

28 August 2015

Lilian Topic
Secretary
Legal and social issues committee
Legislative Council Parliament House
Spring St, Melbourne Vic 3002

Dear Secretary

Inquiry into End of Life Choices

Thank you for the invitation to contribute to this important inquiry. This submission has been prepared by the senior staff of the Centre for Palliative Care and also reflects the views of St Vincent's Health Australia. Our insights and viewpoints are not based on legal expertise but focus on the social, clinical, and academic aspects of palliative care.

We hope our recommendations can influence legislative and societal frameworks to improve the provision of palliative care in Victoria and we would be willing to provide further input at a public hearing.

Yours sincerely



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The Centre for Palliative Care (CPC)

The CPC is part of St Vincent's Hospital (Melbourne) and is a Collaborative Centre of The University of Melbourne, Australia (www.centreforpallcare.org). The CPC has a state-wide role in palliative care education and research in Victoria, with networks and collaborative projects extending nationally and internationally. The CPC plays a pivotal role in the development and implementation of training and education programs for health professionals from a variety of disciplines, while undertaking cutting-edge research to set benchmarks and improve practices in palliative care. The CPC facilitates a significant number of palliative care initiatives including: Victorian Palliative Medicine Training Program; Victorian Nurse Practitioner Collaborative; Victorian End of Life Care Coordinating Centre; Palliative Care Research Network Victoria; International Palliative Care Family Carer Research Collaborative; Victorian Medical Communication Skills Training Collaborative; the Victorian Aboriginal Palliative Care Collaborative; and the University of Melbourne Graduate and Specialist Palliative Care Certificate Programs (for adult and paediatric palliative care).

St Vincent's Health Australia

St Vincent's Health Australia (SVHA) is the nation's largest Catholic not-for-profit health and aged care provider. SVHA is a clinical, research and education leader working in private hospitals, public hospitals and aged care services in New South Wales, Victoria and Queensland. Palliative care is provided at all SVHA hospitals. At St Vincent's Hospital Melbourne, in addition to the CPC, clinical services include: palliative care consultancy service, day hospice, out-patient clinics, telephone advice services, and 34 palliative care in-patient beds.

Palliative care

The World Health Organisation and national standards mandate that palliative care be available to patients with advanced, incurable disease. Palliative care plays a key role in providing opportunities for people with advanced disease to make choices about what treatments are acceptable to them and focuses on enhancing their quality of life along with their family carers. Palliative care is about helping people to live as well as possible with advanced deteriorating illness in the days, weeks, months and even years before they die and is provided by a multidisciplinary team of health professionals. Hence palliative care involves care toward the very end of life but is not restricted to this phase. Accordingly, for the purposes of this submission we use the term 'palliative care' rather than 'end of life care'.

Benefits of palliative care

Palliative care has established benefits for patients with advanced cancer including improved symptom relief, quality of life, and communication around health care goals. These benefits extend to the patient's family, enhancing caregiver quality of life and bereavement outcomes after the patient's death. Public health benefits have also been reported, with survival gains demonstrated for spouses of patients who received palliative care. Benefits also extend to health care utilisation and therefore costs, with reduced aggressive and futile care at the end of life, reduced hospitalisation and presentation to emergency department, and greater likelihood of death at home for those patients who receive palliative care.

Current issues

Unfortunately, the majority of Australians are missing out on access to quality palliative care and are not being given the opportunity to discuss their end of life care choices. There is insufficient health care professional training about end of life care and little investment in research. For example, less than 1% of the cancer research dollar is allocated to palliative care, yet approximately one in three people diagnosed with cancer will die of the disease. The overwhelming majority of people with a

terminal illness want to be cared for in their own homes for as long as possible; however, inadequate resourcing often means this does not happen, with only about 15 percent of Australians able to do so.

Responding to a deteriorating patient in the days, weeks, months, even years before their dying is increasingly becoming 'complex care'. The chronic aspects of advanced disease often means that the burden(s) upon a patient, carers and family are magnified. Palliative care enables patients, their families and carers to be clear in avoiding any treatments that are overly burdensome or futile.

To manage the complexity and burdens – enabling good advance care planning (ACP) and good end of life care (EOLC) – our system needs to be much more responsive to complex care needs. This requires earlier integration of palliative care practices across health care settings, with staff trained to communicate and facilitate appropriate ACP and EOLC, and modelling capacity to share care between areas of practice. For example, primary disease specialists, primary GP care and specialist palliative care working cooperatively to support urgent/complex care in the home of the imminently dying patient.

Recommendations to inform legislative and societal frameworks

In addition to our collective multidisciplinary clinical and academic insights our perspectives and recommendations that follow are underpinned by several seminal publications, including:

- The Senate inquiry into palliative care in Australia (2012);
- Grattan Institute's 'Dying Well' report (2015);
- Australian Commission on Safety and Quality in Health Care's National Consensus Statement 'Essential elements for safe and high quality end of life care' (2015);
- The Victorian Auditor General's Report on Palliative Care (2015); and
- United Kingdom's Access to Palliative Care Bill (2015).

