



SUBMISSION INTO THE INQUIRY INTO THE RIGHTS OF THE TERMINALLY ILL (EUTHANASIA LAWS REPEAL) BILL 2008

Summary

Palliative Care Australia thanks the Senate Standing Committee on Legal and Constitutional Affairs for the opportunity to comment on the Euthanasia Laws (Repeal) Bill 2004 [2008], which seeks to repeal the *Euthanasia Laws Act 1997* preventing the Northern Territory Legislative Assembly, the Australian Capital Territory Legislative Assembly and the Norfolk Island Legislative Assembly from legalising voluntary euthanasia.

Palliative Care Australia, the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all, recognises that the ethical issue of whether a person should have the right to choose the time, place and means of their own death is a wider and separate issue to the provision of quality care at the end of life.

Palliative Care Australia believes that the reported community interest in “supporting voluntary euthanasia” is misrepresented and that the key issues individuals seek assurance for are that their pain and suffering will be relieved and that their end of life decisions will be respected.

Palliative Care Australia believes that informed community discussion about euthanasia cannot be had until quality palliative care is available for all who require it and there is enhanced community understanding of existing end of life decision making options, including advance care planning.

Palliative Care Australia recommends that the Committee commit to promoting open and frank community discussion about death and dying and enhanced access to needs-based palliative care that accords with patients’ care preferences. In realising this commitment we ask that the Committee consider an inquiry into identifying and addressing the barriers to greater use of advance care plans and directives, to ensure patients’ rights to determine their course of care are respected.

Palliative Care Australia believes that Australia can do better than enact laws regarding voluntary euthanasia prematurely, before national care and communication systems are in place that ensure widespread access to quality care at the end of life for a community equipped to openly discuss death and dying.

What is palliative care?

Palliative Care is a concept of care that provides coordinated nursing, medical and allied services for people with a terminal illness. Quality palliative care improves the quality of life of patients living with a terminal illness and their families, by the provision of physical, emotional, social, cultural and spiritual support. Palliative care is provided, where possible, in the environment of that person's choice.

With appropriate palliation, pain and other symptoms can be helped and relieved for most terminally ill patients.

Palliative Care Australia believes that dying is a natural process and that declining or withdrawing futile treatment is acceptable if in alignment with the desires of the patient. Palliative care practice does not, however, include deliberate ending of life (euthanasia), even if this is requested by the patient.

Equitable access to quality care at the end of life must precede further consideration of euthanasia

Commonly the 'euthanasia debate' is framed and understood by members of the community and by the Parliament that represents us, in the context of avoidance of pain and suffering, and loss of control over care options and the way in which death occurs.¹

Many of these fears can be addressed through the provision of quality care at the end of life. For most patients access to appropriate palliative care can help control pain and suffering and patients can be given the opportunity to articulate their care preferences for circumstances in which they may be no longer able to express their wishes.

In providing quality care at the end of life we should be able to deliver on promises to patients to provide access to:

- evidence-based medical care
- care customised to patient preferences, including, where possible, preference in location of care
- good symptom control
- planning to articulate end of life care preferences and ensure they are respected
- help to live life fully despite the constraints of terminal illness.²

For many Australians with terminal illness we cannot make these guarantees. This is a public policy failure which must be addressed, and to which the Senate Standing Committee on Legal and Constitutional Affairs could make an important contribution.

Some Australians, with the support of a care team, are able to go through the dying process with minimalised pain, in the environment of their choice and in accordance with their care preferences. Access to palliative care and appropriate support services, however, are not

¹ Indeed a systematic literature review by Hudson et al. suggested that similar fears informed 'desire to die statements' made by terminally ill people. (Hudson, PL. et al. (2006) 'Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review.' *Palliative Medicine* 20; 693-701.

² Lynn, J. (2008) (Re)orienting toward quality care at the end of life. Keynote paper at *A matter of life and death; confronting the new reality*, 13 March 2008, Canberra.

uniform. Services are highly limited in some geographical areas and service demand outstrips supply in many others.

For many Australians access to appropriate care at the end of life is not a reality. For these people the fear of unnecessary pain and suffering, poor quality of life and loss of control over care - which drives much of the community discussion about euthanasia - is justified.³

Informed choice about the place and type of care received at the end of life is an aspiration shared by most members of our community.

A number of mechanisms are available for people to articulate their health care preferences, and to plan for these to be implemented. These include appointment of a proxy decision-maker and written specification (in consultation with a medical practitioner) of health care preferences planned for possible future health events, in the form of advance care plans and/or advance care directives.

Advance care plans enable terminally ill people to articulate their care preferences including planning for emergencies, and to articulate their wish to refuse life-saving or sustaining treatment if they wish to. Advance care directives add legal weight to articulated preferences and can help ensure a patient's request to forgo treatment is respected.

There are significant barriers to articulation of, and compliance with, individual preferences around end of life. These include variation and inconsistency in the legislation governing the implementation of advance care directives across Australian states and territories. The most significant barrier, however, is limited knowledge about, and understanding of, the role of advance care planning and advance care directives among the community and the medical profession.

Open and frank community discussion about voluntary euthanasia cannot be realised until we can deliver on promises to patients to provide quality end of life care, guaranteeing access to palliative care to all who need it and that patient care preferences will be sought and respected. Until we can make these guarantees community discussion of voluntary euthanasia will be fuelled by fears, that are currently warranted, but which need not be necessary.

Facilitating informed discussion of death and dying

With the increasing medicalisation of death and dying our communities have lost the capacity to confront the end of life and engage in open and considered discussion of death and dying. Yet frank and informed discussion is imperative for individuals to plan for their own death, support others in the grieving process and make important ethical considerations about death, as is demanded by consideration of voluntary euthanasia.

To provide for informed discussion, further consideration of voluntary euthanasia must be preceded by:

- enhanced community capacity to rationally discuss death and dying;
- a guarantee of access to quality care at the end of life for all terminally Australians; and

³ Palliative Care Australia (2006) Position statement on voluntary euthanasia on voluntary euthanasia palliative care practice and end of life decisions, <http://www.palliativecare.org.au> [accessed April 9, 2008.]

- a guarantee to all terminally ill people of support in considering and articulating their end of life care preferences and a promise that their preferences will be respected.

Recommendations

Informed discussion about voluntary euthanasia is hindered by our failure to guarantee access to quality care at the end of life in which patients' rights to articulate the terms of their care are respected, and by limited community capacity to engage in frank and open discussion about death.

To promote informed broader community consideration of end of life issues and alleviate unnecessary community fears that continue to frame the 'euthanasia debate', Palliative Care Australia recommends that the Committee promote access to quality care at the end of life for all and greater community capacity to confront death, through recommending:

- that the importance of health care reform to enhance access to quality palliative care be acknowledged through the Government's healthcare reform agenda and through prioritising in the next round of Australian Health Care Agreements;
- ongoing and enhanced commitment to communication initiatives to increase community capacity to consider and plan for end of life;
- the Senate conduct an inquiry into the barriers to greater use and respect of advance care plans and directives and mechanisms for overcoming them; and
- further investment in ensuring health practitioners are competent and resourced to engage in sensitive and open discussion of end of life care and facilitate the development of advance care plans for terminally ill patients, for example by a full measurable implementation of the NHMRC-endorsed guidelines for communicating end-of-life issues.⁴

Palliative Care Australia would be pleased to assist the Committee in its inquiry.

⁴ Clayton, JM et al. (2007) Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers' *MJA* 186 (12); s77-s108.