

A guide for people considering their future health care

foreword

Recently, Catholic Health Australia has been approached for guidance over the issue of advance care planning for patients and residents in Catholic health and aged care services.

Since a variety of approaches already exists in the wider community, Catholic Health Australia thought that prospective patients and residents of Catholic facilities, and the health professionals who take care of them there, would appreciate guidance that is consistent with Catholic, and indeed with good secular, ethics.

To that end, a drafting group comprising Bishop Anthony Fisher OP, Rev Dr Gerald Gleeson, Dr Elizabeth Hepburn IBVM, Dr Bernadette Tobin and Dr Nicholas Tonti-Filippini was asked to prepare a first draft of guidelines for patients and residents and for health care professionals. These drafts were circulated for comment from

doctors, nurses and other health professionals, managers, patients and the general public.

Responses received in that consultation process then informed the writing of this guide for people considering their future health care needs, and the accompanying guide for health care professionals.

Both documents have now been approved for use in Catholic health and aged care services by the Committee for Doctrine and Morals of the Australian Catholic Bishops Conference and by the Stewardship Board of Catholic Health Australia. We thank all those who contributed to their preparation.

We now commend these guidelines to Catholics, and indeed to all Australians, who are considering their future health care.



George Cardinal Pell
Chairman, ACBC Committee
for Doctrine and Morals



Sr Therese Carroll RSJ
Chairperson, CHA Stewardship Board

1 Introduction

1 This guide is written for people who are considering their health care needs and treatment preferences in future cases where they may be unable to do so. Its purpose is to:

- Help people nominate a representative to make health care decisions based on their wishes and values;
- Help people provide reasonable and adequate guidance for their representative; and
- Recognise the issues that need to be taken into account to achieve this.

2 This guide is intended to supplement the *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* (approved by the Australian Bishops and published by Catholic Health Australia in 2001,¹ and hereafter referred to as ‘the Code’) and aims to help people prepare for illness and death. It is issued in response to proposals for ‘advance directives’ or ‘living wills’, which are documents that detail a person’s wishes about specific medical treatment in case an illness or accident leaves him or her unable to communicate. In addition to this guide, there is a corresponding document for health professionals, called *A Guide for Health Care Professionals Implementing a Future Health Care Plan*.

3 In a truly democratic society, the life of every member is respected and protected, and each member is provided with the basic necessities for life and health, no matter how frail or disabled he or she is. In addition, for believers, God is the author of life and we belong to Him and thus have stewardship, not ownership, of our own lives. We care for our life and health, and seek assistance from others, especially when we are sick. In illness, we face the reality of our mortality and the limitations of health care. If approached well, the days leading up to death can have a positive meaning for many people.

4 Because we know that a time may come when we are unable to make decisions about our own care, it is a good idea to ensure that someone we trust will be in a position to make such decisions for us. For the same reason, it can be sensible

to let trusted people know our values and our wishes for medical treatment, to help guide them to make such decisions.

5 No one, however, should be compelled to issue instructions about future care, nor should any guidance we leave be too prescriptive. Disability and dependence may be unavoidable in our later years, and we should not expect to control the dying process fully. We should leave those entrusted with our care free to respond to the course of illness as it unfolds in the mystery of our lives. Like Jesus at Gethsemane, believers strive to place their trust in God’s will.

Key point 1

Though illness can be unpredictable, we may choose to offer those entrusted with our care some guidance about our wishes for our future health care.

2 Planning future health care

1 People often need time and assistance to reflect on the meaning of death in their lives – to face and resolve personal differences within families, and to minimise future conflict between family members.

2 You can guide your future medical treatment in different ways; it is not necessary to leave written instructions. Many people trust their families and their health care professionals to know and do what is best for them. In some cultures and ethnic groups, this is the normal way in which health care decisions are made.

3 Talking to your family and your health care professional is important. It is best if you seek out a personal doctor with whom you can develop a good, continuing relationship. As trust and understanding between you and your health care professional develop, it becomes easier to communicate your fears, hopes and desires.

