 2017 <<https://www.newswire.ca/fr/news-releases/le-ministre-gaetan-barrette-depose-le-rapport-de-la-commission-sur-les-soins-de-fin-de-vie-653342363.html>>; and Amy Hasbrouk, 'Quebec euthanasia data from the Commission on end-of-life care,' *Euthanasia Prevention Coalition*, 31 October 2017 <<https://alexschadenberg.blogspot.com/2017/10/euthanasia-report-from-commission-on.html>>

668 Footnote (a) at page 22 of the Commission sur les soins de fin de vie Report tabled in the Quebec National Assembly, 26 October 2017, cited in Amy Hasbrouk, 'Quebec euthanasia data from the Commission on end-of-life care,' *Euthanasia Prevention Coalition*, 31 October 2017 <<https://alexschadenberg.blogspot.com/2017/10/euthanasia-report-from-commission-on.html>>

669 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 18 May 2018, Session 1 at 7.

*we might think about when looking at safeguarding assisted dying would give its attention to safeguarding the integrity of the decision-making process, rather than providing a criminal defence for the medical practitioner. That would include things such as having access to genuine alternatives—the example being someone in a remote area who does not have access to palliative care; potentially you could say that the decision-making process is compromised in that situation.*⁶⁷⁰

- 3.149. Patient-rights advocates in Canada have expressed concern that the dramatic increase in the number of cases of assisted suicide partly reflects the reality that palliative care is lacking in some parts of Quebec and the living conditions in long-term care centres are far from ideal.⁶⁷¹
- 3.150. A 2017 study found that the legalization of medical assistance in dying could reduce annual health care spending across Canada by up to \$138.8 million, exceeding the maximum \$14.8 million in direct costs associated with its implementation.⁶⁷² This evidence directly contradicts the evidence given to the Committee by Mr Neil Francis that ‘potential savings would be very minor.’⁶⁷³ Studies suggesting savings in annual health spending in Canada are very worrying, particularly in light of the recent case of Mr Roger Foley, who lives with a cerebellar ataxia (a degenerative neurological condition) and who has launched a lawsuit naming the London Health Sciences Centre and South West Local Health Integration Network in Ontario Canada, stating that they are willing to provide him with assisted death under the MAID legislation, but that they are unwilling to fund his care to provide him with an assisted life.⁶⁷⁴
- 3.151. All of this evidence demonstrates the unsoundness of the recommendation made to the Committee by Dying with Dignity (WA) that the Canadian model is ‘workable’ and the ‘best model to follow.’

Finding 100

In 2016 the Canadian Parliament enacted an assisted suicide law for a person facing a reasonably foreseeable natural death, only to have the Supreme Court of Ontario

670 Dr Sinclair, Research Fellow, University of Western Australia, JSCEOLC Transcript, 26 February 2018, Session 3 at 12.

671 Aaron Derfel, ‘Physician-assisted deaths have jumped 282% in one year: commission,’ *Montreal Gazette*, 26 October 2017.

672 Sprung et al (2018) ‘Physician-Assisted Suicide and Euthanasia: Emerging Issues from a Global Perspective,’ *Journal of Palliative Care* [sagepub.com/journalsPermissions.nav DOI: 10.1177/0825859718777325](https://doi.org/10.1177/0825859718777325), at 3 – citing Trachtenberg and Manns (2017) ‘Cost analysis of medical assistance in dying in Canada,’ *CMAJ* 189(3).

673 Mr Neil Francis, Dying for Choice, JSCEOLC Submission 642 at 27.

674 “‘The solution is assisted life’”: Offered death, terminally ill Ont man files lawsuit,’ *CTVNews*, 15 March 2018.

Chapter 3

interpret the provision so as to extend its application to a person not terminally ill but who has an irreversible deteriorating chronic illness.

Finding 101

In late 2016 the Canadian Government commissioned reviews to explore a further extension of assisted suicide laws to minors, to those making an advance request and to those where mental illness is the sole underlying condition.

Finding 102

In February 2018 a Canadian Court has ruled that physicians with a conscientious objection to assisted suicide are nevertheless obliged to refer their patient to a practitioner who will execute the assisted suicide.

Finding 103

In the first nine months following the passage of an assisted suicide law in Quebec it was found the law had been breached in 21 cases. In the second year of operation, breaches occurred in 31 cases.

Finding 104

In the short experience of the Canadian law on assisted suicide there has already been at least one case of a doctor assisting a suicide by lethal injection notwithstanding that the patient did not suffer a serious incurable illness.

Recommendation 17

The Government and the Parliament of Western Australia should reject the advice of Dying with Dignity WA (formerly known as the Western Australian Voluntary Euthanasia Society) and rule out introducing an assisted suicide regime based on the Canadian model.

The North American Experience—Oregon

- 3.152. Proponents of assisted suicide present Oregon as an example of a jurisdiction with a long and successful history, where the scope of the legislation has remained unchanged since its introduction:

*Oregon... is, apart from the Northern Territory, the first operative assisted dying regime in the world. It is the longest standing in operation and it is the one most like the Victorian model. It has not changed in terms of its scope.*⁶⁷⁵

⁶⁷⁵ Prof White, Director, Australian Centre for Health Law Research, JSCEOLC Transcript, 26 February 2018, Session 2 at 11.

- 3.153. Practical issues arising from the Oregon model are not acknowledged and only glowing reviews are offered. Mr Denton, for example, asserted that:

*There is abundant evidence from Oregon to demonstrate that providing legal, regulated access to life-ending medication has strong palliative power and likely helps prolong life.*⁶⁷⁶

- 3.154. There is abundant evidence from Oregon, including case examples, which reveal that there are serious issues with the Oregon model that present significant risk to vulnerable members of the community in that State. These are the cases the proponents will not acknowledge. It is important that the cases are heard, and heeded.

Medical errors in prognosis

- 3.155. The issue of medical error in prognosis has been considered at length in Chapter 2 of this Report. There the Oregon Health Authority data is analysed in detail and reveals that the prognosis of many Oregonians whose assisted suicide was facilitated under the *Dying with Dignity Act* was incorrect.
- 3.156. Dr Kenneth Stevens has written about his experience of how the prognosis of six months to live works in practice under Oregon's law:

*Oregon's assisted-suicide law applies to patients predicted to have less than six months to live. In 2000, I had a cancer patient named Jeanette Hall. Another doctor had given her a terminal diagnosis of six months to a year to live. This was based on her not being treated for cancer. At our first meeting, Jeanette told me that she did not want to be treated, and that she wanted to opt for what our law allowed—to kill herself with a lethal dose of barbiturates. I did not and do not believe in assisted suicide. I informed her that her cancer was treatable and that her prospects were good. But she wanted "the pills." She had made up her mind, but she continued to see me. On the third or fourth visit, I asked her about her family and learned that she had a son. I asked her how he would feel if she went through with her plan. Shortly after that, she agreed to be treated, and her cancer was cured. Five years later she saw me in a restaurant and said, "Dr. Stevens, you saved my life!" For her, the mere presence of legal assisted suicide had steered her to suicide.*⁶⁷⁷

676 Mr Denton, Go Gentle Australia, JSCEOLC Response to Questions on Notice, 13 May 2018 at 9.

677 Kenneth Stevens 'Doctor helped patient with cancer choose life over assisted suicide,' *Missoulian*, 27 November 2012, quoted in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 15.

Chapter 3

Optional referral for psychiatric assessment

- 3.157. Chapter 2 of this Report addresses the complexity in assessing patient competence in an assisted suicide case. The low rates of referral to a psychiatric specialist under the 'optional referral' model in Oregon is discussed in detail there.
- 3.158. A tragic real-life scenario is presented by Dr Charles J Bentz, who recounts that one of his patients should have received psychiatric care, but was instead offered a lethal prescription:

In 2011 Dr. Charles J. Bentz of the Division of General Medicine and Geriatrics at Oregon Health & Sciences University explained that Oregon's physician-assisted suicide law is not working well. He cited the example of a 76-year-old patient he referred to a cancer specialist for evaluation and therapy. The patient was a keen hiker and as he underwent therapy, he became depressed, partly because he was less able to engage in hiking. He expressed a wish for assisted suicide to the cancer specialist, who rather than making any effort to deal with the patient's depression, proceeded to act on this request by asking Dr Bentz to be the second concurring physician to the patient's request. When Dr Bentz declined and proposed that instead the patient's depression should be addressed the cancer specialist simply found a more compliant doctor for a second opinion. Two weeks later the patient was dead from a lethal overdose prescribed under the Act. Dr Bentz concludes "In most jurisdictions, suicidal ideation is interpreted as a cry for help. In Oregon, the only help my patient got was a lethal prescription intended to kill him." He urges other jurisdictions "Don't make Oregon's mistake."⁶⁷⁸

- 3.159. The example of the treatment of this 76-year-old Oregonian evidences issues of doctor shopping, issues around the assessment of capacity and the risk that a patient's request for assisted suicide may be influenced by undiagnosed or untreated depression or demoralisation, and issues around doctor bias toward assisted suicide and their willingness to accept a patient's wish to hasten death as a request to die.
- 3.160. Like the evidence given to the Committee by Dr Miller, Consultation Liaison Psychiatrist, Dr H Rex Greene explains that demoralisation syndrome is very common in chronic and life threatening illness:

the features of which (hopelessness, helplessness, and despair) fit the profile of the victims of Oregon's law, who are consistently reported not

678 Charles Bentz 'Oregon's assisted suicide law isn't working,' *The Province*, December 5 2011, quoted in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 5.

to be in pain or disabled by their allegedly terminal illness but request [assisted suicide] because of fears of... the future: helplessness, dependency, becoming a burden. Oregon in fact has proven that the only symptom driving requests for [assisted suicide] is psychological distress. Clearly the standard of care for depression and demoralization is not a lethal overdose of barbiturates.⁶⁷⁹

- 3.161. Further evidence from Oregon also demonstrates that the introduction of assisted suicide undermines standards of care offered to patients:

A woman in her mid-50s with heart disease, but otherwise with no significant pain or mobility limitations, requested a lethal prescription from her cardiologist. The cardiologist, in turn, referred her to another physician who was willing to write lethal prescriptions. This physician determined she was not terminally ill. But rather than ask about the origins of her suicidal wishes and give her a psychiatric referral, the physician simply told her to see her cardiologist again. Her cry for help unanswered, she committed suicide the following day.⁶⁸⁰

Doctor bias toward euthanasia

- 3.162. Doctor bias toward granting assisted suicide requests is considered in Chapter 2 of this Report. It was noted there that in Oregon, a physician member of a pro-assisted suicide lobby group provided the consultation in 58 of 61 consecutive cases of patients receiving physician-assisted suicide in Oregon.⁶⁸¹
- 3.163. Dr Peter Goodwin, Oregon's Compassion & Choices former Medical Director, said that about 75 per cent of reported Oregon assisted suicide deaths in 2002 were undertaken with the organisation's assistance. In 2003, the group was involved in 79 per cent of the assisted deaths that occurred, and 'in 2008 the proportion of Compassion & Choices physician assisted suicide deaths significantly increased to 88% (53/60) of all reported deaths.'⁶⁸²

679 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide' *Disability and Health Journal* 3(1) 16-30 at 23, quoting H Rex Greene MD 'Letter to the council on ethical affairs, California Medical Association' 22 February 2006 <<https://dredf.org/public-policy/assisted-suicide/opposition-to-neutrality-on-ab-651/>>

680 Ibid at 24.

681 Hendin and Foley (2008) 'Physician-assisted suicide in Oregon: a medical perspective,' *Mich Law Rev* 106, 1613-40.

682 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1) 16-30 at 21.

Chapter 3

- 3.164. This raises concerns about the objectivity of the process and the safety of the patients, and raises questions about the influence of bias on the part of these physicians on the process.⁶⁸³

Doctor shopping

- 3.165. The first known assisted suicide death under the Oregon statute represents a clear example of doctor shopping. This was a patient whose name is unknown, who was in her mid-eighties and who had been battling cancer for twenty-two years. Initially, two doctors, including her own physician who believed her request was due to depression, refused to prescribe her lethal drugs. Compassion & Choices in Oregon, then operating under the name Compassion in Dying, became involved in her case and referred the woman to a doctor willing to write the prescription.⁶⁸⁴
- 3.166. Evidence also exists that even in those rare instances where psychiatric referral occurs in Oregon, the psychiatric evaluation can be unreliable or insufficient as a result of doctor shopping:

as N Gregory Hamilton MD pointed out, physicians who support assisted suicide will refer patients to psychiatrists or psychologists who agree with that view, and ‘the evaluations tend to be pro forma,’ or else alternative opinions that favour assisted suicide are found, providing no protection for people with depression and psychiatric disabilities.⁶⁸⁵

Complications rates in Oregon

- 3.167. The risks of complications are discussed in detail in Chapter 2 of this Report. The evidence from the Oregon Health Authorities own reports indicates that complications do arise and that patients seeking assisted suicide under the *Death With Dignity Act* (DWD Act) are not guaranteed a ‘good death.’

The requirement of ‘terminal illness’ is not strictly applied

- 3.168. Oregon’s DWD Act requires that a person be certified by two physicians as suffering from a terminal illness before a lethal dose of medication can be lawfully prescribed. The annual report released in February 2017 shows that conditions that have been accepted as meeting this definition include benign and uncertain neoplasms, other respiratory diseases, diseases of the nervous system (including multiple sclerosis, Parkinson’s

683 Pereira J (2011) ‘Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls,’ *Current Oncology* 18(2) 38-45 at 40.

684 ‘Some Oregon and Washington State Assisted Suicide Abuses and Complications,’ Disability Rights Education and Defense Fund <<https://dredf.org/public-policy/assisted-suicide/some-oregon-assisted-suicide-abuses-and-complications/>> and Golden and Zoanni (2010) ‘Killing Us Softly: The Dangers of Legalizing Assisted Suicide,’ *Disability and Health Journal* 3(1) 16-30 at 21.