Recommendations for clinical practice and service delivery

1. Fundamentally important that resources are allocated to provide all Victorians with access to quality palliative care as necessary.
2. Early integration of palliative care as core factor to providing quality care across all health care settings.
3. Invest in out-patient clinics and re-configuration of community services to provide urgent/imminently dying care, delivering complex care in home, and capacity-building ability in niche settings such as Aboriginal health services (eg: Residential Aged Care Facility-consultancy model).
4. Review of funding models to avoid 'silos' of care. For example, schemes such as the aged care and national disability packages should be broadened to include the palliative care sector.
5. Standards of care to clearly discern criteria for referral to specialist palliative care and the expectations of generalist health care providers.
6. Health services are formally and regularly assessed regarding the quality of palliative care provided.
7. Mandate that anyone diagnosed with an advanced, life threatening illness be made aware of palliative care and that when disease appears incurable, palliative care is routinely offered.
8. Specialist palliative care services are available 24 hours per day.
9. Sufficient equipment to enable the delivery of services to meet all reasonable requirements in the home.
10. Telephone advice from healthcare professionals who are qualified as specialists in palliative care which is available at all times to health care providers.
11. Facilities to enable healthcare professionals to access essential medication at all times for palliative care patients being cared for in their own homes.
12. A health professional be available at all times for people with palliative care needs who are being

cared for in their own home, and for their family carer (in the event that access to their usual sources of professional support is not available).

13. Direct admission of people with palliative care needs to palliative care beds.
14. Improved access to out-patient allied health services such as occupational therapy and physiotherapy.

Recommendations for education and training

All health professionals should be appropriately qualified to provide the fundamentals of palliative care. A strategy should also be in place to ensure there are sufficient numbers of multidisciplinary palliative care specialists for patients with complex needs. This should be achieved by:

1. Developing a national competency framework for all health professions involved in the delivery of specialist palliative care.
2. Ensuring sufficient numbers of training positions to meet current and future needs of the specialist palliative care workforce by developing a Palliative Care Workforce Strategy. Build upon the modelling and achievement of programs such as the Victorian Palliative Medicine Training Program, to facilitate development of supportive programs for advanced practice in nursing and allied health professional groups involved in palliative care.
3. Continued funding to develop training programs and scholarships that support specialists and generalists, building upon post graduate development of course work and practice placements.
4. Strategies to ensure all generalist health care providers receive training in the essential aspects of palliative care provision (eg: symptom management, psychosocial support, communication skills, family carer support, and bereavement care).
5. Health care service provider competencies assessed on a regular basis.
6. Systematic approach to communication skills regarding palliative care for all health professionals (including further development of guidelines for responding to requests for euthanasia), and building competencies into health care professional training skill sets.

Recommendations for research

Develop a sufficiently resourced framework for palliative care research that:

1. Provides funding for the development of research programs specifically addressing symptom management, psychosocial support (including family carers and bereavement), health service evaluation, and legal and ethical aspects of decision-making processes.
2. Invests in capacity-building by developing a critical mass of palliative care researchers.
3. Creates a “whole of health” approach to palliative care research agenda that incorporates cancer care and non-malignant diseases.
4. Focuses on strategies to translate research into practice in specialist and generalist settings.
5. Enables specialist palliative care teams to participate in research, advance innovations in palliative care, and ensure that employees are aware of innovations in palliative care.

Recommendations for family support

1. That current best practice standards for psychosocial support and bereavement support are systematically implemented.
2. Systematic approaches are established for routine assessment of unmet family carer needs and discerning those at risk of distress.
3. That a primary family carer is formally identified and offered support and training in the carer role.
4. Evidenced-based approaches for preparing family carers for the role of supporting a dying relative/friend are systematically implemented and resourced.

Recommendations for public health/community engagement

1. A systematic and sustained public education program akin to other highly successful prevention programs to encourage mature discussion around end of life issues, the limits of medicine, and preferences for decision making.
2. Public education approaches to encourage understanding of, and engaging with, the preparation of advance care plans.
3. Development of literature to support patients and the public who wish to engage in advance care plan and facilitate discussions with their health care providers.
4. Promote the use of *My Health Record* – the new version of the *Patient Controlled Electronic Health Record* (PCEHR) – for recording and saving advance care plans and directives so that they are available to palliative care specialists, other clinicians and family members at the appropriate times.

Recommendations related to EOLC plans and advance directives

1. Achieve nationally agreed standards of ACP and EOLC across settings.
2. Build upon successful work already being done – such as that established by the Victorian EOLC Coordinating Program and auspiced by the CPC – that provides a state-wide resource for integrating best-evidence EOLC into practice. Such a resource could assist organisations maintain and train staff in the implementation and management of EOLC standards, particularly in the recognition of dying and the initiation of EOLC plans to facilitate best-practice care at end of life .
3. The principles and essential elements for quality EOLC as recommended in the ACSQHC's National Consensus Report (2015) be adopted.