¹ Available at <http://www.cha.org.au>

- 4 Patients need their health care professionals to explain the likely course of an illness, the various treatment options available, and their benefits and side effects.
 - 5 Health care professionals need to hear from patients about their hopes and goals in life, their relationships with their families and communities, their tolerance of treatment side effects, their religious commitments, and what will be important to them as death approaches.
 - 6 The best way to establish this communication is through conversations over the years with your family, friends and health care professionals. If you gradually and gently introduce conversations about these matters, then it will be easier to discuss specific and immediate questions relating to a terminal illness, should it arise. In addition, new opportunities for conversation may occur if an illness or disability changes your life situation.
- A court or tribunal appoints someone after you become unable to do so; or
 - Your spouse, carer, other next of kin, or close friend, according to law, may have that authority automatically.
- 3 If you do not have confidence in the persons(s) who would automatically become your representative, then you need to appoint someone specifically. There are legal processes for doing this.
 - 4 Your representative will need to make decisions about your medical treatments if you become unable to do so. The representative will need to assess what a particular treatment may achieve and what difficulties it may cause.
 - 5 To fulfil this role, your representative needs to know about your current health issues and what may be involved in your future health care.

Key point 2

Planning future health care relies on good, long-term communication between you and your family, friends and health care professional.

3 Appointing a representative

- 1 Illness and disability may change your life situation, affecting your independence and relationships with the people around you. How you endure, and the new relationships that form through illness and dependency, are an important part of your journey that continues until death. These relationships continue even when your own ability to communicate is diminished. For Christians, in becoming more dependent on others, there is an opportunity to share in the suffering of Christ.
 - 2 If you become unable to make decisions for your own medical treatment, there are three ways in which someone may be or become your representative:
 - You have appointed someone previously;
- 7 The advantage of appointing such a person is that he or she is able to respond, on your behalf, to the changing circumstances in which treatment decisions may be needed. Your representative's formal role is to make decisions on your behalf and to communicate with the treatment team. However, he or she might also have a less formal role in coordinating discussion among your family, where this is desirable and practicable.

Key point 3

A representative can make health decisions on your behalf, based on your advice, the advice of your health care professionals, and your representative's own good judgement. These health decisions have the advantage of being flexible in response to changing circumstances.

4 Guiding your representative

- 1 You may wish to give your representative some guidance about how you want decisions made for you. You may simply be happy to discuss what may happen, or you may want to provide something in writing as a reminder for that person, when the time comes.
- 2 You can record your values and wishes in several ways:
 - a) Your health care professional may (and usually should) keep his or her own notes of what you have said and review them regularly in the light of changing circumstances.
 - b) You may prepare a statement of general principles about what you would like done in the future.
 - c) You may prepare a specific plan for your care in the immediate circumstances of a degenerative illness about which you have been well informed. When you prepare this plan, it is important that you communicate with your health care professional as much as possible, because usually only a medical practitioner has the expertise and experience to inform people of their prognosis and of the treatment options. Guidance from other health care professionals, pastoral carers, ministers of religion or community elders may also be helpful.
 - d) In some jurisdictions, advance directives or advance care plans have been given a legal status. However, these plans are likely to be inflexible and their legal status may prevent health care professionals from changing your care to suit changes in the circumstances. Such directives may also suggest wordings that refuse care that should be provided, or insist on inappropriate treatment.
- 3 It is best to avoid documents that attempt to be too directive. Rather, your written wishes should guide what happens, while being flexible enough to allow your representative to respect your values as he or she adjusts to new situations on the advice of health care professionals.

Key point 4

You can allow your representative to make health decisions for you, or you can provide that person with specific advice, verbally or in writing, or by having it recorded in your doctor's records.

5 Understanding responsibilities and rights

- 1 By giving guidance to others, such as your representative, about your future treatment and care, you may relieve the anxiety and burden of decision-making for them. However, the guidance that you give should respect their moral responsibility to value and care for you until death intervenes. The person who accepts the role of representative takes on the same responsibility that each of us has to protect and sustain our own life.
- 2 You can help your representative and health care professionals by considering the possible course of your illness and indicating your priorities. We have a moral responsibility to use those means of sustaining our lives that are effective, not overly burdensome and reasonably available. (Such means are referred to in the Catholic tradition as 'ordinary' or 'proportionate'.)
- 3 You or your representative have a moral right to refuse any treatment that is futile, or that you judge to be overly burdensome or morally unacceptable (referred to in the Catholic tradition as 'extraordinary' or 'disproportionate'). Such refusals must also be respected by health care professionals.
- 4 Treatments are futile if they provide no benefit to a particular patient. Assessing the benefits of a treatment includes judging whether the intervention corresponds to the real situation of the person before and after the intervention. The benefits of treatment include:

- Slowing down the progress of disease;
- Sustaining the patient's life; or
- Relieving the patient's distress or discomfort.

5 Treatments are burdensome when they cause distress and suffering to you, cause difficulties for you or your family (or the community), or are costly to obtain or provide. For example, if you were suffering from a degenerative disease with a predictable course (e.g. renal failure, cardiac disease, cancer or dementia), you should be informed of the likely progress of the disease, and of the likely benefits and burdens of treatment options – especially in the later stages.

