

14 August 2015

Ms Lilian Topic
Secretary
Legal & Social Issues Committee
Parliament House
Spring Street
MELBOURNE VIC 3002



Dear Ms Topic

**RE: SUBMISSION TO THE STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES
INQUIRY INTO END OF LIFE CHOICES**

I am grateful for the opportunity to contribute to the committee's consideration and deliberation of the issues in end of life care choices.

Cabrini is a Catholic health care service sponsored by the Missionary Sisters of the Sacred Heart of Jesus (Cabrini Sisters). We provide acute, sub-acute, palliative and residential aged care services primarily serving the south-eastern corridor of Melbourne.

We established a palliative care service in 1999 to better meet the needs of our growing cancer patient population. Ours was the first palliative care service in the private sector and we remain the only fully integrated private specialist palliative care service in Australia.

Over time the service has expanded to provide palliative and supportive care to patients from the time of diagnosis of advance cancer and to those with end-stage non-malignant disease such as cardio-respiratory failure, stroke, advance neurological diseases and dementia. Today our palliative service comprises 3 distinct program arms to ensure the patient and their family can access the level of palliative care required, wherever they are. The program arms are:

- 22-bed palliative inpatient unit specialising in symptom management, psychosocial and end of life care;
- Palliative home-care service operating 24 hours per day, seven days per week to support patients and families in the community;
- Palliative consultative service to support patients with a life limiting illness in Cabrini's acute hospitals, rehabilitation services and the residents in Cabrini's aged care facility.

Each arm offers a patient and family model of care, and involves multi-disciplinary teams to address physical, emotional, social and spiritual needs. Our service is fully accredited to the Australian Safety and Quality Commission standards and to the Australian Palliative Care Standards. We benchmark our clinical outcomes nationally and work in close collaboration with other public and private health services in metropolitan and regional Melbourne.

Since 2010, we have care for more than 2,500 individuals in our inpatient palliative care unit and countless others through our home care program. Our commitment to and continuing investment in end of life care informs our submission to the inquiry.

The Victorian legislative framework currently supports the nomination of a substitute decision maker and a formal process for refusal of medical treatment. We believe that these are the most important issues to be addressed in law and we do not support the law being extended to any other form of advance care directive.

The legal framework is best complemented by institution-based policies and procedures to enable the withdrawal or withholding of treatment that is considered therapeutically futile or overly burdensome and the institution of supportive and palliative care in the terminal phase of an illness. These decisions require input from the patient (or substitute decision maker), family or loved ones and the care team based on realistic and current situations, rather than being theorised on a hypothetical future events.

To this end, we suggest the committee must consider further investment in community-based advance care planning initiatives and expansion of specialist palliative care services. Implementation of these initiatives will have the most positive impact on end of life choices being respected and incorporated into care. Our recommendations in this regard are further detailed in the attachment.

We anticipate that the committee will receive submissions advocating for access to voluntary euthanasia and/or assisted suicide. We believe that intentionally inflicting death on another person is inherently wrong and we do not support the legalisation of either voluntary euthanasia or assisted suicide.

The Hippocratic Oath obliges doctors to 'do no harm'. The goals of medicine are to save life, cure illness, slow progression of disease, relieve distressing symptoms and otherwise help people to live well. Proposing that medical personnel should be licensed and compensated by society to terminate the life of another person is the complete antithesis of the goals of healthcare as we understand them.

Euthanasia is proving to present grave risks to the community. Despite the best attempt in each jurisdiction where euthanasia has been legalised, it has proven difficult to assure tight limits on its practice. In Belgium, the age limit for those requesting euthanasia was removed in 2014, making it available to minors.¹ In Oregon, one uninsured man with prostate cancer was denied coverage for additional treatment and offered doctor-assisted suicide instead.² There is evidence from the Netherlands that the practice there remains beyond effective control.³ It is reported that 50 or 60 people in Belgium with a mental illness are now euthanized by their psychiatrist each year.⁴ In the latter case, it is easy to see the logic of

¹ Caroline Ong **Legalising Euthanasia for Children: Dying with 'dignity' or killing the vulnerable?** Chisholm Health Ethics Bulletin 2014; 20 (1): 5

² Zoe Fitzgerald Carter **What Doctor Assisted Suicide Really Looks Like** 26 May 2011 see http://www.salon.com/2011/05/25/how_to_die_in_oregon/

³ Henk Jochemsen and John Keown **Voluntary Euthanasia Under Control? Further empirical evidence from the Netherlands** Journal of Medical Ethics 1999; 25: 16-21

⁴ See <http://www.nationalreview.com/human-exceptionalism/415771/shrinks-treat-suicide-wish-euthanasia-wesley-j-smith>

expanding access to euthanasia from people with unbearable suffering from a terminal illness to people with unbearable suffering from a mental illness, particularly in a mental illness where there may be no end in sight. The 'slippery slope' is proving to be a real phenomenon, not a hypothetical risk.