Recommendations related to euthanasia and physician-assisted suicide (EAS)

Potential legalisation of EAS is a contentious and much debated issue. SVHA explicitly opposes the legalisation of EAS. In this submission, we do not address the ethical issues related to the potential legalisation of EAS. This does not mean we dismiss their importance; however, we expect other submissions will address these issues at greater length.

We wanted to draw on our clinical experience and focus our submission on what we believe are the significant practical and clinical challenges raised by legalising EAS. Several of us from the CPC (and other palliative care specialists) recently published an article in the international *Journal of Palliative and Supportive Care*¹ (DOI: <http://dx.doi.org/10.1017/S1478951515000176>), arguing that many practical and clinical aspects related to the euthanasia debate have largely been ignored. A summary of the issues and perspectives raised in our paper is provided herewith.

Such aspects include:

- Which health professionals would provide EAS and how would this be resourced?
- What training would health professionals who administer EAS require?
- Some health professionals will continue to have a sincere and deeply-held belief that EAS is not morally acceptable. How will their right to conscientious objection to EAS be respected and managed?
- What is the longer term impact on the health professionals who administer EAS and those who elect not to provide it (ie: those who are opposed to EAS)?
- What is the longer term impact on the family?
- What are the resources needed to implement and monitor EAS?

¹ Hudson P, Hudson R, Philip J, Boughey M, Kelly B, Hertogh C. *Legalizing physician-assisted suicide and/or euthanasia: Pragmatic implications*. Published online, Palliative and Supportive Care. 2015

- What community education would occur?
- What ongoing research and evaluation would occur?
- What are the specific implications for palliative care provision and how would they be effectively managed?
- What assessment criteria would be needed to establish the 'unbearableness' of a person's suffering?
- What would be the time point in the disease trajectory when EAS would be available?(prognostication in terminal disease is typically inaccurate)
- How will those who are very vulnerable, such as those from non-English speaking backgrounds and those living in poverty, be protected in any EAS proposal?

By solely raising practical concerns, it should not be construed that we would support the legalisation of EAS if efforts were made to address them. On the contrary, it is difficult to see how the very significant practical and clinical implications of EAS listed could ever be effectively addressed and overcome.

Running in parallel to these largely unanswered questions around the introduction of EAS, there exists a broad misconception in the community – including among many health professionals – about what dying involves.

Adding fuel to this misconception – and creating a good deal of anxiety – is the use of a poorly-informed media by EAS proponents about end of life and terminal illness, which portrays death as inherently painful, undignified and traumatic for both patient and family.

When combined with an inability or unwillingness among many medical practitioners to have meaningful conversations about these concerns, there's little doubt it is influencing community views on EAS.

The reality is that among the thousands of deaths we have witnessed, most patients have been comfortable and able to communicate their wishes and say farewells. Families have commented on how peaceful the death was and identified the positive aspects associated with their caregiving role, amid the inevitable distress and grief.

Palliative care cannot guarantee every patient a pain-free death. We acknowledge that even with well-resourced palliative care some people will still request euthanasia. But such requests are infrequent, even rare, with around 50,000 palliative care patients admitted to Australian hospitals each year, and approximately less than 1% having a sustained desire for EAS.

Despite the very low number of requests for euthanasia among patients receiving palliative care, these requests nevertheless require a professional and compassionate response. Such a response requires exquisite skills, judicious timing and the capacity to engage in shared decision-making, particularly when confronting the less tangible 'existential' aspects of suffering. These skills are neither commonplace nor included in existing health professional curricula. In contrast to palliative care's multi-disciplinary team approach, well-meaning general clinicians may be ill-equipped or poorly supported to address this suffering, leaving them overwhelmed by a sense of helplessness.

We believe the broader community – including healthcare professionals – needs to be reassured of palliative care's significant role in attempting to relieve all aspects of suffering. Palliative Care is part of a multidisciplinary holistic and person-centred care approach that involves accompanying patients and their family as they confront the implications of life threatening illness; which in some cases may be for several years. It is more the norm than the exception that in the lead up to death, palliative care providers witness human affection, reconciliation and alleviation of suffering.

However, increased resources and effort must be directed toward training, research, community

engagement, and ensuring adequate palliative care. Investment in palliative care will have much greater community impact than investment in facilitating widely-available legal EAS, without the clinical and practical implications we have already noted above. If Victorians are able to make informed choices about their end of life – and receive compassionate and competent care – then every one of us should have access to quality palliative care.

Conclusion

A well-resourced and managed palliative care system is a critical part of our state's health infrastructure and yet this crucial segment is often underfunded and misunderstood despite the benefits it provides vulnerable Victorians and their families.

Across funding, clinical practice and service delivery, education and training, research, family support, public health and community engagement there is a need for a series of reforms to deliver a standard and level of access to palliative care that all Victorians deserve as they reach end of life.

We believe priority must be given to the policies and resources necessary to ensure all Victorians have access to palliative care before any consideration is given to legalising EAS.