



23 October 2017

Joint Select Committee on End of Life Choices  
Legislative Assembly  
Parliament House  
PERTH WA 6000

Via email: [eolcc@parliament.wa.gov.au](mailto:eolcc@parliament.wa.gov.au)

Dear Committee Members,

**CHA Submission to Western Australian Inquiry into End of Life Choices**

Catholic Health Australia (CHA) represents Australia's largest non-government grouping of hospitals, aged and community care services, providing approximately 10 per cent of hospital and aged care services in Australia, including around 30 per cent of private hospital care as well as approximately 5 per cent of public hospital care.

CHA welcomes the opportunity to provide feedback on behalf of our Western Australian members to the inquiry into end of life choices. Western Australian members of CHA requested and guided this submission.

We note that the panel requests feedback on the need for laws to allow citizens to make informed decisions about end of life care. Our members' offer a wealth of clinical expertise and experience in this area, particularly with regard to delivering quality end of life care and palliative care - services which Catholic health providers have a long history of providing. CHA has consulted with these experts in tandem with other healthcare professionals integral to providing our hospital and aged care services.

Please find **attached** our submission for your consideration in which CHA presents a unifying call to action for the Western Australian government and stakeholders to better support and resource quality end of life care and palliative care.

Should you have any questions or require further information on any aspect of our submission, please do not hesitate to contact me directly: (02) 6203 2777, or email [suzanneg@cha.org.au](mailto:suzanneg@cha.org.au).

Regards,

Suzanne Greenwood LLM LLB FAIM MAIDC MCHSM  
Chief Executive Officer  
Catholic Health Australia



## Inquiry into End of Life Choices

### Introduction

Catholic Health Australia (CHA) represents Australia's largest non-government grouping of hospitals, aged and community care services, providing approximately 10 per cent of hospital and aged care services in Australia, including around 30 per cent of private hospital care as well as approximately 5 per cent of public hospital care. Our members operate 77 hospitals, over 800 aged care facilities and numerous community care and care in the home services across Australia. Our members in Western Australia (WA) include St John of God Health Care, Southern Cross Care, Mercy Care and Catholic Homes.

CHA members have always valued the delivery of person-centred care that is founded in a respect for human dignity and life. We welcome the opportunity to offer a response to the Inquiry into End of Life Choices, and we do so from the position that it is the medical profession's duty of care to preserve and protect life. CHA's view is that it is never permissible to purposefully end an individual's life through euthanasia or assisted suicide because we believe it compromises the inherent value of the person, and erodes trust in the medical profession who must care for individuals at all points in their journey. Based on our experience, CHA believes high quality palliative and end of life care is the best solution to allow freedom of choice, comfort, dignity and respect as a person nears the end of life, not just for the individual, but also for the family and community that surrounds them. We support the approach outlined by the Productivity Commission that to address gaps in end of life care, state and territory governments need to increase the availability of palliative care services across their jurisdictions (Australian Government Productivity Commission, 2017).

### **Palliative Care Assessment under the First Term of Reference**

Compassionate, person-centred palliative care is an indispensable service within the Australian health care system, particularly in the context of Australia's aging population. Palliative care provides holistic care to patients with debilitating and terminal illness. It is coordinated between the patient, the clinician, and necessary allied supports to address the physical, psychological, spiritual, and social needs of the individual. Clinicians assist patients and their family in the progression of their condition to improve quality of life, relieve suffering, coordinate symptom relief, and provide support for their comfort and wellbeing until their natural death. Palliative care practitioners are equipped to ease the fears and anxieties associated with death and dying for the individual and the family carers whilst



playing a key role to provide opportunities for individuals with advanced disease to make informed choices about treatments that are acceptable to them.

