



**Submission**

To the

**WA Parliament Joint Select Committee on End of Life Choices**

Inquiring into

**The need for laws in Western Australia to allow citizens to make informed decisions  
regarding their own end of life choices.**

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## Introduction

The University of Notre Dame Australia, through the combined expertise of health professionals, philosophers, bioethicists and legal practitioners, is pleased to respond to the request of the Joint Select Committee on End of Life Choices for submissions addressing its Terms of Reference. Given the relatively short time period for the preparation of submissions, we regard this submission as a preliminary response, and would welcome the opportunity to engage more deeply with the Committee over the coming months to assist in the significant and important work it is undertaking.

Dying and death are an inevitability for all. Likewise, pain and suffering, while not inevitable for all, are not new phenomena, and many have experienced and will continue to suffer and experience intense pain throughout their lives, and particularly so at the end of life. Such experiences are often traumatic and confronting, not only for the patient, but also for their loved ones. It is right and proper that a society reviews and considers the way in which it holistically supports those who are in pain and those who are dying, and this holistic review should include a) the type of health care provided and the access to it; b) the legal and regulatory framework and c) the spiritual and pastoral support services provided.

The review must also take place within an ethical context. How a society treats its most vulnerable is a key reflection of – and key element of – the good of the society itself.

Fully respecting the separation of “State” and “Religion”, the University of Notre Dame Australia is a University with a tradition that seeks to bring the substance and values of Catholic faith into open and creative engagement with deeper questions of individual and societal life. We believe that there is much within the Christian tradition and more specifically, the Catholic Moral tradition which can assist in guiding and informing societal decisions, particularly in relation to end of life issues. One fundamental belief within these traditions is the inherent dignity, uniqueness and sacredness of all human life – from conception through to natural death.

Before addressing the specific terms of reference in the inquiry, the following general points are made:

1. A good society takes all possible steps to support, protect and care for the most vulnerable people within that society. In the context of those suffering immense pain and/or dying, the primary focus should be on the provision of an excellent standard of care, support and relief. Unless and until a particular society has ensured that this is being provided, all other considerations (including changing the law to permit assisted dying) should be avoided.
2. In Australia today, choice and options regarding end of life already exist. Unfortunately, the general community has limited understanding of end of life/ palliative care and discussions around death and dying are often only approached in the last days or even hours of life (if not totally avoided). Before any changes to the law are considered, a concerted focus needs to be placed on raising awareness about

palliative care: about its capacity to give comprehensive symptom relief and improve a patient's quality of life during its final stages.

3. Any consideration of amending the law must be founded on the principle that the lives of all peoples are of equal value, deserving equal respect and all should be protected by the law. Changes, such as those which may permit Assisted Suicide and/or Physician Assisted Suicide (PAS), are inconsistent with this basic principle as they open up avenues in which the most vulnerable may be exploited.
4. Changes to the current law regarding End of Life Health Care directives which make them more accessible and useable should be considered and reviewed before any other legal changes are contemplated. Similarly, promotion and awareness of these should be priorities.
5. The goal of all health care, based on the Hippocratic principle of "first do no harm", is patient health. Any changes to the law which permit health care providers to be involved in 'assisted suicide' are completely inconsistent with this goal.
6. Catholic health care providers and individual health care practitioners (irrespective of their beliefs) will be seriously impacted by any change to the law which permits assisted suicide practices.

### **Responses to Terms of Reference**

***(a) Assess 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 when experiencing chronic and/or terminal illnesses, including the role of palliative care;***

The World Health Organisation states 'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'<sup>1</sup> The definition goes on to confirm that palliative care acknowledges dying as a normal process and intends to neither hasten nor postpone death. Therefore assisted suicide cannot be seen as part of palliative care practice under this definition.

Referral to Specialist Palliative Care Services does not mean that active treatment has to end. Palliative care teams often work in partnership with the patient and disease-specific specialists in order to optimise disease control, and therefore quality of life, as long as active intervention is appropriate and in keeping with the patient's wishes. Supporting patients and their families around the time of death is a part of this work, but patients may be known to the team for many months, or even years, prior to this time.

New options for symptom control are constantly under development. In recent years, new medications for pain relief and management of chemotherapy-induced nausea in particular have been successfully introduced. These alternatives to more traditional drugs are generally more effective, have fewer side effects and are easier for the patient to manage. In addition, the evidence base for palliative care interventions is growing rapidly, so that multidisciplinary management can be more confidently tailored to the patient's particular needs and preferences.

