

Voluntarily stopping eating and drinking (VSED):

A call for guidance



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Foreword

The right to make informed decisions and be supported compassionately and confidently to do so by your healthcare team is a cornerstone of good end-of-life care. Having worked in palliative and end-of-life care for many years, I know that voluntarily stopping eating and drinking as a means of hastening one's death is not new, which makes this call for guidance timely and right.

This report demonstrates how important it is for people making complex end-of-life care decisions to have the right support in place. Everybody's death is unique to them and we must do all we can to ensure the care people receive reflects this; inconsistent practice can have a devastating impact on individuals, those close to them and clinicians.

There is unquestionably a clear need to develop information and guidance around voluntarily stopping eating and drinking. If we can do this in an evidence-based, open, honest and collaborative way, it will reflect how far we have come in making person-centred end-of-life care a reality.

**Dame Barbara Monroe, DBE, FRSA
Compassion in Dying Chair**

Summary

“VSED is not an easy process – mum was forced to endure, not one but two battles: forgoing food and water and also convincing professionals that she wished to die the way she lived – on her own terms.”

Compassion in Dying receives calls from people considering voluntarily stopping eating and drinking (VSED) as a means to hasten their death. With no clear information publicly available in the UK, people turn to us – as a charity that is willing to have open conversations about all aspects of death and dying – to understand the legality and practicalities of it.

These calls have highlighted a stark lack of guidance. As a consequence, some people who want to stop eating and drinking to hasten their death are not receiving adequate support to make an informed decision or to have their symptoms managed. Some people feel abandoned and experience preventable distress. There is also a lack of clarity for families, and many health and care professionals struggle to provide the right care or information for their patients.

The lack of guidance on VSED leads to significant inconsistencies in how it is managed by clinicians. It also gives people the impression that VSED is a legal and ethical grey area. In reality, the law is clear but a lack of guidance undermines good clinical practice.

This report:

- **Shines a light on people’s diverse experiences of VSED**
- **Outlines existing research in the area**
- **Calls for the development and dissemination of clear guidance for clinicians and the public**

We believe that high-quality guidance and information would contribute to a culture where people can have honest conversations with their healthcare team about what is right for them. It would help to ensure that, for the people who do make a decision to stop eating and drinking as a means to hasten their death, the decision is an informed one. Furthermore, guidance would help to ensure people consistently receive appropriate support and symptom management from a healthcare team that feels confident to provide this.



What is voluntarily stopping eating and drinking?

Voluntarily stopping eating and drinking (VSED) is a practice by which an adult with mental capacity to decide to do so,¹ and in the absence of control or coercion, makes a decision to hasten their death by completely stopping the oral intake of all food and fluids.

VSED is fundamentally different from the natural loss of appetite that occurs at the end of life. This is because the individual makes a deliberate decision to forego food and drink with the intention of controlling the manner and timing of their death.

Dying from VSED can typically take between 10 to 14 days, but the exact process will be unique to each person and depend on their physical condition and if they decide to temporarily eat or drink at any point. For people who are not living with an advanced or progressive condition, dying by VSED can take much longer.²

The symptoms that someone who chooses VSED might experience, such as dry mouth and delirium, need careful management by clinicians and carers,³ so that the person remains comfortable and free from pain, especially in the final stages. These symptoms are, however, similar to those which typically occur as part of the ordinary process of dying, and providing relief of these symptoms is within the scope of palliative and end-of-life care.

Evidence suggests that people nearing the end of life who are determined to end life on their own terms find VSED to be a tolerable and meaningful way to control their death, provided they receive experienced clinical support to explore all end-of-life options and manage symptoms effectively.⁴ Significant support from carers, working diligently to respect the person's decision, is equally vital for the process to be comfortable and peaceful.

In a study among carers of patients with dementia and progressive illness who had the capacity to consider VSED and had died this way, the carers consistently said that the alternative death expected by the patient through disease progression was "horrible," "unacceptable," or "pretty sad," with low quality of life or heavy symptom burden. VSED, by contrast, was "peaceful" and "a very good death." Importantly, most carers found meaning in their loved ones being able to exert control in their life at the end, particularly when poor health had limited their independence.⁵

The decision to stop eating and drinking as a means to hasten death is a hugely individual one, and only the person can decide if it is right for them.



