



**Australian Catholic
Bishops Conference**

**Submission to the
Senate Community Affairs References Committee
inquiry into
Palliative Care in Australia**

March 2012

Introduction

The Australian Catholic Bishops Conference (ACBC) is a permanent institution of the Catholic Church in Australia and the instrumentality used by the Australian Catholic Bishops to act nationally and address issues of national significance.

The Catholic Church and its agencies (the Church) contribute in a wide variety of ways across the spectrum of Australian society. As an integral part of its core mission, the Church seeks to assist people experience the fullness of life. It is concerned with all that impacts on human wellbeing. It comprises many thousands of different entities which have different purposes, many in the health sector and many in palliative care.

The ACBC supports the more detailed submission of Catholic Health Australia.

The ACBC supports the provision of palliative care and efforts to improve resourcing for palliative care services, so that palliative care can be integrated into the treatment of all people who need help to help manage their symptoms, whether they are terminally ill or have a chronic illness.¹

The Senate inquiry is focused on structures, processes and funding. These issues are important, but the ACBC believes that the motivations and philosophy behind palliative care are crucial and so will make some comment on the key issues of human dignity and spiritual wellbeing. The ACBC will also provide some comments on the important area of advance care planning.

Human dignity

The ACBC supports palliative care because by treating people with respect and ensuring they do not feel they are a burden, it promotes human dignity.² Human dignity is the concept that all human beings have an intrinsic worth just because they are human. Each patient needs to be recognised as a real person rather than their illness. How we treat each other can promote or undermine a person's sense of dignity, though not their inherent dignity. Chochinov warns that:

Not being treated with dignity and respect can undermine a sense of value or worth. Patients who feel that life no longer has worth, meaning, or purpose are more likely to feel

¹ Maddocks, I (2003), Palliative care in the 21st century. *Medical Journal of Australia*, Vol. 179, page S4; National Health and Medical Research Council (2011), *An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions*. September. NHMRC, Canberra.

² Chochinov, H (2007), Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ*, Vol, 335, 28 July, page 184; Rosenstein, D (2011), Depression and end-of-life care for patients with cancer. *Dialogues Clin Neurosci*, March, Vol. 13(1), page 104; Beuken, G (2003), The spiritual dimension of palliative care in the local Christian community. *Scottish Journal of Healthcare Chaplaincy*, Vol. 6(1), page 45.

they have become a burden to others, and patients who feel they are little more than a burden may start to question the point of their continued existence.³

So the manner in which patients are treated and the philosophy behind their care is central to the wellbeing of patients and therefore the success of palliative care.

Good palliative care exemplifies the parable of the Good Samaritan, which offers guidance on how we should serve our neighbour. The parable is the story of a man who had been attacked and beaten by robbers and left on the roadside. Two travellers passed by without helping. But the Samaritan stopped, had compassion and tended to the man's wounds, took him to an inn and paid his expenses.⁴ The practice of palliative care involves being a good neighbour and reaffirming the dignity of people in need of care.

Spiritual wellbeing

The Church also has an interest in the spiritual wellbeing of people. To be at peace spiritually, or find purpose and meaning in life through religious faith, is a worthwhile human aspiration.

Spirituality, defined as "the way in which a person understands his or her life in view of its ultimate meaning and value",⁵ is an important consideration in the multi-disciplinary approach to palliative care. Patients can find peace and improved mental health from developing their spiritual wellbeing,⁶ protecting against feelings of helplessness and self-destructive thoughts.⁷

Beuken points out that "a 'good death' can be achieved when the dying person is relieved not only of their physical pain but also of their emotional pain and relief of emotional pain is somewhat achievable through good honest and open communication with others and God."⁸

³ Chochinov, H (2007), Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ*, Vol, 335, 28 July, page 184-5.

⁴ Apostolic letter "Salvifici Doloris" of the Supreme Pontiff John Paul II to the Bishops, to the Priests, to the Religious Families and to the Faithful of the Catholic Church on the Christian Meaning of Human Suffering, 11 February 1984.

⁵ Maytal, G and Stern, T (2006), The desire for death in the setting of terminal illness: a case discussion. *Prim Care Companion J Clin Psychiatry*, Vol 8(5), page 303.

⁶ Mystakidou, K (2008), Predictors of spirituality at the end of life. *Canadian Family Physician*, Vol.54, December, page 1721; McClain, C et al (2003), Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *The Lancet*, Vol 361, May 10, page 1606.

⁷ Maytal, G and Stern, T (2006), The desire for death in the setting of terminal illness: a case discussion. *Prim Care Companion J Clin Psychiatry*, Vol 8(5), page 303.

⁸ Beuken, George (2003), The spiritual dimension of palliative care in the local Christian community. *Scottish Journal of Healthcare Chaplaincy*, Vol. 6(1), page 46.

