



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Secretary,
Select Committee on End of Life Choices in the ACT,
Legislative Assembly for the ACT,
GPO Box 1020,
CANBERRA ACT 2601

Dear Committee Members,

CHA Submission to Australian Capital Territory Inquiry into End of Life Choices in the ACT

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. In the ACT, our member hospital services include Calvary Public Hospital Bruce, Calvary John James Hospital Deakin, the new Calvary Bruce Private Hospital, and specialist palliative care at Clare Holland House, Barton. We also provide aged care services in Aranda, Braddon, Bruce, Campbell, Deakin, Garran, Manuka, Page, and Yarralumla.

CHA welcomes the opportunity to provide feedback on behalf of our Australian Capital Territory (ACT) members to the inquiry into end of life choices. ACT 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 ACT 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, please do not hesitate to contact me directly: (02) [REDACTED] or email [REDACTED]

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 80 hospitals, over 25,000 aged care beds, and more than 36,500 care in the home and support services across Australia. In the ACT, our member hospital services include Calvary Public Hospital Bruce, Calvary John James Hospital Deakin, the new Calvary Bruce Private Hospital, and specialist palliative care at Clare Holland House, Barton. We also provide aged care services in Aranda, Braddon, Bruce, Campbell, Deakin, Garran, Manuka, Page, and Yarralumla.

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 in the ACT, 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 option 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, carers, 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).

[Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care.](#)

Palliative Care

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, the family and carers whilst providing opportunities for individuals with advanced disease to make informed choices about treatments that are appropriate for them.

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 to relieve that suffering. However, CHA strongly believes this is not the case. Palliative care currently incorporates many practices that accommodate choice, alleviates suffering, provides comfort, and neither hastens nor postpones death when a terminal illness renders it inevitable. This can include withdrawal of treatment, palliative sedation, or the slow increase and control of pain medications. In the majority of cases, these practices are highly effective and patients experience peaceful deaths. 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 (Hudson et al, 2015). High-quality palliative care is best practice to alleviate suffering and provide comfort allowing a respectful and peaceful end of life.

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, all 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 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, 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 (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 in numerous regions across Australia, and inaccessible to many vulnerable groups.

The demand for community palliative care services far exceeds its availability in Australia (Australian Government Productivity Commission, 2017). It is estimated that '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 213 physicians in all of Australia as of 2015. The ACT number of specialists fares even worse, with **only 4 palliative care specialists available in the territory** (AIHW, 2015). 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.

The recent passage of Voluntary-Assisted Dying (VAD) legislation by the Victorian Parliament raises many safety and ethical concerns about how the government views end of life supports for the most vulnerable patients facing terminal diagnoses. CHA maintains that improved resourcing of palliative health care in Victoria, especially in regional and rural areas, is crucial to delivering compassionate care for those who need it. Resorting to the legalisation of euthanasia is an abandonment of the appropriate and evidence-based practice of palliative medicine to ensure those who are dying may live with the confidence they will be provided with comfort and dignity.

It is CHA's view that no resident of the ACT should be considered eligible for VAD when the policies and resources necessary to ensure access to alternatives such as affordable, high-quality and multi-disciplinary palliative care are currently inadequate. To introduce such a policy risks endangering lives, placing vulnerable people at risk, and limits funding and resources for a practice that could potentially assist entire communities of people, to benefit a small minority of individuals that would meet the strict criteria necessary for VAD.

[Advanced Care Planning](#)

Advance care planning is a key component of palliative care service provision throughout Australia. This fundamental process enhances 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 by empowering patients to establish agency over their 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 the patient would want.

To help achieve this, CHA has a dedicated website, 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. The ACT should prioritise educating and resourcing current advanced care planning systems that have been proven to benefit the community instead of developing a new intensive practice of euthanasia that will require many complex layers of bureaucracy.



If allowing citizens to make informed decisions regarding their own end of life is an important 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 or assisted killing.

ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.

CHA represents 10.3 per cent of the residential aged care market share in the ACT and 7.3 per cent of the home care package market share with members including Calvary, Mercy Care, and Southern Cross Care providing aged care services to the ACT Community.