Who considers VSED as an option and why?

“I have had control over everything - my decisions, my life. And the one time I felt out of control was when my kidneys began to fail and my doctors told me to get my affairs in order. I no longer have that feeling. With VSED, I have researched and decided that this is the one way I can decide that, when I have no quality or energy left, I can exit life under my own terms.”

Compassion in Dying caller, 2022

The vast majority of callers to our nurse-led information line ask about Living Wills (advance decisions to refuse treatment), advance statements, Health and Welfare Power of Attorney, and Do Not Attempt Cardiopulmonary Resuscitation decisions. However, a small but steadily increasing number of people contact us because they want information about VSED.

In a study conducted by the International Observatory on End of Life Care at Lancaster University, it was found that people choosing VSED fit one of three categories: a diagnosis of early dementia; progressive, terminal illness; or severely reduced independence as a result of frailty and chronic health problems.⁶ Other studies have similarly concluded that individuals who consider VSED tend to be older, have one or many serious health conditions, and place a high value on independence.⁷

Some of the people we support would like the option of a safeguarded assisted dying law which would allow greater choice for terminally ill, mentally competent adults in the UK. For these people, in the absence of such a law, death by VSED provides an alternative, even if less preferable, option.

“My husband had motor neurone disease. He looked into Dignitas but it proved to be extremely expensive with a lot of red tape involved. He then made the decision that he would stop feeding by mouth once he could not communicate.”

Compassion in Dying contact 2021

By contrast, fasting at the end of life is an accepted practice in many cultural and religious traditions, therefore, even in places where assisted dying is legal, some people might find VSED to be a form of hastening death that is more consistent with their values and beliefs.⁸

The International Association for Hospice and Palliative Care notes that there are dying people who strongly value self-sufficiency and self-determination. Their unmet need to maintain control over the timing and manner of their death causes them distress, and for these people, voluntary stopping eating and drinking with appropriate and adequate symptom control provides comfort.⁹



What people tell us about VSED

Over the last five years, Compassion in Dying's information line has received approximately one new enquiry a month about voluntarily stopping eating and drinking. The support we provide to people who contact us about VSED can be detailed – from regular calls over many weeks, to writing letters to clinicians explaining the law and helping to identify experts to support individuals. See "Appendix C" on page 19 for an overview of the information we provide. It should be noted though, that without national guidance explaining VSED and the support that can (or cannot) be expected, the information we are able to give people is limited.

Based on conversations with people who are going through the process of VSED and their bereaved loved ones, we know that some people feel supported to discuss VSED and are given high quality care and symptom management. However, the majority have negative experiences with their healthcare team that range from unhelpful to traumatising.

People often find it difficult to access quality information and are met with an unwillingness to have an open conversation

While some information, particularly from the USA, can be found online, people who come to us generally do not know where to go for accurate and honest guidance. The people we speak to often want to know what dying by VSED will be like and what clinical support they need to arrange or should expect. The equivalent information for the UK does not exist.

Some have been met with a wall of silence or discouraged from trying to talk to a member of their healthcare team about VSED. The most common concerns raised by callers are about being force-fed after they have stopped eating and drinking; whether they will be given support by their healthcare team; and whether they would be detained under the Mental Health Act if they talk about or go ahead and attempt to stop eating and drinking.

"My mother is 95 and has recently lost much of her independence. She has always been very headstrong and her mind is set on this. I know that she has a right to refuse food and water but I am not sure how she can best discuss this with her GP and ask for their support in an honest and risk-free way."

Compassion in Dying caller 2018

What people tell us about VSED

People are sometimes wrongly detained under the Mental Health Act

People who have decided to stop eating and drinking, and have capacity to make that decision, have frequently told us that their doctor has automatically and without an explanation referred them to psychiatric services.

