

A guide for health care professionals implementing a future health care plan

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.

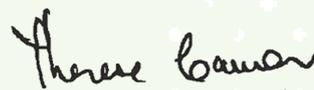
Responses received in that consultation process then informed the writing of this guide for health care professionals, and the accompanying guide for people considering their future health care needs.

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 health care professionals who are involved with people considering their future health care needs and wishing to give advice about their values and wishes. Its purpose is to:
 - inform health care professionals about the role of a patient representative;
 - identify professional and ethical responsibilities associated with implementing future health care plans; and
 - identify the responsibilities of people involved in a person's future health care plan.
- 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'). Also, it is intended to be read in conjunction with *A Guide for People Considering their Future Health Care*.
- 3 The principles in this guide apply also to 'advance directives' or 'living wills' — documents that detail people's wishes about medical treatment in case an illness or accident leaves them unable to communicate.

2 Using a future care plan

- 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. When considering their values and wishes for their future health care, many people trust their families and health care professionals to know and do what is best for them; others prefer to provide specific guidance for their treatment in the form of a health care plan.
- 2 People can express their future health care wishes in several ways. However, the legal status of these expressions may vary depending on the jurisdiction; therefore, legal advice relevant to the jurisdiction should be sought.
- 3 When a person becomes incompetent, he or she is no longer able to respond to the current circumstances. There is always a moral responsibility to provide reasonable care, and the progress of illness can be uncertain. Thus, an incompetent person's earlier wishes and values should guide, rather than direct, the specific treatment and care decisions to be made in the actual circumstances that later arise. Although the earlier expression provides evidence of the person's past wishes, the health care professional must still make responsible decisions in the actual circumstances with the guidance of the person's representative.
- 4 Accordingly, when a health care professional or health or aged care institution first begins to care for someone who has an existing future care plan, the documentation should be reviewed. Health care professionals should assess the applicability of the plan in the actual circumstances, and judge whether any requests made can be met in keeping with responsible medical practice, individual professional conscience and the values of the institution.
- 5 Usually, collaborative discussion with the person or representative leads to agreement about a revised future care plan. There may sometimes be an unresolved difference, especially if the person or the person's representative insists on elements in the health care plan that require the health care professional or institution to act unethically. In such cases, the health care professional or institution may have to decline to be involved further in the care of the person or resident, provided that no one is endangered by that decision.

Key point 1

The health care professional's role is to be familiar with the person's values and earlier wishes, to review his or her wishes with the person's representative in light of any changes in the current situation, and to resolve differences, where possible, according to his or her individual professional conscience and professional and institutional codes of ethics.

3 The role of the patient representative

- 1 The most helpful part of future health care planning is the fact that someone is able to speak on behalf of the person when that person is unable to do so. A patient representative is responsible for being adequately informed about the circumstances and the treatment options, as well as about the person's values and previous wishes. The fact that someone has been appointed as the patient's representative should not lead to the exclusion of other people who are close to the patient. Usually, the representative should inform and consult those who are professionally or emotionally close to the patient, so that they can provide relevant information, and can understand and be part of the process of caring for the person.
- 2 There are three ways in which someone may become a representative:
 - the representative was appointed previously by the person;
 - the representative was appointed by a court or tribunal after the person became incapable of making decisions about his or her own medical treatment; or
 - the representative has legal authority automatically, as the person's spouse, carer, other next of kin or close friend.
- 3 To pre-empt problems arising from unexpected circumstances, the patient's family, representative, primary caregivers and those involved as health professionals need to address the following questions:
 - a) Do the present circumstances correspond to the situation that the patient imagined when he or she recorded his or her values and wishes?
 - b) Do the treatment and care options available correspond to those of the patient's future health care plan?
 - c) Do the effects of implementing the patient's values and wishes correspond to the effects that the person understood would be their consequence?
 - d) Are there new or changed factors in the present circumstances that the patient may not have taken into account but might have wanted to be considered in the present circumstances?
- 3 To lessen uncertainty about these issues, continuity of care and carers is highly desirable.

