31 August 2015

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

Via email: lsic@parliament.vic.gov.au

Dear Members of the Legal & Social Issues Committee,

Consultation on End-Of-Life Care in Victoria on behalf of Catholic Health Australia

Catholic Health Australia (CHA) is Australia’s largest non-government grouping of hospitals, aged and community care services, providing approximately 10% of healthcare services in Australia. An integral part of our services and mission is the care for people with life-limiting illnesses and their significant others.

For CHA members, delivery of palliative care services that are person and family centred, provided for people with a life-limiting illness or living with a condition which has no prospect of cure are fundamental to holistic health care. The emphasis of care is on quality of life, for patients and their families. CHA believes that such services are intrinsic to health care.

CHA welcomes the opportunity to provide comments on the terms of reference of the Legislative Council’s Legal & Social Issues Committee on management of end-of-life care and potential changes to the legislative framework in Victoria:

- The practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end-of-life, including the role of palliative care;
• The current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
• The type of legislative change that may be required, including an examination of any federal laws that may impact such legislation.

Please find attached our Submission for your consideration.

CHA also welcomes the opportunity to participate in a public hearing to further discuss management of end-of-life care and potential changes to the legislative framework in Victoria.

Should you wish to seek clarification of any aspect of our submission, please do not hesitate to contact me directly: (02) 6203 2777.

Regards,

Suzanne Greenwood  
LLM LLB FAIM MAIDC  
Chief Executive Officer  
Catholic Health Australia
Catholic Health Australia Response to the Terms of Reference:

1. The practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end-of-life, including the role of palliative care.

Palliative care

In Australia, the care for people with a life-limiting illness and their significant others has improved dramatically in recent years. Recognition of the importance of a holistic approach to symptom control, improving quality of life, and providing the necessary spiritual and psychosocial care through palliative care has been an integral part of these improvements.

Palliative medicine is embedded in a philosophy of care. The development of palliative care has proven that treating pain and treating the whole person alleviates suffering and gives the person a sense of being whole again and provides a space for them to be cared for.

The World Health Organisation (WHO)\(^1\) defines palliative care to be where physical, psychological, spiritual and existential care is provided to people with a life limiting condition throughout the illness trajectory, and not just at the end of life when someone is dying. The WHO advocates that\(^2\):

“Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.

Palliative care is required for a wide range of diseases.”

It is noted that the Department of Health and Human Services Victoria (DHHS) adopts the WHO terminology in State government policy documents\(^3\).

\(^1\) www.who.int/en/
\(^3\) Strengthening palliative care: Policy and strategic directions 2011-2015, DHHS.
The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases, cancer, chronic respiratory diseases, AIDS and diabetes. Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Many people who come to a palliative care unit are discharged home again. They may come to a palliative care service with difficult pain, difficult nausea, psycho-social distress, feel troubled, their families might be burdened, or they are in need of respite care. Catholic services provide comfort and support for the patient and their family. Palliative care is fundamentally whole person care and is about a philosophy of care recognising the variety of domains that individuals might face as they get sick, and understanding their connections to family and community.

**Specialist Palliative Care Teams**

CHA members support a team work approach. Working in a multidisciplinary environment, to ensure a range of skills and clinical backgrounds is represented, palliative care teams - whether working in a hospital, hospice or in the community - may typically include:

- Specialist palliative care doctors – medical care is provided under the supervision of specialist care Physicians. The Medical Director and the Director of Nursing ensure clinical standards are met.
- Specialist palliative care nurses – Senior nurses qualified in palliative care who are skilled at assessing and planning patient care needs. Nurses work in teams, led by a senior nurse and supported by a nurse manager. The Director of Nursing oversees the nursing staff.
- A full range of multidisciplinary services, including allied health, such as physiotherapists, occupational therapists, social workers, speech therapists and dieticians.
- Pastoral care and bereavement support staff - Pastoral care practitioners provide person-centred care that takes particular account of the spiritual needs and issues arising from life-threatening illness and the changes it creates within patients themselves, their relationships and their environment.
- Specially trained volunteers to support patients, through company and conversation, reading and general assistance.
- Music therapy / Art Therapy - the planned and creative use of music and/or art to support emotional, social, physical, psychological and spiritual aspects of health, shared within a therapeutic relationship.
Many CHA members services also provide support in innovative and non-traditional ways. For example, by providing a biography service to assist people to record their stories⁴.

