



HEALTH PROFESSIONS COUNCIL OF SOUTH AFRICA

**GUIDELINES FOR THE WITHHOLDING AND
WITHDRAWING OF TREATMENT**

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THE SPIRIT OF PROFESSIONAL GUIDELINES

Practice as a health care professional is based upon a relationship of mutual trust between patients and health care practitioners. The term "profession" means "a dedication, promise or commitment publicly made".^[1] To be a good health care practitioner, requires a life-long commitment to sound professional and ethical practices and an overriding dedication to the interests of one's fellow human beings and society. In essence, the practice of health care professions is a moral enterprise. In this spirit the HPCSA presents the following ethical guidelines to guide and direct the practice of health care practitioners. These guidelines form an integral part of the standards of professional conduct against which a complaint of professional misconduct will be evaluated.

[Note: The term "health care practitioner" in these guidelines refers to persons registered with the HPCSA].

^[1] Pellegrino, ED. Medical professionalism: Can it, should it survive? *J Am Board Fam Pract* 2000; 13(2):147-149 (quotation on p. 148).

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GUIDELINES FOR THE WITHHOLDING AND WITHDRAWING OF TREATMENT

1 INTRODUCTION

- 1.1 Health care practitioners have a responsibility to make the care of their patients their first concern. This is essential when considering any of the growing range of life-saving or life-prolonging treatments which make it possible to extend the lives of patients who, through organ or system failure, might otherwise die. The benefits of modern techniques such as cardiopulmonary resuscitation, renal dialysis, artificial ventilation, and artificial nutrition and hydration are considerable. However, life has a natural end and the existence of such techniques of life support may, in certain cases, sustain life artificially for many years for patients for whom there is little hope of recovery. The quality of life which may follow some treatments might raise questions as to whether it is in the best interests of the patient to start or continue treatment.
- 1.2 The guidance which follows is intended to provide an ethical framework of good practice for health care practitioners in circumstances where they are faced with making a decision on whether to withhold or withdraw life-prolonging treatment. It is based on those areas of broad consensus so far established and recognises the need to ensure that patients can die with dignity and that their families and others close to them are appropriately involved in their care. It takes account of existing law in this area, that allowing for withholding and withdrawing of life sustaining treatments and that which prohibits killing, active euthanasia, and assisted suicide. It is, therefore, based on the premise that any medical intervention where the health care professional's primary intention is to end the patient's life is both contrary to the ethics of health care and unlawful.
- 1.3 Council finds active euthanasia, or the willful act by a health care professional to cause the death of a patient unacceptable, notwithstanding whether or not such an act is performed at the request of the patient or his or her closest relatives or of any other person. The health care professional may alleviate the suffering of a terminally-ill patient by withholding treatment, i.e. allowing the natural process of death to follow its course, provided there is consultation with another health care practitioner who is an expert in the field, and where available, discussions with the closest relatives. The withholding of treatment does not exempt the health care professional from the duty to assist the dying person by providing him or her with the necessary medication in order to alleviate the terminal phase of illness. The health care professional shall refrain from employing unusual methods of treatment which are of no benefit to the patient."
- 1.4 The HPCSA also expects health care practitioners to observe the provisions of the World Medical Association Declaration on Terminal Illness.
- 1.5 Health care practitioners have a duty to give priority to patients on the basis of clinical need, while seeking to make the best use of resources and using up to date evidence about the clinical efficacy of treatments. Health care practitioners must not allow their views about, for example, a patient's age, disability, race, colour, culture, beliefs, sexuality, gender, lifestyle, social or economic status or other irrational grounds to prejudice the choices of treatment offered or the general standard of care provided. A non-discriminatory policy also applies to patients infected with HIV. In any event a diagnosis of HIV infection, without further examination, provides only incomplete information about a person's prognosis or actual state of health.

