Submission

on

Palliative Care in Australia

to the

Senate Standing Committees on Community Affairs

PO Box 6100
Parliament House
Canberra ACT 2600

Tel: 02 6277 3515

Fax: 02 6277 5829

Email: community.affairs.sen@aph.gov.au

Website: www.aph.gov.au/Parliamentary_Business/Committees

by

FamilyVoice Australia

4th Floor 68 Grenfell St

Adelaide SA 5000

Phone: 1300 365 965

Fax: 08 8223 5850

Email: office@fava.org.au

Website: www.fava.org.au

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TABLE OF CONTENTS

1. **Introduction** 1

2. **Palliative care** 1

3. **To neither hasten nor postpone death** 2

4. **Advanced care planning** 3

5. **Endnotes** 5

1. Introduction

On 23 November 2011 the Senate referred to the Standing Committees on Community Affairs the matter of providing palliative care in Australia.

The Committee has called for public submissions on this reference to be received by 23 March 2012. The Committee is due to report by 12 September 2012.

2. Palliative care

The World Health Organisation defines palliative care as follows:

> *Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:*
>
> - *provides relief from pain and other distressing symptoms;*
> - *affirms life and regards dying as a normal process;*
> - *intends neither to hasten or postpone death;*
> - *integrates the psychological and spiritual aspects of patient care;*
> - *offers a support system to help patients live as actively as possible until death;*
> - *offers a support system to help the family cope during the patients illness and in their own bereavement;*
> - *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
> - *will enhance quality of life, and may also positively influence the course of illness;*
> - *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*[1]

This definition has been adopted by Palliative Care Australia.[2] Palliative Care Australia is an incorporated body whose members are the eight state and territory palliative care associations and the Australian and New Zealand Society of Palliative Medicine. The membership of those associations includes palliative care service providers, clinicians, allied health professionals, academics, consumers and members of the general community.[3]

All the elements of this definition are important in considering the provision of palliative care in Australia.

Palliative care is not limited to pain control. It also addresses other distressing symptoms, including physical symptoms such as nausea and incontinence, as well as psychological, social and spiritual matters.

Palliative care takes into account the patient's family as well as the patient. It focuses on the need to provide support systems both "*to help patients live as actively as possible until death*" and "*to help the family cope during the patient's illness and in their own bereavement*".

The last bullet point in the definition makes it clear that palliative care is not limited to the relief of symptoms only after all therapeutic interventions have failed but should be initiated in conjunction with therapeutic interventions.

Recommendation 1:

The provision of palliative care in Australia should take into account all the elements of palliative care as defined by the World Health Organisation, to ensure a broad and comprehensive approach to the funding and provision of palliative care.

3. To neither hasten nor postpone death

One essential tenet of palliative care is "*to neither hasten nor postpone death*".

Death is, of course, inevitable for all human beings.

Palliative care recognises that there is a point in the progression of many illnesses when therapeutic interventions are no longer justified, as the burdens they impose are not proportionate to the likelihood of benefit to the patient in terms of prolonged life or cure from the illness.

The WHO definition does acknowledge that, while directed primarily at improving the quality of life, palliative care may also "*positively influence the course of illness*".

For example, contrary to popular belief that the use of morphine to control pain is likely to hasten death, "*Research findings suggest that aggressive pain management at the end of life does not necessarily shorten life, but rather pain management may be life-prolonging by decreasing the systemic effects of uncontrolled pain that can compromise vital organ function*".[4]

Palliative care aims at helping "*patients live as actively as possible until death*". It rejects the notion that hastening death through active measures, such as a lethal injection, is an appropriate response to end of life issues.

The provision of palliative care in Australia should be made on the basis that euthanasia and assisted suicide are outside the scope of palliative care and contrary to its philosophy and practice. Attempts to blur the distinction between palliative care and euthanasia should be rejected. For example palliative sedation should be used only to relieve refractory suffering, not to hasten death.[5]

Recommendation 2:

The provision of palliative care in Australia should respect the tenet of palliative care "to neither hasten nor postpone death" as excluding all forms of euthanasia and assisted suicide. Palliative care does not include any measures which are intended to hasten death or directly end the life of the patient.

4. Advanced care planning

Advanced care planning can play an important role in ensuring that patients' preferences for treatment and care are respected even after they become incompetent in communicating these preferences.

There is some merit in seeking national uniformity in the approach to advanced care planning and in working to include advance care plans in patients' electronic records. However, this is essentially a matter for State law and any proposal for uniform legislation requires the agreement of the States. There should be no attempt at a Commonwealth take over of legislation in this area.

However, any such schemes ought to acknowledge the inherent difficulties of advanced care plans and avoid legislation or policy practice that interprets preferences expressed in such plans as binding directives which would prevent medical practitioners and other health care providers from acting in accord with good medical practice and in the patient's best interests.