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<sup>1</sup> World Health Organisation "WHO definition of Palliative Care"  
<http://www.who.int/cancer/palliative/definition/en/> accessed 20.11.17.

Palliative care specialists work with patients to identify their needs and concerns, and to plan care in keeping with their preferences. In order to do this, full and frank discussion is needed by skilled professionals who are able to fully explore problems in a holistic sense, answer questions and deal with distress that may arise. Where a patient expresses a sense of hopelessness, or requests ‘an end to it all’, sensitive exploration, encouragement of open discussion, management of symptoms, mood disturbance, spiritual distress and practical difficulties, and the offer of ongoing support for the person and their family are usually able to result in the reintroduction of a sense of calm, meaning and worth for a person.

Part of good holistic care is to establish the patient’s wishes in relation to future treatment and care. These wishes may change, and should therefore be revisited at intervals. However, a well-informed and honest discussion can lead to a clear individualised plan for care, that may help to avoid unnecessary or inappropriate admissions to hospital and active treatment where this is not wanted or unlikely to be effective. Such discussions also increase the chance of the person dying in the place of their choice. Ideally these plans should be written down in an Advance Care Plan, Advance Health Directive or Goals of Care document, and the information communicated between professionals involved in the person’s care.

With regard to therapeutic communication, conversations can be led by the patient around goal directed care which respects their needs and wishes. Inappropriate invasive investigations and treatments may only increase the patient’s suffering – patients do have the right to refuse treatment, and many people are not aware of this. Good end of life care is “doing things with the patient and their family, not to them”. Good end of life care supports a better quality of life before death. Many aspects of palliative care defy common stereotypes; for instance, there are many people who come to palliative care and are later discharged and return home.<sup>2</sup>

#### *Access to specialist palliative care*

Access to specialist palliative care is currently dependent on GP or specialist referral. This requires someone to recognise or acknowledge a patient’s palliative care needs, yet specialist palliative care teams are those people best placed to define these needs in conjunction with the patient. This is particularly true for patients with non-malignant disease, where there is evidence of equivalent need to patients with cancer, yet these patients often form a very small proportion of the workload of specialist palliative care teams. People with dementia, for whom the disease trajectory is such that the dying phase may be prolonged, and for whom care needs are often complex, with carers becoming tired and failing to cope, are representative of this group. Barriers to referral mean that patients are often referred late, or not at all.

In addition, people living in aged care facilities and rural areas have limited access to specialist services, and those with English as a second language may also find challenges in accessing appropriate care and support. Services are not designed or funded to cope adequately with the particular needs of these groups. There are also opportunities to improve the education of health professionals located in rural and remote areas to respond better to end of life care. This

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<sup>2</sup> Catholic Health Australia “Consultation on End-of-Life Care in Victoria on behalf of Catholic Health Australia”, *Inquiry Into End of Life Choices* (2016) 4, Submission 937.

could be done with staff having access to consultations with multidisciplinary teams utilising the WA telehealth network.

It is not only access to specialist palliative care that can be a challenge. Accessing adequate support at home is also difficult, in both metropolitan and rural areas but especially the latter. Carers frequently request respite, which is not readily available in the home, particularly night sits where the patient has disturbed nights, as lack of sleep contributes to carer burnout and results in unnecessary admissions to hospital. Additional provision and support to carers needs to be addressed.

It is worth noting within this context that Physician Assisted Suicide can have a substantial adverse emotional impact on doctors.<sup>3</sup> Doctors usually enter careers in medicine with an intent to bring about healing, and build relationships with patients based on trust. PAS alters that dynamic and may fundamentally change the way the doctor views himself/herself. In addition, doctors may feel powerless, shocked, isolated, pressured and intimidated in situations where they are asked to contribute to the process. Palliative care doctors have been shown to be the least likely to be in favour of PAS, whilst support for PAS is highest among those who are less experienced and more anxious when dealing with patients approaching death.<sup>4</sup>

***(b) Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions***

Suicide is not illegal in Australia, nor is the refusal of treatment. Whilst there is no criminal liability for committing suicide in WA, there is a legal prohibition against assisting suicide contained in section 288 of WA's *Criminal Code*.<sup>5</sup>

Voluntary euthanasia (assisted suicide) is not currently legal in any Australian jurisdiction, although there is currently a bill before the Victorian Parliament.

Legislation allowing for voluntary euthanasia has been passed in Belgium, Luxembourg, the Netherlands and Canada. It is illegal in New Zealand, most of the United States,<sup>6</sup> Norway, Ireland, the United Kingdom, France, India, Israel, Italy, Russia and Spain.