2 GOOD PRACTICE FRAMEWORK: PROCEDURES TO BE FOLLOWED

- 2.1 The National Health Act (Act No. 61 of 2003) allows patients in writing to mandate a person to act on their behalf when they are no longer able to do so. Therefore, patients should be encouraged to appoint in writing a person to make decisions on their behalf when they are no longer capable of doing so. The patient-selected proxy decision-maker must then be regarded as the substitute for the patient whenever reference is made to the patient in these provisions.
- 2.2 Patients and their families, unless a contrary wish is expressed, must be kept informed of treatment, treatment alternatives and outcome probabilities.
- 2.3 Patients should be given the opportunity and be encouraged to indicate their wishes regarding further treatment and to place in writing their directives for future care in possible critical circumstances, (e.g. permanent coma or terminal illness). An appropriately drafted "living will" may be used for this purpose. These instructions can also be set out in the mandate to a third party mentioned in para 2.1 above. Patients should also be given the opportunity to reconsider their directives from time to time and to alter instructions, should they wish to do so.
- 2.4 When the patient is incapable of being involved in making a decision related to treatment and no advance directive or other information regarding the patient's wishes is available, close family must be consulted and a decision taken in what are considered to be the patient's best interests.
- 2.5 Before taking definitive action, the responsible health team should carefully consider and discuss the issue, obtain the advice of other health care practitioners, the family, patient (if possible) and a person with a background in ethics. Health care practitioners should always involve the family and patient (where practicable) in the discussions, and should never act in haste.
- 2.6 When the patient or the family request continued treatment against health advice that considers such treatment to be futile, the patient or the family must be given the choice of transferring to another institution where such treatment is available. If this option is refused and the health team considers treatment to be futile, and this is confirmed by an independent health care practitioner, treatment may be withheld or withdrawn.
- 2.7 All decisions should be fully and clearly documented in the notes, including the reasons for the decision and the procedure adopted in the decision-making process. Where significant disagreement arises about a patient's best interests, health care practitioners should seek a clinical and / or ethical review, independent of the health care team. If this fails to resolve the disagreement, they must seek legal advice on whether it is necessary to apply to the court for a ruling.

3 CLINICAL RESPONSIBILITY FOR DECISIONS

A decision to withhold or withdraw life-prolonging treatment should be made only by the senior clinician in charge of a patient's care, taking account of the views of the patient or those close to the patient.

4 DIAGNOSIS AND PROGNOSIS

Before a decision is made to withhold or withdraw treatment, the treating health care practitioner must carry out a thorough assessment of the patient's condition and the likely prognosis, taking account of current guidance on good clinical practice. The practitioner should always consider seeking a second opinion. Health care practitioners must seek a second opinion in cases where they are not sufficiently experienced or knowledgeable.

5 OPTIONS FOR TREATMENT

- 5.1 Health care practitioners should only identify treatment options as being appropriate if based on up-to-date clinical evidence about efficacy, side-effects and other risks, while also referring to any relevant clinical guidelines on the treatment and management of the patient's condition, or of patients with similar underlying risk factors.
- 5.2 Health care practitioners must reach a considered judgment on the likely benefits, burdens and risks (including non-clinical ones) for the particular patient of each of the treatment (or non-treatment) options identified. They should always consult a clinician with relevant experience in cases where:
- 5.2.1 The health care practitioner and the health care team have limited experience of a condition; or
 - 5.2.2 The health care practitioner is in doubt about the range of options or the benefits, burdens and risks of a particular option for the individual patient; or
 - 5.2.3 The health care practitioner is considering withholding or withdrawing artificial nutrition and hydration.

6 EMERGENCIES

- 6.1 In an acute life threatening emergency where any delay might prejudice the outcome and where it is impossible to obtain all relevant information or hold any consultations required - or where there is uncertainty about the diagnosis or the likelihood of recovery, health care practitioners should start treatment which may be of some benefit to the patient until a clearer assessment can be made.
- 6.2 If the treatment referred to in para 6.1 above, was done without the consent of the patient the health care practitioner should inform the patient about the procedures that were done – as soon as the patient is mentally capable of understanding such information.

7 CHOOSING BETWEEN OPTIONS: PATIENTS WHO CAN DECIDE FOR THEMSELVES

7.1 SEEKING THE PATIENT'S VIEWS

- 7.1.1 Where a patient is competent to participate in decision-making, health care practitioners must discuss with the patient their conclusions about diagnosis, prognosis and which options they consider may be in the patient's best interests. It is for the patient to judge what might be acceptable; what weight or priority to give to any burden or risks; and to decide which of the options would be in his or her best interests.