Calvary provides a significant proportion of the health care in the ACT maintaining over 500 hospital beds across 3 facilities, with 56,000 presentations per year occurring at the Calvary facilities in Bruce. They also provide over 100 residential aged care places and are a leading provider of palliative and end of life care in the ACT through the Clare Holland House (Calvary, 2017). Calvary has publically stated that it will not participate if any legislation enabling VAD is passed.

“Calvary cannot support the notion that assisting a person to commit suicide, or to end their life directly and intentionally, is an expression of care. We strive to eliminate suffering but not the people who are experiencing the pain or physical incapability (Calvary, 2017).”

Calvary provides a large proportion of community and health care in the ACT and represents a leading community voice on health matters. If an organisation such as this, whose mission and values are based around caring for the community, is unwilling to provide VAD as a service and actively speaks out against it, should we not determine that such a practice is not in the best interests of the ACT community?

Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.



CHA believes that there is no form of legislation that would enable VAD to be implemented in a way that ensures public safety. The risks of VAD are wide-ranging and uncontrollable, threatening the health and safety of vulnerable groups, individuals, and communities, as well as fundamentally undermining the values and ethics that form the fabric of Australian society. It is CHA's belief that there is no way to adequately manage the risks of VAD.

Safety concerns of experts

The World Medical Association (WMA) has publicly stated 'Physician assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession.' It called on jurisdictions throughout the world to reject VAD bills warning that 'vulnerable people will be placed at risk of abuse' and 'a precedent will be set that physician assisted suicide and euthanasia are ethically acceptable'. The Australian Medical Association (AMA) shares this view strongly opposing the implementation of VAD legislation in Victoria, but that is ultimately a matter for society and government to decide. Despite conjecture that VAD can be implemented in a safe way, expert physicians and clinical groups clearly state that legalising VAD is dangerous, inherently risky, and could have many unintended harmful consequences for patients, family members, clinicians and the greater community.

Risk of undermining community trust in the medical profession.

A large number of clinical experts agree that VAD will erode trust in the medical profession. Historical ethical traditions in medicine are strongly opposed to taking life. For instance, the Hippocratic Oath states, 'I will not administer poison to anyone where asked,' and I will 'be of benefit, or at least do no harm.' Linking VAD to the practice of medicine risks harming both the integrity, and the public's view, of the profession.

Public fear around death and dying has been exacerbated as euthanasia has become associated with palliative care practices in some Australian communities. People fear the goals and treatment strategies of palliative care are designed to hasten death, particularly when it comes to the use of some medications such as opioids. These medications are thought by some to be used to administer euthanasia as exemplified by the following example described by Hudson et al (2015):

"In a busy hospital palliative care consultative service, there are daily discussions with patients, often elderly, who are fearful of opioids precipitating their death. On this day, an 82-year-old Greek man with newly diagnosed pancreatic cancer is concerned that the low dose of



morphine prescribed for pain relief will result in his premature death. A great deal of time and reassurance is given, yet still he remains uneasy and reluctant to take effective analgesia.”

Fear of end of life care practices has the potential to be heightened by any attempts to legalise VAD, particularly among vulnerable and at risk patients. There is a very real risk that patients may begin refusing lifesaving and pain reducing treatments because their trust in the medical profession has been fundamentally eroded and they fear that medical interventions may be used to end their life or that of a loved one.

Risk of Undermining Palliative Care

A great deal of misunderstanding about palliative care services exists within Australia, both in the community and within the medical profession. Legalising VAD risks compounding the problem with people becoming even more confused about what palliative care is and what services it provides. It also risks undermining the role of palliative care within the community with people coming to believe it is an either/or scenario and choosing to forgo vital palliative care services in the hope of accessing VAD.