Quality palliative and end of life care have significant economic benefits. Patients who access palliative care are consistently shown to have fewer hospitalisations, shorter stays in hospital, reduced use of intensive care facilities and fewer admissions to emergency departments, amounting to significant savings for the health system (Palliative Care Australia, 2017). There is also increasing evidence that appropriate end of life and palliative care reduces unnecessary testing and vital treatments. Currently in Australia, 'almost two-thirds of terminally ill people for whom home or hospice palliative care would be appropriate die in hospital, often receiving heroic interventions' that are frequently distressing and unnecessary (Australian Government Productivity Commission, 2017). Silver Chain Group, a leading provider of community based palliative care in WA, have estimated that the total amount saved in the last year of life for patients accessing their comprehensive palliative care services was \$5,114 per patient in the period 2008-11 (Silver Chain, 2015). The evidence is overwhelming that high-quality palliative and end of life care is best practice, cost saving, and highly effective as a life-preserving intervention (Hudson et al, 2015). While this field has seen welcome growth and better resourcing over the last 20 years, there are still significant gaps with services not accessible to numerous regions across Western Australia, and many vulnerable groups.

Residents of aged care facilities are one example of a vulnerable group. In WA they are currently ineligible to receive community palliative care such as Silver Chain services due to complex state and federal funding structures and aged care facilities are in effectively resourced to provide permanent palliative care expertise. Making community palliative care expertise, such as Silver Chain services available to support aged care staff would be a very cost effective way of improving end of life care in residential facilities.

The *Productivity Commission Draft Report on Human Services* indicates that while Australia provides some of the best palliative care in the world, the vast majority of Australians are unable to access these services. More than 80,000 Australians die in hospital each year and 60,000 die in residential aged care facilities, two of the least preferred places to die (Australian Government Productivity Commission, 2017). 70% of Australians indicate that they would prefer to die at home yet only 15% do, which is low compared to other OECD countries such as New Zealand, Ireland, France, United Kingdom and the USA (Palliative Care Australia, 2017). A report from the Gratin Institute showed



estimates from Palliative Care Australia that 90% of cancer patient and 50% of non-cancer patients could benefit from additional palliative care services. This amounts to 100,000 people dying in Australia each year who need palliative care (Swerissen and Duckett, 2014). From the limited publically available state based data in 2006, it was found that while 68% of Western Australians who died of cancer received specialist palliative care, only 8% of people who died of non-cancer related conditions received specialist palliative care. Vulnerable people such as those who were widowed, aged over 85, lived in a region outside a major city, or were of Aboriginal or Torres Strait Islander background were less likely to have access to palliative care services (Rosenwax and McNamara, 2006).

The demand for community palliative care services far exceeds its availability in Australia (Australian Government Productivity Commission, 2017). It is estimated that 'many, perhaps tens of thousands of, people cannot access desired support to die in their own home and die in hospital instead' (Australian Government Productivity Commission, 2017). The specialist skills attributed to palliative medicine are currently neither commonplace nor incorporated into existing healthcare professional curricula. Specialist palliative care clinicians' account for 5 in every 1000 employed medical specialists in Australia with an estimated mere 148 physicians in all of Australia in 2012. Western Australia fares even worse with **only 12 palliative care specialists in the state** (AIHW, 2014). Nine out of ten of these physicians work in major cities further disadvantaging those who live in rural and remote communities like many Western Australians. Our health and aged care systems cannot provide the highest level of care to patients when palliative and end of life services are so inadequately resourced.

Education is key to increasing awareness of palliative care for Australians who are unaware of the benefits that palliative care can have to relieve suffering, and provide a dignified death where they have control and their wishes respected. A public awareness of what services are available for end-of-life care is often not effectively communicated, resulting in misunderstandings and fear around palliative care. CHA is concerned that many people, especially those that are particularly vulnerable – such as Aboriginal or Torres Strait Islanders or older people – may mistakenly fear palliative care will hasten their death, and hence miss out on its benefits. CHA is adamant that any changes to legislation around end of life choices in Western Australia must prioritise the adequate resourcing of end of life and palliative care, in conjunction with education and awareness raising for health care professionals, stakeholders and the community about the profound benefits of creating a world class palliative care system.