CHA members also provide palliative care services in specialist areas, such as Calvary Health Care Bethlehem which has a Victorian state-wide role in caring for those with a progressive neurological illness. This service enables people to live well knowing they have a progressive incurable illness and supports individuals and their families through the dying process.

**Carer Support**

As noted above, support for family members and caregivers is a core function of the palliative care services provided by CHA members.

These people would often like more information, education, preparation and personal support.

For example, at Cabrini Palliative Care, the crucial role of family members/care givers in the care of the patient is acknowledged by the interdisciplinary team and accordingly, general support and bereavement support are fully incorporated into their service philosophy and standards of care⁵.

Our members also produce a number of resources to assist understanding and better support carers and loved ones which are easily accessible on the internet. An example of this is Mercy Health which has a number of bereavement support publications including *Young People and Grief, Children’s Grief, Younger Bereaved Partners* and *About Grief*⁶. The Mercy Health Palliative Care Patient Information Booklet⁷ is also a key resource of individuals and their carers.

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Research and Clinical Education

CHA members also undertake research and provide clinical education in palliative care. A significant Victorian example of this is The Centre for Palliative Care\(^8\), a statewide service based at St Vincent’s Hospital Melbourne which is a Collaborative Centre of The University of Melbourne. The Centre’s primary function is to provide training and conduct research in palliative care and in doing so assists Victorians to receive world’s best practice in palliative care. Education programs within the Centre include the Victorian Palliative Care Nurse Practitioner Collaborative and the Victorian Aboriginal Palliative Care Collaborative.

Palliative Care instead of euthanasia or assisted suicide

This model of palliative care practiced by CHA member services is unfortunately not what many Australians witness when their own loved-ones need care at the end of their lives.

The Performance Audit Report Palliative Care\(^9\) by the Victorian Auditor General’s Office (VAGO), 2015, recognised that clearly current demand is not being met and called on the Department of Health and Human Services to provide sufficient and appropriate funding. The overall message of VAGO in the report is that the department needs to renew efforts to support carers and better plan to meet demand for palliative care.

Accordingly, CHA in turn calls on the Legal & Social Issues Committee to draw attention to the need for improved palliative care services in Australia. This needs to be achieved through training and education of more palliative care specialists, through provision of improved services in appropriately funded facilities, through raising awareness and understanding of the support offered to individuals and their families through good palliative care.

It is CHA’s view that Australia should, as a matter of priority, ensure that a humane, dignified alternative to euthanasia is always available. CHA’s view is that it is never permissible to end a person’s life through the action of euthanasia. Where euthanasia has been legalised, such as Flanders in Belgium, there has been considerable lack of transparency, with only half the euthanasia cases reported as legally required\(^10\).

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\(^8\) Centre for Palliative Care website - http://centreforpallcare.org/
\(^9\) Performance Audit Report Palliative Care, Victorian Auditor General Office (VAGO), tabled 15 April 2015, pages 12 – 25...
\(^10\) Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases by Smets T, Bilsen J, Cohen J, Rurup M, Mortier F, Deliens L accessed on-line at: BMJ 2010; 341:c5174doi;10.1136/bmj.c5174
Instead of euthanasia, we recognise the need for appropriate relief from pain and suffering through quality care and respect of an individual’s end-of-life decisions. Quality care also entails that treatments are effective, not overly burdensome for the person, and reasonably available. Relief from pain, suffering and discomfort should be provided, reasonable fluid and food should be delivered and palliative care made available to the patient.

CHA does not support the use of the dishonest euphemism of ‘dying with dignity’, as we believe it would do better, and be more human, by dignifying the lives of the dying.

**Investment and incentives for specialist palliative care services to support choice of setting**

Place of death is an important consideration for end-of-life care as most patients prefer to die in a non-hospital setting\(^\text{11}\), yet a majority of patients still die in hospitals\(^\text{12}\). This also has important impacts on health care costs; end-of-life care in hospitals is more expensive than in other settings such as aged care homes or at home.

Advances in palliative care provision are enabling more people to die in the setting of their choice. Access to specialist services in non-hospital settings is central to the ability of individuals to be able to die in a setting of choice, and in this respect specialist services in rural and regional Victoria are in need of targeted intervention. Access to home-based palliative care has been shown to double the probability of dying at home, reduced symptom burden, with no adverse impact on caregiver grief\(^\text{13}\).

Changes with a positive impact in this area include:

- Develop primary care services capability and capacity to provide end-of-life care.
- Implement greater integration of palliative care into ambulatory chronic disease clinics and cancer clinics which offer shared care, between specialists and supportive palliative care.
- Additional investment and incentives for specialist palliative care services directed to services for people at home or in non-hospital based care.