CHA palliative care practitioners believe that their roles as specialist medical providers will be limited and undermined if VAD is implemented. When VAD was enacted in the Northern Territory between 1996 and 1997, the role of the palliative care practitioner was minimised and became tokenistic. A requirement was implemented that all people wishing to access VAD seek approval from a palliative care specialist, as they were deemed the only medical specialist specifically qualified to determine a patient's holistic health status as they neared end of life. However, instead of being allowed to fully explore their physical, social, emotional, spiritual and psychosocial health as is the unique and essential role of this medical speciality, they became merely a checked box on the path to euthanasia. This completely undermined the role of palliative care within the community and led palliative care specialist to be viewed negatively and associated with fear and death (Hudson et al, 2015).

If VAD is legalised, it will require substantial government funding to implement, administer, and ensure essential safety standards and protocols. CHA is concerned that this will result in vital funding and investment being allocated to implement a practice that would be utilised by a small minority of people, when vital palliative care services that have proven population health impacts are chronically underfunded and under resourced (Hudson et al, 2015).

Risk of inaccurate prognosis

Clinicians have highlighted the risks associated with providing an accurate clinical prognosis regarding the longevity of a patient at the advanced stages of disease, and the difficulties of defining an individual as being 'at the end of life'. A study on the prognosis of people with central nervous system cancers found that physicians had incorrectly predicted patient survival by as much as 12 to 18 months. Of the 2700 predictions, 45 per cent were incorrect by more than 6 months and 18 per cent were incorrect by more than 12 months (MacKillop and Quirt, 1997).

The requirement set out by the Victorian VAD legislation defining advanced terminal disease as a 'serious and incurable condition' is problematic, as there are many serious and incurable diseases that are not considered terminal but manageable with the right evidence-based treatments and access to appropriate models of care. CHA is concerned that legalising VAD may lead people to end their life prematurely when they may otherwise have led long fulfilling lives as technology develops and treatments improve.

Risk to Vulnerable

VAD legislation is particularly dangerous for vulnerable members of the community including; the elderly and frail, marginalised groups such as non-English-speaking Australians, prisoners, homeless, mentally and physically disabled, those living alone without supportive families, and Aboriginal and Torres Strait Islander peoples. These groups face increased susceptibility to abuse, mixed messaging, misinformation, and pressure from others.

Legalising assisted killing advances the misguided belief that the elderly, sick and vulnerable constitute a burden to society. This type of thinking along with internal and external pressures including; financial concerns, inadequate access to alternative services, physical and psychological abuse, misinformation about treatment options, or a reduced sense of worth, may impact on the individual's choice to make a request. These pressures may push an individual toward accessing VAD when it is a decision that they would not otherwise make. Hudson et al (2015) presents the following scenario

"An elderly woman was afraid of being a burden to her adult daughter, knowing that her daughter would need to take leave from work to care for her. This fear led her to express a desire to 'end it all'."



Legalising VAD risks signalling to our most vulnerable members of the population that they lack value and are a burden. CHA maintains its position that person-centred compassionate care is founded on respect for human dignity to improve the living person's ability to experience a meaningful period of life, leading to death, rather than neglecting the person at a point when they are the most vulnerable and in need of the greatest support.

There is also no way to ensure with complete certainty that vulnerable members of our community will not be coerced into accessing VAD. Evidence from the Netherlands shows that despite legislation that assisted dying must be voluntary and free from coercion, it has been estimated that in 0.7 per cent of cases a life was ended without the explicit and recurrent requests from a patient. This is equivalent of around 1000 patients since the Danish legislation was implemented (Van der Mass, 1996: Kowen 1995). This raises the question whether our society is willing to assume the risk if even one life ends prematurely due to coercion or guilt. CHA believes that it is the role of health care providers and governments to protect the vulnerable, not expose them to greater risk.

[Risk of legalising lethal drugs](#)

The risks associated with the distribution of dangerous and lethal drugs that would be needed to end someone's life if VAD was to be legalised are vast. Strict legal requirements currently exist around the storage, handling and dispensing of medicines defined as Schedule 8 (S8) under the Standard for the Uniform Scheduling of Medicines and Poisons because of the high risk of misuse. They have to be prescribed, dispensed, documented and destroyed in specific ways that are in compliance with each state and territory's different drug regulations. There exist very strict regulations for health professionals, yet in order to legalise VAD it is proposed that people with no training or experience be allowed to handle dangerous lethal drugs in their homes, without the checks and balances we mandate for experienced health professionals. How can this be considered safe? Who will ensure the appropriate use of these drugs and that they are not left around endangering the lives others? If the individual dies through natural causes, what requirements will be put in place for recovery of 'unused' lethal dose medication? As such, unused medications could command a price on the black market. If an individual takes with them a lethal dose medication, what safeguards will prevent them being induced to take the medication by coercion, psychological or personal pressure, or misinformation?