It may be helpful to others for you to think about the circumstances in which you would regard some intrusive life-sustaining interventions (such as cardiopulmonary resuscitation, renal dialysis or mechanical ventilation) as overly burdensome.

6 Alternatively, you may wish to guide your treatment and care in the foreseeable circumstances of a life-threatening situation (e.g. a stroke, heart failure or accident). In such a case, you can give only general guidance about the treatments you would want and the kind of benefits and burdens of treatment that you would judge reasonable. For example, a frail, elderly person might consider resuscitation (including intubation, cardiac massage and defibrillation) after a heart attack as overly burdensome. However, that person might want other care to continue in the meantime, such as antibiotics for infection or assistance with feeding.

7 If the time comes when you cannot feed yourself, others would be expected to provide you with food and water as part of the normal obligation to sustain you. If you have swallowing difficulties, tube feeding is appropriate if it nourishes you and/or alleviates your suffering, unless it would be overly burdensome. As death approaches, your body may not be able to digest food, feeding may overload a failing system, or the burdens associated with tube feeding (e.g. discomfort or the risk of choking) may make it overly burdensome.

8 Given the continuing debates over euthanasia and the withdrawal of medical treatment, it is important to state explicitly that you do want life-sustaining treatment that is reasonable to be provided unless it becomes futile or is overly burdensome.

9 In addition, when planning your future health care, you need to realise that there are ethical and legal limits to what can be requested of your representative or health professional.

Key point 5

You may wish to clarify the burdens that you would find acceptable, for example, by requesting that you be given only the kind of treatment or care that can be provided in your home, without the need for prolonged hospital care.

6 Summary

1 Planning your future health care requires good communication between you and your family, friends and health care professional. It is also based on careful consideration of the benefits and burdens of treatment options, including what can reasonably be expected of the person(s) chosen to be your representative, as well as your health care professional.

2 A good future health care plan should also take into account the ethical and legal responsibilities of your health care professional and representative, and aim to provide them with clear guidance for providing you with the best and most appropriate health care, which can also be adapted according to changing circumstances.

7 A model statement

1 The 'model statement for future health care', which is found over the page, contains some suggestions about the kinds of things you might like to think about, and perhaps to record, to guide your future medical treatment.

A model statement for future health care

I, (name) _____

of (address) _____

ask that this document be used to inform decisions about my health care, in the event that I am not able to communicate my wishes. This statement is intended to guide but not direct my representative.

Person(s) appointed

Name (s): _____

Contact details: _____

Alternative: _____

Contact details: _____

Statement of my wishes for my future health care

- 1 I wish to be given appropriate care to sustain my life, to cure disease, or to reduce deterioration in any physical or medical condition that I suffer.
- 2 I know that death need not be resisted by every possible means. I ask that I not be given any treatment that would not sustain me, or give me comfort or relieve a condition that I have, or would be overly burdensome to me or to others.
- 3 I ask that I be given adequate palliative treatments to manage uncomfortable or distressing symptoms, while maintaining as much function as possible, especially lucidity, during the dying process. If the only way to manage my distress is with treatments that have the side effect of reducing lucidity or even shortening life, then I am prepared to accept these consequences.
- 4 I wish to be provided with food and fluid, and with other basic means of sustaining my life and making me comfortable, for as long as I need them. This may need to be done by tube, unless or until such methods of treatment and care are ineffective or are overly burdensome.
- 5 I do not want my life to be ended, or my death to be hastened, by any act or omission that is intended to cause my death.
- 6 When it is thought that I am in the final stages of terminal illness or injury, or that my death is imminent, I ask that all reasonable steps are taken to allow me to be with my family and be reconciled to anyone from whom I may have become estranged, and if it is practicable, that I be allowed to die at home or at least in a home-like hospice or other institution.
- 7 (Strike out, if not applicable) In my medical care, I wish to follow the rites and teachings of my religion _____ (insert the name/denomination of your religion). I ask that I receive pastoral care and the appropriate ministry, both early in the course of my illness and again when death approaches.
- 8 (Strike out, if not applicable) I ask that those looking after me observe the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia (CHA 2001) and subsequent Catholic Church documents.
- 9 (Strike out, if not applicable) I am suffering from the following degenerative illness:

In the following circumstances:

I would want effective, non-burdensome treatment and care that is reasonably available to be continued, but would consider the following to be overly burdensome:

I would also want the following:

Signature _____

Date _____

Witnesses _____