“My dad was 84 when he died by VSED. He suffered a stroke 10 years ago and had deteriorated since. He decided that he wanted to stop eating and drinking because he felt his life was no longer worth living, and, to be sure that no one was implicated in assisting his death, he called a lawyer who in turn called his GP, to record a conversation about it all. The GP confirmed his capacity but thought he needed a psychiatrist too.

A few days later, three people arrived and sectioned him.

Dad was sectioned for a full 7 days. When he returned home, he lived only another 7 days.

My parents were both devastated by the fact that a full week at the end of Dad’s life was spent inappropriately incarcerated in a psychiatric ward, despite him being mentally sound. I am angry that Dad was unable to spend all of his dying days at home which was his wish. It was so unfair and frightening that he was taken off like that after he had a rational and clearly thought through conversation with a doctor and lawyer.

While he was in hospital, they did not force-feed him but he continued to have sips of water. He was eventually discharged home with no concerns about his capacity but without any palliative support.

Understanding that drinking water can often make the dying process longer and less comfortable, Dad promptly stopped drinking when he got home. I didn’t know how best to care for him so contacted Compassion in Dying who introduced me to experts in end-of-life decision-making and palliative care. With their support, I was able to help with Dad’s mouth care, pain and slight delirium. We had a few nice days together as a family and seven days after being discharged from hospital he died peacefully surrounded by love.”

Compassion in Dying caller 2020

What people tell us about VSED

Some people receive poor or no symptom management

People have also reported that their healthcare team refused to provide pain relief and symptom management when stopping eating and drinking.

“In August 2020, my mum was 92. She had long term heart conditions which had taken their toll. In line with her long held beliefs about making informed decisions and choices about life and death, she decided she wanted to stop eating and drinking to have some control over her death. She discussed her plans with her GP, the GP practice matron and the local palliative care doctor. No one was concerned about her capacity and the matron completed a ReSPECT⁰ form with her which she held together with her long-standing advance decision.

A few days after stopping eating and drinking, she needed more medication to relieve her pain and discomfort. She just wanted to be asleep. My sister and I were worried about how best to care for her and called the palliative care doctor for support. My mum’s case was then suddenly described as ‘moving from palliative to psychiatric.’

Before long, a safeguarding concern was raised and we had visits from the Mental Health Team and two uniformed police officers came to ask mum if she was okay. They told us we could be charged with assisting her suicide or her murder. The mental health team didn’t listen to her or try to understand what mattered to her. They assumed she was depressed and tried to build a “therapeutic relationship” by asking her what her favourite food was – it was insulting and cruel.

VSED is not an easy process – so she was forced to endure, not one but two battles: foregoing food and water, and convincing professionals that she wished to die the way she lived – on her own terms.”

Cont.

What people tell us about VSED

People report feeling abandoned when requests for information or support from their healthcare team are met with judgment or an unwillingness to discuss the topic. For some, this has resulted in significant levels of anxiety at the end of life.

Inappropriate mental health referrals also often result in a breakdown of trust between people and health and care professionals. This in turn has a negative impact on the quality of a person's death and on their loved ones' bereavement.

“As a result of having to constantly state her case, bravely and coherently, to various clinicians who were not listening to her, while foregoing food and water, my mum lost all trust in most of her care team and didn't want to see them any more.

My sister and I were worried that Mum was going to be taken into a hospice which was not what she wanted. The clinicians were trying to bargain with us, claiming she would receive more pain relief in a hospice than at home, but we were in the middle of Covid and being admitted to a hospice was not what she wanted.

There was no professionalism, just passing the buck and panic.

Eventually, I heard back from the GP who had spoken to the psychiatrist and safeguarding lead to confirm that Mum's mental health and capacity were no longer in question, and that my sister and I should instead focus on keeping mum comfortable.

However, because we were regarded with suspicion by the healthcare professionals for respecting Mum's wishes we really struggled to get Mum proper clinical support and symptom relief as she persevered with her decision to VSED.

We are heartbroken that she was denied the peaceful death that she so desperately wanted and deserved.”

Compassion in Dying caller 2020

What people tell us about VSED

When people receive supportive care and symptom management they can have a positive end-of-life experience

While some people struggle to find appropriate care and support, we know that when asked, some hospices and nursing homes are willing and able to support people who choose to stop eating and drinking as a means of hastening their death.