685 Golden and Zoanni (2010) ‘Killing Us Softly: The Dangers of Legalizing Assisted Suicide,’ *Disability and Health Journal* 3(1) 16-30 at 24.

disease and Huntington’s disease), musculoskeletal and connective tissue diseases, viral hepatitis, diabetes mellitus, and alcoholic liver disease.⁶⁸⁶ Earlier annual reports specifically mention some diseases that would not normally be classified as a terminal illness: myelodysplastic syndrome (not terminal unless it develops into acute myeloid leukemia, which itself is not necessarily terminal),⁶⁸⁷ Hepatitis C,⁶⁸⁸ and digestive organ neoplasm of unknown behaviour,⁶⁸⁹ among others. It was suggested to the Committee that this evidence from the OHA reports reveals that the requirement that an illness be terminal is not being strictly applied in Oregon.⁶⁹⁰

- 3.169. Stahle and Randal also identify a significant problem with the requirement of a ‘terminal illness’ under the DWD Act. Under the Oregon Act, a person can be classed as being ‘incurably’ sick even when the disease can be treated! With treatment, these people would not be classed as ‘terminally ill’ but rather ‘chronically ill,’ thus all diseases which, without treatment, would be expected to result in death within six months are considered under the DWD Act to be ‘incurable’ and therefore qualify for assisted death. Consequently, a far greater number of patients can technically qualify for medically assisted suicide than just the extreme cases for which the law was originally said to apply.⁶⁹¹ Stahle was also given advice from the Oregon Health Authority that if ‘the patient cannot pay for the treatment, then the disease remains incurable.’⁶⁹²
- 3.170. The impact of this statement is evident in the cases of Barbara Wagner and Randy Stroup:

The impact of the Oregon Health Plan’s drastic limitations became very real to Medicaid recipients Barbara Wagner and Randy Stroup. Wagner, a 64-year-old great-grandmother, had recurring lung cancer. Her physician prescribed Tarceva to extend her life. Studies show the drug provides a 30% increased survival rate for patients with advanced lung cancer, and patients’ 1-year survival rate increased by more than 45%.

686 Oregon Public Health Division (2017) ‘Oregon Death With Dignity Act: Data Summary 2016, Table 1. Characteristics and end-of-life care of 1,127 DWDA patients who have died from ingesting a lethal dose of medication as of January 23, 2016 [sic = 2017], by year,’ Oregon, 1998-2016 at 9 and 11, footnote 2, cited in Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 19.

687 Oregon Health Authority, Public Health Division (2003) *Fifth Annual Report on Oregon’s Death With Dignity Act* at 19.

688 Ibid at 21.

689 Ibid.

690 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 19.

691 Dwight Randal, President, Coalition for the Defence of Human Life, JSCEOLC Response to Questions on Notice, 17 April 2018 at 6.

692 Communication between Fabian Stahle and Craig New, Research Analyst, Oregon Health Authority, Center for Public Health Practice, Public Health Division, in December 2017 in the testimony of Julie Hocker, ACUF Senior Policy Fellow, and Senior Policy Fellow for the Centre for Human Dignity, to the New York Assembly Committee on Health, Public Hearing on Bill 2383-A, 3 May 2018 – referred to by Prof Somerville, Professor of Bioethics, University of Notre Dame Sydney, in Supplementary Information provided to the JSCEOLC, dated 8 May 2018.

Chapter 3

But the Oregon Health Plan sent Wagner a letter saying the plan would not cover the beneficial chemotherapy treatment “but ... it would cover ... doctor-assisted suicide.” Stroup was prescribed mitoxantrone as chemotherapy for his prostate cancer. His oncologist said that while the drug may not extend a patient’s life by very long, it helps make those last months more bearable by decreasing pain. Yet Stroup also received a letter saying that the state would not cover his treatment but would pay for the cost of assisted suicide.⁶⁹³

- 3.171. In the reasons for patient request for lethal medication under the DWD Act, patient concern about treatment costs has been recorded at 3.1 per cent (representing 30 reported cases in a studied cohort).⁶⁹⁴ This evidence, and the cases of Wagner and Stroup, clearly evidence the real risk in Oregon that patients will be provided with lethal prescriptions in lieu of other more expensive medical treatments.

Lack of safety around patient-administered lethal drugs

- 3.172. In 2016 either the prescribing physician (in 10.1 per cent of cases) or another healthcare provider (10.5 per cent) was known to be present at the time the lethal medication was ingested. For the remaining 79.4 per cent of people there was no physician or other healthcare provider known to be present at the time of ingestion.⁶⁹⁵ Aside from the obvious issue around complications with the medication ingested without a medical professional present (already considered above), it was suggested to the Committee that in nearly four out of five cases in Oregon in 2016, ‘there is no independent evidence that the person took the lethal medication voluntarily. It may well have been administered to them by a family member or other person under duress, surreptitiously or violently. We can never know.’⁶⁹⁶ Further, it was suggested that we cannot be sure that at the time the patient ingests the drug, which the reported data indicates may be up to two years after the prescription is provided, whether they have lost competency.⁶⁹⁷
- 3.173. The presence of a health care professional at the time of the patient ingesting the lethal medication has been reducing since the introduction of the legislation.⁶⁹⁸ This reduction in the presence of a health care professional at the time of ingestion is associated with a significant reduction in safety for the patient.

693 Golden and Zoanni (2010) ‘Killing Us Softly: The Dangers of Legalizing Assisted Suicide,’ *Disability and Health Journal* 3(1) 16-30 at 19.

694 Blank et al (2017) ‘Characterizing 18 Years of the Death With Dignity Act in Oregon,’ *JAMA Oncol* 3(10) 1403-1406.

695 Oregon Public Health Division, Oregon Death With Dignity Act: Data Summary 2016 at 7.

696 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 30.

697 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Transcript, 9 March 2018, Session 1 at 11.

698 Hedberg and New (2017) ‘Oregon’s Death With Dignity Act: 20 Years of Experience to Inform the Debate,’ *Ann Intern Med* 167, 579-583 at 582.

- 3.174. It is also worth noting at this point the introduction of Senate Bill 893 in Oregon to address the perceived shortcoming of Oregon's DWD Act where a person's disability may impede their assisted suicide. Brought to the attention of the Committee by Ms Re of Identity WA,⁶⁹⁹ Bill 893:

Permits expressly identified agent, pursuant to lawfully executed advance directive and in accordance with Oregon Death with Dignity Act, to collect and administer prescribed medication for purpose of ending patient's life in humane and dignified manner if patient ceases to be capable after having received prescription for life-ending medication.

- 3.175. The passage of such a Bill would signal a further reduction in patient safety in Oregon.

The Oregon suicide rate

- 3.176. Evidence was given to the Committee by Mr Francis of Dying for Choice, that there is no evidence of suicide contagion and that prior to the Oregon DWD Act, Oregon's suicide ranking amongst US states was worsening, while since the passage of the Act it has been improving.⁷⁰⁰ Such an assertion is not supported by suicide statistics from Oregon:

In 2012, the age-adjusted suicide rate among Oregonians was 17.7 per 100,000, 42 per cent higher than the national average. The rate of suicide among Oregonians has been increasing since 2000. Suicide rates among adults aged 45-64 years rose more than 50 per cent from 18.1 per 100,000 in 2000 to 28.7 per 100,000 in 2012, with the rate increasing more among females than among males.⁷⁰¹

- 3.177. Deaths relating to the DWD Act are not classified as suicides by Oregon law and are therefore not included in this data.⁷⁰² Earlier in this Report, when examining the Swiss model, it was noted that in evidence from Swiss assisted suicide provider Dignitas it was conceded that the suicide rate in Oregon has risen. In any event the sheer volume of suicides (both assisted and non-assisted) remain of great concern.

Palliative care in Oregon

- 3.178. Research strongly suggests that Oregon has seen a reduction in the quality of end-of-life palliative care since the Oregon law went into effect. Dying patients in Oregon are nearly twice as likely to experience moderate or severe pain during the last week of life, as

699 Ms Re, Chief Executive Officer, IdentityWA, JSCEOLC Response to Questions on Notice, 10 April 2018 at 2.

700 Mr Neil Francis, Dying for Choice, JSCEOLC Submission 642 at 43.

701 Shen and Millet (2015) *Suicides in Oregon: Trends and Associated Factors 2003-2012*, Oregon Health Authority, Portland, Oregon at 3.

702 Ibid at 7.

Chapter 3

reported by surviving relatives, compared with patients before the law took effect. Several recent studies show inadequate palliative and end-of-life care in Oregon.⁷⁰³

What happens when the law is violated in Oregon?

- 3.179. Golden and Zoanni suggest that the death of Wendy Melcher in August 2005 illustrates the indirect impact of legalisation of assisted suicide on medical practice and law enforcement:

Two nurses, Rebecca Cain and Diana Corson, gave Melcher large overdoses of morphine and phenobarbital. They claimed that she had requested assisted suicide, but they administered the drugs without her physician's knowledge, in clear violation of the law. Yet no criminal charges have been filed against the two nurses. Proponents of assisted suicide argue that this case has no connection to the Oregon law. But it is a strong indication of the legal erosion of public protections due to assisted suicide. The case prompted one newspaper to write, "If nurses or anyone else dare willing to go outside the law, then all the protections built into [Oregon's] Death with Dignity Act are for naught." Supporters of assisted suicide frequently assert, without evidence, that the underground practice of assisted suicide disappears where it is legal. But Melcher's death suggests the opposite, that underground assisted suicide probably does occur, and may in fact be thriving in Oregon in the wake of assisted suicide's legalization, due to the breakdown in legal rules and codes of conduct that elsewhere protect patients.⁷⁰⁴

- 3.180. Annie O Jones, John Avery and three other patients are reported to have been killed by illegal overdoses of medication administered to them by a nurse, and none of these cases have been prosecuted in Oregon.⁷⁰⁵
- 3.181. Dr Katerina Hedberg of the Oregon Department of Human Services confirmed 'We are not given the resources to investigate [assisted suicide cases] and not only do we not have the resources to do it, but we do not have any legal authority to insert ourselves.'⁷⁰⁶

703 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1) 16-30 at 19, citing Fromme et al (2004) 'Increased family reports of pain or distress in dying Oregonians: 1996-2002,' *J Palliat Med* 7, 431-42 and Hendin and Foley (2008) 'Physician-assisted suicide: a medical perspective,' *Mich Law Rev* 106, 1613-40.

704 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1) 16-30 at 19.

705 Peter Korn 'Nursing chaos – Is Oregon State Board of Nursing Protecting Nurses at the Expense of Public Safety?' *Portland Tribune*, 6 March 2006.

706 Oregon Department of Human Services, News Release, 'No authority to investigate Death With Dignity case, DHS says,' 4 March 2005, quoted in 'Some Oregon and Washington State Assisted Suicide Abuses and Complications,' *Disability Rights Education and Defense Fund*

Finding 105

The law on assisted suicide in Oregon has been in force for 20 years and requires a prognosis of less than six months to live.

Finding 106

The data from the Oregon Public Health Division between 1998 and 2015 indicates that the longest recorded duration between initial request for assisted suicide and ingestion of the prescribed lethal drug was 1009 days.

Finding 107

The data from the Oregon Public Health Division in 2015 indicates that the longest recorded duration between initial request for assisted suicide and ingestion of the prescribed lethal drug was 517 days.

Finding 108

The data from the Oregon Public Health Division between 1998 and 2015 indicates that in 4 of the 17 years there was at least one case where the duration between initial request for assisted suicide and ingestion of the prescribed lethal drug was more than two years.

Finding 109

The experience in Oregon demonstrates the inadequacies of safeguards due to consistent medical error in prognosis.

Finding 110

In Oregon a 76-year-old cancer patient was assisted to suicide by his cancer specialist notwithstanding the presence of depression and the non-concurrence of the original doctor who referred the patient to the specialist for treatment.

Finding 111

In Oregon an octogenarian cancer patient was assisted to suicide notwithstanding that two doctors, including her own physician, were concerned about the presence of depression and refused to prescribe the lethal drug requested.

Finding 112

The experience in Oregon demonstrates the ease with which the prolific practice of doctor shopping pierces the veil of even well intentioned safeguards.

<<https://dredf.org/public-policy/assisted-suicide/some-oregon-assisted-suicide-abuses-and-complications/>>

Chapter 3

Finding 113

The data from the Oregon Public Health Division for 2016 indicates that in 79.4 per cent of assisted suicides no physician or healthcare provider was known to be present at the time of ingestion of the prescribed lethal drug.

Finding 114

The rate of suicide among Oregonians has been increasing even when assisted suicides are excluded from the data set.

Finding 115

The inherent difficulty in prosecuting after the event is underscored by at least five assisted suicides in Oregon that occurred by illegal overdoses administered by a nurse.

Finding 116

The experience observed in Oregon should be reason alone to militate against legalisation in Western Australia.

Recommendation 18

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime based on the Oregonian experience.

The Gaping Hole—Issues with Reporting, Investigation, Prosecution and Redress

- 3.182. Within the jurisdictions considered above, where assisted suicide has been legalised, there have been practitioners who have breached the framework established within those jurisdictions. This begs the question, how are such deaths to be investigated in Western Australia should assisted suicide also be legalised here?

A retrospective model of oversight

- 3.183. Professors White and Willmott propose a retrospective model of oversight, and suggest that the value of reducing suffering is relevant to the question of the timing of the review of the decision-making:

the value of reducing suffering points us towards a retrospective model rather than requiring further delay for the person who is in this intolerable state while yet another body be satisfied that he or she is eligible to receive assistance.

...

[A new retrospective body] removes questions or associations of unlawful or inappropriate behaviour... The body's functions could

*include independent review of assisted dying cases (retrospectively), systems-level monitoring of the assisted dying regime (including the ability to make recommendations for systemic reform), and appropriate data collection and reporting.*⁷⁰⁷

- 3.184. Mr Mark Teale, Chief Executive of the Council on the Ageing WA (Inc), also saw value in establishing ‘an independent body to investigate any cases that are not on the surface as they appear they should be.’⁷⁰⁸ He too suggested that the review conducted by this body should be retrospective in its operation.⁷⁰⁹
- 3.185. Mr Perron was also adamantly opposed to a review process prior to the assisted suicide of the patient like that recently adopted in Victoria, where the Victorian Civil and Administrative Tribunal has the power to review an application for assisted suicide while it is in process. This level of review was included in the Victorian legislation as a safeguard against doctor error or oversight, where there may be issues of competency and undue influence that had been overlooked at first instance. ‘Well, for goodness sake, let us have some thought for the patient,’ was Mr Perron’s response to such a safeguard.⁷¹⁰ ‘[A]nything that brings an external authority in to delay the process is undesirable.’⁷¹¹
- 3.186. The real risk of undue influence has been considered in depth in this Report in Chapter 2 and was raised with Mr Perron by Hon Nick Goiran in the Committee hearing:

Hon NICK GOIRAN: Might a relative have a better understanding on whether somebody was under duress than a practitioner who meets the person for the first time in a brief consultation?