There are also reported instances of these dangerous drugs not working effectively and recipients experiencing a prolonged, painful death. Differences in personal medical history and body



composition can make accurate prescription of lethal drugs very difficult that can result in serious unintended consequences. In Oregon, a longitudinal study found that 3 per cent of assisted suicides have complications including distressing symptoms, with the longest death recorded lasting 104 hours (4 days and 8 hours) (Hedberg et al, 2003: Oregon Public Health Division, 2017). In the Netherlands, it was found that 7 per cent of people experienced unexpected side effects such as regaining consciousness, vomiting, gasping for breath, and seizures (Groenewoud, 2000).

Furthermore unintended effects of ineffective medication administration can create additional stress and grief for surviving family members which may have long-lasting implications. Research from Switzerland demonstrates evidence of post-traumatic stress disorder and complicated grief for families witnessing suicide (Wagner, Muller and Maercker, 2012). If the primary argument for allowing VAD is to reduce pain and suffering, why would we risk increasing pain and suffering for not only the patient but also the community that surrounds them? This is not a compassionate solution.

CHA would like to call the committees attention to **Annexure 2** which outlines the lengthy and invasive processes that are required to facilitate medical assistance in dying. This document is an eight-step guide to providing intravenous medical assistance in dying produced by experts in Toronto, Canada. It highlights the distressing and lengthy processes that are involved in providing medical assisted dying. As this procedure indicates, It is not as simple as taking a pill, nor is it a peaceful passing, as members of the public are being encouraged to believe.

The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;

Victoria

Victoria has claimed to have the safest VAD legislation in the world. However, it is CHAs belief that there is no way to ever implement VAD in a manner that does not put people at risk and threaten public health and safety. As demonstrated above, even experts agree that the application of VAD is problematic and undermines fundamental values that underpin Australian communities. The Victorian legislation has numerous failings and should not be held up as a model to be replicated in the ACT.

Drug Administration

There are numerous dangers associated with the provision of medications used to end the lives of citizens that no jurisdiction has been able to adequately address to ensure the safety of communities.



Nembutal and Secobarbital are the drugs most commonly used to terminate life in overseas jurisdictions where euthanasia is legal. These drugs have been trialled and tested over years of use with dose ranges determined, though patients still experience adverse consequences. However, in upholding its objective of 'the establishment and maintenance of a national system of controls relating to the quality, safety, efficacy, and timely availability of therapeutic goods' the TGA has determined these drugs to be unsafe and illegal for human consumption in Australia.

In absence of the ability to prescribe Newbutal and Secobarbital, Victoria has proposed the development of a drug cocktail to terminate life, an idea fraught with danger. Medications undergo years of testing and trials before they are considered safe for use, and even then many are heavily regulated. Untested medical combinations intending to be lethal can have unforeseen consequences by inhibiting or exacerbating each other. Determining medication dosage is also very difficult, as characteristics of each individual need to be accounted for. What is an adequate level of morphine for one person many have disastrous consequences for another. This is even more important for individuals suffering long-term illnesses, many of whom are likely accessing a variety of long-term treatments to manage symptoms that could inhibit the effects of the proposed drug cocktail with painful and frightening results. Victoria has provided no solution to this dangerous problem and is yet to adequately explain how they intend to provide lethal drugs in a way that does not create increased pain and suffering.