The relief felt by individuals receiving compassionate care is notable.¹¹ Where clinical support has been forthcoming, patients and their loved ones have found this invaluable.

“The hospice team were really excellent. I think it was an unfamiliar process for them to know that our mum had some agency in the decision, but in terms of care requirements I’m not sure that our mum’s needs would have been that different to others, older than her, who were unable to eat or drink. The big thing was that the clinical nurse specialist who coordinated her care was incredibly good at advocating for her needs with other medical and care staff, and just so great at talking through her particular decision with her very sensitively and respectfully.”

Compassion in Dying contact, 2022

A daughter, in describing her father’s experience with VSED in the US after living several years with rapidly progressing motor neurone disease, said:

“The fact that dad could talk openly with his hospice about his decision was a relief. He died peacefully. VSED was a gift to himself and to us as we gathered around to comfort each other.”

Compassion in Dying contact, 2022



How healthcare professionals feel about VSED

To gather more insight into health and care professionals' understanding of VSED, we commissioned YouGov to conduct research in July 2022.¹² The survey of over 500 professionals revealed that 50% of the respondents did not have correct information about the legal status of VSED – this included 14% who thought it was illegal and 36% who did not know. 40% of respondents said they would not feel confident having a conversation with a patient about VSED. Worryingly, of the 54% who said they were confident discussing VSED with their patients, 12% believed that it was illegal and 24% said they didn't know.

94% of the respondents said it would be helpful for health and care professionals to have guidance on the legal and clinical aspects of VSED and 92% thought that individuals and their loved ones would benefit from similar information.¹³

This unusually high level of consensus demonstrates a need for clear guidance on VSED.

We know from the people we support that some clinicians find it ethically difficult to support people who wish to stop eating and drinking as a way to hasten their death. We also know that some people have experienced their healthcare team being unwilling to provide adequate symptom management. Conversely, we also know some clinicians provide helpful and appropriate support to people who wish to exercise this decision.

“I work in end-of-life care and a patient wanted information and support on VSED. I felt able to discuss this openly and honestly which the patient appreciated. My team, however, were not confident about how to address VSED and so the patient went home unsupported. The patient eventually received excellent care from district nurses and stopped eating and drinking and died several weeks later.”

Compassion in Dying contact, 2022

“I am a social worker and I am supporting a woman in her 80s living with multiple morbidities who wants to stop eating and drinking to have some control over the end of her life. She has been assessed by the mental health team who consider that she does have capacity to make this decision and that she does not have psychiatric problems. The hospice at home service and her GP are involved in providing care for the woman. Still, my colleagues and I feel unsure of the legal status of VSED and how best to support her.”

Compassion in Dying contact, 2021

How healthcare professionals feel about VSED

“I am a GP and had a patient in her mid-40s, virtually bedbound with severe chronic fatigue syndrome, who was being tube-fed because she found eating too difficult. She was able to drink by mouth but she wanted to stop taking all fluids because she found that her quality of life was no longer tolerable. She asked me to visit her regularly to support her. I assessed her capacity over a couple of visits before agreeing to support her decision and also discussed her plan with her carer. We did a ReSPECT form together and I was ready to administer palliative care medication although such a need did not arise. She died peacefully three weeks later.”

Compassion in Dying contact, 2022

Professor Michael Rosen had Parkinson’s disease and decided to refuse food and water towards the end of his life when his condition deteriorated. He was 91. He discussed his plan to stop eating and drinking with his palliative care consultant who prescribed some sedatives. His daughter explained:

“One of the nurses said, ‘We need to ask if he wants his food,’ and they brought him a tray of a three-course meal at one point, like a pantomime. He had to be the one to say he didn’t want any food. He said, ‘Please, I don’t want any food’. They said, ‘We have to offer it to you every time’ and he found that irritating. Of course he was hungry and he was being presented with food he didn’t want. I think the staff found it incredibly difficult. I think they were worried about being sued.”¹⁴

The inconsistency in confidence and knowledge around supporting someone who wishes to voluntarily stop eating and drinking at the end of life clearly has an impact on individuals. While some people struggle to obtain the care they need, others have supportive clinicians. Whether or not a person is well supported when making decisions that are right for them at the end of life should not depend on luck.