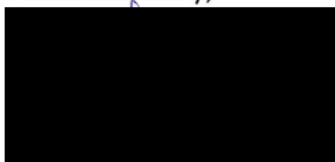
We strongly support the view that *"euthanasia is not just an incremental expansion of current ethically and legally accepted end-of-life decisions ... but rather a radical and massive shift in our society's and civilisation's foundational values."*⁵

Our experience reveals that the desire for legalisation of euthanasia is a symptom of a broader failure in our community to develop a better response to dying and the fear of unbearable pain or artificial prolongation of life in intolerable circumstances.⁶

Further, we agree that voluntary euthanasia and assisted suicide cloud the debate about good end of life care.⁷ In Western society, dying has become increasingly institutionalised and medicalised so that death is often perceived as a 'failure of medicine' rather than a normal event that every person will experience.⁸ Changes to legislation will not be able to reverse this trend, a condition we believe is fundamental to improving the end of life care experience.

I would be pleased to nominate a representative to address the committee should you wish to draw on our experience or require further information about our recommendations.

Yours sincerely,



Dr Michael Walsh
Chief Executive

⁵ Dr Margaret Somerville speaking at Notre Dame University 3 July 2015 see <http://www.cam.org.au/News-and-Events/News-and-Events/News/Article/19474/Euthanasia-a-dangerous-radical-shift-in-society-s-foundational-values-Aussie-ex#.VZoZ6fmqqkq>

⁶ Herbert Hendin **Lessons from the Dutch Experience** see <http://www.life.org.nz/euthanasia/abouteuthanasia/history-euthanasia11/>

⁷ Hal Swerisson and Stephen Duckett **Dying Well** Grattan Institute Report September 2014

⁸ William Silvester and Karen Detering **Advance Care Planning and End of Life Care** Medical Journal of Australia 2011; 195 (8): 435 - 436



SUBMISSION TO THE STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES INQUIRY INTO END OF LIFE CHOICES

1 INVEST IN COMMUNITY-BASED ADVANCE CARE PLANNING INITIATIVES

Despite significant investment, widespread professional and public endorsement, and supporting legislation in every Australian jurisdiction, uptake of advance care planning is slow.⁹ Australia is not unique in this regard. In the US, 90% of people in a national survey indicated they thought it important to talk about end of life care wishes however less than 30% had done so.¹⁰

For the purposes of this submission, advance care planning is understood as a **process** of thinking about what would be most important to you when faced with a life-limiting illness, and discussing your views with family, loved ones or another trusted person. The emphasis on process is intentional. Advance care planning should encompass the questions: Where do you hope to be when you die? Who do you want with you? What will give you comfort?¹¹

Currently, many advance care plans are initiated in an acute hospital setting, or in the period following an acute event. However, patients can feel particularly vulnerable at this time. Their choices about the worth of treatments may be influenced by their recent experience and decisions made in this immediate post-acute phase may not be consistent with their later views. For example, when a person is experiencing an acute event, the suffering may feel overwhelming. Further, he/she may feel the care is placing an unfair burden on family and loved ones. However, as independence is regained and the person re-engages with life, the treatment may be considered worthwhile given the health outcome achieved.

Our experience in palliative care demonstrates patients and families reconsider their goals of care and judgement as to what constitutes a treatment burden throughout the course of their illness. For example, the desire to live long enough to see a grandchild born might lead one person to a decision to continue chemotherapy. Equally, the desire to spend all available time with family and friends may lead another patient with a similar disease to forego further treatment. In essence, treatment options and choices need to be regularly discussed as the illness progresses and the

⁹ Joel J. Rhee, Nicholas A. Zwar, Lynn A. Kemp **Uptake and Implementation of Advance Care Planning in Australia: findings of key informant interviews** Australian Health Review, 2012; 36: 98–104; Ian A Scott, Geoffrey K Mitchell, Elizabeth J Reymond and Michael P Daly **Difficult but Necessary Conversations — the case for advance care planning** Medical Journal of Australia 2013; 199 (10): 662-666

¹⁰ **The Conversation Project** see <http://theconversationproject.org/press-release-first-national-survey-on-end-of-life-conversations/>

¹¹ **Palliative Care Australia Media Release** 25 May 2015 see <http://palliativecare.org.au/media-releases/>

goals of care change. It is very difficult to determine which treatments would be acceptable or unacceptable in a hypothetical situation in advance of an illness.

Many existing programs also focus on encouraging people to record their preferences in relation to potential treatment options. This is particularly true in the residential aged care setting where advance care plans may be completed on admission to the facility and then filed for future reference. The regular review and, where necessary, documentation of changing wishes needs to be incorporated into the care planning process for an advance care plan to be an effective end of life planning tool.

Unfortunately, we also often see the dilemmas and decisions faced by many of our residents, families, staff and doctors when end of life choices have not been discussed. We are frequently told by families that they have not had a conversation with their loved one about his/her end of life wishes, despite the health, social and/or other physical disabilities that have led to the requirement for residential care.