Assessment of eligibility

Victorian legislation has proposed that for a person to be considered eligible for VAD, that person must be assessed by two doctors with one needing to have experience in the field of the disease that will end the patient's life. Yet, there is no requirement for physicians to possess expertise in treating patients at the advanced stages of disease. Physician experience with patients suffering advanced disease or at end-of-life, knowledge of treatment options, and competency to assess cognitive ability is significantly variable. Having medical expertise does not guarantee the ability to understand the nuances of the physical, psychosocial and existential health of a person nearing end of life, and there is a substantial lack of training in this area within the Australian medical community.

One of the greatest difficulties for health professionals is determining the mental wellbeing and decision-making capacity of a person nearing end of life. Terminal illness obviously has a profound impact on a person's state of mind contributing to significant periods of depression and low mood. In



a study of 321 psychiatrists in Oregon, only 6 per cent were very confident that they could adequately determine whether a psychiatric disorder was impairing the judgement of a patient requesting assisted suicide (Ganzini, 1996). Our legislative bodies cannot expect clinicians outside of the mental health specialities to be adequately able to determine mental capability and decision-making capacity when even the experts are not completely confident in their diagnoses.

Palliative care specialists or psychiatrists working in palliative care likely possess the expertise and skillsets required to assess the basis of an individual's request for VAD, however it is CHA's concern that the expertise to make such important assessments is not adequately available in the Australian healthcare system. With only 213 palliative care specialists Australia wide (AIHW, 2015), it would be unjust to expect palliative care specialists, many of whom do not support the practice of VAD, to become the arbiters of this process and to have their time dedicated to VAD requests when their expertise is currently so severely lacking in the wider community.

Protections for health organisations

The Victorian legislation has outlined protections for the conscientious objections of individuals, but organisations have been omitted from these protections. Conscientious objection for individuals is a basic right and must be protected. However, it is CHA's belief that this is not sufficient with more consideration needed to protect the rights and freedoms of health care organisations. The Victorian legislation is leaving health care facilities and their staff exposed to statutory uncertainty and jeopardising their ability to provide quality care. Protections must be guaranteed otherwise we risk individuals undermining professional practices and the quality standards of health care services.

In Canada, protections for organisation have not formally been legalised, though in practice the right to not provide VAD has been informally respected. However, recently there has been a growing number of calls for all organisations that receive public funding, including those with religious and ethical objections, to be required to provide VAD upon patient request, undermining fundamental ethical and religious freedoms of these services. There has also been some instances of health professionals overstepping profession boundaries to administer VAD in organisations without permission. In one shocking recent case, a medical professional snuck into health care facilities where VAD is not offered, disregarding all protocols and procedures designed to protect patients and staff, and administered lethal drugs to a patient. This caused significant distress and trauma to staff and



patients of the facility (Lazaruk, 2008). The right of organisations to object must be protected by law to prevent additional pain and suffering to health professionals and community members.

Many of the so-called “safeguards” in the Victorian legislation are merely explanations of procedures, not safeguards. There is no compelling evidence that these procedures will result in the “safest” legislation - only an illusion of safety.

Overseas Jurisdictions

CHA hopes the above evidence demonstrates just some of the many inadequacies of the Victorian VAD legislation that have proven inadequate to safeguard the safety and dignity of patients in jurisdictions who have previously legalized euthanasia. Advocates have marketed the Victorian bill as the safest in the world, yet experts, including members of the WMA and the AMA, agree that the inherent dangers of this legislation combined with the role of the medical profession to not intentionally end life make this a medically dubious practice. It therefore follows that there is no form of legislation from any jurisdiction throughout the world that demonstrates an ethical and safe model of VAD implementation.

There is extensive evidence in jurisdictions all over the world of the countless benefits of providing quality palliative care. CHA would like to call attention to the experiences of Catalonia and the United Kingdom, two case studies that highlight the substantial worth of appropriately and adequately funding and resourcing palliative care while rejecting the implementation of euthanasia. Not only did these jurisdictions receive great economic benefit but they also demonstrated vast improvement in patient experience and indicators of quality care. CHA urges the committee when considering end of life care policy to fund and resource palliative care models, which have wide-ranging population impacts, instead of using limited resources to legislate a highly dangerous practice.