*Mr PERRON: My answer simply is the patient’s view in these circumstances, being competent, being assessed as competent and being determined as they are to commit to this process, their view should prevail. Whether there was one or more relatives who were protesting most loudly, I believe should be of no consequence in delaying the process.*⁷¹²

707 Willmott and White (2017) ‘Assisted Dying in Australia: A Values-based Model for Reform,’ in *Tensions and Traumas in Health Law* at 508 and 509, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

708 Mr Teale, Chief Executive, Council on the Ageing WA (Inc), JSCEOLC Transcript, 2 March 2018, Session 5 at 5.

709 Ibid at 5-6.

710 Mr Marshall Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 6.

711 Ibid at 7.

712 Ibid.

Chapter 3

- 3.187. Mr Perron’s response disregards the risk that undue influence presents to an individual seeking assisted suicide.
- 3.188. Even if a review model such as that adopted in Victoria were to be introduced here in Western Australia, such a review would only be conducted upon the application of a family member where the assessment process is believed by that person to have been compromised. Retrospective review of cases would still be necessary for all other cases.
- 3.189. In evidence given to the Committee, Professors White and Willmott favoured the establishment of a new retrospective body dedicated to overseeing an assisted suicide regime and did not favour oversight by the Coroner. They did not consider that deaths resulting from a practice that is recognised as lawful should be in the same category as ‘reportable deaths’ currently investigated by the Coroner, which they suggested sometimes includes connotations of these deaths being ‘suspicious.’⁷¹³
- 3.190. This opinion directly conflicts with evidence given to the Committee by the Western Australian Coroner, the Commissioner of Police and the Director of Public Prosecutions, who all agreed that a full investigation of each assisted suicide case is warranted, including post-mortem examination.⁷¹⁴
- 3.191. As will be demonstrated below, evidence was also provided to the Committee by each of these expert witnesses as to the difficulties currently experienced in Western Australia in relation to the investigation of suspicious deaths, which is relevant to consider before proceeding with the legalisation of assisted suicide in this State.

The self-reporting of doctors

- 3.192. When asked by the Chair of the Committee as to how WA Police currently deal with reports that doctors have intentionally hastened the deaths of their patients the Commissioner of Police, Commissioner Chris Dawson replied that WA Police rarely receive such reports, however when such reports are received there is insufficient evidence to substantiate the criminal charge:

One such matter that I have been briefed on was an allegation of a medical practitioner having administered a lethal injection. That investigation failed to identify sufficient evidence to substantiate the criminal charge. At the conclusion of that police investigation, which

713 Willmott and White (2017) ‘Assisted Dying in Australia: A Values-based Model for Reform,’ in *Tensions and Traumas in Health Law* at 509, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

714 Ms Fogliani, State Coroner of Western Australia, JSCEOLC Submission 537 at 1 and 2; and Miss Forrester, Director of Public Prosecutions and Mr Dawson, Commissioner of Police, JSCEOLC Transcript, 27 February 2018, Session 1 at 14.

*was in August 2016, we did refer the matter to the Health Practitioner Regulation Agency and provided information from that investigation.*⁷¹⁵

3.193. WA Police are very much reliant on the matter being reported to them; if the next of kin of the patient or the doctor involved in the death do not report the case to WA Police, the case is not investigated.⁷¹⁶ Commissioner Dawson confirmed that in the case of legalised assisted suicide, if the medical authorities in charge of those patients did not report a suspicious death then it would be impossible for WA Police to scan institutions for all such deaths.⁷¹⁷

3.194. The State Coroner of Western Australia, Ms Ros Fogliani, also confirmed in evidence to the Committee that she is reliant on suspicious deaths being reported to her office where a doctor's actions are believed to have hastened the death of a patient:

*we are not in the minds of the doctors. I am relying on people complying with their legal requirements, and their ethical duties as well if they are medical practitioners, to report a death to the coroner.*⁷¹⁸

3.195. The self-reporting of doctors has been raised as a serious concern in jurisdictions where assisted suicide has been legalised.

3.196. In conflict with evidence given to the Committee by proponents that the law in Oregon 'has been working well with mandatory reporting and annual assessment by the Department of Health with no evidence of abuse,'⁷¹⁹ serious concerns have been raised about reporting requirements and practices in Oregon:

The reporting requirement [in Oregon] lacks teeth. On paper, the law requires physicians to report all lethal drug prescriptions, but sets no penalties if physicians fail to report. Thus, this requirement is not enforced. Noncompliance is not monitored. The law requires annual statistical reports from the Oregon Public Health Division (OPHD), but OPHD does not monitor underreporting, noncompliance, or violations. Many of Oregon's reports acknowledge that the state cannot confirm compliance with the law. For example, OPHD announced in its first year that the state cannot determine if assisted suicide is practiced outside

715 Mr Dawson, Commissioner of Police, JSCEOLC Transcript, 27 February 2018, Session 1 at 9.

716 Ibid at 6.

717 Ibid.

718 Ms Fogliani, State Coroner of Western Australia, Coroner's Court of Western Australia, JSCEOLC Transcript, 1 March 2018, Session 1 at 16.

719 Dr Syme, Medical Practitioner and Vice President of Dying With Dignity Victoria, JSCEOLC Submission 316 at 5.

Chapter 3

the law's framework, stating "[W]e cannot detect or collect data on issues of noncompliance with any accuracy."⁷²⁰

...

There is no investigation of abuse. The state has no resources or even authority to investigate violations, cases of expansion, and complications reported in the media or documented by others. There is no method for the public to report abuse. The Oregon Department of Human Services (DHS, of which OPHD is a part) acknowledged in a press release that DHS "has no authority to investigate individual Death with Dignity cases" [cited earlier in this Report] ...DHS further lacks the time and desire to investigate. As the years go by, it makes public less and less information. Secrecy pervades the operation of assisted suicide. There is an unnecessarily high level of secrecy about assisted suicide that undermines the public's right to know, as well as any independent, in-depth research. Oregon's law states "the information collected [for the annual reports] shall not be a public record and may not be made available for inspection by the public."⁷²¹ Moreover, as Hendin and Foley explained, the statute includes "no provision for an independent researcher or evaluator to study whatever data are available," and the lack of available data violates medical standards that "require openness about facts, research data, and records to assess the appropriateness of treatment."⁷²²

The underlying data are destroyed annually. Alarming, officials have acknowledged that OPHD destroys each year's records after it issues the report.⁷²³

- 3.197. Issues with reporting were also raised by Blank et al in their recent study 'Characterizing 18 Years of the Death With Dignity Act in Oregon,' where they state that:

The quality of our data is limited by the fact the attending physicians supplied the state with the underlying information... In addition, because the physicians attested to the patients' reasons for requesting

720 Oregon Public Health Division (1999) 'Oregon's Death With Dignity Act: the first year's experience,' Portland: Public Health Division.

721 Oregon Revised Statute 127.860 3.11.2.

722 Hendin and Foley (2008) 'Physician assisted suicide: a medical perspective,' *Michigan Law Review* 106 at 1613-40.

723 Golden and Zoanni (2010) 'Killing Us Softly: The Dangers of Legalizing Assisted Suicide,' *Disability and Health Journal* 3(1) 16-30 at 24 and 25, citing Hedberg K, 'Hearings Before the Select Comm. on the Assisted Dying for the Terminally Ill Bill of the House of Lords,' (9 December 2004) in House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill [HL] vol II: evidence (2005).

*[Death With Dignity] there is no way to ascertain whether the questioning of the patient was comprehensive.*⁷²⁴

- 3.198. Canada, the Netherlands and Belgium all have similar self-reporting requirements as those prescribed in Oregon. Aside from issues with the self-reported data as identified by Blank et al above, there is evidence that indicates that a substantial amount of assisted deaths are not reported at all. Studies show that more than 40 per cent of assisted deaths in Belgium were not reported at all in 2013, and that 23 per cent of assisted deaths in the Netherlands were not reported in 2015.⁷²⁵
- 3.199. Downie acknowledges that in all the jurisdictions where assisted suicide has been legalised, ‘nobody yet has developed a system that gathers reliable data on all requests (which can provide important evidence on a variety of issues such as patient access) or that facilitates research in an efficient, reliable, and cost-effective manner.’ In relation to reporting in Canada, she notes that ‘we are in a sense building the ship while sailing it and this is definitely not ideal.’⁷²⁶

The best witness is dead

- 3.200. In relation to investigating cases of elder abuse, Mr Michael Bowyer, Principal Legal Officer of the Public Trustee, gave evidence to the Select Committee on Elder Abuse on 26 March 2018, that ‘it is very difficult when your best witness cannot give evidence.’⁷²⁷
- 3.201. The unavailability of a witness in these cases was also identified by Western Australia’s Director of Public Prosecutions as an issue in evidence to the Committee. In relation to the prosecution of cases where it is alleged that a doctor has wrongly hastened the death of a patient, Miss Forrester states:

in all of these cases the trouble is working out the facts. It is all well and good for allegations to be made, and part of the problem is that there is only one person left, usually, to tell what happened, and that is the person who is under investigation. That is a real problem for us.

If you have a situation where you have a doctor administering this treatment and the patient who says, “I want you to administer this treatment,” it depends on whether that is recorded and how it is

724 Blank et al (2017) ‘Characterizing 18 Years of the Death With Dignity Act in Oregon,’ *JAMA Oncol* 3(10) 1403-1406.

725 Chambaere et al (2015) ‘Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium,’ *N Engl JM* 372(12) 1179-81 and van der Heide et al (2017) ‘End-of-Life Decisions in the Netherlands Over 25 Years,’ *N Engl JM* 377, 492-94.

726 Downie J (2017) ‘Medical Assistance in Dying: Lessons for Australia from Canada,’ *QUT Law Review* 17(1) 127-146 at 144.

727 Mr Michael Bowyer, Principal Legal Officer, Office of the Public Trustee, Select Committee on Elder Abuse Transcript, 26 March 2018, Session 2 at 15.

Chapter 3

*recorded, but at the end of the day it is one person's say-so and that is the person administering the treatment. The patient, of course, is deceased.*⁷²⁸

- 3.202. This inherent challenge of this evidentiary issue was further unpacked in the following exchange:

Miss FORRESTER: That is a problem we routinely encounter in these situations. The one person who says, "Well, that person wanted to die," is the person who is alleged to have killed them.

Hon NICK GOIRAN: What capacity is there for you to compel that person to give evidence?

*Miss FORRESTER: Zero. The coroner has different capacities, but they could not be used in a criminal setting, obviously.*⁷²⁹

- 3.203. This evidence from the Director of Public Prosecutions clearly highlights that the self-reporting of the doctor, and the fact that the best witness is deceased, will mean that the investigation and prosecution of assisted suicide cases outside of the law will be effectively impossible.

What redress can be offered to the deceased patient?

- 3.204. In relation to the recent Victorian legislation, Mr Denton submitted that 'If a breach [of the Victorian regulations by a medical practitioner] is detected, either doctor can be reported to the relevant authority, be that Victoria Police, the Coroner, or the Australian Health Practitioner Regulation Agency.'⁷³⁰
- 3.205. Aside from the inherent issues in detecting a breach that relies on self-reporting by the doctor and in the absence of the key witness, as discussed above, the question that then follows is: What remedy or redress does Mr Denton suggest would be available to the party wronged by a breach?
- 3.206. Mr Perron acknowledged that 'there is no redress for family or friends in the event that a death was hastened and one or more of the eligibility requirements was not met. Obviously one cannot be brought back from the dead.'⁷³¹

728 Miss Forrester, Director of Public Prosecutions, JSCEOLC Transcript, 27 February 2018, Session 1 at 11 (emphasis added).

729 Ibid (emphasis added).

730 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 41.

731 Mr Marshall Perron, Private Citizen, JSCEOLC Response to Questions on Notice, undated (emphasis added).

- 3.207. Associate Professor Blake of the University of Western Australia referred the Committee to the case of *Malette v Shulman*,⁷³² in which a blood transfusion was administered to a Jehovah's Witness patient who had not consented to that treatment. In relation to the redress offered to the patient in this instance, Associate Professor Blake noted that the patient can be compensated with a monetary payment, but '[the problem] is not fixed in the sense that it cannot put her in the position that she would have been in, but it is the way the law addresses those sorts of claims.'⁷³³
- 3.208. The distinction between a claim of wrongful life-sustaining treatment and one of wrongful assisted suicide is readily apparent. In the former the outcome of the treatment leaves a plaintiff or claimant capable of seeking redress. There is no capacity for a victim of a wrongful assisted suicide to seek redress. The wrongful act is not only irrevocable, but it also eliminates the person who has been wronged.
- 3.209. The irrevocable argument was one of the key arguments put forward for the abolition of the death penalty in Australia in 1955:

*The death penalty is irrevocable. Though the odds against an innocent person's being convicted of murder and hanged may be very great, the risk should never be taken. The death penalty is irreparable, and an irreparable judgement should never be pronounced except by an infallible tribunal. If an innocent person is hanged no redress is possible. Death admits of no compensation. Further, in executing the person, the mainspring of any movement to reverse the verdict is destroyed.*⁷³⁴

- 3.210. Professor Quinlan, Dean of the School of Law Sydney at the University of Notre Dame Australia, notes that the irrevocable argument in this context did not rely on evidence of the execution of the innocence for its force:

Sheehan refers to no such case. He could not do so. Whilst some Parliamentarians referred to cases involving the inadvertent execution of innocent persons overseas, capital punishment was not abolished in Australia because there was a consensus that any innocent person had been executed in Australia. It was abolished for all—even those who had confessed to the most violent of murders or volunteered for capital

732 67 DLR (4th) 321, 72 OR (2d) 417.

733 Assoc Prof Blake, Legal Researcher, University of Western Australia, JSCEOLC Transcript, 26 February 2018, Session 3 at 14.

734 NSW Legislative Assembly, Crimes (Amendment) Bill Second Reading Speech, W.F. Sheehan, 23 March 1955 (3225) quoted in Quinlan M (2016) "'Such is Life': Euthanasia and capital punishment in Australia: consistency or contradiction?' *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* 6(1) at 6.