Why guidance is needed

“I work as a GP. I have had to explain to patients who asked, that, if they did not eat or drink, it would hasten their death as their kidneys fail. If there are guidelines on this topic one could use, that would be really helpful.”

Compassion in Dying contact, 2022

“I work in end-of-life care and have had a few people ask me about refusing food and drink in order to have some control over their deaths. It would really help to have clear guidance on what I can and cannot do to support them.”

Compassion in Dying contact, 2022

Inadequate pain relief, inappropriate use of mental health legislation and a breakdown of trust between people and their care teams are all likely consequences of not having clear, practical guidance on VSED for clinicians, individuals and their families.

Anecdotally, we know it is often fear and anxiety about what is legal and ethical that makes clinicians feel worried about repercussions of supporting someone to voluntarily stop eating and drinking and prevents them from fully supporting their patients in the way they would wish to.

There has also been negative sentiment towards the core principles of VSED from some areas of medicine. For example, in a case of VSED reported in The Guardian one doctor was quoted as saying, ‘It is not illegal to starve and dehydrate oneself to death but neither is it right.’¹⁵ **The absence of guidance is therefore likely to create situations where practice depends too much on the ethical judgment of individual clinicians and leaves people facing inequitable access to care.**

People and clinicians almost universally see the need for clear guidance. While only 5% of the professionals surveyed reported having been asked for information on VSED, those people unanimously agreed it would be helpful to have clear guidance which would allow them to provide personalised and appropriate care.¹⁶ Getting care right for everyone, regardless of how unique their circumstances might be, is what personalised end-of-life care is about.

100% of health and care professionals with experience of responding to questions about VSED would find it helpful to have guidance on the legal and clinical aspects of it.¹⁷

Evidence from overseas (see “International experience” on page 18 for more detail) shows that with both appropriate clinical support to manage symptoms and practical information for the individual and their carers, VSED can, for people with an advanced or progressive condition, result in a peaceful death.¹⁸

Conclusion

With greater openness about death and dying and increased focus on care and treatment in line with a person's values and preferences, the ability for an individual to decide to stop eating and drinking to hasten their death is gaining increased attention in policy and practice. Calls to Compassion in Dying on the topic are also increasing; we received more calls on VSED in just the first half of 2022 than we have had in any previous calendar year.

The absence of guidelines on VSED means that some dying people feel abandoned and experience preventable distress; families are left unsupported and anxious; and clinicians struggle to provide the right care for their patients.

YouGov's research with healthcare professionals¹⁹ found that the majority of respondents wished to see guidance on VSED from specialist organisations such as the British Geriatrics Society, the Association for Palliative Medicine, the National Institute for Health and Care Excellence, the Royal Colleges, the British Medical Association (BMA) and the General Medical Council (GMC).

Based on what people have told us about current practice, Compassion in Dying is calling for a multi-disciplinary group including people who are considering VSED or people who cared for someone who died by stopping eating and drinking, clinicians from a range of specialities, and legal experts to develop clear guidance for clinicians and individuals on voluntarily stopping eating and drinking. For consistency of approach, the guidance should be applicable in all four nations. See "Appendix A" on page 16 to understand what the guidance could include.

Developing guidance is entirely achievable. It has already been done for complex end-of-life care decisions such as on clinically assisted nutrition and hydration and the withdrawal of assisted ventilation at the request of a patient with Motor Neurone Disease. As detailed on "Appendix B" on page 17, numerous academic papers have been published on the ethical and legal considerations around voluntarily stopping eating and drinking and there are some helpful guidance documents from a variety of international sources, including from palliative care organisations and people with first-hand experience of VSED, which we can learn from here in the UK.

The current lack of quality guidance about VSED for both clinicians and the public results in inconsistencies in practice and means that people and their families can sometimes face pain, anxiety and distress instead of the peace and dignity they wished for at the end of life. We support further research about VSED in the UK to increase our collective understanding of its use.