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 per cent of Catalonia covered by palliative care services after 10 years. In 2005, 79 per cent of people dying from cancer and 25-57 per cent 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 recognised disparities in patient preference and service provision by implementing 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 per cent of people in 2012 in the UK dying at home, or in home care where death occurs and where end of life care is received, compared to just 15 per cent 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 few through the implementation of euthanasia, a policy that has been continuously voted down in the UK.

CHA urges the ACT to follow the lead of countries, such as Catalonia and the UK, which have invested in resourcing palliative care and become a world leader in quality end of life care, instead of diverting resources to legalising the unethical and dangerous practice of VAD.

The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change

The capacity of the ACT to determine its own policy on VAD is limited by the statement in the Australian Capital Territory (Self-Government) ACT 1988 - SECT 23 Matters excluded from power to make laws which states:

'(1A) The Assembly has no power to make laws permitting or having the effect of permitting (whether subject to conditions or not) the form of intentional killing of another called euthanasia (which includes mercy killing) or the assisting of a person to terminate his or her life.'

CHA recognises the ACT would require cooperation from the federal government in order to develop a policy legalising VAD. The federal government has up until this point demonstrated an unwillingness to engage with the issue of VAD which could make the establishment of a policy in the ACT very difficult, time consuming, and costly. CHA believes it should be a priority of the ACT government to allocate their time and resources to improving access and funding of necessary palliative care services, training, and supports.

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 citizens of the ACT should have access to affordable, high-quality and multi-disciplinary palliative and end of life care before any alternatives 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 ACT government needs to consider what type of society it wants to promote. We urge you to heed the words of experts and peer medical bodies and reject the idea of following in Victoria's footsteps to implement legislation to legalise assisted killing. As the above submission shows, there is no safe and ethical way to implement VAD that does not risk the health and safety of individuals and communities. The ACT has the opportunity to become a world leader in the field of end of life by modelling the successful palliative care overseas examples, adequately resourcing services, developing policy that is inclusive and community focused, and educating the community on the profound benefits of end of life and palliative care.

We thank you for the opportunity to participate in this inquiry and if you require any further information or clarification please contact Suzanne Greenwood on (02) [REDACTED] or email [REDACTED]

References

Amarasekara, K, and M Bagaric. *"The Legalisation Of Euthanasia In The Netherlands: Lessons To Be Learnt."*. Monash University Law Review 27(2): (2001): 179-96. Print.

Australia Institute for Health and Welfare, *Palliative care services in Australia, 2015*. Palliative Care Workforce, Canberra <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>.

Australia Government Productivity Commission 2017, *'Introducing Competition and Informed User Choice into Human Services: Reform to Human Services*, Draft Report, Canberra <
<http://www.pc.gov.au/inquiries/current/human-services/reforms#report>>

Calvary, *Little Company of Mary Healthcare Limited Annual Review 2016/2017*, (Sydney: 2017).

Calvary. Voluntary Assisted Dying Bill 2017 (VIC) Calvary's Position
<https://www.calvarycare.org.au/wp-content/uploads/2017/08/calvary-position-vad-20170815-final.pdf>

Calvary. Voluntary Assisted Dying Bill 2017 (NSW) Calvary's Position
<https://www.calvarycare.org.au/wp-content/uploads/2017/08/Calvary-Position-VAD-NSW-20171005.pdf>

Department of Health, *'End of Life Care Strategy: Fourth Annual Report'*, National Health Service (NHS) (London: 2012).

Ganzini, Linda et al., 'Attitudes of Oregon psychiatrists toward Physician-assisted suicide', *American Journal of Psychiatry* 1996; 153;pp. 1469-75.

Groenewoud, J. et al (1000). 'Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands'. *New England Journal of Medicine*; 2000; 342.

DOI:10.1056/NEJM200002243420805, pp. 551-556.

Hedberg, K .et al (2003) 'Five Years of Legal Physician- Assisted Suicide in Oregon', *New England Journal of Medicine*. March 2003 348.

<http://www.nejm.org/doi/full/10.1056/NEJM200303063481022>, pp. 961-964.