- 7.1.2 Health care practitioners should bear in mind that the decisions of competent adult patients to refuse a particular medical intervention must be respected, even where this would result in serious harm to them or in their own death.
- 7.1.3 Where the possibility of withholding or withdrawing of life-prolonging treatment is being considered as an option, health care practitioners should discuss with the patient how his or her care would be managed if such a decision were made. This should include arrangements for providing basic care and other appropriate treatment; and what might be his or her palliative or terminal care needs and how these would be met. In addition the patient's preferences about who should be involved in decision-making or in providing additional support if he or she becomes incapacitated should also be discussed.
- 7.1.4 Discussions of the sort in the above paragraph will allow patients the opportunity they need to decide what arrangements should be made to manage the final stages of their illness; and to attend to personal and other concerns which are important in ensuring that patients can die with dignity.
- 7.1.5 Discussions about the possibility of withholding or withdrawing a potentially life-prolonging treatment may be difficult and distressing. However, this does not mean that such discussions should be avoided. Instead, the discussions should be handled sensitively and with appropriate support being provided to the patient. Health care practitioners should also consult with those close to the patient about the best means of withholding or withdrawing treatment where this is appropriate.
- 7.1.6 Where patients clearly indicate that they do not wish to know or discuss the details, health care practitioners should still provide the patient with sufficient information about his or her condition and its treatment to enable the patient to make an informed decision.
- 7.1.7 A linguistic or cultural barrier may exist between health care practitioners and the patient. Under these circumstances, an interpreter fluent in the language used by the patient should be present in order to facilitate communication when discussions are held and decisions regarding the treatment of the patient are to be made.

7.2 TIMING OF DISCUSSIONS WITH THE PATIENT

- 7.2.1 Health care practitioners should hold discussions at a time when the patient is best able to understand and retain information. They should allow the patient sufficient time to reflect and ask questions before deciding.
- 7.2.2 Health care practitioners should also discuss the patient's right to change his or her mind about the decision. Where a patient has an existing condition and the likely progression of the disorder is known, the health care practitioner should consider formulating an advance management plan with the patient and the clinical team.

8	CHOOSING BETWEEN OPTIONS: PATIENTS WHO CANNOT DECIDE FOR THEMSELVES
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8.1	ASSESSING CAPACITY TO DECIDE
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- 8.1.1 In most cases where the dying process itself affects the patient's mental capacity, the correct course of action for the patient should have been decided previously. Where no such advance management plan had been agreed, or the plan has not been reviewed recently, or is not relevant to the patient's current condition, health care practitioners are advised as follows:.
- 8.1.2 Where patients have difficulty retaining information, communicating their views, or are only intermittently competent, health care practitioners should provide any assistance a patient might need to enable him or her to reach and communicate a decision.
- 8.1.3 Where there are doubts about a patient's capacity at making a decision, health care practitioners should consult with the relevant health care practitioner taking into account any legal tests of capacity.

8.2	MAKING DECISIONS FOR THE PATIENT
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- 8.2.1 Where a patient lacks the capacity to decide, health care practitioners must respect any valid advance refusal of treatment.
- 8.2.2 Where there is no advance refusal of treatment the senior clinician responsible for the patient's care must make the decision about what course of action would be in the patient's best interests:
- 8.2.2.1 The senior clinician should consult the patient's authorised representative if such a person was appointed.
- 8.2.2.2 The clinician should also consult the health care team and the patient's authorised representative and, wherever possible, those close to the patient. The latter may be able to provide insights into the patient's preferences, and be able to offer an opinion on what would be in the patient's best interests.
- 8.2.2.3 Health care practitioners should pay due regard to any previous wishes of the patient about not disclosing information to particular individuals.
- 8.2.2.4 If the patient is new to the health care practitioner at the time decisions are needed, the health care practitioner must satisfy himself or herself whether or not such consultations have previously been carried out and if so, find out what had been agreed.
- 8.2.3 The health care practitioner should consider what support could be provided to family members and others close to the patient.

8.3	REACHING CONSENSUS
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The consultations between the clinician and the health care team and those close to the patient should aim to achieve consensus on what course of action would be in the best interests of the

patient. The factors considered in assessing best interests should take into account guidance from the HPCSA, pertinent ethical principles and relevant statutory requirements,