People must be supported to make informed decisions about their care and clinicians must have access to information they need to feel confident reacting to the wishes and needs of their patients.

Guidance will never be enough in itself to address the problems highlighted in this report, but clear and consistent information is a necessary starting point which will help create a culture of openness and honesty around VSED, ultimately leading to better and more personalised care.



Appendix A

What VSED guidance needs to include

Based on what the people we support regularly ask us and tell us, guidance on VSED would need to cover the law and details of what good quality care for VSED looks like while ensuring that the individual and their preferences remain at the heart of the decision-making process. Information should be produced both for professionals and for the public and backed up with a clear plan for implementation and training in health and care settings.

The law

- Under what conditions healthcare professionals can provide support and care for a person choosing VSED
- When to offer food and drink and when to respect its refusal
- How to apply the Mental Health Act, the Mental Capacity Act and inherent jurisdiction
- Conscientious objection

The role of clinicians and allied care professionals

- How to respond to someone who refuses food and drink
- How to establish whether someone has the mental capacity to make a decision to refuse food and drink
- How to assess whether someone is subject to coercion or influence which is preventing them making a genuine choice

- How to differentiate between people who cannot eat and those who make a choice not to eat, and how to explore their individual circumstances and preferences in line with GMC guidance²⁰
- How to openly and honestly discuss all available end-of-life options
- How to make referrals for and provide comprehensive palliative care

The paperwork required

- A statement on how the individual choosing VSED would wish to have their potential thirst addressed
- A tailored Advance Decision referencing the decision to VSED and the person's preference not to be offered food and drink in this unique circumstance²¹
- A ReSPECT/Do Not Attempt Cardiopulmonary Resuscitation form
- A palliative care plan

Information and support for individuals and carers

- What to expect and prepare for during the dying process
- How to ensure comfort and manage symptoms
- Where to get additional support



Appendix B

Existing law and guidance

The Supreme Court has clarified the law in this area and some medical organisations have made brief statements on the role of clinicians. Yet detailed guidance which could support individuals, their loved ones, and their health and care team to make informed decisions about voluntarily stopping eating and drinking at the end of life remain absent.

The law regarding the refusal of food and water was set out in the 2014 Supreme Court decision in the Nicklinson, Lamb and Martin case which ruled that:²²

- A person who is mentally competent is entitled to refuse food and water, and to reject any invasive treatment, even though it will lead to their death. Medical practitioners must comply with such refusals.
- The doctor is in no danger of incurring criminal liability simply because they agree in advance to manage any pain or discomfort that may arise.

The GMC published guidance in 2015 on patients seeking advice or information about assistance to die.²³ The guidance explained that, where patients ask for information that might encourage or assist them in ending their lives, doctors should be prepared to listen and to discuss the reasons for the patient's request and to limit any advice or information in response to objective advice about the lawful clinical options (such as sedation and other palliative care) which would be available if a patient were to reach a settled decision to end their life. It went on to say:

“For avoidance of doubt, this does not prevent a doctor from agreeing in advance to palliate the pain and discomfort involved for such a patient should the need arise for such symptom management.”

In 2019, the BMA restated these principles in its guidance on responding to requests to assisted dying.²⁴

“An informed refusal by a competent adult must be respected, even if it will result in serious injury or death. This includes a competent refusal of food and fluids. In these cases, it would be appropriate to discuss with the patient in advance what pain and symptom relief will be available at such a point in time that it becomes necessary.”

The Royal College of Physicians' (RCP) 2021 guidance on supporting people who have eating and drinking difficulties states:²⁵

“Some patients with capacity may choose for themselves to stop eating and drinking, as they are free to do. Some staff may find this particularly challenging and need support to respect the patient's decision.”

Existing law and guidance

It is clear that relevant legal and clinical statements exist but they are often inaccessible and do not cover the details that we know individuals and clinicians need. Comprehensive guidance which could practically support individuals, their carers, and their health and care team to make informed personal and clinical decisions about voluntarily stopping eating and drinking at the end of life is urgently needed.