### **Advance Care Planning assessment under the Fourth Term of Reference**

Advance care planning is a key component of palliative care service provision throughout Western Australia. A process that enables patient choice as individuals are able to examine their values and priorities, reflect with family, and make decisions about future treatment options. CHA and our members provide information for people considering their future health care needs and encourage patients to reflect, plan and appoint a person who will represent them if they are unable to express their wishes. Advance Care Planning is part of good stewardship and taking responsibility for our lives. If someone is unable to speak for themselves, an advance care plan can help support carers - their community of care - ensure that the person is supported in the way that they would want.

To help achieve this, CHA has a dedicated website, [www.myfuturecare.org.au](http://www.myfuturecare.org.au), where resources are available for members of the community and health professionals. This website aims to provide support to prospective patients and residents of Catholic facilities and health professionals who take care of them, and provides guidance that is consistent with good ethics. Resources available at the website include our Advance Care Plan form, policy documents, video gallery, training modules for health carers, and answers to frequently asked questions.

CHA has developed the **Catholic Health Australia Advance Care Plan** which is available at <http://myfuturecare.org.au/resources/> and is **Annexure 1** to this submission. This resource is designed to help people think about end of life options and plan for the future.

A key component of advance care planning is identifying those that are coming to the end of their life. Unfortunately, this advanced planning does not often occur within Australia's health care system. Only 61% of clinical units in New South Wales (NSW) local health districts routinely identified patients approaching the end of life in order to engage in end of life planning (Australian Government Productivity Commission, 2017). It is also important that health care administrators and patients keep these documents current and up to date so that in the event of an emergency, or when a patient's decision-making capacity is compromised, health care professionals can be assured these documents represent the current wishes of the patient.



If allowing citizens to make informed decisions regarding their own end of life is the primary aim of the committee, then resourcing and incentivising health professionals to identify patients approaching end of life, and promoting discussion and planning around death and dying is essential. Raising awareness of advance care planning within the scope of palliative care should be a priority. CHA does not support any changes to legislation that would allow advance care plans to be used in order to deliberately end a life in the form of voluntary euthanasia.

### **Overseas Jurisdictions consideration under the Second Term of Reference**

The committee has asked for a review of legislation and frameworks that have been implemented in other jurisdictions. CHA would like to call the committees attention to the experience in Catalonia and the United Kingdom, two case studies that highlight the incredible benefits, both economic and to quality of care, that investing in palliative care can have for communities.

#### Catalonia

A number of years ago, Catalonia embarked on a project to implement the World Health Organization (WHO) world standard guidelines of palliative care. This process has revolutionised its health care system, providing improved care for patients, and providing a substantial financial saving to government. In order to do this Catalonia focused on a number of priority areas including:

- Training health care professionals in basic palliative care.
- Developing a new palliative care funding model.
- Ensuring palliative care was integrated into traditional health care services.
- Improving the provision of specialist palliative care throughout the health care system.
- Developing professional standards.
- Creating a monitoring and evaluation strategy (World Health Organization, 2011).

Through adequately funding and resourcing their system Catalonia achieved a substantial increase in palliative care provision, with over 95% of Catalonia covered by palliative care services after 10 years. In 2005, 79% of people dying from cancer and 25-57% of those dying from other long-term chronic conditions received specialist palliative care services (WHO, 2011). Patients who accessed palliative care services reported reductions in symptom severity and increased rates of satisfaction with end of life care. Hospital admissions, hospital bed days, length of hospital stay and emergency room



admission all decreased over this period which led to an estimated net saving to the Catalan Department of Health of €8 million per year in 2005 (WHO, 2011).

### United Kingdom

The United Kingdom (UK) is another powerful example highlighting the benefits of a well-resourced palliative care system. In 2008 the UK, recognising disparities in patient preference and service provision, implemented a whole system approach to drive improvement in end of life care. The *End of Life Care Strategy* was developed with strong support from both government and non-government stakeholders. This strategy has generated substantial results. It has reversed entrenched trends in place of care and death, with 42.4% of people in the UK dying at home or in home care in 2012, compared to just 15% of Australians (Department of Health, 2012: Palliative Care Australia, 2017). It created a discussion about death and dying through implementation of a well-planned media strategy which raised public awareness and engagement with these issues. Governments worked with health professionals to provide workforce development and organisational guidance which resulted in increased early identification of people nearing end of life, thus enabling discussion, planning, and choice for patients. This has led to one third of patients with expected deaths to be seen by palliative or hospice services (The National Council for Palliative Care, 2016). Improved evidence and data collection was also developed to enable further evaluation and planning (National Council for palliative care, 2014). The *End of Life Care Strategy* has seen vast improvements to the care of many, instead of catering to the individual wishes of a privileged few thought the implementation of euthanasia, a policy that currently remains illegal in the UK.