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\(^{11}\) Billingham MJ, Billingham SJ. Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: a systematic review and meta-analysis. BMJ Support Palliat Care 2013; 3: 144–154


• Adequate out of hours nursing and medical cover for palliative care patients at home.
• Development of an interdisciplinary, patient centred approach to care.

**Advanced Care Planning**

Advanced care planning (ACP) is an important part of end-of-life management. Please see attached our CHA Advance Care Plan document. Through this document, patients and residents in Catholic health and aged care services are encouraged to reflect on their future health care needs.

To assist members of the community and health care professionals, CHA has also developed web-based resources that are available on our “My Future Care” website.

ACP provides a framework for health professionals and other staff to improve care of individuals, by taking into consideration the individual’s wishes, values and beliefs about future health care. If someone can’t speak for themselves, ACP can help healthcare workers and significant others to ensure that the person is supported in the way that they would want.

People with a life-limiting illness should be encouraged, while competent, to discuss their preferences for treatment options with their families, their doctors and other relevant people. They should be informed of their right to appoint someone to make decisions about their health care should they become unable to make their own decisions. Patients and residents in CHA member hospitals and aged care services are encouraged to reflect on their future health care needs and to appoint a person who will represent them if they are unable to express their wishes. A patient representative may be appointed previously by the person, or alternatively appointed by a court or tribunal after the person became incapable of making decisions about his or her own medical treatment, or has legal authority automatically, such as the person’s spouse. This patient representative can make health decisions for a patient, based on the patient’s previous advice and values, input from the health care professionals and their own judgement. A patient representative is a valuable resource for when health professionals want to discuss options with someone who is familiar with a patient’s health care wishes.

**Private health insurance has a role in end-of-life care**

Patients with private health insurance should be covered throughout illness even when curative treatment is not available.

The number of palliative care programs funded by private health insurers remains low, with only a small number of private health insurance funded community based palliative care programs available.

Such programs would increase the incidence of Australians receiving palliative care in their home, thus reducing the burden on hospitals. Furthermore, this would reduce costs to private health insurers through a reduction in inpatient days for palliative care patients.

CHA recommends to the Inquiry that the government of Victoria requests the Federal government to include this issue as an aspect for investigation by the Federal government when it commences the proposed private health insurance inquiry which is expected to be announced shortly.

**Perinatal end-of-life-care**

End-of-life care also encompasses perinatal palliative care and death, which starts at the time of diagnosis in the womb and aims to support parents and families when a pregnancy will most likely result in the death of the baby.

There have been few studies in perinatal or neonatal palliative care\(^{15}\), but this is an important topic that should be captured by this Victorian Inquiry.

Birth-planning and advanced decision-making are an important considerations for perinatal end-of-life care. Planning should include assessment and minimisation of physical, emotional, and spiritual suffering of the child and family, regardless of the prognosis (please see the CHA Code of Ethical Standards\(^{16}\)). Spiritual and pastoral care should be offered to the parents and family as they form an integral part of the healing process.

Significant barriers to the provision of perinatal palliative care remain, including the lack of appropriately trained health care professionals, resources to finance care, and scientific

\(^{15}\) Perinatal Palliative Care in Australia and New Zealand: Provision, Problems and Solutions, D Wilkinson, Associate Professor of Neonatal Medicine and Bioethics at University of Adelaide, published 18/7/2013, eHospice, accessed 27/8/2015 - http://www.ehospice.com/australia/Default/tabid/10688/ArticleId/5782

research to inform evidence-based policies and treatment. Studies are needed to identify the infrastructure and resources health care providers need to be able to support improved communication with parents and overcome barriers to delivery of perinatal palliative care\textsuperscript{17}.

Strategies are needed to integrate the joint clinical management and philosophies of palliative care, intensive care, antenatal and postnatal care teams in order to guarantee continuity of care and respect the process of parenthood\textsuperscript{18}. Early management of an infant’s pain or symptoms is important to reduce suffering, as is effective communication and education of the family to inform decision-making.

Accordingly, CHA also calls on the Legal & Social Issues Committee to draw attention to the need for improved research, training, funding and accessibility of perinatal palliative care services in Australia.