Once legalised, euthanasia accounts for an increasing number of deaths within a society. The increase occurs at a rapid rate. This may be demonstrated by examining the official statistics. The statistics below encompass both euthanasia (where another person performs the act causing death)<sup>7</sup> and assisted dying (where the person who dies performs the act)<sup>8</sup>:

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<sup>3</sup> Portenoy R, Coyle N, Kash K, et al 'Determinants of the willingness to endorse assisted suicide: a survey of physicians, nurses and social workers', *Psychosomatics* (1997) Vol 38, pp.277-287. Stevens KR Jr, 'Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians', *Issues Law Med*, (2006) Vol. 21, No. 3, pp.187-200.

<sup>4</sup> Portenoy 1997, 287.

<sup>5</sup> s288, *Criminal Code 1913* (WA) (the *Code*).

<sup>6</sup> The exceptions being Washington DC, California, Colorado, Oregon, Vermont, and Washington

<sup>7</sup> For example, by giving a lethal injection.

<sup>8</sup> For example, by taking an overdose of drugs given by a doctor to cause death.

- **Belgium** - euthanasia rates increased annually<sup>9</sup> and by 19.6 per cent over 12 years.<sup>10</sup>
- **Switzerland** – an increase of 19.2% over 16 years.<sup>11</sup>
- **The Netherlands** – an increase of 13.1 per cent over 7 years.<sup>12</sup>
- **Oregon** – an increase of 13.2% over 17 years.<sup>13</sup>
- **Washington State** – an increase of 21.6% over 6 years.<sup>14</sup>

Research and news reports analyzing jurisdictions which have legal euthanasia indicate there are a number of potential reasons for the increase, some of which are disturbing and must be thoroughly reviewed and considered in the context of this Review. These include the following:

- (1) There are reports that some people feel *compelled* to resort to euthanasia, when available, rather than be a burden on society. Where an earlier death is an option, euthanasia candidates can easily be made to feel selfish for choosing to die naturally. Similarly, it has been asserted that some feel compelled to resort to euthanasia out of fear because of an absence of effective pain relief.<sup>15</sup>

Holland provides an important case study for both of these points. It was the first country to legalise voluntary euthanasia. Now, the architect of the legislation has expressed regret at having pushed it through because of its adverse impact on services for the elderly.<sup>16</sup> Dr Els Borst, the former Health Minister and Deputy Prime Minister, regretted the resulting deterioration of medical care for the terminally ill, and said more should have been done to protect those wanting to die naturally.<sup>17</sup>

In contrast to the growing options around palliative care in Australian jurisdictions and globally, it was reported in 2009 that Amsterdam (with a population of 1.2 million) was serviced by a mere two hospices, and that the pro-euthanasia movement was seeking to close both of these.<sup>18</sup> If accurate, in so far as this reflects societal attitudes and public policy, it is not surprising if a person with a terminal illness would consider that they are viewed as a burden on resources, who are failing in their

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<sup>9</sup> Calculated as a compound annual growth rate.

<sup>10</sup> Between 2003 and 2015. Data compiled from the official statistics of the Federal Control and Evaluation Commission, which are reported to the Belgian legislature, cited in Legal and Social Issues Committee, Legislative Council of Victoria, *Inquiry Into End of Life Choices* (2016) 360.

<sup>11</sup> Between 1998 and 2014. Data derived from a number of sources, cited in Legislative Council of Victoria, *Inquiry Into End of Life Choices* (2016) 361.

<sup>12</sup> Between 2008 (2331 deaths) and 2015 (5516 deaths). Data sourced from the Dutch Regional Euthanasia Review Committees, cited in Legislative Council of Victoria, *Inquiry Into End of Life Choices* (2016) 360.

<sup>13</sup> Data sourced from the Oregon State Health Authority, Death With Dignity Act, Annual Report 2014, cited in Legislative Council of Victoria, *Inquiry Into End of Life Choices* (2016) 361.

<sup>14</sup> Washington State Department of Health, Death with Dignity Act Report, 2014, cited in Legislative Council of Victoria, *Inquiry Into End of Life Choices* (2016) 361.

<sup>15</sup> *Ibid.*

<sup>16</sup> Simon Caldwell, 'Now the Dutch turn against legalised mercy killing', *Mail Online* (9 December 2009) <http://www.dailymail.co.uk/news/article-1234295/Now-Dutch-turn-legalised-mercy-killing.html>

<sup>17</sup> *Ibid.*

<sup>18</sup> *Ibid.*

duty to end their lives early. It would not be surprising if they came to the view that they are a burden on society. There is a real risk that people who do not have a terminal illness but are otherwise vulnerable, may be encouraged to feel the same way.