Hudson P, Hudson R, Philip J, Boughey M, Kelly B, Hertogh C. *Legalizing physician-assisted suicide and/or euthanasia: pragmatic implications Palliative and Supportive Care*. 2015; 13 (5) p. 1399-1409.

Komesaroff, Paul, Transcript of the Standing Committee on Legal and Social Issues Inquiry into End-of-Life Choices. 23 July 2015.

Lazaruk, S. (2018, January 5). Jewish care home accuses doctor of 'sneaking in and killing someone'. *Vancouver Sun*.

MacKillop, MS., and Quirt, CT. (1997). 'Measuring the accuracy of prognostic judgements in oncology'. *Journal of Clinical epidemiology*, Jan:50(10):pp. 21-9

National Council for Palliative Care, *'The end of life care strategy: New Ambitions'*, (London: 2014).

National Council for Palliative Care, *New Edition of Minimum Data Set highlights vital trend in End of Life Care*, 2016.

Oregon Public Health Division (2017), 'Oregon Death With Dignity Act: Data Summary 2016', p.11.

Palliative Care Australia, *The Economic Value of Palliative Care and End of Life Care*, Economic Research Note. Web. 13 Oct. 2017.

Palliative Care Australia (2003) Palliative care service provision in Australia, Palliative Care Australia
Parliament of Australia, *Australian Capital Territory (Self-Government) ACT 1988*.

Rosenwax, LK and McNamara, BA, "Who received specialist palliative care in Western Australia- and who misses out?" *Palliative Medicine* 20(4): (2006): 439-45. Web. 13. Oct. 2017.

Silver Chain, 'Silver Chain Group Submission on the Consultation Paper on the Pricing Framework for Australian Public Hospital Services 2016-17' (2015).

Swerissen, Hal and Duckett, Stephen 2014, 'Dying Well', Gratin Institute.

Van der Maas, PJ. et al (1996). 'Euthanasia, physician assisted suicide, and other medical practice involving the end of life in the Netherlands, 1990 -1995.' *New England Journal of Medicine* 335.22:pp1699-1705; J Keown (1995). 'Euthanasia in the Netherlands: Sliding down the Slippery Slope', 9 Notre Dame J.L. Ethics & Pub. Pol'y 407



Wagner, B., Miller, J., and Maercker, A (2012). 'Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide.' *European Psychiatry* 27.7; pp. 542-546.

White, Benjamin P, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011.

World Health Organization, *Palliative Care for Older People: better practices*. (Denmark: WHO European Regional Officer, 2011).



CATHOLIC HEALTH
Australia

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*

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 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

You could also seek the advice of your solicitor.



UHN

Toronto General
Toronto Western
Princess Margaret
Toronto Rehab

Information for intravenous medications for Medical Assistance In Dying

This document is to provide background information. It is recognized that care may be modified to meet the best interests of the individual patient. The following medications are to be administered by the physician on the Intervention Team.

It is recommended that a "Do Not Disturb" sign be placed on the door to the patient's room and that all cell phones and pagers of staff participating in the procedure are either turned to silent mode or left with a colleague to decrease the potential for interruptions during the procedure.

1. Intravenous access

The importance of reliable intravenous access is emphasized to ensure successful uninterrupted administration of all the medication.

For central lines or peripherally-inserted central catheters (PICC):

- o Site is secured
- o Blood can be withdrawn
- o Saline 10cc flush is given with little or no resistance
- o Gravity set flows freely

For peripheral lines:

- o Size 20G or larger (18G, 16G)
- o Site is secured
- o Saline 10cc flush is given with little or no resistance. There is no evidence of interstitial flow, swelling around the site, or pain throughout the duration of the flush
- o Gravity set flows freely
- o Consider a second peripheral intravenous line if there is a history of difficult access, "blown" IVs, intravenous chemotherapy, or if the primary IV is 20G or smaller

2. Intravenous setup

Intravenous setup includes a 1L bag of Ringers Lactate or Normal Saline connected to a free-flowing gravity set connected directly to the IV catheter.