The Law Reform Commission of Western Australia pointed out the deficiencies of an advanced health directive: "*[T]he fundamental difficulty [is] that it prescribes a form of medical treatment without knowing the precise circumstances which would exist when the directive is required to be used. Therefore it is likely to be either too specific, failing to cover all circumstances, or too general, causing interpretative problems.*"[6]

This and other problems with advanced health directives are confirmed in the landmark paper examining the extensive experience with such directives in the United States by Angela Fagerlin and Carl E.Schneider.[7]

> *[P]eople who sign living wills have generally not thought through its instructions in a way we should want for life-and-death decisions. Nor can we expect people to make thoughtful and stable decisions about so complex a question so far in the future … [D]rafters of living wills have failed to offer people the means to articulate their preferences accurately. And the fault lies primarily not with the drafters; it lies with the inherent impossibility of living wills' task. … [L]iving wills seem not to increase the accuracy with which surrogates identify patients' preferences. And the reasons we surveyed when we explained why living wills do not affect patients' care suggest that these problems are insurmountable.*[8]

Consent to medical treatment is not held to be legally valid unless an appropriately qualified medical practitioner has explained to the patient the nature and purpose of the treatment, as well as any risks or side effects, and what alternatives are available. It is simply not possible to ensure that a person completing an advanced health directive is adequately informed before signing it.

Fagerlin and Schneider write:

> *Nor do people reliably know enough about illnesses and treatments to make prospective life-or-death decisions about them… For such information, people must rely on doctors. But doctors convey that information wretchedly even to competent patients making contemporaneous decisions. Living wills can be executed without even consulting a doctor, and when doctors are consulted, the conversations are ordinarily short, vague, and tendentious. In the Tulsky study, for example, doctors only described either 'dire scenarios ... in which few people, terminally ill or otherwise, would want treatment' or 'situations in which patients could recover with proper treatment.*[9]

Section 103 of Queensland's *Powers of Attorney Act 1998* provides that a health professional is protected from liability for departing from a direction given in an advance health directive:

> *(a) if a health provider has reasonable grounds to believe that a direction is uncertain;*

(b) if a health provider has reasonable grounds to believe that a direction is inconsistent with good medical practice; or

(c) if a health provider has reasonable grounds to believe that circumstances, including advances in medical science, have changed to the extent that the terms of the direction are inappropriate.

These are all appropriate conditions for a protection for liability and help ensure that advanced health directives, which can be a useful guide to a person's preferences for health care treatment, are not inappropriately applied in ways that could be contrary to the person's actual intentions or that violate good medical practice.

The recently passed provisions in Western Australian law[10] contain a useful requirement for health providers to consider certain matters before putting an advanced health directive into effect in order to determine:

if circumstances exist or have arisen that —

(a) the maker of that directive would not have reasonably anticipated at the time of making the directive; and

(b) would have caused a reasonable person in the maker's position to have changed his or her mind about the treatment decision.

These matters include:

(a) the maker's age at the time the directive was made and at the time the treatment decision would otherwise operate;

(b) the period that has elapsed between those times;

(c) whether the maker reviewed the treatment decision at any time during that period and, if so, the period that has elapsed between the time of the last such review and the time at which the treatment decision would otherwise operate;

(d) the nature of the condition for which the maker needs treatment, the nature of that treatment and the consequences of providing and not providing that treatment.

If advanced care plans are to be made binding in law then provisions such as these in the Queensland and Western Australia legislation should be included to ensure that they are applied appropriately.

Recommendation 3:

Any move toward national uniform legislation on advanced care planning should respect the right of the States to legislate on this matter as they see fit.

If advanced care plans are to be made legally enforceable in any way, then provisions such as those incorporated in Queensland's Powers of Attorney Act 1998 and Western Australia's Guardianship and Administration Act 1990 regarding the application of such directives should be included.

5. Endnotes

1. http://www.who.int/cancer/palliative/definition/en/

2. *Palliative and end of life care: Glossary of terms*, Palliative Care Australia, 2008, p. 11: http://www.palliativecare.org.au/Portals/46/docs/publications/PCA%20Glossary.pdf

3. http://www.palliativecare.org.au/

4. Mularski, R.A. *et al.*, "Pain Management Within the Palliative and End-of-Life Care Experience in the ICU", *Chest*, 2009,135:1360-1369, p 1364: http://chestjournal.chestpubs.org/content/135/5/1360.full.pdf+html

5. *Ibid.*, p 1365.

6 Medical Treatment for the Dying: Discussion Paper, p.13 at: http://www.health.wa.gov.au/publications/documents/Medical%20Treatment%20for%20the%20Dying%20Discussion%20Paper%20May%202005.pdf

7 Fagerlin A and Schneider CF, "Enough: the failure of the living will", *Hasting Centre Report*, March-April 2004, p 30-42: http://www.thehastingscenter.org/Pdf/Publications/Hcr_Mar_Apr_2004_Enough.Pdf

8. *Ibid.*, p 38.

9. *Ibid.*, p 33, citing J.A. Tulsky *et al.*, "Opening the Black Box: How Do Physicians Communicate about Advance Directives?" *Annals of Internal Medicine* 129 (1998): 441-444.

10. *Guardianship and Administration Act 1990 (WA)*, s 110S(3)-(4).