- (2) Euthanasia laws may be quite narrow when introduced, but are often later broadened, causing an increase in the number of deaths by euthanasia.

The above points may be illustrated by examining The Netherlands (the first country to legalise voluntary euthanasia in 2002) and Belgium (which legalised it in the same year).

In 2014 Belgium became the first country in the world to abolish age restrictions on active euthanasia, altering its laws to allow children with capacity of any age to be euthanised.<sup>19</sup>

In the Netherlands, children over 12 may be euthanised with their parents' consent, but parental consent is not required after they turn 16.<sup>20</sup> Since 2005, the Groningen Protocol<sup>21</sup> in the Netherlands has legalised the active euthanizing of infants with poor prognosis.<sup>22</sup> This has attracted strong criticism, including from the Catholic Church.<sup>23</sup>

Such amendments to the law broaden the scope of euthanasia beyond what may have been envisaged initially.

- (3) There are examples cited in various reports and news articles which indicate that legalising euthanasia also makes death an attractive option for people at low points in their lives, and may remove the incentive for them to look for broader solutions to the problem at hand. Examples include:
- A 64-year-old Dutch woman euthanised in 2012 because of her depression;<sup>24</sup>
  - Identical twins in Belgium euthanised in 2013 at the age of 43 after discovering they had a genetic condition leading to loss of sight;<sup>25</sup>

<sup>19</sup> Barbara Miller, 'Euthanasia law: Belgium passes legislation giving terminally ill children right to die', *ABC News* (online), 14 Feb 2014 <http://www.abc.net.au/news/2014-02-14/belgium-child-euthanasia-law/5259314>

<sup>20</sup> 'Belgium Minor First to be Granted Euthanasia', *BBC News – Europe* (online), 17 September 2016 <http://www.bbc.com/news/world-europe-37395286>

<sup>21</sup> *Groningen Protocol* (19 March 2017) Wikipedia [https://en.wikipedia.org/wiki/Groningen\\_Protocol](https://en.wikipedia.org/wiki/Groningen_Protocol)

<sup>22</sup> For example, those with severe spina bifida. See Eduard Verhagen and Pieter J.J. Sauer, 'The Groningen Protocol — Euthanasia in Severely Ill Newborns', *The New England Journal of Medicine* (online), 10 March 2005 <http://www.nejm.org/doi/full/10.1056/NEJMp058026#t=article>

<sup>23</sup> Monsignor Elio Sgreccia, *Legalizing euthanasia for children in the Netherlands*, Pontifical Academy for Life [http://www.vatican.va/roman\\_curia/pontifical\\_academies/acdlife/documents/rc\\_pont-acd\\_life\\_doc\\_20040903\\_euthanasia-netherlands\\_en.html](http://www.vatican.va/roman_curia/pontifical_academies/acdlife/documents/rc_pont-acd_life_doc_20040903_euthanasia-netherlands_en.html)

<sup>24</sup> Peter Comensoli, 'Growing euthanasia statistics should be a warning', *The Sydney Morning Herald*, 19 April 2016 <http://www.smh.com.au/comment/growing-euthanasia-statistics-should-be-a-warning-20160419-go9rr8.html>

<sup>25</sup> Ibid.

- An 85-year-old Belgian woman euthanised because she could not cope with the loss of her daughter; and<sup>26</sup>
- A transgender person euthanised in Belgium because of dissatisfaction with his gender re-assignment surgery.<sup>27</sup>

If such individuals were offered better support, rather than death, they may have found themselves able to cope with their challenges; euthanasia is a decision taken at one point in time which is irreversible. The seriously ill, elderly, disabled, those with low self-esteem and those at a low place in their lives are particularly vulnerable. These are the people a civilized, developed society should be seeking to protect, rather than dispose of by lethal injection. As noted by Catholic Social Services Victoria:

*“person-centred support and therapy, especially when provided by professionals working in partnership – social workers, medical practitioners, psychologists and so on – can lead to healing and a regaining of the desire to live as fully as possible.”*<sup>28</sup>

A further issue which has arisen in jurisdictions which have legalized euthanasia is that of **consent**. A report published in the *Canadian Medical Association Journal*<sup>29</sup> alleged that one third of euthanasia cases in Flanders, Belgium are without explicit consent.<sup>30</sup> In a five month period,<sup>31</sup> out of 208 reported Flemish deaths involving ‘life-ending drugs,’ 142 were euthanised with ‘an explicit patient request,’ and 66 ‘were without an explicit request.’<sup>32</sup> The authors note that the majority of the cases where consent was not provided were in ‘vulnerable’ patient groups.<sup>33</sup>

There is also the risk that the appropriate **level of reporting** is not being undertaken where euthanasia has been legalized. The *British Medical Journal* has claimed that only half the euthanasia cases in Flanders are reported as legally required.<sup>34</sup> This makes monitoring of the actual euthanasia rates extremely difficult.