Because of noisy alarms, temperamental tubing sets and a machine-dictated delay in diagnosing compromised or interstitial venous access, electronic pumps and electronic pump sets are not recommended.

All other intravenous infusions should be discontinued to avoid backflow of medications.

Run IV at 50-100mL/hr until time of injection, and then run "wide-open."

3. Medications

- The pharmacy department will prepare two complete kits including all pre-filled syringes labeled as described below. The kits will be dispensed from the pharmacy department by a pharmacist to a member of the MAID team on a patient-specific basis pursuant to a prescription from the intervention physician that has been verified by a pharmacist.
- Physician to administer all medications completely, sequentially and rapidly as detailed below with minimal or no delay between syringes.
- If a gravity set is not used consider flushing with 10mL of saline after every syringe.
- Midazolam 10mg (1mg/mL = 10mL). Use 10mL syringe. Label as **Syringe A: midazolam**
For deep sedation/coma
Consider Advising those who are present that the patient may gasp following administration of this medication.
Inject over 10 seconds
- Lidocaine 2% 100mg (20mg/mL = 5 mL). Use 5mL syringe. Label as **Syringe B: lidocaine**
Necessary for peripheral venous access only
For reduction of discomfort on injection of propofol
Inject over 5 seconds
- Propofol 1000mg (10mg/mL = 100mL). Use two 50mL syringes. Label as **Syringe C: propofol and Syringe D: propofol**
For induction of coma, myocardial depression, respiratory depression, and vasoplegia
Warn the patient that there may be some discomfort on injection, and that the goal of lidocaine is to relieve this but some patients may still experience pain. Consider advising those who are present that after the injection is completed an assessment of awareness will be completed.
Inject each syringe continuously and promptly over 30 seconds
After completing the injections, check eyelash reflex and whether there is any response to verbal stimulus. If there is no response to stimuli then proceed to injection of rocuronium.
- Rocuronium 200mg (10mg/mL = 20mL). Use 20mL syringe. Label as **Syringe E: rocuronium**
For muscle paralysis

Consider advising those who are present that cardiac arrest can occur up to 20 minutes after respiratory arrest has occurred. In other words, the patient's heart may continue to beat for some time after the procedure is complete. Inject promptly over 5 seconds

Rocuronium should always be administered after propofol, even if respiratory and/or cardiac arrest has already occurred with propofol alone.

A minimum of time should elapse between the administration of midazolam, lidocaine and propofol, i.e. these should be administered in a short sequence.

Painful stimuli (e.g. sternal rub, trapezius squeeze, pressure on orbital bone or nailbed) should be avoided as these may cause distress to those who are present, and are likely unnecessary.

Should there be a response to stimuli, do not administer rocuronium. Instead, administer a further:

- o Midazolam 10mg (Syringe 1)
- o Propofol 1000mg (Syringes 3 and 4)

Then check for response to stimuli. If there is none, then administer rocuronium 200mg (Syringe 5)

- o Bupivacaine 0.5% plain (5mg/mL = 80 mL). Use 2x 50mL syringes. Label as **Syringe F and G: bupivacaine**
For inducing asystole
Inject continuously and promptly over 30 seconds per syringe

It is anticipated that all of the pre-filled syringes will be used for each patient. For whatever reason should this not be the case (e.g. patient changed their mind to proceed) ensure all unused pre-filled syringes are returned to the pharmacy department for proper tracking and disposal.

Step	Syringe Label	Drug	Rate of administration
1	Syringe A	Midazolam	Over 10 seconds
2	Syringe B	Lidocaine	Over 5 seconds
3	Syringe C	Propofol (1 of 2)	Over 30 seconds
4	Syringe D	Propofol (2 of 2)	Over 30 seconds
5	<i>confirm coma achieved</i>		
5b	<i>If still responding to stimuli, administer second set of midazolam and propofol from second kit</i>		
6	Syringe E	*Rocuronium	Over 5 seconds
7	Syringe F	Bupivacaine (1 of 2)	Over 30seconds
8	Syringe G	Bupivacaine (2 of 2)	Over 30 seconds

* Rocuronium should only be administered once coma is ascertained