### **Legislative change considerations under the Third Term of Reference**

One of the primary arguments for changes to end of life legislation is that people are suffering at the end of life and current legislation does not facilitate choice and effective treatment that relieves suffering. However, CHA strongly believes this is not the case. Palliative care currently incorporates many practices that accommodate choice, alleviate suffering, provide comfort and neither hasten nor postpone death when a terminal illness renders it inevitable. This can include withdrawal of treatment, sedation, or the slow increase of pain medications which may ultimately result in death. In the majority of cases these practices are highly effective and patients experience a peaceful death. Of the approximately 50,000 palliative care patients admitted to Australian hospitals each year, less than 1% express a sustained desire for additional intervention in the form of physician-assisted suicide.



The evidence is overwhelming that high-quality palliative care is highly effective at alleviating suffering and providing comfort (Hudson et al, 2015).

It has been argued that the delivery of drugs for pain relief and sedation create misunderstandings and legal uncertainties for medical professionals with some clinicians fearful of facing criminal charges for engaging in these practices. However litigation against medical professionals in the palliation of pain and suffering for ill and terminal patients has not occurred. Professor Paul Komesaroff, the Director for the Centre in Ethics and Medicine and leading researcher at Monash University, acknowledged in hearings before the *Standing Committee on Legal and Social Issues Inquiry into End-of-Life Choices* that 'no doctors have ever been prosecuted in Australia for prescribing too much pain relief' (Komesaroff, 2015). In fact medical practitioners are currently protected by the 'doctrine of double effect'. This is when 'an act performed with good intent can still be moral despite negative side effects'. This is applicable in a palliative care context when:

1. Administering palliative medication is not, in itself, immoral.
2. The intention is to relieve pain, not to hasten the patient's death.
3. The relief of pain is not achieved through causing the patient's death.
4. Proportionally, the need to relieve pain is such that it warrants accepting the risk of hastening death (White et al, 2011).

In WA, this doctrine has been codified in legislation with Criminal Code Act Compliance Act 1913 stating 'A person is not criminally responsible for an act or omission which occurs independently of the exercise of the persons will.' Healthcare professionals are therefore protected to engage in compassionate and appropriate care if their intention is not to cause death but to alleviate suffering. Current WA legislation allows sufficient structures and flexibility to protect and promote compassionate end of life care. What is needed is not a change to legislation, but education for health professionals and the community on their rights, responsibilities and existing opportunities in managing end of life care.

## Conclusion

CHA members are committed to providing the best possible, evidence based compassionate care to all members of society. We believe that quality end of life and palliative care is the best and most effective way to provide choice and ease suffering at the end of life. All Western Australians should





have access to affordable, high-quality and multi-disciplinary palliative and end of life care before any alternative are considered. As the *United Kingdom End of Life Care Strategy* states:

‘How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services (National Council for Palliative care, 2013).’

The WA government needs to consider what type of society it wants to create. WA has the opportunity to become a world leader in this field if you learn from successful overseas models, adequately resource services and educate the community on the profound benefits of end of life and palliative care.

## References

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# Advance Care Plan

It is good to think about future health care 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 health care,**

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 this 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 back 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*

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**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*

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

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

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**Other wishes** – *for example, reconciliation with friends or family, biography writing, music & art, dying at home if possible*

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## 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 451 510

#### **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 066 969

#### **Northern Territory**

Office of Adult Guardianship,  
ph (08) 8922 7343

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You could also seek the advice of your solicitor.