\textbf{Catholic Health Australia Response to the Terms of Reference:}

\begin{enumerate}
\item The current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
\item The type of legislative change that may be required, including an examination of any federal laws that may impact such legislation.
\end{enumerate}

\textit{Legislation – Refusal of treatment}

The Victorian \textit{Medical Treatment Act 1988}\textsuperscript{19} allows for a health consumer to pronounce their refusal of medical treatment for a current condition. CHA believes that a doctor who, in good faith and in reliance on a refusal of treatment certificate, refuses to perform or continue medical treatment which he or she believes on reasonable grounds has been refused in accordance with that Act are adequately protected in law by virtue of section 9 of that legislation.

Legislation – Advance Care Plans

Similarly, CHA does not submit that any amendment is required to this Act or any legislation is required to be introduced to mandate advanced care plans (discussed above). A variety of approaches to advanced care plans already exist in the Australian community and each state and territory has different legislation in place with regards to formally appointing legal representatives.

Importantly, advanced care plans should be used to guide rather than a mandated document for use in end-of-life care for the patient as the health care environment and an individual’s health care status are dynamic. Earlier expressions of advanced care plans provide evidence of the individual’s past wishes, however the ability for health care professionals to make decisions, with the guidance of the individual’s appointed representative must remain.

Legislation – Pain Management

Palliative care physicians need to work closely with acute pain specialists, or other clinical specialties to best manage a person’s care and manage any pain. For example, working with cancer providers, such that chemotherapy or radiotherapy might help pain. It is also important to recognise that the pain might not be purely physical – that the use of simple analgesia itself is not the answer. We use the concept of “total pain” in palliative medicine where pain is physical, psychological, spiritual and existential. The palliative care team manages all of these to best manage a person’s pain.

Amongst the many who are treated, there will be a small cohort of patients, despite the use of the most complex drugs and interventions, for whom the pain becomes difficult to manage. The person may be suffering intractable pain. Their care team may need to go down the more complex path of discussing some level of sedation, utilising guidelines that are available to ensure that nobody suffers at the end of their life, such as the EAPC framework for procedural guidelines 2009\(^\text{20}\). This framework also includes guidance for decisions regarding hydration and nutrition.

Palliative sedation is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden or

\(^\text{20}\) European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care, N I Cherny, L Radbruch, the Board of the European Association for Palliative Care, 2009, 23(7) 581-593.
otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health care providers\textsuperscript{21}. Intractable suffering is determined on the basis of a patient evaluation, or if this is impossible, proxy judgements in collaboration with families and staff\textsuperscript{22}. Refractory is where all other possible treatments have failed, or it is estimated by team consensus, based on repeated and careful assessments by skilled experts, that no methods are available for alleviation within the time frame and risk-benefit ratio that the patient can tolerate\textsuperscript{23}. The goal is to relieve the burden of suffering.

There is a difference between the intentional killing of someone and alleviating their pain through the use of medicines which potentially might reduce the level of consciousness. The guidelines for the use of continuous deep sedation are very clear about the indications of its use, the drugs that the care team need to use, the prognosis that the patient might need to have, how the decision of sedation is to be taken within a multi-disciplinary context, the conversation with the family, and so on. These are very delicate ethical decisions to make and they must be made by professionals who are trained and skilled in this area.

This is best medical practice with the intention and action being to relieve pain and symptoms.

Euthanasia and assisted suicide are not medical actions and should never be considered as being an element in good palliative medicine. Providing a lethal substance or the promise of a lethal injection is never palliative in the true sense of that medical discipline.

CHA does not believe that changes to the law are necessary to provide good care for people at the end of their life and to dignify the dying.

\textit{Reporting}

CHA member services continue to actively participate in Department of Health and Human Services reporting requirements, including reporting under the Policy Implementation Audit Tool specifically monitoring the use of advance care plans in identified palliative care patients.

Further, CHA member services note and support the Department of Health and Human

\textsuperscript{21} Cherny et al EAPC recommended framework for the use of sedation in palliative care, 2009.
\textsuperscript{23} Cherny & Portenoy 1994, Morita 2002.
Services commitment to implementation of the recommendations of the Performance Audit Report Palliative Care (discussed above). The indicative timeframes as detailed in Appendix A of the Report, requiring completion of implementation by 1 July 2017, is also noted and should be taken into consideration by this Inquiry.

**Conclusion**

CHA calls on the Legal & Social Issues Committee to affirm the value of people at the end of their lives by recognising and calling for greater investment in palliative care and to reject attempts to introduce deliberate killing or assisted suicide.

Catholic Health Australia will continue to provide resources for the community such as our advanced care planning website, My Future Care (www.myfuturecare.org.au), and our perinatal palliative care website, PNPC PeriNatal Palliative Care (www.pnpc.org.au).