Chapter 3

*punishment... The very small risk that an innocent person may be executed was considered unacceptable.*⁷³⁵

- 3.211. The irrevocable argument also prevailed in relation to capital punishment, despite infamous cases of recidivism. Professor Quinlan notes one of the most infamous cases of recidivism in Australia, that of artist Leonard Keith Lawson who was sentenced to death in May 1954 for tying up and raping three models. His sentence was commuted to life and, as he was an ideal prisoner, he was released in 1962. Within weeks of his release he had murdered a school mistress and a student.⁷³⁶ Despite this case and others like it, where fear of recidivism was well founded, capital punishment was abolished in Australia.
- 3.212. Professor Quinlan notes that impact of the fear of recidivism can be seen in an opposite trend in relation to dangerous animals. Contrasts between the treatment of human beings and animals are regularly made by proponents of assisted suicide, for example, Mr Bob Dent, the first person to die in Australia under the ROTI Act, wrote in his final letter 'If I were to keep a pet animal in the same condition I am in, I would be prosecuted. If you disagree with voluntary euthanasia, then don't use it, but don't deny the right to me to use it.'⁷³⁷ Elsewhere, in a 2013 interview with the BBC, Professor Stephen Hawking said 'I think those who have a terminal illness and are in great pain should have the right to choose to end their lives and those that help them should be free from prosecution. We don't let animals suffer, so why humans?'⁷³⁸ In Australia, capital punishment of criminals for serious and violent crimes, even taking into account the recidivism of a criminal, has been prohibited. In contrast, legislation in every Australian jurisdiction allows for the destruction of dangerous dogs in the event of an unprovoked attack.⁷³⁹ Professor Quinlan suggests that the reason that dangerous animals and dangerous humans are treated so differently under Australian law warrants further consideration.⁷⁴⁰

735 Quinlan M (2016) "'Such is Life': Euthanasia and capital punishment in Australia: consistency or contradiction?" *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* 6(1) at 6-7.

736 Ibid at 7.

737 Mr Bob Dent, quoted in Seth Mydans, 'Legal Euthanasia: Australia Faces a Grim Reality' *The New York Times*, 2 February 1997 <<https://www.nytimes.com/1997/02/02/world/legal-euthanasia-australia-faces-a-grim-reality.html>>

738 Prof Stephen Hawking, quoted in Sarah Boseley 'Professor Stephen Hawking backs right to die for the terminally ill,' *The Guardian*, 18 September 2013.

739 *Companion Animals Act 1998* (NSW) Pt 5, Div. 3, 4; *Animal Management (Cats and Dogs) Act 2008* (Qld) Ch 5 Pt 4; *Dog and Cat Management Act, 1995* (SA) s 51; *Dog Control Act 2000* (Tas) Pt 3, Div 4, 5; *Domestic Animals Act 1994* (Vic) Pt 7A, Divs 2, 6, s 84P; *Dog Act 1976* (WA) Pt 7; *Domestic Animals Act 2000* (ACT) Pt 2, Div 2.7 and see also Cao, Sharman and White, *Animal Law in Australia*, 184-186.

740 Quinlan M (2016) "'Such is Life': Euthanasia and capital punishment in Australia: consistency or contradiction?" *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* 6(1) at 8.

- 3.213. Professor Quinlan suggests that the irrevocable argument, when applied to assisted suicide, would suggest that assisted suicide should remain prohibited if even a very small risk existed that a person's assisted suicide may have been carried out in error, or in circumstances beyond the eligibility criteria which the state specifies for permissible access to it:

Whilst there were no definitive instances of innocent prisoners being executed, over the 196 year history of capital punishment in Australia, in the brief period in which euthanasia was lawful in the Northern Territory, 2 out of the 7 patients who sought euthanasia were provided with inadequate information of their true medical condition and of their treatment options.

...

Whilst some might argue that the irrevocable argument against euthanasia could be overcome in Australia through legislation with better safeguards and monitoring compliance, this defies the experience in the Northern Territory and other jurisdictions where euthanasia is lawful. If the safeguards provided in Australia's criminal justice system were not sufficient to overcome the irrevocable argument against capital punishment, it is very difficult to conceive of a euthanasia regime which could ensure that there was no risk of error.⁷⁴¹

- 3.214. The gaping hole in the proponents' argument that assisted suicide can be safely regulated is clear when issues around self-reporting, lack of witnesses and the irrevocable nature of assisted suicide are considered. Since investigation and prosecution present such a challenge, including in jurisdictions where assisted suicide is already legalised, together with the fact that there is no redress for the person who has been killed, the Parliament of Western Australia should rule out legalising assisted suicide in this State.

Finding 117

None of the jurisdictions where assisted suicide has been legalised have yet developed a system that gathers reliable data on all requests and instead rely on the self-reporting of doctors notwithstanding the inherent conflict of interest present.

Finding 118

Western Australia's Director of Public Prosecutions has no capacity to compel evidence from the sole surviving witness in an assisted suicide.

⁷⁴¹ Ibid at 7 and 12.

Chapter 3

Finding 119

There is no capacity for a victim of a wrongful assisted suicide to seek redress.

Finding 120

Capital punishment was abolished in Western Australia, notwithstanding the extensive safeguards in the State's criminal justice system, due to the risk that an innocent person may be executed.

Finding 121

Authentic oversight of an assisted suicide regime is made difficult by a reliance on self-reporting and is made impossible by the unavailability of the best witness.

Recommendation 19

The Government and the Parliament of Western Australia should rule out introducing any assisted suicide regime due to the known unresolved issues with reporting, investigation, prosecution and redress.

Jurisdictions where Assisted Suicide Laws have Failed to Pass

- 3.215. The focus of the Committee has been on those jurisdictions where assisted suicide has been legalised, including Victoria, Oregon, Canada, the Netherlands, Switzerland and Belgium. No investigative travel was undertaken by the Committee to any of these jurisdictions.
- 3.216. The Committee's majority report has not assessed evidence from those jurisdictions that have rejected, and in some cases repeatedly rejected, assisted suicide laws.
- 3.217. Professor Somerville noted in evidence to the Committee that seven US States have approved physician-assisted suicide (and have rejected euthanasia), but that 17 States have expressly rejected assisted suicide.⁷⁴²
- 3.218. In contrast to the Canadian Supreme Court decision in *Carter*, so heavily relied upon in Committee evidence by the academic experts who were proponents of assisted suicide, the High Court of Ireland in *Fleming v Ireland & Ors* stated:

In [Carter v Canada (AG)], the Canadian court reviewed the available evidence from other jurisdictions with liberalised legislation and concluded that there was no evidence of abuse. This Court also reviewed the same evidence and has drawn exactly the opposite conclusions. The medical literature documents specific examples of abuse which, even if exceptional, are nonetheless deeply disturbing. Moreover, contrary to

⁷⁴² Prof Somerville, Professor of Bioethics, University of Notre Dame Sydney, JSCEOLC Transcript, 1 May 2018, Session 8 at 2.

the views of the Canadian court, there is evidence from this literature that certain groups (such as disabled neonates and disabled or demented elderly persons) are vulnerable to abuse. Above all, the fact that the number of LAWER ('life ending acts without explicit request') cases remains strikingly high in jurisdictions which have liberalised their law on assisted suicide (Switzerland, Netherlands and Belgium)—ranging from 0.4% to over 1% of all deaths in these jurisdictions according to the latest figures—without any obvious official response speaks for itself as to the risks involved.⁷⁴³

3.219. The House of Lords in the United Kingdom concluded that:

We do not think it possible to set secure limits on voluntary euthanasia... it would not be possible to frame adequate safeguards against non-voluntary euthanasia if voluntary euthanasia were to be legalised. It would be next to impossible to ensure that all acts of euthanasia were truly voluntary, and that any liberalisation of the law was not abused. Moreover to create an exception to the general prohibition of intentional killing would inevitably open the way to its further erosion whether by design, by inadvertence, or by the human tendency to test the limits of any regulation. These dangers are such that we believe that any decriminalisation of voluntary euthanasia would give rise to more, and more grave, problems than those it sought to address.⁷⁴⁴

3.220. This decision has not been overturned in the United Kingdom, despite more than 10 attempts to introduce assisted suicide in that country since that time. As recently as 2015, a physician-assisted suicide bill was voted down in the United Kingdom, 330 votes to 118.

3.221. Between 1994 and 2017, a total of 231 bills to legalise assisted suicide have been introduced in the United States. Only seven of these bills have been successful. In 2017 alone, 43 bills were introduced in 26 states—all of which failed to pass.⁷⁴⁵

3.222. Assisted suicide legislation has also been unsuccessful introduced some 50 times by Australian legislatures since 1993.⁷⁴⁶ Only two legislatures in Australia have passed

743 [2013] IEHC 2 (emphasis added).

744 Report of the Select Committee on Medical Ethics, House of Lords, Vol 1, Session 1993-1994, 1994 London HMSO at 49, paragraph 238.

745 Alex Schadenberg, 'Assisted suicide legalisation defeated in the US in 2017,' 31 July 2017, citing the research of Dr Jacqueline H Abernathy, Tarleton State University.

746 Willmott, White, Stackpoole, Purser and McGee (2016) '(Failed) voluntary euthanasia law reform in Australia: Two decades of trends, models and politics,' *UNSW Law Journal* 39(1) 1 at 4, provided by Prof Willmott and Prof White, Directors, Australian Centre for Health Law Research, and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, in JSCEOLC Submission 560.

Chapter 3

assisted suicide laws in that time, being the Northern Territory (the operation of the *Rights of the Terminally Ill Act 1995* (NT) is considered in detail earlier in this Chapter) and the recent passage of the *Victorian Assisted Dying Bill 2017* (Vic) that has not yet come into effect. Notwithstanding this development, the AMA remains opposed to euthanasia and physician-assisted suicide.⁷⁴⁷

- 3.223. These statistics provide a proper context in which to consider the statements made by euthanasia proponents Dying With Dignity (WA) to the Committee that ‘euthanasia and physician-assisted suicide are increasingly being legalised’ and that ‘the number of jurisdictions around the world providing assisted dying is growing steadily.’⁷⁴⁸
- 3.224. In fact, in the first half of 2018 assisted suicide legislation has already been rejected in Finland,⁷⁴⁹ Guernsey,⁷⁵⁰ and Portugal.⁷⁵¹
- 3.225. In a ruling passed down in June this year the UK Court of Appeal rejected the argument brought by Mr Noel Conway that the current blanket ban on assisted suicide under the *Suicide Act* is incompatible with his human rights.⁷⁵²
- 3.226. Mr Antonio Filipe, Member of the Portuguese Parliament, explained that the Communist Party in Portugal saw euthanasia:

not as a sign of progress but a step towards civilizational regression with profound social, behavioural and ethical implications.

In a context in which the value of human life is frequently made conditional on criteria of social utility, economic interest, family responsibilities and burdens or public spending, legalisation of early death would add a new dimension of problems.

First of all accelerating the deaths of those to whom society refuses to respond and support in situations of fragility and need. Faced with

747 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript 18 May 2018, Session 1 at 5.

748 Dying with Dignity (WA), JSCEOLC Submission 565, at 15 and 24.

749 A citizens’ initiative on ‘active death help,’ or euthanasia, was overwhelmingly rejected by the Finnish Parliament by a vote of 128 to 60 in May 2018: ‘Riksdagen går inte vidare med att legalisera eutanasi – rösterna föll 128–60,’ Hufvudstadsbladet, 4 May 2018.

750 In May 2018, a requete, similar to a private member’s bill, was voted down 24 votes to 14 in Guernsey: Sarah Knaption, ‘Guernsey rejects assisted dying after three day debate,’ *The Telegraph*, 18 May 2018.

751 A euthanasia bill drafted by the ruling Socialist party in Portugal was defeated in May 2018, 115 votes to 110. The Communist party, usually a strong ally of the ruling Socialist party, joined the conservative CDS People’s Party in voting against the euthanasia bill: Andrei Khalip, ‘Portugal parliament rejects legal euthanasia in divisive vote,’ *Reuters*, 30 May 2018.

752 *Noel Douglas Conway v The Secretary of State for Justice* [2017] EWCA Civ 16; see Lizzie Dearden, ‘Terminally ill man loses latest round of legal battle against UK’s ban on assisted dying,’ *The Independent*, 27 June 2018

*human suffering, the solution is not to divest society of responsibility by promoting early death but to ensure conditions for a dignified life.*⁷⁵³

- 3.227. It is clear that ‘The relief of suffering, loneliness and helplessness in the terminally ill is one of the major challenges facing our society in general and the health care professions in particular.’⁷⁵⁴ However, as Antonio Filipe asserts, assisted suicide is not the solution. Western Australia should follow the lead of Portugal, and countless other jurisdictions both here in Australia and around the world, who have refused to promote early death and have not decriminalised assisted suicide. Instead, efforts should be made by the government of Western Australia to ensure conditions for a dignified life for all Western Australians.

The Victorian Model and Logical Incremental Extension

Heavy Criticisms of the Victorian legislation by Proponents of Assisted Suicide

- 3.228. Unlike the Northern Territory experience, the Victorian experience is not a lived experience. This was noted by Clinical Professor David Forbes, Acting Chief Medical Officer of the Department of Health, Western Australia. When asked about the implications and impact in Victoria of the *Voluntary Assisted Dying Bill 2017* (Vic), Professor Forbes gave evidence to the Committee that, from discussion with his colleagues in Victoria, ‘My impression is that they do not know what they do not know, having legislated. There are a lot of complex issues about management of people that are still to be resolved that legislation does not solve.’⁷⁵⁵
- 3.229. Concern was raised from a medico-legal perspective about the management of Schedule 8 drugs in the community under the Victorian model, where, like the practice in Oregon, ‘a drug that is potentially even more lethal than many drugs on [the Schedule 8 list] ...may just be placed into the hands of an individual to then take back to their home and possibly administer... so then we are left with what is potentially a very lethal drug being out in the community.’⁷⁵⁶
- 3.230. In addition, before the legislation has even come into force, it has been the subject of significant criticism by many assisted suicide proponents.
- 3.231. Dr Sinclair of the University of Western Australia criticised the *Voluntary Assisted Dying Act 2017* (Vic) as being too narrowly framed. It is his view that the Victorian framework for eligibility, which requires people to have a life-limiting illness with a life expectancy

753 ‘Portugal votes against decriminalising euthanasia,’ 31 May 2018

<<https://morningstaronline.co.uk/article/portugal-votes-against-decriminalising-euthanasia>>

754 Zalberg JR and Buchanan JD (1997) ‘Clinical issues in euthanasia,’ *MJA* 166 150 at 151.

755 Prof Forbes, Acting Chief Medical Officer, Department of Health, JSCEOLC Transcript, Session 2, 18 May 2018 at 45.

756 Mrs Greenwood, Chief Executive, Catholic Health Australia, JSCEOLC Transcript, 28 February 2018, Session 1 at 15.

Chapter 3

of less than six months, or 12 months in the case of it being a progressive neurological condition, is too narrow. Also said to be too narrow is the requirement that the patient have full legal capacity to execute their own decisions. Dr Sinclair was critical that advance directives for assisted suicide were also explicitly not permitted within this legislation.⁷⁵⁷ Dr Sinclair elaborates:

*As Professor Kathy Eagar commented in relation to the Victorian legislation, it is very narrow in scope and incorrectly frames the matter as a health issue, rather than a social issue. Perhaps this strategy might have been taken as a political compromise, but she also argues that it sidesteps the difficult debate about the real reasons why people choose assisted dying—that it is more often about wanting to maintain independence and control, rather than avoiding severe pain at the end of life. That is what we see from the empirical evidence from people who actually request and follow through on a request for assisted dying.*⁷⁵⁸

- 3.232. In their submission to the Committee, Dr Sinclair and Associate Professor Blake argue that the Victorian model is too narrow in its scope in that it can only be accessed by those with a terminal illness who are expected to die within a year. They suggest that setting time limitations is not useful or practical, and that access should not be limited only to those with a terminal illness, but that other chronic conditions should also be included.⁷⁵⁹
- 3.233. Like Dr Sinclair and Associate Professor Blake, Professors White and Willmott were also critical of the inclusion of time frames or time limits in assisted suicide legislation:

*First, the balancing of values... does not point to the need for a specified period of time. Secondly, it is difficult to predict with any certainty when a person is likely to die, making the eligibility certification a challenging if not impossible task for the doctor. Thirdly, a practical harm that can occur when temporal limits are imposed is that people who have a relevant medical condition that will cause their death but are outside the relevant time period may choose to starve themselves until they are close enough to death that the time condition is satisfied.*⁷⁶⁰

- 3.234. The Professors suggest that the removal of a time limit to require a particular proximity to death would enable people with fatal illnesses such as cancer, motor neurone disease

757 Dr Sinclair, Research Fellow, University of Western Australia, JSCEOLC Transcript, 26 February 2018, Session 3 at 11.