9 WITHHOLDING TREATMENT DUE TO SCARCITY OF RESOURCES AND ALLOCATION OF SCARCE RESOURCES

- 9.1 There are circumstances when withholding treatment, even if it is not in the best interest of the patient is permissible. This will apply to continued care in special units such as critical care and chronic dialysis units for end stage kidney failure.
- 9.2 A health care institution has the right to limit life-sustaining interventions without the consent of a patient or surrogate by restricting admission to these units. However, such restriction must be based on national admission criteria agreed upon by the expert professional bodies in the relevant speciality, as well as the HPCSA.
- 9.3 A health care institution is, however, obliged to provide the appropriate palliative care and follow up when specialised care is withheld.
- 9.4 If, however, the patient does satisfy all the criteria for admission, but cannot be admitted because of limited resources at a particular institution, the health care practitioner must transfer the patient to another institution where such resources exist. However, this should be done only after the necessary emergency treatment has been instituted.
- 9.5 The HPCSA considers it unethical to continue with life-prolonging treatment for the sole purpose of financial gain. Moreover, it is unacceptable that patients are transferred to state institutions after all their funding has been exhausted as a result of prolonging futile treatments.

10 COMMUNICATING DECISIONS

- 10.1 Whatever decision is made, health care practitioners must ensure that all those consulted, and especially those responsible for delivering care, are informed of the decision and are clear about the goals and the agreed management plan.
- 10.2 It is particularly important where treatment is to be withheld or withdrawn that everyone involved is clear about the arrangements for providing appropriate palliative or terminal care and about their own roles.
- 10.3 Health care practitioners should discuss what the role of the family or other carers will be and what support they will receive from the health care team.

11 RECORDING DECISIONS

- 11.1 Health care practitioners must ensure that decisions are properly documented, including the relevant clinical findings; details of discussions with the patient, health care team or others involved in decision-making; and details of treatment or other significant factors which may affect future care.
- 11.2 Health care practitioners should record the information at the time of the events described or soon thereafter. The record should be legible, clear, accurate and unambiguous. It should, for example, avoid abbreviations or other terminology that may cause confusion to those providing care.

- 11.3 Health care practitioners should ensure that the records are appropriately accessible to team members and others involved in providing care to the patient.

12 REVIEWING DECISIONS

- 12.1 Health care practitioners must review their decisions at appropriate intervals during the agreed treatment or the period of palliative or terminal care to determine whether the goals of treatment or the management plan remain appropriate.
- 12.2 Health care practitioners should seek a second opinion where, for example the patient's condition is not progressing as expected.

13 AUDIT

- 13.1 As in other areas of decision making, health care practitioners must carry out clinical audits of the process which can improve their own and others' knowledge about the outcomes of different treatment and non-treatment decisions.
- 13.2 Where possible health care practitioners should help to disseminate best practice, for example, by contributing to the education of students and colleagues about good practice in the area concerned.

14 CHILDREN

- 14.1 The general principles of good practice set out in this framework also apply to decision-making in cases involving children - including premature babies where the decisions may be particularly difficult for everyone involved.
- 14.2 Health care practitioners should respect the decisions of children who have the legal capacity to make decisions about refusing health care – except in cases where the practitioners believe that it is not in the child's best interests – in which case they should approach the court for a decision.
- 14.3 In all cases, health care practitioners and others who make decisions on behalf of a child have to consider only those options that are in the best interest of the child.
- 14.4 If the child does not have the legal capacity to make a decision, but is sufficiently mentally mature to understand the procedures to be adopted, he or she should be consulted during the decision-making process.

ANNEXURE

World Medical Association Declaration on Terminal Illness

Adopted by the 35th World Medical Assembly Venice, Italy, October 1983
and Revised by the WMA General Assembly, Pilanesberg, South Africa, October 2006

Preface

1. When addressing the ethical issues associated with end-of-life care, questions regarding euthanasia and physician-assisted suicide inevitably arise. The World Medical Association condemns as unethical both euthanasia and physician-assisted suicide. It should be understood that WMA policy on these issues is fully applicable in the context of this Statement on Terminal Illness.

Preamble

2. When a patient's medical diagnosis precludes the hope of health being restored or maintained, and the death of the patient is inevitable, the physician and the patient are often faced with a complex set of decisions regarding medical interventions. Advances in medical science have improved the ability of physicians to address many issues associated with end-of-life care. However, it is an area of medicine that historically has not received the attention it deserves. While the priority of research to cure disease should not be compromised, more attention must be paid to developing palliative treatments and improving the ability of physicians to assess and address the medical and psychological components of symptoms in terminal illness. The dying phase must be recognized and respected as an important part of a person's life. As public pressure increases in many countries to consider physician assisted suicide and euthanasia as acceptable options to end suffering in terminal patients, the ethical imperative to improve palliative treatment in the terminal phase of life comes into sharp focus.
3. The World Medical Association recognizes that attitudes and beliefs toward death and dying vary widely from culture to culture and among different religions. In addition, many palliative and life-sustaining measures require technologies and/or financial resources that are simply not available in many places. The approach to medical care of the terminally ill will be influenced significantly by these factors, and thus attempting to develop detailed guidelines on terminal care that can be universally applied is neither practical nor wise. Therefore, the World Medical Association articulates the following core principles to assist physicians and National Medical Associations with decision-making related to terminal care.