Hospice pioneer Dame Cicely Saunders points out “patients need to look back over the story of their lives and believe that there was some sense in them and also to reach out towards something greater than themselves, a truth to which they can be committed.”⁹

The Church supports providing people, whether they believe in God or not, with the opportunity to address their spiritual wellbeing as a part of palliative care and to share their journey with family and friends and those on the palliative care team.

As the newspaper *The Guardian* recently commented, “... death poses us all, religious and non-religious alike, with the question of what life is all about. ... Where death becomes a private matter, it becomes so much more difficult to reach out to others precisely when they need it most.”¹⁰

Advance care planning

The Church has set out a clear approach to advance care planning in the documents ‘*A guide for people considering their future health care*’ and ‘*A guide for health care professionals implementing a future health care plan*’,¹¹ issued by the ACBC and Catholic Health Australia (CHA).

The documents were prepared partly in response to concern over the usefulness of written advance care plans, such as the Respecting Patient Choices program¹², which can put too much emphasis on trying to define outcomes a patient wants rather than more usefully focusing on the patient indicating an appropriate approach to care.

The problems of advance care plans, sometimes also called living wills or advance directives, were well documented in a study published in the *Hastings Center Report*. The authors pointed out that despite significant efforts and funds expended over many years to promote the use of advance care plans, most people do not have them. For those who do have plans, many have not given sufficient thought to the instructions that will direct life and death decisions, the nature of the directives mean it is difficult to clearly communicate preferences, the documents often do not get to the relevant medical staff and the documents do not help health care proxies better represent the preferences of the patient.¹³

⁹ Saunders C and Baines M (1989), *Living with dying: the management of terminal disease* (second edition). Oxford University Press, Oxford. Page 53.

¹⁰ Editorial, Ash Wednesday: the lost art of dying, *The Guardian*, 21 February 2012.

¹¹ See <http://cha.org.au/site.php?id=223>

¹² See <http://www.respectingpatientchoices.org.au/>

¹³ Fagerlin, A and Schneider, C (2004), Enough: The Failure of the Living Will. *Hastings Center Report*, Vol. 34(2), March-April, page 38.

Other problematic aspects of advance directives are that:

- they are difficult to interpret because illnesses and the course of illness are unpredictable and medical staff need to discuss the burdens and benefits of treatments with the patient or proxy before a decision is made;
- they are a snapshot of past wishes of the patient and can be given more weight than a contemporary assessment of reasonable care. They also do not recognise that patient preferences change as circumstances change. What might seem unacceptable to a healthy patient might become more than acceptable in a life threatening situation;
- written directives can ignore the important distinction of intention. There is a great difference between a patient refusing treatment that is burdensome or futile and refusing treatment for the sole intention of ending life.¹⁴

A more useful approach is to appoint a health care proxy, such as someone who has been given a durable power of attorney, who can act as the patient's representative and discuss treatment options with the medical staff and family, making informed judgements on the relative usefulness or burden of treatment options as the patient's illness progresses.¹⁵ But proxies need help and support from the palliative care team in what is often a very confronting and unfamiliar situation, dealing with life and death questions.¹⁶

In response to these and other concerns, the guide documents issued by the ACBC and CHA encourage people to talk to their family, friends and health care professionals about how they may like to be treated in the event of illness and to develop that understanding over years, rather than in an isolated conversation. The guides recommend appointment of a representative or proxy who can make decisions on the patient's behalf in the event they can no longer make decisions themselves.

The guides also provide a model statement which people can use as a basis for giving guidance to their proxy. The model statement is written in such a way that it provides a framework for decision-making which emphasises the human dignity of the patient and allows judgements to be made on whether a treatment is futile or burdensome. This would be an appropriate approach for any national developments in advance care planning.

Conclusion

The ACBC supports the Committee in its efforts to improve the provision of palliative care in the Australian community. Two vital components of palliative care that should not be neglected are an emphasis on the human dignity of each and every person undergoing treatment and the part spirituality plays in the overall wellbeing of the person.

¹⁴ Tobin, B (2008), More talk, less paper! Why health care proxies are a better means of extending traditional morality than are living wills. *Bioethics Outlook*, Vol 19(3), September, page 5.

¹⁵ Tobin, B, *op cit*, page 5.

¹⁶ Neveloff Dubler, N (2008), Tell me about Mama: Facilitating end-of-life decisions, ethics committees and ethics consultations. *Bioethics Outlook*, Vol. 19(4), December, pages 1-4.

Advance care planning provides an important opportunity for people with a terminal or chronic illness to discuss and consider their future care, but it is more helpful to appoint a health care proxy who can represent the patient's interests as their illness progresses and react flexibly to the changing situation on the basis of the values and approach discussed with the patient, which is something a static document cannot manage.