758 Ibid.

759 Assoc Prof Blake and Dr Sinclair, University of Western Australia, JSCEOLC Submission 584 at 9.

760 Willmott and White (2017) 'Assisted Dying in Australia: A Values-based Model for Reform,' *Tensions and Traumas in Health Law* at 503-4, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

and dementia (provided he or she retains capacity) to obtain assistance to suicide, and would also include a person with a medical condition such as quadriplegia who required artificial nutrition and hydration to survive.⁷⁶¹

- 3.235. Dr Lancée also gave evidence to the Committee that the Victorian legislation was too ‘bureaucratic:’

*The group Doctors for Assisted Dying Choices is preparing a review of the Victorian Act, which has 142 sections and 130 pages. This compares to the 12 pages of the Oregon Act. The group Doctors for Assisted Dying Choice is very keen to see a simplified less bureaucratic bill for Western Australia.*⁷⁶²

- 3.236. The 68 criteria in the Victorian bill were considered by Dr Lancée to be ‘excessive and create needless barriers to the most vulnerable, the terminally ill.’⁷⁶³
- 3.237. Mr Perron gave evidence that ‘[t]he Victorian bill has unfortunately been drafted with a view to minute control of the process at every stage and that has made it overly bureaucratic and unnecessarily expensive.’⁷⁶⁴
- 3.238. Dr Nitschke considered the Victorian legislation to be ‘so safe as to be almost unworkable.’ He stated ‘I have indicated that I believe the Victorian law, which will come in next year, is probably the world’s most unworkable piece of legislation.’⁷⁶⁵

Political pragmatism

- 3.239. In direct contrast with those criticisms made of the Victorian legislation above, Mr Denton was supportive of the Victorian Act. Reassuring the Committee that the Victorian Act will not open the floodgates to assisted suicide on demand, Mr Denton states:

*Surrounding this framework and these principles and conditions is a complex administrative structure involving 68 safeguards. It will not be an easy matter to obtain assistance to die. Nor for a doctor to sign off on it.*⁷⁶⁶

- 3.240. And:

761 Ibid at 504.

762 Dr Lancée, Medical Practitioner, JSCEOLC Transcript, 5 April 2018, Session 6 at 7.

763 Dr Lancée, Medical Practitioner, Doctors for Assisted Dying Choice, JSCEOLC Transcript, 2 March 2018, Session 3 at 2.

764 Mr Marshall Perron, Private Citizen, JSCEOLC Submission 23 at 6.

765 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 2.

766 Mr Denton, Go Gentle Australia, JSCEOLC Submission 539 at 40.

Chapter 3

Of the small number of dying persons who will consider the option of VAD [voluntary assisted dying] (as many do now) only a tiny majority will satisfy its strict eligibility criteria.⁷⁶⁷

3.241. These assurances from the non-medically and non-legally qualified witness are curious in light of his stated concern for the ‘5% of souls beyond the help of palliative care who suffer so terribly as they die.’⁷⁶⁸ To applaud a regime that will not be accessible by all those said to be in need of the regime seems, at best, counterintuitive.

3.242. Mr Denton’s reassurance to the Committee in his submission is also hollow when considered in the light of comments made during his hearing that:

Part of the reason I think [the Victorian legislation] is superior is that it has become law. I think part of the issue and problem with this debate over 20 years is that there have been attempts to pass a very wide piece of legislation through a very narrow political reality.⁷⁶⁹

3.243. In Mr Denton’s opinion it is not that the Victorian legislation is particularly safe, or workable, that makes it superior to other legislative models and warrants consideration by the Parliament of Western Australia, but that it was simply narrow enough to get through Parliament in the first place.

3.244. That assisted suicide legislation comes down to what is politically pragmatic is further illustrated in this comment by Mr Denton, with regard to the assisted suicide of the elderly and those without a terminal illness:

I deeply understand this. I think there are many older people who do not have what we call a terminal disease who have so many different illnesses and ailments that their life is absolutely miserable. Their life is full of suffering. I deeply understand that. I know in the Netherlands and Belgium that under their law, which is very differently framed to other places, which refers to unbearable or unendurable suffering, that they do allow cases of people with multiple ailments but not necessarily a terminal disease. Personally, I think that is a humane thing to do but I think politically in Australia, it is probably not an acceptable thing to do... [Dr Nitschke] would argue that, “But you are just actually not sectioning off a particular group of the community.” In some ways, that is true, but that is because I believe, as I said before, that there is a political reality in this country. We have to write laws that suit our society and that suit our medical profession. So I understand where that

767 Ibid at 38.

768 Ibid at 7.

769 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 4.

*desire comes from but it is my belief that it is not a political reality in this country at this time.*⁷⁷⁰

- 3.245. Evidence of political pragmatism is seen in this exchange between Committee member Hon Dr Sally Talbot and Mr Francis, assisted suicide proponent:

Hon Dr SALLY TALBOT: Mr Francis, can I explore with you a bit further the question of who is included in the provisions. You mentioned the difficulty presented, for example, by the Victorian legislation for people with motor neurone disease. The committee is familiar with that statistical evidence that people with cancer will often have quite a high quality of life until relatively shortly before they die whereas people with other sorts of diseases, particularly neurodegenerative diseases, will have a rapid decline fairly early on. One of the things that has interested me about watching the Victorian process is a concern about people with dementia and the various forms of dementia, not just Alzheimer's, so the movement-related dementias associated with Parkinsonism, your Parkinson-type diseases. Do we need to include people with those diseases in this kind of legislation? I will just start with that broad question.

*Mr FRANCIS: Thank you, Dr Talbot. That is an excellent question. I would preface my remarks by saying include in a bill those provisions that are likely to enjoy the support of the majority of members on the floor of the house, politics being the art of the possible. It would be wise to consult members as to what their views were.*⁷⁷¹

- 3.246. Despite criticising the Northern Territory ROTI Act as containing too many safeguards that were difficult to work with, Dr Nitschke states that 'I suppose people learnt from that, in particular people seeking legislative change, that there needs to be perhaps even tougher laws so that they actually pass the parliamentary process.'⁷⁷²

- 3.247. In reference to the Victorian legislation, Mr Perron gave evidence to the Committee that in order to get it through parliament:

they have made it, as the Premier has declared, probably the most conservative legislation in the world. I am not sure that that is a thinking

770 Ibid at 11.

771 Mr Neil Francis, Dying for Choice, JSCEOLC Transcript, 9 April 2018, Session 1 at 17 (emphasis added).

772 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session1 at 2 (emphasis added).

Chapter 3

*we should be so proud of, but at least we have legislation. I understand in politics it is the art of the possible.*⁷⁷³

- 3.248. In discussing his *Voluntary Euthanasia Bill 2009* (WA) in a Western Australian Voluntary Euthanasia Society Newsletter, Hon Robin Chapple MLC also identified the need for political pragmatism in first getting a restrictive piece of legislation passed so that extension can follow:

*I realise this is a very restrictive Bill. However, it was my intention to draft a restrictive Bill. This is because a restrictive law has the best chance of being passed by the current Western Australian Parliament. I know many readers will be disappointed that this Bill does not go further, does not apply to more people and does not allow for administration of euthanasia by a person other than a medical practitioner. But this law is a good start, and a step in the right direction.*⁷⁷⁴

One person's safeguard is another person's obstacle

- 3.249. Proponents of assisted suicide encouraged the Committee to consider whether safeguards are really necessary since the protection of patients from abuse can be achieved 'without subjecting ill people to a protracted bureaucratic process in an already stressful and likely painful situation.'⁷⁷⁵ Mr Francis advised 'what I would encourage you to do is to think actively about how precious we are going to be about a gazillion criteria in relation to a physician-assisted death.'⁷⁷⁶ Meanwhile Dying With Dignity's submission recommended that 'such limitations should be confined to those that are reasonably necessary to ensure that the individual's wishes regarding their end of life are given primacy.'⁷⁷⁷
- 3.250. In his book *Angels of Death: exploring the euthanasia underground*, Magnusson notes that 'For some, safeguards are an obstacle to patient autonomy, an invitation for 'compassionate totalitarians' to dominate weak and frail patients at the very time they most need to have their autonomy respected' and 'The stricter the process for screening out wrong reasons, however, the more difficult it becomes for patients to have their 'right' reasons vindicated.'⁷⁷⁸

773 Mr Marshall Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 5 (emphasis added).

774 Hon Robin Chapple discussing his *Voluntary Euthanasia Bill 2009*, quoted in *WAVES News*, Vol 30, Issue 1, February 2010 (emphasis added).

775 Exit International (WA), JSCEOLC Submission 100 at 2.

776 Mr Neil Francis, Dying for Choice, JSCEOLC Transcript, 9 April 2018, Session 1 at 11.

777 Dying with Dignity (WA), JSCEOLC Submission 565, at 3.

778 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 252 and 253.

- 3.251. Dr Nitschke was highly critical of the safeguards written into the ROTI Act, suggesting that they made very sick people ‘jump through hoops’ and in his experience were not workable in practice:

Of course, what we got in that piece of legislation, that Rights of the Terminally Ill Act, was a piece of legislation that made very sick people jump through hoops. When the law passed, I found myself dragging very sick people—in the first case, Bob Dent—from doctor to doctor to get the signatures necessary to demonstrate eligibility to die. The irony of that was not missed on people like Bob Dent who was so sick, yet he said, “I have to qualify to be eligible to die.” I felt cruel having to drag him around to make him satisfy those onerous restrictions of that law. I saw the need for safeguards, but they were particularly difficult ones to comply with.⁷⁷⁹

- 3.252. In discussing the Canadian experience, Downie argues that criteria for access and procedural safeguards have had negative consequences and have caused suffering and that safeguards (such as capacity required at the time of provision, mandatory waiting periods, access limited to those for whom death is ‘reasonably foreseeable’ and allowing providers and institutions to opt out) must be avoided:

beware of negative consequences that can accompany particular turns of phrase in legislative drafting and particular positions taken on substantive issues in the debate about criteria for access and procedural safeguards. In particular, as illustrated earlier, there are serious negative consequences flowing from the following elements of the Canadian legislation: capacity required at time of provision; mandatory waiting periods; access limited to those for whom death is ‘reasonably foreseeable’; and allowing providers and institutions to opt out. This is not to say that legislators must avoid all of these elements (although I would argue for that). Rather, it is to say that legislators must be aware of the consequences of proceeding with those elements. It might be argued that the Canadian government did not know and therefore should not be blamed for the consequences of their legislative drafting. However, any jurisdiction that follows Canada will have been forewarned and will therefore bear the responsibility for the suffering that ensues.⁷⁸⁰

- 3.253. Dying with Dignity also note restrictions ‘imposed by society’ based on a terminal prognosis timeframe, like those contained in the Victorian legislation and recommended

779 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 2.

780 Downie J (2017) ‘Medical Assistance in Dying: Lessons for Australia from Canada,’ *QUT Law Review* 17(1) 127-146 at 144-5.

Chapter 3

by Mr Denton, are ‘cruelly drawn’ and ‘arbitrary’ categories that should be minimised and that maximal weight should be attached to the right of a rational and informed person to make their own choices.⁷⁸¹

Arbitrary eligibility criteria and discrimination

- 3.254. Professors White and Willmott note that a key principle of the rule of law identified by the Law Council of Australia is that ‘the law should be applied to all people equally and should not discriminate between people on arbitrary and irrational grounds.’⁷⁸²
- 3.255. The Professors suggest that there is a right to assistance to die that applies under certain prescribed and limited conditions. However, as Carr correctly asserts, ‘Once you introduce rights to one group of people, it is a political inevitability that others will soon demand to have those rights extended to them in the name of equality. Anything less than this incremental extension of rights is surely discrimination, is it not?’⁷⁸³
- 3.256. The issue of rights discrimination was also identified by former Attorney General Hon Michael Mischin MLC in parliamentary debate about the establishment of the Joint Select Committee on End of Life Choices and the terms of reference of the Committee:

If we are talking about a fundamental right to choose to end one’s life and to get assistance to achieve that end, why should it be under any constraint from any legislation? It is either a right or it is not. If it is a right that should be granted to people—if it is to be allowed, if you like, forgetting about the terminology or detail about how it is done—and if it is such a fundamental right for someone subject to a chronic and painful illness that is untreatable and unbearable, why should it be limited to any time limit before that? Why should it be limited at all to terminal, chronic illnesses when the pain is unbearable and untreatable? Surely, if someone has a lifetime of chronic pain that is unbearable and incapable of relief ahead of them, I would have thought that having a time limit is less persuading as to why someone should be allowed to kill themselves with assistance than being able to kill themselves well in advance. Why should it be limited to physical pain and not mental anguish? Why should it be limited to adults of sound mind? Should there be some kind of assistance from, perhaps, experts

781 Dying with Dignity (WA), JSCEOLC Submission 565 at 18.

782 Willmott and White (2017) ‘Assisted Dying in Australia: A Values-based Model for Reform’ *Tensions and Traumas in Health Law* at 495, submitted in Professors Willmott and White, Directors, Australian Centre for Health Law and Research and Ms Neller, Centre Coordinator, Australian Centre for Health Law Research, JSCEOLC Submission 560A.

