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Senate Standing Committee on Community Affairs
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Australia

Submission
on the
Inquiry into the provision of Palliative Care in Australia

I. Introduction

Senator Madigan, after representation from constituents, welcomes this opportunity to make a submission to this inquiry. The provision of palliative care is an important contribution to the wellbeing of the Australian community in assisting those suffering from life-threatening illnesses and their families. These representations strongly support the WHO definition of palliative care that provides physical, psychological, social, emotional and spiritual support for patients, families and friends.

Senator Madigan welcomes this inquiry as a means of ensuring the respect of the dignity of every human person. This inquiry is also welcome as a means of increasing knowledge and awareness of the effectiveness of palliative care for the terminally ill as there is still much ignorance and misinformation concerning the effectiveness of palliative care in delivering effective care and pain relief in end-of-life situations.

This submission will address itself principally to those areas where we have received representations.

II. Factors influencing access to and choice of appropriate palliative care that meets the needs of the population

(i) People living in rural and regional areas

Senator Madigan's electorate office is based in Ballarat, and well placed to hear the concerns of regional and rural constituents. In particular, constituents are concerned that quality care for the dying be equally available to all especially those in regional, rural and remote locations. Access to health care and palliative care provisions for constituents in rural Victoria is limited due to distance from service towns. The provision of palliative care in rural areas is important in ensuring the rights of a patient to be cared for in the place of choice: at home or in an institution. Home care is preferable to many as institutional care for people in rural settings adds another layer of burden on families who may have to travel large distances or incur accommodation costs in order to be with their loved ones. Many perceive that the options are either the additional financial and emotional burden of institutional care or inadequate and possibly distressing home care. These burdens may be alleviated by utilizing available allied health professionals and training them in the provision of palliative care, and by training locally-based palliative care volunteers. Further assistance can also be made available through the provision of palliative care advice and information through telephone and internet services.

Recommendation: That funding be targeted to providing improved availability of palliative care in regional, rural and remote areas through:

- Wider provision of palliative care services;
- Training of allied health workers in palliative care provisions;
- Training palliative care volunteers
- Provision of palliative care advice through telephone and internet services

(ii) Children and Adolescents, and perinatal palliative care

The provision for palliative care services for children and adolescents requires particular sensitivity to the needs of children. As noted in the document: *Strengthening care for children with a life threatening condition*¹, Children cannot be regarded as "little adults" but have their own particular needs. This is also the case for adolescents, neonates, aboriginal children and children from culturally and linguistically diverse backgrounds.² One significant category which is omitted is the provision of perinatal palliative care.

Presently if woman's unborn child is diagnosed, *in utero*, with a life threatening condition, there is no uniform availability of referral to palliative care. This is a time of considerable distress for the mother and extended family particularly the father and siblings. Many health facilities routinely offer abortion in such circumstances. Where the woman refuses abortion she is doubly burdened emotionally and spiritually. From constituent representation we have had two divergent experiences: One where the mother and extended family was supported in her choice to continue the pregnancy and was cared for

in a sensitive manner by the local public health service and resulted with the baby dying at home a week after birth surrounded by family; in the other case, the woman whose baby was diagnosed with a terminal genetic condition was referred for a termination by her specialist and when she resisted that advice was left to her own and her family's resources to find alternative acceptable care. Alternatives to abortion should be offered in these situations with information about the condition and access to appropriate and sensitive perinatal palliative care.

Recommendation: That perinatal palliative care services be established and offered to all women who may give birth to a child with a life limiting diagnosis.

III the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

The majority of Australians would prefer to die at home with only about 20% preferring to die in a hospital or hospice.³ Unfortunately in the present situation most Australians are dying in a hospital or hospice. About 69% of cancer sufferers died in hospitals in 2008-09.⁴

Apart from assisting the patient in exercising their right to choose their place of death, there are considerable financial advantages to providing extended palliative care in the home:

Some older people are going to hospitals to receive palliative care when they could be better cared for at home or in an aged care service. A public hospital bed can cost taxpayers up to three to four times more per day to operate than an aged care bed, where very often older people would be better off.⁵

Recommendation: That resources to home and community based palliative care services be increased.

IV Advance care planning

Palliative care aims to provide the best available treatment and to ensure that patients have the right to access expertise when and where it is required, the right to choose treatment or not to choose treatment, and the right to be cared for in the place of choice.⁶ In order to make these choices patients need to be informed of availability of treatment options. Surveys show that many Australians are ignorant of these choices and have given little or no thought as to how they might deal with a life-threatening illness.⁷

Clearly, Australians need to be encouraged to discuss these options with their family, friends, and healthcare professionals.

Advanced care planning is one way in which this conversation can take place, however many are concerned that ‘advanced care directives’ may be problematic especially where they have legal status which may be applied inflexibly. Further, ‘advanced care directives’ cannot adequately ensure informed consent when decisions are being made about future events – health care professionals may have to make decisions at a future time about what the person understood at the time of making a decision.⁸

It is important that any ‘advanced care plan’ be flexible enough to allow for health care professionals to change patient care in response to changing circumstances in order to provide best possible care.

An alternative to ‘advanced care planning’ is that of ‘future care planning’ which provides that flexibility. This involves the patient appointing someone who will represent their best interests and who will, in the event of the incapacity of the patient, be able to make the necessary choices on their behalf. It would be necessary to ensure the patient trust the appointed person; have discussed their values, thoughts and fears about the end of life and provide them with guidance rather than directives.⁹

Recommendation: It is important for patients to be aware of care and treatment options and that they be able to exercise informed consent. It is important therefore:

- **That terminally ill patients be informed of their options for future care as their condition changes, but that their plans ensure an ability to respond to changing circumstances.**
- **That they be encouraged to discuss these options with a trusted family member or friend who will act for them in the event of disability or incapacity.**

¹ *Strengthening care for children with a life-threatening condition: a policy for health, palliative care, disability, children’s service and community care providers 2008-2015*, State Government of Victoria.

² Ibid. p.5

³ “We need to talk about dying” Media Release, Palliative Care Australia.

<http://www.palliativecare.org.au/Portals/46/National%20Palliative%20Care%20Week%20Media%20release.pdf>

⁴ AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW

⁵ Catholic Health Australia, Media Release, 20 October 2011.

<http://www.cha.org.au/site.php?id=168&media=104>

⁶ Media Release, Palliative Care Australia, 1 February 2008.

⁷ Op.cit. “We need to talk about dying.”

⁸ “To Love . . . Until the End. Who will make your choices?” Nicholas Tonti-Filippini, Lecture, 27 March, 2012, Fitzroy.

⁹ Ibid, see also Nicholas Tonti-Filippini, *About Bioethics: caring for people who are dying or sick*. Connorcourt, Ballan: 2012, chapter 3 pp121-147.