We believe an advance care planning program will be most effective when it is undertaken as a community initiative that supports and enables the discussion of end of life care wishes openly in the family and/or friends. Normalising the conversation about death will require a reframing of community attitudes. Acknowledging that death is inevitable for all of us at some future point in time is a critical step to achieving this goal. Primary care practitioners can play a pivotal role by encouraging their older patients to consider and talk about what will be important to them at the end of the life.

Appointment of an Enduring Power of Attorney (Medical) as a substitute decision maker will also help end of life care choices to be respected. This role comes into effect when the person represented does not have decision-making capacity, so that the substitute decision maker can represent the person's wishes. Knowing the person's preferences, the substitute decision maker can also play a support role when decision-making capacity is present, particularly in an acute health event when the care team may be advocating a treatment path that is inconsistent with stated wishes. Whilst appointing a substitute decision maker is helpful in all circumstances, it is even more important where family relationships have broken down, the family are distant or there are no family relationships at all.

For the substitute decision maker role to work effectively, there needs to be an understanding that he/she is acting as an agent to represent the person's wishes and that these wishes can change over time and in changing health circumstances. Therefore, the conversation between the person and their agent about end of life choices must be ongoing, not a one off event. More community education and support is required to ensure that this role is enacted as it is intended in law.

When the family and, particularly, the substitute decision-maker where appointed, have had a conversation about end of life care preferences, it breaks the taboo around the subject. Then, when an acute health event occurs, "patients, residents, practitioners, family and carers [are able to] become a small community united in working for a person's good ... [forming] a trusting collaboration in a common purpose."¹²

¹² Catholic Health Australia **Code of Ethical Standards for Catholic Health & Aged Care Services in Australia** 2001 p.7

2 EXPANDING THE REACH OF SPECIALIST PALLIATIVE CARE SERVICES

“About 36 000 people die in Victoria each year and this figure is projected to double in the next 25 years. Of those people, about half will die following a period of chronic illness such as heart disease, cancer, stroke or neurological illness—it is these people who will most benefit from palliative care. Palliative care aims to improve the quality of life of people with terminal illnesses by managing pain and distressing symptoms, and assisting patients to start making choices about how they want to be cared for as they die.”¹³

The World Health Organisation defines palliative care as *“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.”¹⁴* Palliative care supports both the person who is dying, their caregivers and their family. The current focus of the health care system has been described as *“giving patients the medical equivalent of lottery tickets that will almost certainly not win.”¹⁵* Advance care planning should help people be clearer about what is important to them. The health care system needs to respond by enabling these choices to be realised.

Research demonstrates that specialist palliative care services improve the quality of life of patients and their families, as well as providing more effective and efficient use of health resources. Population growth, the ageing of the population, an increase in chronic disease and the increase in the number of deaths per year in Victoria, all point to a growing demand for specialist palliative care services.¹⁶ Community based services, in particular, are already struggling to meet the demand.¹⁷ Lack of community-based support has a critical impact on respecting end of life choices.

Australians report that having a say in where they wish to die and knowing that their pain will be well controlled at the end of life are important issues in determining the quality of care they receive.¹⁸

Although 70 percent of people express a desire to die at home, about half of the deaths currently occur in hospital and about a third occur in residential care.¹⁹ In 2013, Australia rated 19th of 20 OECD countries with 14% of deaths of people over 65 occurring at home, half the rate achieved in Ireland, New Zealand, USA and France and a third of the rate of Cyprus and Croatia.²⁰ Despite the best efforts of services and staff, the fragmentation of the Australian health care system often results in disjointed end of life care for patients and their families.

Much of the community interest in euthanasia and physician-assisted suicide is based on fears of uncontrolled pain and suffering and not having control over end of life care decisions.²¹ This is the

¹³ **Palliative Care** Victorian Auditor General’s Report, April 2015, p.ix

¹⁴ See <http://www.health.gov.au/palliativecare>

¹⁵ John Wilwol **Notes on: ‘Being Mortal’ by Atul Gawande** accessed at <https://www.advisory.com/international/research/global-forum-for-health-care-innovators/the-forum/2015/04/atul-gawande-being-mortal>

¹⁶ Palliative Care Victoria **Palliative Care Call to Action 2015 – 2019** see <https://www.pcvlibrary.asn.au/>

¹⁷ **Palliative Care** Victorian Auditor General’s Report, April 2015, p.vii

¹⁸ **Palliative Care Australia Media Release 25 May 2015** see <http://palliativecare.org.au/media-releases/>

¹⁹ **Dying Well** Grattan Institute Report p.2

²⁰ **Dying Well** Grattan Institute Report p.4

²¹ Palliative Care Australia **Euthanasia and Physician Assisted Suicide Position Statement October 2011** see <http://palliativecare.org.au/policy/>

'bread and butter' of specialist palliative care services. Better access to specialist palliative care services is fundamental to improving end of life care. A palliative approach to care ensures that care goals are revised regularly during the course of the illness. Access to the various parts of the health care system can be coordinated. Disease progression is monitored and the terminal phase of illness is recognised. In this setting, it is most likely that end of life care choices can be respected.