783 Carr L (2017) ‘“It’s about people like me”: disabled and dead against euthanasia,’ <<https://www.mercatornet.com/careful/view/its-about-people-like-me-disabled-and-dead-againsteuthanasia/20276>> quoted in Rev Dr Parkinson, LJ Goody Bioethics Centres, JSCEOLC Submission 53 at 7.

to make these decisions for others who are incapable of making those decisions themselves? Where do we cross the line between doctors being the ones who we can entrust with the responsibility of saving our lives to the ones who will counsel, “You are going to die anyway. Let me try to relieve your pain by helping you kill yourself”?

...

If there is such a right, I hope that no constraints will be put on the exercise of that right because only then is it a proper right. If it should be, as Hon Alannah MacTiernan has told us, that people ought to decide when to draw the line under their own lives, why should it be limited in the way that has been hinted at? Those are some of the things that I hope this committee will explore and do so robustly and not with any preconceived wishy-washy idea of limiting this to specific circumstances, knowing that someone will fall beyond those particular lines that will be arbitrarily drawn and having to extend them from time to time as time goes on.⁷⁸⁴

- 3.257. That exclusionary criteria are considered to be discriminatory by proponents of assisted suicide is illustrated by the evidence given to the Committee by Dr Syme about the exclusion of children from assisted dying laws:

I do believe that there is a very reasonable place for allowing children under 18 who have got the mental capacity to make these decisions, that that could be allowed, but in saying that, I do acknowledge that politics is the art of the possible and all of you politicians face the difficult issue of reaching a piece of legislation which will be acceptable to everybody.

...

I do believe that not extending the legislation to children of mature age and capacity can be discriminatory.⁷⁸⁵

- 3.258. Dr Syme goes on to suggest that although the Victorian legislation was pragmatically restrictive in order to get passed by Parliament, it is discriminatory in its operation:

But the simple medical fact is that if suffering is the reason why people request assistance to die, not how long they have got left to live, then suffering is not confined to people with a particular period of time to

784 Hon Michael Mischin, *Hansard*, Legislative Council, 22 August 2017 at 3100 – 3101.

785 Dr Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, JSCEOLC Transcript, 13 April 2018, Session 4 at 3 and 4 (emphasis added).

Chapter 3

*live. As I have tried to indicate to you, there are a number of people who will be going to die in a lot longer than six months, but they have intolerable suffering. But, again, you come back to the political question: What is acceptable to you people as politicians? What is possible to be passed as legislation? The Victorian committee and the Victorian Parliament accepted that for legislation to be accepted by the community and by the politicians, there had to be a limitation, and it was accepted that the legislation in Oregon of six months was to be the model. I do not disagree with the fact that that is a reasonable model, but I will make the point that it is discriminatory against some people with some illnesses who will have grievous suffering who will not qualify under that legislation.*⁷⁸⁶

- 3.259. Ironically, in discussing a patient who suffered from a mental illness and who sought his assistance to die in his book *A Good Death*, Dr Syme acknowledges that ‘The reality is that it is not possible to solve, or even begin to solve, everybody’s problems.’⁷⁸⁷ This begs the question on what basis can lawmakers discriminate in drawing criteria around access to assisted suicide?
- 3.260. Dr Michael Gannon, President of the AMA (as he was at the time), in discussing the assisted suicide of Dr Goodall in Switzerland, said ‘I have serious concerns about a community where we make arbitrary decisions about whose life is valuable enough to continue and whose should be ended under the law.’⁷⁸⁸
- 3.261. As Mr Byl, who gave evidence to the Committee about his own experience living with a disability, states:

*It is only logical that if euthanasia is legalised with, of course, safeguards in place, that these safeguards will be challenged. Equality and anti-discrimination demand that they be challenged. Euthanasia with safeguards means a select few will be allowed to die. They are on the right side of the barrier, so to speak. But what are you going to say to the guy on the other side of the barrier or, in fact, even up against it? Are you going to say, “Sorry, mate. Your life isn’t tough enough. You’re not enough of a burden. You’ll have to keep living?”*⁷⁸⁹

- 3.262. Any restriction on eligibility is an arbitrary one and is discriminatory.

786 Ibid at 5-6.

787 Syme R (2008) *A good death: An argument for voluntary euthanasia* at 218.

788 Dr Gannon quoted by Philip Oltermann in ‘David Goodall, Australia’s oldest scientist, ends his own life aged 104,’ *The Guardian*, 10 May 2018.

789 Mr Byl, Private Citizen, JSCEOLC Transcript, 1 May 2018, Session 6 at 2.

Restrictive legislation will be amended through logical incremental extension

- 3.263. The Committee received evidence that during the legislative proposal phase the focus is almost universally on an alleged group of hard cases, small in number, who, it is said, are suffering from unbearable physical pain or other physical symptoms that cannot be relieved by even the best palliative care. After implementation, however, it becomes clear that the real focus is on autonomy, an alleged right to assistance to die, the application of which is extended to more and more categories of suffering.⁷⁹⁰
- 3.264. Proponents of assisted suicide were very aware of the need to endeavour to distance themselves from any ‘slippery slope’ argument:

Mr WOOD: I think that in an ideal situation—and it is not a slippery slope-type argument—as time goes by, the act will be reviewed with a view to saying, “Well, what problems have we got here? Can we solve them?” and go from there.⁷⁹¹

...

Mr WOOD: ...I think we should start small, possibly start with a very tight bill, and, as society progresses and the demand and the logic is there to expand slightly, well then that is the prerogative of Parliament.

Hon NICK GOIRAN: So, Mr Wood, you are a supporter of the slippery slope, then?

Mr WOOD: That is not the slippery slope.

Hon NICK GOIRAN: You would like to describe it in some other fashion?

Mr WOOD: I think there is a difference between a slippery slope, which is where somebody alleges that a progression from one state to another is inevitable.

Hon NICK GOIRAN: Right, because I thought I just heard you say that we should start small and then continue to progress.

Hon Dr SALLY TALBOT: That is not a slippery slope.

Mr WOOD: If society suggests and the Parliament agrees that we should have it available in a wider form.

790 Mr Egan, Research Officer, Defend Human Life!, JSCEOLC Submission 5 at 1.

791 Mr Wood, Christians Supporting Choice for Voluntary Euthanasia, JSCEOLC Transcript, 13 April 2018, Session 3 at 4.

Chapter 3

Hon Dr SALLY TALBOT: The slippery slope is actually a technical definition of the way of arguing that is false. Mr Wood is exactly right.

Hon NICK GOIRAN: I am intrigued by the distinction that is being drawn by both Mr Wood and my colleague.⁷⁹²

- 3.265. Mr Luley of Dignitas described this logical incremental extension in the following way:

What you have, of course, and that is a development in society—when you have new needs for society coming, then you might have the situation that some people say, “Thank you for this law which gives, let us say, terminally ill people with six months’ life expectancy the possibility for end-of-life choice,” but then after 10, 20 years, you might have a development in society that people want more freedom of choice. Then they might call for, “Let’s extend that to 12 months.” That is not a slippery slope. That is a development in society where people want to have more freedom of choice. I think that our opponents mix that up to make an argument against even freedom of choice.⁷⁹³

- 3.266. Dr Nitschke also gave evidence to the Committee that in adopting ‘an extremely safe piece of legislation with many safeguards,’ Western Australia may in fact:

end up with a model that really does not serve the interests of people who are seeking help to die. You can see some of these problems because when you start trying to codify—that is, set up the conditions under which a person can get help to die, and make those conditions very, very clear and strict—then of course there will be argument about whether or not people qualify... What qualifies? Do you have to be terminal? What is wrong with chronic suffering as a reason for wanting to die?⁷⁹⁴

- 3.267. Dr Nitschke continues:

What has happened where we have seen laws change... such as places like Holland, where I am now a resident, is that over the years people realised that the onerous restrictions cause difficulty and, of course, there is an erosion or a change to those requirements. We have seen changes here, first of all, to the age of eligibility, and then the nature of the condition and the nature of suffering that entitles a victim to make

792 Mr Wood, Christians Supporting Choice for Voluntary Euthanasia, Hon Dr Sally Talbot, Hon Nick Goiran, JSCEOLC Transcript, 13 April 2018, Session 3 at 6-7.

793 Mr Luley, Board member, Dignitas, Switzerland, JSCEOLC Transcript, 9 April 2018, Session 2 at 3 (emphasis added).

794 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 2.

use of these laws. The rest of the world says, "That's an example of the slippery slope, the fact that we are seeing populations say, 'These laws don't really serve what people want.'" I think, quite correctly, we have seen a change and a modification of those laws. Rather than go through that process, I would urge the Western Australian Parliament to consider the fact that there will be this pressure to erode these laws—I do not think erosion is a good word, but to modify the laws to better serve the broader interests of the people. As time moves on in these 20 years, we are seeing a growing clamour for people to say, "Look, I want this option myself." In other words, we are seeing it finally coming to the point where people are saying, "This is not just some medical privilege for the very sick to be judged by a panel of doctors, but this is a fundamental human right." In the history of this issue with countries that have had 20 years or so experience with such laws, such as here [in the Netherlands], the question is now: is it a right or not for an elderly person to simply say, "If I want these drugs, I should be provided with them?" In other words, we are seeing a change from it being considered not just as a medical privilege for the seriously ill who qualify, but as a basic human right.

...

*I want to see a debate held about a "tired of life" argument such as we are seeing here in the Netherlands. Should every person over a certain age be issued with those drugs? That is where the debate will go. I am predicting that. It will happen even in Western Australia and other Australian states, because that is where the debate around the world is heading.*⁷⁹⁵

- 3.268. Dr Syme also acknowledged a broadening of the scope of assisted suicide practice in countries with assisted suicide laws:

*Most of those countries **initially** regarded terminal illness as the critical point, but in fact the legislation was broader than that, and as time has gone on they have understood better the question of intolerable suffering. As a result, some other conditions, such as those I have mentioned, have come to be included in the criteria of acceptance. That*

⁷⁹⁵ Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 3 and p8 (emphasis added).

Chapter 3

*is not a slippery slope; that is simply a better understanding of the nature of the legislation.*⁷⁹⁶

- 3.269. Dr Syme's comments suggest that the original intent of the legislation in other jurisdictions was quite narrow and applied only to the rare cases of terminal and competent adult patients with severe suffering from a physical illness at end of life, but that over the passage of time, even where the wording of the legislation has not changed, the category of persons for whom the legislation was intended to apply has grown by interpretation to include children, persons with non-somatic illness and persons without capacity including Alzheimer's and dementia patients.
- 3.270. This expansion beyond the original intent of the legislation has been identified by opponents of assisted suicide legislation in their concern that it:

*is not just about later amendment of the original statute; even though that is also likely and the possibility of that is inherent in the enabling act. But it is also about interpretation and the reality that black-letter law is never going to be able to keep any legislation so tightly interpreted as always to reflect the original intentions.*⁷⁹⁷

- 3.271. Such a concern is not purely theoretical, but was evidenced in the administration of the ROTI Act, where a patient who was not suffering from a terminal illness was euthanised, to which Mr Perron, as Chief Minister and architect of the Northern Territory legislation responded that 'it was not necessarily in accordance with the legislation's intent, but no party involved regrets what they did in that circumstance.'⁷⁹⁸ Kissane suggests that '[s]uch breaches of the Regulations were permitted by a legal system wanting to facilitate the legislation, thus removing the very safety features that had been designed to protect the vulnerable.'⁷⁹⁹
- 3.272. Dr Syme also, in effect, acknowledges that indeed the laws in the Netherlands have changed through judicial interpretation (as already identified earlier in this Chapter):

The Netherlands have dealt with this issue through the courts and the courts have determined, and I agree, that a person with a severe, chronic psychiatric illness, which has been present for years and years and has been resistant to all treatment, may very well have severe intolerable suffering. You know, our suffering occurs in the mind. A very

796 Dr Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, JSCEOLC Transcript, 13 April 2018, Session 4 at 3 (emphasis added).

797 Paul Russell quoted in Debra Vermeer, 'Euthanasia – Quebec, Dutch, Belgian and Oregon laws a "mess",' *NewsWeekly*, 11 February 2017.

798 Mr Marshall Perron, Private Citizen, JSCEOLC Transcript, 13 April 2018, Session 2 at 9.

799 Kissane DW (2002) 'Deadly days in Darwin,' in *The Case Against Assisted Suicide*, Foley and Hendin (eds) at 192-209.

*famous Australian psychiatrist, whose name escapes my mind—he developed lithium for manic depression—said that depression is the most painful illness known to man, equal in severity to somebody suffering with cancer. It is undeniable that some people with chronic, untreatable psychiatric illness have the most severe suffering. Nevertheless, the Victorian Parliament decided that that was not to be part of the criteria, and I bow to their judgement, although, in my opinion, there is a sound argument for including such people, but that is a political judgement. Whether it is acceptable to your parliamentarians and the public is another matter.*⁸⁰⁰

- 3.273. In relation to the careful drafting of restrictive legislation to decriminalise assisted suicide in Western Australia, Dr Nitschke gave evidence to the Committee that:

*It is pragmatics. It is politics. I understand all that. But there are risks, too, because what you will get, and what the Victorians would get, I predict, is a law that very quickly comes under challenge from people saying this is inhumane and needs to be modified.*⁸⁰¹

- 3.274. In order to avoid the ‘arduous process’ of future legislative amendment, Dr Nitschke made the following suggestion to the Committee:

*Yes, I think it might be wise just to omit the time line completely... In countries that have had legislation for a long time, that is generally where they have gone. They have tried to avoid the time line issue. They have tried to avoid statements such as “terminal” and used this idea of “chronic suffering” and, increasingly, as I have indicated, moved towards it simply being “patient request in the light of an informed decision”, with the patient deciding that their life is no longer worth living. That is going to take a while to get to, I suspect, in Australia, but I think that is ultimately where the laws will head. I suppose you can perhaps short-circuit or at least cut off some of the arduous process over the next few years by having some progressive legislation in place, get it through the Western Australian Parliament, to sort of bypass some of these inevitable pieces of conflict which will come up over the coming years.*⁸⁰²

800 Dr Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, JSCEOLC Transcript, 13 April 2018, Session 4 at 9 (emphasis added).