International experience

In their overview of VSED, Lancaster University researchers report that: 32% of Japanese hospice and palliative care physicians had experience with a patient choosing VSED; a survey of Swiss nursing home directors estimated that 1.7% of nursing home residents died by VSED; and Dutch studies have produced estimates of 0.4% to 2.1% of annual deaths by VSED.²⁷ In 2001, one third of hospice nurses in Oregon reported that at least one patient for whom they had cared in the previous four years had deliberately hastened death by stopping food and fluids.²⁸

The symptoms that someone who chooses VSED might experience include a sore mouth and thirst, weakness, anxiety, delirium, agitation and pain. These are similar to the symptoms which typically occur at the end of life and providing relief of these symptoms is understood to be within the scope of palliative and end-of-life care. An inter-professional working group of the Austrian Palliative Society developed a position paper on VSED, explaining that caring for dying people refusing food and fluids and accepting their choice is part of medical

and nursing care for people during their dying process.²⁹ The American Academy of Hospice and Palliative Medicine suggests that when unacceptable suffering persists over a timeline determined by the patient, despite palliative care intervention, voluntary cessation of oral intake could be considered as an alternative plan if ethically acceptable to the patient and treating practitioners.³⁰

The Royal Dutch Medical Association (KNMG) and the Dutch Nurses' Association (V&VN) produced guidance in 2014 in collaboration with geriatricians and religious groups setting out all the steps required for caring for people who consciously choose not to eat and drink so as to hasten the end of life.³¹ The position paper of the Austrian Palliative Society also sets out the safeguards that ought to be considered when discussing the option of VSED with an individual.³² The Benton Hospice Service in Oregon has a policy document and a template for a tailored Advance Decision for VSED.³³ Compassion and Choices, an American organisation dedicated to improving care, expanding options and empowering everyone to chart their end-of-life journey, has developed a user-friendly website explaining the process and what to consider when deciding on VSED as an end-of-life option.³⁴ Resources such as the video of Dr Michael Miller's journey with VSED are also available for training and education purposes.³⁵



Appendix C

Information provided by Compassion in Dying to people who enquire about VSED

Compassion in Dying's free information line is led by a nurse and staffed by a team trained to provide individualised information and support on end-of-life choices and decision-making.

Research by YouGov, commissioned by Compassion in Dying, consistently shows that over 76% of individuals have strong feelings about end-of-life care.³⁶ Having supported over 71,000 people with decision-making at the end of life, we have learned that when end-of-life care aligns with what matters to a person – their wishes, feelings, values and beliefs – this enables them to have peace of mind in the present and a better end-of-life experience.

A summary of the key points we raise with callers who want information on VSED is below:

- We establish who the caller is (individual, friend, relative etc.) and why the individual is considering or has chosen VSED
- We explain with reference to the Nicklinson judgment that a person who has capacity to make the decision is entitled to refuse food and water even if doing so would bring about their death, and even if that is their intention.
- We state upfront that there is no formal guidance for clinicians or individuals specifically about VSED
- We explain the symptoms a person might experience, and how the length of time it takes for their life to end through stopping eating and drinking varies greatly depending on the person's health and overall physical and mental health condition
- We strongly emphasise that this is not a course of action that should be undertaken without clinical support and encourage callers to contact their GP, local hospice or any other clinician involved in their care for support
- We explain that the symptoms experienced by a person with a terminal or progressive illness choosing to VSED can be similar to the ordinary process of dying, management of which is within the scope of current palliative care
- We encourage all callers, especially those who do not have a terminal or progressive physical health condition, to seek clinical support and signpost them to other organisations that may be able to support them with mental health or social care issues as appropriate