Key point 2

A person's representative makes health decisions for the patient, based on the patient's previous advice and the patient's own values, input from the health care professional and their own good judgement.

Key point 3

Health care professionals and others involved in a patient's health care need to consider changes in a person's health situation, and their consequences, when applying a future care plan.

4 Interpreting a future health care plan

- 1 Interpreting a future health care plan is not always straightforward. Even when a patient has a progressive illness with a predictable course, unanticipated circumstances may arise. Similarly, a life-threatening event may occur when there

5 Understanding responsibilities and rights

- 1 The person who accepts the role of a patient's representative takes on the same moral responsibility that each of us has to sustain our own life. In addition, the guidance provided by the patient about his or her values and wishes should respect the health care professional's moral responsibility to value and care for the patient until death intervenes.
- 2 Patients or their representatives have a moral right to refuse any treatment that is futile, or that they 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.
- 3 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.
- 4 Treatments are burdensome when they cause distress or suffering, cause difficulties for the patient or the family (or the community), or are costly to obtain or provide.
- 5 Those responsible for the patient (e.g. health care professionals, family members and representatives) need to judge whether the patient's future health care plan, applied in the actual circumstances, is in accord with the patient's values and represents what the patient would have wanted. They also need to establish that acting on those wishes is ethical and lawful, given both the patient's and their own moral responsibilities.
- 6 The right to refuse treatment is not unlimited, and there are ethical and legal limits to what may be requested of a health professional or

any other person, even by a competent person or representative.² For instance, there is an ethical obligation to prevent suicide when this is possible³ and in most jurisdictions the law allows one to do so. A health care professional cannot be expected to act upon a future health care plan that expresses a suicidal or homicidal intention.

Key point 4

Health care professionals need to assess the relative benefits and burdens of treatment, taking into account the person's values and previously expressed wishes and advice from the representative. However, health care professionals also need to be aware of their own ethical and legal responsibilities.

6 Recognising the responsibilities of representatives

- 1 Usually, representatives have the same moral responsibilities to request or refuse treatment as the patient had while competent. However, in some circumstances, the rights of the patient and the rights of his or her representative are not identical. For example, people are permitted to act generously by placing themselves in some danger for the sake of others (e.g. to donate tissues or to lessen a burden on their family), whereas their representatives are not free to make a similar choice for them. A representative should only allow a patient to be endangered if the course of action would have been morally permissible for the patient while competent, and provided it is explicitly in accord with the patient's earlier clearly expressed wishes.
- 2 In addition, while respecting the patient's wishes, a representative making a decision for a person who cannot make his or her own decision is always obliged to act in the best interests (respecting life and health) of that patient. The representative is also constrained by objective moral principles and his or her own conscientious judgments.⁴

- 3 To become a person's representative for medical treatment decisions is to assume a publicly accountable responsibility. Health professionals and other concerned people need to ensure that such representation is reviewed by the appropriate legal authority if a representative does not appear to be fulfilling the role adequately.
- 2 In addition, planning for unexpected events requires health care professionals — together with representatives, friends and family — to consider the consequences of potential changes and how these differ from the person's values and original wishes.

Key point 5

When making decisions about treatments, the rights of representatives may differ from those of the person. A representative must act in the best interests of the person, and health care professionals should ensure that this occurs.

7 Summary

- 1 Developing and implementing a successful future health care plan depends on good, long-term communication between the health care professional, the person and the person's representative, family and friends.

- 3 Above all, when implementing a future health care plan, health care professionals must comply with their personal, professional and institutional ethical responsibilities, while ensuring that they provide appropriate care.
- 4 This guide for health care professionals is intended to be read in conjunction with the guide for patients, *A Guide for People Considering Their Future Health Care*. More information about people considering their future health care needs and treatment preferences can be found in that document.

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

2 See the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, section 1.17 (available at <http://www.cha.org.au>)

3 See the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, section 1.16 (available at <http://www.cha.org.au>)

4 See the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, section 1.21 (available at <http://www.cha.org.au>)