801 Dr Nitschke, Exit International, JSCEOLC Transcript, 13 April 2018, Session 1 at 12 (emphasis added).

802 Ibid at 14 (emphasis added).

Chapter 3

- 3.275. Dr Nitschke's comments not only identify that the practice of assisted suicide in those countries where it has been legalised has modified over time, or moved toward a wider scope of operation, but also indicates that any so-called restrictive laws in Western Australia will also be challenged and change over time.
- 3.276. Opponents of assisted suicide have long called for caution and have identified that the category of persons able to access assisted suicide will expand:

Past the door marked 'the terminally ill' are an endless number of other doors—the chronically ill, the demented, the crippled, the deformed, the chronically depressed, the terminally sad, the heartbroken, the hopeless, the unloved, the lonely, the simpletons, the economically unviable. Not to mention the passageway leading to the doors marked 'infants and children'.⁸⁰³

- 3.277. Such statements are dismissed as scare mongering and a slippery slope argument unsubstantiated by fact.⁸⁰⁴
- 3.278. Yet the truth in the quote from Mr Michael Gawenda is evident in the very evidence presented by proponents of assisted suicide to the Committee, considered below, which illustrates that 'maintaining a line between killing which can or cannot be legally justified will be difficult'⁸⁰⁵. As the Dying with Dignity submission states:

As in so many aspects of life, in the end this issue of boundaries on eligibility may come down to matters of fact and degree, and will call for the drawing of a line which will not completely satisfy many on either end of the debate spectrum, but which will represent a reasonable and sensible middle course.⁸⁰⁶

- 3.279. The question then becomes where does this reasonable and sensible middle course lie?

Non terminal cases

- 3.280. Given that it is the suffering of the patient that is central to the argument for legalising assisted suicide, it was suggested to the Committee that the requirement of terminal illness is actually counter-intuitive, and that the longer the person has to live with suffering, the more urgent their need for assisted suicide:

803 Michael Gawenda, 'Change of heart on euthanasia,' *The Age*, 27 May 1996 at 15, quoted in Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 231.

804 See Professors White and Willmott in White, McGee and Willmott 'As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric,' (2017).

805 Sprung et al (2018) 'Physician-Assisted Suicide and Euthanasia: Emerging Issues from a Global Perspective' *Journal of Palliative Care* (sagepub.com/journalsPermissions.nav DOI: 10.1177/0825859718777325) at 2.

806 Dying with Dignity (WA), JSCEOLC Submission 565 at 19.

If you have no quality of life, I could actually cope with knowing I have no quality of life but I have only six months to put up with it. If I knew I had 20 years to put up with it, I would want out. It is almost like it should be an inverse scale, from my appreciation.⁸⁰⁷

- 3.281. In evidence to the Committee concerning the very real suffering of people with Huntington's disease, concern was raised that a conservative piece of legislation like that passed in Victoria would not allow access to assisted dying for Huntington's sufferers and that the law would require further amendment:

There are so many other people who are going to be let down by these decisions. I am just asking you to take into account different scenarios. Do not make a law just because some other country is doing it. I think this is an opportunity for you guys to really assess what we need as a society and whether it is going to make a change to people, because you are going to be back here again talking about the same things because there are all these people who are not happy with the laws that you have made. I think society just has become complacent and people are not prepared to change and I think it is important that we do change and make a good change, and then we do not have to go back through this again.⁸⁰⁸

- 3.282. Mr Ireland also gave evidence to the Committee that a requirement of terminal illness is too constraining:

The very fact that I am here—I am asking you to broaden the scope of your legislative decisions, rather than Victoria. I would find the Victorian legislation very constraining in that it revolves around people who have a terminal illness. In my mother's case, she was not terminally ill. I believe that the focus on terminal illness and chronic illness needs to be broadened to the extent that it encompasses people like my mother, whose life was intolerable but not through terminal illness. My comment would be that I do not think the Victorian legislation goes far enough.⁸⁰⁹

- 3.283. Magnusson notes that limiting assisted suicide to the terminally ill is not logically consistent with the two principles which underpin calls for assisted suicide, that of autonomy and the desire to end a person's suffering:

807 Dr Beilby, Veterinarian, JSCEOLC Transcript, Session 11, 1 May 2018 at 4.

808 Mrs McBarron, Private Citizen, JSCEOLC Transcript, 30 April 2018, Session 8 at 3.

809 Mr Ireland, Private Citizen, JSCEOLC Transcript, 30 April 2018, Session 3 at 4.

Chapter 3

More fundamentally, as Kamisar points out, ‘if either [respect for personal] autonomy or the merciful termination of an unendurable existence’ is the basis for the right to die, ‘why limit it to the terminally ill?’ Why not extend euthanasia as a choice for those whose chronic illnesses, injuries or disabilities (AIDS, spinal paralysis, advanced emphysema, amyotrophic lateral sclerosis, multiple sclerosis etc.) are the cause of chronic and intractable suffering? If self-determination and compassion are the controlling values, why limit assisted death to illness at all? Why not make it available to those who are constantly miserable?’⁸¹⁰

- 3.284. This is evident in this comment made by Mr William Spanbroek, following Mrs Katherine McBarron’s evidence above that restrictive legislation will prevent access for people suffering from Huntington’s disease, that:

No, [the Victorian legislation] would not be enough, because the law should encompass every possibility in every illness. As Katherine said, everyone is different. For a person in a nursing home or a person dying of cancer or with what Michael died of or they are dying of emphysema, they are all different. It should not be six months. Far from it. We should do better than that and we have the opportunity to do better than that.⁸¹¹

- 3.285. Similar sentiments were echoed by Ms Marcelle van Soest, who had witnessed the suffering of her husband who had died from Mesothelioma:

I do not believe in the Victorian laws. I think they have not gone far enough. You have got to go through too much for a sick person to cope with. If you want to die, you should be allowed to die. It does not matter what other people think—family, friends, nobody. It is your life. If you have come to the end of the road and you feel that you do not want to be here anymore, you should not be, and that is how I feel.⁸¹²

- 3.286. To which Hon Dr Sally Talbot, Committee member, responded ‘That is a very clear statement and it has a lot of resonance in this room, I can tell you.’⁸¹³

- 3.287. Calls for ‘death on demand’ are now being made in Canada and Dr Yves Roberts, a central advocate for the legalisation of assisted suicide in that country at the time at which the legislation was passed, has since expressed shock at what has happened in Quebec in

810 Magnusson RS (2002) *Angels of death: exploring the euthanasia underground* at 275.

811 Mr Spanbroek, Private Citizen, JSCEOLC Transcript, 30 April 2018, Session 8 at 3-4.

812 Ms van Soest, Private Citizen, JSCEOLC Transcript, 1 May 2018, Session 4 at 8.

813 Hon Dr Sally Talbot, JSCEOLC Transcript, 1 May 2018, Session 4 at 8.

the two years since the passage of the Medical Assistance in Dying Act with calls for death on demand, and investigations into the extension of the laws to allow assisted suicide for mature minors, psychiatric illness and Alzheimer's and dementia.⁸¹⁴

The elderly

- 3.288. The extension of assisted suicide to include the elderly who are frail but otherwise physically well is made by Dr Syme:

In my own workshops discussing end-of-life preparations, I never find a single person who is looking forward to entering a nursing home. Much of my counselling work involves talking to elderly folk living alone, whose dread is of being forced to enter a nursing home. They would prefer the choice of ending their life with dignity. As more people with experience of having placed their parents in nursing homes reach the prospect of a similar experience, the chorus of voices for another option will swell. Will their voices be heard?⁸¹⁵

- 3.289. When asked by the Committee what they thought of the Victorian legislation, euthanasia advocates for the elderly Mrs Trendall and Mrs Marshall replied:

Mrs TRENDALL: I think it is a good start.

Mrs MARSHALL: As far as it goes—it has to go a bit further.⁸¹⁶

- 3.290. Dr Goodall, prior to his assisted suicide, stated that the passage of assisted suicide legislation, even a restrictive model, would be 'a step in the right direction' toward assisted suicide for the elderly:

I certainly hope my story will increase the pressure for people to have a more liberal view on the subject of voluntary euthanasia ... I think there probably will be a step in the right direction.⁸¹⁷

814 Yves Roberts MD, Secretary, College des medecines du Quebec, 'Towards death a la carte?' 10 May 2017 <<https://collectifmedecins.org/en/dr-roberts-regrets/>> referred to in evidence by Professor Somerville, Professor of Bioethics, University of Notre Dame Sydney, JSCEOLC Transcript, 1 May 2018, Session 8 at 3.

815 Syme R (2008) A good death: An argument for voluntary euthanasia at 198.

816 Mrs Trendall, Senior Citizen, and Mrs Marshall, Retired Public Servant and Senior Citizen, JSCEOLC Transcript, 7 March 2018, Session 1 at 6.

817 Claire Tyrell 'Euthanasia was Perth scientist David Goodall's dying wish,' *PerthNow*, 11 May 2018.

Chapter 3

Children

- 3.291. Mr John McGrath, Committee member, expressed concern that euthanasia could be considered for children, saying ‘Most people would not agree with that principle, I am sure. Most people in society would not agree with that with children.’⁸¹⁸
- 3.292. Yet, as has already been noted above, Dr Syme gave evidence to the Committee that ‘there is a very reasonable place for allowing children under 18 who have got the mental capacity to make these decisions, that that could be allowed,’ and that it would be discriminatory not to allow the euthanasia of minors.⁸¹⁹ Dr Syme writes in his submission ‘Does anyone think suffering from illness only starts at 18? It is well recognised by experienced paediatricians that children who suffer prolonged illness develop a maturity well beyond their years.’⁸²⁰
- 3.293. Stahle refers to this as a gradual disengagement of self-censure and of becoming accustomed to the abhorrent:

*Voltaire has said that those who can make you believe absurdities, can make you commit atrocities. The first absurdity may be to claim, against better knowledge, that it is possible to construct a safe system for the medical termination of people’s lives. Once that absurdity has been elevated to truth status, you and those you have seduced into agreeing, can actually end up supporting an activity that you initially felt was abhorrent—now with hardly any regrets at all. The abominable thing has thus been normalized or even glorified. Black has become white.*⁸²¹

Psychiatric illness

- 3.294. The Chief Psychiatrist of Western Australia, Dr Gibson, was adamant in his advice to the Committee that mental illness in the absence of any other qualifying illness should be an absolute exclusion category for assisted suicide and considered it ‘a slippery slope if we include any mental illness per se on that list [of illnesses for which assisted suicide should be available].’⁸²²

818 Mr John McGrath, JSCEOLC Transcript, 1 May 2018, Session 6 at 4.

819 Dr Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, JSCEOLC Transcript, 13 April 2018, Session 4 at 3 and 4.

820 Dr Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, JSCEOLC Submission 316 at 5.

821 Stahle F (2017) ‘Moral disengagement – Mechanisms Propelling the Euthanasia/PAS Movement,’ *Journal of Ethics in Mental Health* 10 at 14.

822 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Submission 655 at 4 and JSCEOLC Transcript, 14 December 2017, Session 5 at 5.

- 3.295. Despite admitting that ‘it is not possible to solve... everybody’s problems’ and his inability to help ‘Frank,’ a person suffering from mental illness, earlier in *A Good Death*, (considered above) Dr Syme continues

*The suffering that these people endure may be no less intolerable than those with severe physical illness—it may be worse, as John Cade asserts. Because we cannot see their disability does not mean it does not exist. They deserve our consideration. Making such assessments is a matter of high skill and the province of a panel of psychiatric experts, and should be done only after the apparent failure of prolonged, sustained and intensive treatment. There needs to be the utmost restraint, but the possibility should not be denied.*⁸²³

- 3.296. In the Netherlands, where assisted suicide was extended to people suffering from psychiatric illness through judicial interpretation, Dr Chabot, the psychiatrist involved in that landmark case, has recently expressed his total opposition to the current practice of euthanasia for those with psychiatric illness, and never anticipated at the time of his case the large number of cases for which euthanasia would be deemed acceptable.⁸²⁴

Alzheimer’s disease and dementia

- 3.297. Assisted suicide for Alzheimer’s and dementia patients is considered difficult as most legislative models (with the exception of the Netherlands and Belgium) require the person to have capacity at the time at which lethal medication is administered.
- 3.298. However, despite being firmly against assisted suicide for psychiatric illness in both his submission and in oral evidence given to the Committee, the Chief Psychiatrist of Western Australia acknowledged that excluding dementia as a mental illness from accessing voluntary assisted dying:

*is a really tough one, because someone may have had a lifelong view with regard to dementia, particularly in the context of having seen family members with dementia, and they may be very clear and it may be consistent over a long period of time that they would not wish to go through that process.*⁸²⁵

- 3.299. Alzheimer’s and dementia cases were considered by some proponents of assisted suicide as ‘a bridge too far’ at the present time:

823 Syme R (2008) *A good death: An argument for voluntary euthanasia* at 223.

824 Prof Somerville, Professor of Bioethics, University of Notre Dame Sydney, JSCEOLC Transcript, 1 May 2018, Session 8 at 3; and see Dr Chabot’s interview in *Fatal Flaws: Legalizing Assisted Death* (2018) by Kevin Dunn.

825 Dr Gibson, Chief Psychiatrist of Western Australia, JSCEOLC Transcript, 14 December 2017, Session 4 at 3.

Chapter 3

Hon Dr SALLY TALBOT: It is striking that on the list of underlying illnesses, we do not have dementia. Can you foresee any system of voluntary assisted dying that would include people with dementia?

Mr HINDLE: I do not think in the short term. I think that probably we will become a little more sophisticated with our advance health directives and that sort of thing. Maybe there will be a provision that a person can do an advance healthcare directive and say that if, in the event—because dementia is the greatest problem we are going to have in the future —

Hon Dr SALLY TALBOT: Do your members raise that as a reason for joining the organisation?

Mr HINDLE: Not necessarily. I think they would all like to have the opportunity if they became demented. But I do not think that they see that as a reality. I think they think that is probably a bridge too far. Who knows? It is a terrible disease. It is a condition so—

Mr WALKER: Sorry; can I add something again?

Mr HINDLE: Yes.

Mr WALKER: Many people raise it as a great concern and it seems to be one of those pressures that leads some people, I think, to take their lives sooner than otherwise they would have. They fear that they will lose capacity—we have not got a law yet, I know—they cannot communicate their wishes at the time when ideally they would want to, when they are in a certain kind of condition. I really have felt that some people have probably taken their lives sooner than they wanted to ideally because of the fear of dementia coming on.⁸²⁶

3.300. Dr Syme also noted that:

Dementia is the most difficult medical condition to deal with under this sort of approach. They cannot manage it, despite the fact that in the Netherlands they have been dealing with this effectively for over 35 years. We have not managed to really come to grips with the issue of dementia. In my opinion, it is the worst disease known to man, but it suffers from the extreme difficulty that by the time the person has truly intolerable suffering from their dementia, they are quite incapable of making any decision. I think it will take a lot of time for this issue to be

⁸²⁶ Mr Hindle, President, Dying with Dignity (WA) and Mr Walker, Vice President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 10.