CHA is available to participate in further discussions with the Legislative Council’s Legal and Social Issues Committee including appearing at a public hearing on management of end-of-life care. Further, any CHA member who provides palliative care is also pleased to provide any further information requested.

Please contact CHA on or for further information in relation to this response.

Thank you for the opportunity to comment at this stage.
Advance Care Plan

It is good to think about future healthcare needs and to discuss them with others. If a time comes when you are unable to make your own decisions, the law ensures that you will be represented by your closest relative, your primary carer, or someone appointed by you or a tribunal. You can help this person by telling them what would be important to you at this stage in your life. This document suggests some of the issues you might like to discuss with your representative and your treating doctor.

My name: __________________________________________

Date of Birth: ______________________________________

If I am unable to make my own decisions about my healthcare, the person who is to represent me is:

____________________________________________________

Contact details for this person are:

Address: ___________________________________________

____________________________________________________

____________________________________________________

Phone: _____________________________________________

Signed: ___________________________________________

Witness: ___________________________________________

Date: _____________________________________________

CATHOLIC HEALTH Australia

Australian Catholic Bishops Conference
Guiding your representative

Illness, disease and other life events are unpredictable, and it is best to provide guidance about your future medical treatment, rather than specific directives. A trusted representative who knows you well can discuss with the doctors and nurses the options for care that are appropriate at the time. Specific directives ahead of time are not advisable because they may not meet your needs in the actual circumstances.

You should be aware that making decisions for someone else at the end of life can be difficult and distressing. You can make it easier for your representative if you discuss together the beliefs and values, attitudes towards treatment options, and other personal and cultural issues that are important to you. This form suggests some things that would be good to discuss and note as guidance for your representative.

In asking someone to represent you, you are asking them to take good care of you. Though it is not necessary to do everything possible to prolong life, basic nursing care is always essential. Your representative may be asked to consider the benefits of treatment options, and the harm or other difficulties they may cause, in order to judge whether an option is too burdensome for you or others.

Sometimes your representative may need to take into account non-medical circumstances, such as waiting for a relative to arrive, that might affect a decision to cease life-prolonging treatments.

If you want more help with these matters, see A guide for people considering their future health care, A guide for health care professionals implementing a future health care plan, and Code of Ethical Standards for Catholic Health and Aged Care Services in Australia. These documents can be accessed at http://www.cha.org.au/publications.

The law in most Australian jurisdictions requires your representative to act in your best interests. The advice you give your representative in the Advance Care Plan should be used by your representative, and by your doctors and carers, to help to determine what is in your best interests. It will be evidence of your previous values and wishes.

It is a good idea to store this Advance Care Plan with any document that appoints a person to make medical decisions for you under the laws of your state or territory (see book page). Copies of your Advance Care Plan should be given to your representative, members of your family, and your doctor.
When I am ill and unable to make my own decisions, the following would be important to me – for example, time with my family, needs of my family, respect for my culture.

In addition to basic care, ordinarily including the provision of food and water, the following care would be important to me – for example, effective pain relief, being kept comfortable.

Treatments I wouldn’t want – for example, distressing treatment that offers little benefit, excessive or distressing attempts to resuscitate, culturally or religiously inappropriate treatment.

Religious and spiritual care – for example, religious rituals, care from a pastoral practitioner, chaplain, minister or elder.

Other wishes – for example, reconciliation with friends or family, biography writing, music & art, dying at home if possible.
Appointing a representative:

If you become unable to make decisions about your own medical treatment, there are three ways in which somebody may be or become your representative:

- You have appointed the person in accordance with the laws of your state or territory (e.g., an enduring power of attorney or guardian for medical treatment);
- A court or tribunal appoints someone after you become unable to do so;
- Your spouse, carer, other next of kin or close friend, according to law, may have that authority automatically.

Sources of advice on appointing a representative are:

**New South Wales**
Office of the Public Guardian, free call 1800 461 510

**Western Australia**
Public Advocate, free call 1800 807 437

**Victoria**
Office of the Public Advocate, free call 1300 309 337

**Tasmania**
Public Guardian, ph (03) 6233 7608

**Queensland**
Adult Guardian, free call 1300 653 187

**Australian Capital Territory**
Public Advocate, ph (02) 6207 0707

**South Australia**
Office of the Public Advocate, free call 1800 065 969

**Northern Territory**
Office of Adult Guardianship, ph (08) 8922 7343

You could also seek the advice of your solicitor.