References

- 1 As per the Mental Capacity Act 2005, capacity is decision specific, and, as such, all reference to mental capacity in this paper is taken to mean the ability of the person to understand, weigh, retain and communicate their decision to stop eating and drinking as a means of hastening their death.
- 2 Timothy E. Quill et al, 'Voluntarily stopping eating and drinking – A compassionate, widely available option for hastening death', OUP 2021
- 3 Please note that the term 'carers' includes care workers and family members
- 4 Timothy E. Quill et al, 'Voluntarily stopping eating and drinking – A compassionate, widely available option for hastening death', OUP 2021
- 5 Lowers J. et al, 'Experience of Caregivers Supporting a Patient through Voluntarily Stopping Eating and Drinking', *Journal of Palliative Medicine*. 2021 Mar;24(3):376-381
- 6 Lowers J. et al, 'Experience of Caregivers Supporting a Patient through Voluntarily Stopping Eating and Drinking', *Journal of Palliative Medicine*. 2021 Mar;24(3):376-381
- 7 Wax et al, 'Voluntary Stopping Eating and Drinking', *J Am Geriatr Soc*. 2018 Mar;66(3):441-445 and Ganzini et al, 'Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death', *N Engl J Med* 2003;349:359-65
- 8 Dr Naomi Richards, *Is the voluntary refusal of food and fluid an alternative to assisted dying?* University of Glasgow, End of Life Studies, July 16, 2015
- 9 Ladbruch L. et al, 'International Association for Hospice and Palliative Care Response Regarding Voluntary Cessation of Food and Water,' *Journal of Palliative Medicine*, March 2017, 20(6)
- 10 The **ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process** supports conversations between a clinician and a person about care in a future emergency.
- 11 As reported to us by a caller, March 2022
- 12 All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 524 adults. Fieldwork was undertaken between 1st and 11th July 2022. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).
- 13 YouGov 2022
- 14 As reported by his daughter Amanda in Dignity in Dying, 'The Inescapable Truth, How seventeen people a day will suffer as they die', 2019.
- 15 Right-to-die campaigner who starved herself said she had 'no alternative', *The Guardian*, 19 October 2014
- 16 YouGov 2022
- 17 YouGov 2022

References

- 18 Timothy E. Quill et al, 'Voluntarily stopping eating and drinking – A compassionate, widely available option for hastening death', OUP 2021
- 19 YouGov 2022
- 20 GMC guidance on Treatment and care towards the end of life, paras 109-111
- 21 With reference to paragraph 9.28 of the Mental Capacity Act Code of Practice and paragraph 110 and footnote 31 of the GMC guidance on Treatment and care towards the end of life, which cover the offer of food and drink by mouth
- 22 R (Nicklinson) v Ministry of Justice [2014] UKSC 38, para 255
- 23 General Medical Council, Patients seeking advice or information about assistance to die, June 2015
- 24 British Medical Association, Responding to patient requests for assisted dying: guidance for doctors, June 2019
- 25 Royal College of Physicians, Supporting people who have eating and drinking difficulties, March 2021
- 26 Royal College of Physicians, Supporting people who have eating and drinking difficulties, March 2021, page 32
- 27 Lowers J. et al, 'Overview of voluntarily stopping eating and drinking to hasten death', Annals of Palliative Medicine, Vol 10, No 3, (March 2021)
- 28 Ganzini et al, 'Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death', N Engl J Med 2003;349:359-65
- 29 Feichtner A. et al, 'Voluntary stopping eating and drinking (VSED): A position paper of the Austrian Palliative Society' Wien Med Wochenschr 2018 May; 168 (7-8)
- 30 American Academy of Hospice and Palliative Medicine, 'Advisory Brief: Guidance on Responding to Requests for Physician-Assisted Dying' <http://aahpm.org/positions/padbrief>
- 31 KNMG Royal Dutch Medical Association, 'Caring for people who consciously choose not to eat and drink so as to hasten the end of life' 2014 available at www.knmg.nl
- 32 Feichtner A. et al, supra note 29
- 33 Benton Hospice Service, Voluntary Stopping Eating and Drinking, 2015 – available on request
- 34 Compassion and Choices, Voluntarily Stopping Eating and Drinking <https://compassionandchoices.org/end-of-life-planning/learn/vsed/>
- 35 Dying Wish is an award-winning film that has featured at film festivals and at the National Hospice and Palliative Care Organization's Annual Clinical conference www.dyingwishmedia.com/store/
- 36 YouGov survey 2013 (82%); YouGov survey 2020 (76%)

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