*resolved by humanity. My wife is currently suffering from dementia, so I am acutely aware of the problem, quite apart from my affirmative views. It is a tragic disease which we need to continue thinking about, but I do not think it is really effectively possible **at the present time** to include people with dementia in legislation.⁸²⁷*

- 3.301. Mr Denton also addressed the question of whether assisted suicide should be available for Alzheimer's sufferers in Australia:

in Belgium and the Netherlands—the two places where people with dementia can legally be assisted to die; Canada is leaving its options open on it—there is division between doctors about whether or not this is something doctors should be doing. I strongly understand why they feel that way. I think it is a very, very difficult question. I do not think any doctor should be put in the position of assisting someone to die if they are not sure that that person is capable of making that request. Having said that, as I have gone around Australia speaking about this over the last three years, it is the number one question I am asked, and without fail it is the number one example I am given. We know that one in four Australians over the age of 80 suffer from dementia or some form of dementia or Alzheimer's. Even though I have seen the Netherlands model and I have admiration for it, I personally am not sure how it would be framed to help people with dementia in a way that does not put doctors in a very, very difficult situation. That being said, I do not think this is a question that is going to go away and whether it is addressed now, or in 20 years' time or 40 years' time, I think at some point, if this level of degenerative dementia in our society continues and possibly increases, then as a society we are going to want to work out how we deal with it.⁸²⁸

- 3.302. These proponents note that while it is unlikely that Alzheimer's or dementia will be included in any present day legislation, the desirability of their inclusion to eligibility for assisted suicide in the future will remain.
- 3.303. Mr Walker of Dying with Dignity (WA) even suggested that, in light of recent advanced care directives legislation, that assisted suicide for Alzheimer's and dementia patients may in fact be possible in Victoria:

We note that in Canada, that issue of capacity, including, I think, those who have lost capacity even before qualifying—the classic Alzheimer's

827 Dr Syme, Medical Practitioner and Vice President of Dying with Dignity Victoria, JSCEOLC Transcript, 13 April 2018, Session 4 at 7.

828 Mr Denton, Go Gentle Australia, JSCEOLC Transcript, 13 April 2018, Session 6 at 7.

Chapter 3

*cases—has been deferred for further consideration by the Canadian Parliament in December of this year. It is not a lost issue, but it is of importance. Victoria has implemented, as the committee would be well aware, quite new and detailed advance care directives under separate legislation, which on one view would appear to allow—there has been a recent article to this effect—perhaps the Alzheimer’s patient to provide an advance healthcare directive concerning assistance in dying at a particular point, and arguably that is now going to be the scheme operating in Victoria. We would suggest that that could be closely considered here.*⁸²⁹

- 3.304. In Canada, as has already been highlighted in this Report in the section entitled ‘*The North American Experience—Canada*,’ the Health Department is currently considering whether to extend assisted suicide to patients suffering from Alzheimer’s disease. Furthermore, a 2017 survey of Quebec caregivers found that 91 per cent of respondents were in favour of extending medical aid in dying to those suffering from Alzheimer’s and dementia, and 72 per cent said they were for assisted dying of Alzheimer’s patients who did not sign a written directive before their illness.⁸³⁰
- 3.305. In relation to Motor Neurone Disease, evidence was given by the Motor Neurone Disease Association Western Australia that they would be supportive of legislation to allow a person with the disease to put into an advance health directive that they have successfully negotiated a voluntary assisted dying contract to be activated under certain circumstances, *including the advent of a more severe dementia.*⁸³¹ There was no concern expressed by the Association that the patient would no longer have capacity at the time at which the lethal medication is administered by a medical practitioner (with patient administration impossible at that point).
- 3.306. The suggestion that advance health directives can safely provide for the patient’s long held wishes to be carried out after capacity is lost should be considered in light of the Netherlands’ experience of the euthanasia of Alzheimer’s and dementia patients. Dutch authorities are currently investigating the death of an Alzheimer’s patient who had previously written in a living will that she wanted to be euthanised ‘whenever I think the time is right.’ Later, the patient said several times in response to being asked if she wanted to die: ‘But not just now, it’s not so bad yet!’ This patient was drugged by her physician to deliberately reduce her consciousness so as to avoid her resisting being given drugs. Despite this, the patient struggled against the administration of an

829 Mr Walker, Vice President, Dying with Dignity (WA), JSCEOLC Transcript, 13 April 2018, Session 5 at 4-5.

830 Aaron Derfel, ‘Most caregivers favour assisted dying for Alzheimer’s patients: survey,’ *Montreal Gazette*, 21 September 2017.

831 Motor Neurone Disease Association (WA), JSCEOLC Response to Questions on Notice, undated at 7.

intravenous lethal injection and was physically restrained by family members to allow the physician to complete the euthanasia. The doctor claimed that she was fulfilling a written request the patient had made for euthanasia years earlier and that since the patient was not competent, nothing the woman said during her euthanasia procedure was relevant.⁸³²

- 3.307. Dr Sinclair and Associate Professor Blake also recommended to the Committee that the Victorian model is too narrow, in that it excludes access to assisted dying via advance directives, and that the Committee should consider the rationale behind the ‘contemporaneous request’ (versus the ‘anticipatory request’) model given the strong support for end-of-life planning in the legislation in many Australian jurisdictions.⁸³³
- 3.308. Dr Khorshid gave evidence that allowing assisted suicide for a patient after loss of capacity through an advance health directive is a very dangerous position to hold:

*Advance healthcare directives are directives. They are legally binding documents set at a particular point in time. We believe that decisions around end-of-life care are much more fluid; that patients change their minds as they go through a disease process. At some points in a disease process they can be wanting to end their life and then they can come out of that a week later as symptoms resolve et cetera. It is a very fluid process. Having a direction to end someone’s life in a legally binding document is very, very dangerous in our view. The patient at the time of the act would potentially not be competent and that is getting awfully close—in our view it is crossing the line into active euthanasia; into doctors choosing to end someone’s life. We would be very strongly opposed to that.*⁸³⁴

- 3.309. On whether assisted suicide may be presented as the solution to the ‘dementia problem,’ Mr Harkness gave evidence to the Committee that:

I am mindful of Australia having been at the forefront of research into the prevention and treatment of Alzheimer’s disease. It is alarming that advocates of euthanasia sometimes argue that doctor assisted suicide would enable people with dementia a release from their burden. As a former lecturer in Certificate 111 Aged Care, and in which I delivered a

832 Regionale Toetsingscommissies Euthanasie, Jaarverslag 2016, p. 54-58 <<https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2016/april/12/jaarverslag-2016/RTEjv2016.pdf>>, Regional Euthanasia Review Committees *Annual Report 2016* <https://english.euthanasiecommissie.nl/binaries/euthanasiecommissie-en/documents/publications/annual-reports/2002/annual-reports/annual-reports/RTE_annual_report_2016.pdf>

833 Assoc Prof Blake and Dr Sinclair, University of Western Australia, JSCEOLC Submission 584 at 9.

834 Dr Khorshid, President, AMA(WA), JSCEOLC Transcript, 28 February 2018, Session 2 at 19.

Chapter 3

*module on Dementia, I spoke about many employment areas that contained a focus on maintaining, and indeed promoting, the health and wellbeing of this group of predominantly elderly. These include, but were not limited to, nursing, personal care, physiotherapy, and occupational therapy. Will a relaxation of euthanasia legislation lead to a disincentive for graduating students in these fields to work in the area of the elderly, even at a time when the population of elderly in Australia is increasing exponentially?*⁸³⁵

- 3.310. Alzheimer's disease and dementia are on the rise, and how we can better care for sufferers of these diseases at the end of their lives is a critical matter to address. However, the words of Canadian physician Dr Rene Leiva should be heeded. He asks, 'whose suffering does [assisted suicide] really eliminate? ...It certainly eliminates the sufferer, whose pain we are not able to bear.'⁸³⁶ Mr Denton suggests that the problem of whether to allow assisted suicide for Alzheimer's patients will not go away and that it will be addressed at some point. The 'Alzheimer's problem' is yet another example of how difficult it is to maintain a line between killing which can be justified and that which cannot.
- 3.311. In light of the evidence of logical incremental extension in jurisdictions that have legalised assisted suicide and in evidence given to the Committee by proponents of assisted suicide for Western Australia above, barrister and former Labor MP Tim Hammond's comment is apt:

*Perhaps the most troubling thing about the prospect of lawful euthanasia is that we don't know where it will end up... I have a terrible feeling that once we start up this ride, we won't be able to get off it.*⁸³⁷

- 3.312. Similarly, former Labor Prime Minister Paul Keating has said:

*once termination of life is authorised the threshold is crossed. From that point it is much easier to liberalise the conditions governing the law. And liberalised they will be. Few people familiar with our politics would doubt that pressure would mount for further liberalisation based on the demand that people are being discriminated against if denied. The experience of overseas jurisdictions suggests the pressures for further liberalisation are irresistible.*⁸³⁸

835 Christopher Harkness, Private Citizen, JSCEOLC Submission 266 at 3.

836 Leiva RA (2010) 'Death, suffering and euthanasia,' *Canadian Family Physician* 56(6) at 528-530.

837 Tim Hammond 'Euthanasia and why I'm against it,' *PerthNow*, 17 December 2017.

838 Paul Keating, 'Voluntary euthanasia is a threshold moment for Australia, and one we should not cross,' *Sydney Morning Herald*, 19 October 2017.

3.313. The threshold to allow assistance to suicide should not be crossed in Western Australia.

Finding 122

A 2013 review by the High Court of Ireland of the available evidence from jurisdictions with assisted suicide produced the conclusions that the examples of abuse are deeply disturbing, that certain groups are vulnerable to abuse, and that the number of suicides remain strikingly high.

Finding 123

Unlike other jurisdictions, there is yet to be any lived experience with the Victorian model of assisted suicide.

Finding 124

The Victorian model of assisted suicide has been heavily criticised by proponents of assisted suicide, with calls to extend the scope already made before the law has even come into force.

Finding 125

It is a political inevitability that once lawmakers introduce a right for one group of people that others will soon demand the extension of that right to them on the ground of equality.

Finding 126

Any restriction on eligibility within an assisted suicide regime is both arbitrary and discriminatory.

Finding 127

It is at best premature to base any assisted suicide regime on the untested Victorian model.

Recommendation 20

The Government and the Parliament of Western Australia should rule out introducing an assisted suicide regime based on the untested Victorian model.

A handwritten signature in blue ink, appearing to be 'Nick Goiran', written on a light pink background.

Hon Nick Goiran MLC

Appendix One

Letter from Palliative Care WA dated 15 May 2018



Palliative Care WA Inc.
15 Bedbrook Place
Shenton Park, WA 6008
T 1300 551 704 | F 1300 551 704
palliativecarewa.asn.au
pcwainc@palliativecarewa.asn.au
ABN 13 107 780 017

Ms A. Sanderson, MLA
Chair, Joint Select Committee on End of Life Choices
Parliament House
4 Harvest Terrace
West Perth WA 6005

Dear Ms Sanderson

I profusely apologise for the delay in responding to you and hope that these ideas can still be considered.

In relation to conclusion 4 of our previous response on pages 10 and 11, we suggested the following: 'PCWA can assist the committee in suggesting novel models to improve access to palliative care'.

The "novel models" we were referring to are outlined in more detail below.

Co-design workshops

Consider co-design workshop with palliative care consumers (including carers) and care providers to determine what people with palliative care needs actually need, and how best to deliver care and education. PCWA could assist in recruiting and facilitating this action.

Compassionate Communities

Progressing the Compassionate Communities model (with reference to the Guardian article <https://www.theguardian.com/commentisfree/2018/feb/21/town-cure-illness-community-frome-somerset-isolation>)

Shared Care Models

Consider shared care models, where a palliative approach is introduced early in the course of life-limiting illness. At present, most specialist palliative care relies on referral from another doctor, which usually happens too late in the disease process to have optimal benefit to the patient in terms of end of life choices. This is despite growing evidence that access to palliative care early in the course of many life-limiting illnesses can improve quality of life and reduce aggressive treatments without shortening life. Some novel shared care models, which introduce a palliative approach early in the course of life-limiting illness (rather than waiting for a referral), include the following that were all presented in sessions at the 2017 Australian Palliative Care Conference:

- "Kidney Supportive Care" model in Prince Charles Hospital, Brisbane (including people receiving dialysis as well as those electing conservative management), Dr Carol Douglas;

Appendix One

- Palliative care for COPD model from Professor Jennifer Philip, University of Melbourne (<https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/conceptual-model-redesigning-how-we-provide-palliative-care-for-patients-with-chronic-obstructive-pulmonary-disease/F9216912F482829ADA8D9FF2CEDE250B>)
- Palliative care nurse practitioners embedded in aged care facilities, from Peter Jenkins, Nurse Practitioner, Resthaven Inc, Adelaide

Increasing the capacity of Silver Chain

Increase the capacity of the Silver Chain Hospice Care Service model of care to more people with non-malignant life-limiting illness including frailty and dementia, working alongside existing aged care and disability providers

Increasing the capacity of existing outpatient clinics

Increase the capacity of existing outpatient clinics to facilitate Advance Care Planning sessions. This could be delivered in a group setting initially and offered to patients with chronic/life-limiting illness e.g. geriatric medicine, respiratory, renal, oncology, and neurology.

Increase Telehealth

Increase the availability and flexibility of Telehealth for people from rural/regional areas and in metro, to consult with the palliative care multidisciplinary team (and not just doctors) at tertiary centres. This could speed up decision making processes by engaging the local family/community decision makers directly and allow family meetings/case conferences. This could potentially reduce inappropriate transfers to metropolitan hospitals, improve/make decision making and in a more timely way and also improve bereavement outcomes for patients/families of patients dying away from country. This could include inpatients at Perth hospitals (inpatients being a group where Telehealth is under-utilised) for family meetings, planning, grief and bereavement.

Again I apologise for the delay in responding to your request and would be keen to meet to provide further detail on the above if this would be helpful.

Kindest regards

Lana Glogowski
Executive Officer
15 May, 2018



Parliament House
4 Harvest Terrace, West Perth WA 6005
Telephone: +61 8 9222 7222
Email: laco@parliament.wa.gov.au
Website: www.parliament.wa.gov.au