Principles

4. The duty of physicians is to heal, where possible, to relieve suffering and to protect the best interests of their patients. There shall be no exception to this principle even in the case of incurable disease.
5. In the care of terminal patients, the primary responsibilities of the physician are to assist the patient in maintaining an optimal quality of life through controlling symptoms and addressing psychosocial needs, and to enable the patient to die with dignity and in comfort. Physicians should inform patients of the availability, benefits

and other potential effects of palliative care.

6. The patient's right to autonomy in decision-making must be respected with regard to decisions in the terminal phase of life. This includes the right to refuse treatment and to request palliative measures to relieve suffering but which may have the additional effect of accelerating the dying process. However, physicians are ethically prohibited from actively assisting patients in suicide. This includes administering any treatments whose palliative benefits, in the opinion of the physician, do not justify the additional effects.
7. The physician must not employ any means that would provide no benefit for the patient.
8. . Physicians should recognise the right of patients to develop written advance directives that describe their wishes regarding care in the event that they are unable to communicate and that designate a substitute decision-maker to make decisions that are not expressed in the advance directive. In particular, physicians should discuss the patient's wishes regarding the approach to life-sustaining interventions as well as palliative measures that might have the additional effect of accelerating death. Whenever possible, the patient's substitute decision-maker should be included in these conversations.
9. Physicians should endeavour to understand and address the psychosocial needs of their patients, especially as they relate to patients' physical symptoms. Physicians should try to ensure that psychological and spiritual resources are available to patients and their families to help them deal with the anxiety, fear and grief associated with terminal illness.
10. The clinical management of pain in terminal patients is of paramount importance in terms of alleviating suffering. Physicians and National Medical Associations should promote the dissemination and sharing of information regarding pain management to ensure that all physicians involved in terminal care have access to best practice guidelines and the most current treatments and methods available. Physicians should be able to pursue clinically appropriate aggressive pain management without undue fear of regulatory or legal repercussions.
11. National Medical Associations should encourage governments and research institutions to invest additional resources in developing treatments to improve end-of-life care. Medical school curricula should include the teaching of palliative medical care. Where it does not exist, the establishment of palliative medicine as a medical specialty should be considered.
12. National Medical Associations should advocate for the development of networks among institutions and organizations involved in palliative care in order to foster communication and collaboration
13. Physicians may, when the patient cannot reverse the final process of cessation of vital functions, apply such artificial means as are necessary to keep organs active for transplantation provided that they act in accordance with the ethical guidelines established in the World Medical Association Declaration of Sydney on the Determination of Death and the Recovery of Organs.

Ethical guidelines for good practice in the health care professions

The following Booklets are separately available:

- Booklet 1:** *General ethical guidelines for health care professions*
- Booklet 2:** *Ethical and professional rules of the health professions council of South Africa as promulgated in government gazette R717/2006*
- Booklet 3:** *National Patients' Rights Charter*
- Booklet 4:** *Professional self-development*
- Booklet 5:** *Guidelines on over servicing, perverse incentives and related matters*
- Booklet 6:** *General ethical guidelines for health researchers*
- Booklet 7:** *Ethical Guidelines for Biotechnology Research in South Africa*
- Booklet 8:** *Research, development and the use of the chemical, biological and nuclear capabilities of the State*
- Booklet 9:** *Seeking patients' informed consent: The ethical considerations*
- Booklet 10:** *Confidentiality: Protecting and providing information*
- Booklet 11:** *Guidelines for the management of patients with HIV infection or AIDS*
- Booklet 12:** *Guidelines withholding and withdrawing treatment*
- Booklet 13:** *Guidelines on Reproductive Health management*
- Booklet 14:** *Guideline on Patient Records*
- Booklet 15:** *Canvassing of patients abroad*
- Booklet 16:** *Guidelines for the management of health care waste*