What is extremely concerning is the combination of a high rate of euthanasia cases *without* consent, combined with the lack of reporting. It makes the practice of euthanasia much more

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<sup>26</sup> Ibid.

<sup>27</sup> Damien Gayle, ‘Transsexual, 44, elects to die by euthanasia after botched sex-change operation turned him into a ‘monster’’, *Daily Mail* (Australia), 2 October 2013 <http://www.dailymail.co.uk/news/article-2440086/Belgian-transsexual-Nathan-Verhelst-44-elects-die-euthanasia-botched-sex-change-operation.html>

<sup>28</sup> Catholic Social Services Victoria “Submission to 2015 Inquiry into End of Life Choices”, *Inquiry Into End of Life Choices* (2016), Submission 900.

<sup>29</sup> Kenneth Chambaere et al, ‘Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey’ (2010) 182(9) *Canadian Medical Association Journal* <http://www.cmaj.ca/content/182/9/895.full.pdf+html>

<sup>30</sup> Ibid.

<sup>31</sup> Between June and November 2007

<sup>32</sup> Kenneth Chambaere et al, ‘Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey’ (2010) 182(9) *Canadian Medical Association Journal* <http://www.cmaj.ca/content/182/9/895.full.pdf+html>

<sup>33</sup> Ibid.

<sup>34</sup> Tinne Smets et al, ‘Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases’ (2010) 341 *British Medical Journal* <http://www.bmj.com/content/341/bmj.c5174>

difficult to safeguard, and abuses harder to track. It erodes critical and fundamental protections which should be afforded to all members of society.

*Summary*

It is submitted that any change to the law in Western Australia regarding end of life choices should only be further considered if there is conclusive and uncontroverted evidence that (a) the dignity, value and equality of *every* person's life which our society and law must uphold will not be eroded and (b) the most vulnerable in our society will be completely free from abuse and exploitation (whether expressly or by implication). While it is acknowledged that there is considerable debate and contrary research emanating from jurisdictions in which euthanasia has been legalized, and that there are undoubtedly speculative statements and conclusions made by people on all sides of the issue, it is submitted that the evidence from other jurisdictions clearly demonstrates that question marks remain and that *no such guarantees* can be provided. Indeed, it is arguable that the ability of people to make *informed and truly voluntary* decisions regarding their own end of life choices has been *significantly eroded* by the legalisation of euthanasia in Belgium and the Netherlands.

**(c) Consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation**

**(d) Examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and the implications for individuals covered by these instruments in any proposed legislation.**

As it is the premise of this submission that the law should not be changed to permit assisted suicide, neither questions (c) nor (d) will be specifically addressed. However, the following general comments are made in this context:

- There is no requirement in Western Australia to register an *Enduring Power of Attorney*, an *Enduring Power of Guardianship* or an *Advanced Health Directive*. Proving the authenticity of these documents is therefore problematic, particularly if the witnesses are no longer available or they were executed some time ago or if family members or general practitioners of the maker were not aware of their existence. These difficulties often increase the grief, stress and trauma experienced by a patient's loved ones and it is recommended that consideration be given to comprehensively addressing this issue as a priority (such as through the establishment on an online Registry).
- The *Elder Abuse—A National Legal Response* report was published by the Australian Law Reform Commission in June this year.<sup>35</sup> One of the significant issues identified in the Report is the inconsistency in form and to some degree substance in State and Territory legislation regarding Enduring Powers. Again, this inconsistency can increase the grief, stress and trauma experienced by a patient's loved ones and it is

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<sup>35</sup> Australian Law Reform Commission "Elder Abuse – A National Legal Response" (2017) (ALRC Report 131), <https://www.alrc.gov.au/publications/elder-abuse-report>, accessed 20/10/2017.

recommended that consideration be given to addressing this issue as a priority. Once again, there is merit in looking to the practices within the palliative care system; many providers focus specifically on providing high level support to caregivers, including family members. This includes information, and education as well as preparation for end-for-life scenarios.<sup>36</sup>

## **Conclusion**

As a fundamental principle there is no moral or legal right to kill or be killed. In an ageing society there is a need to have a broad conversation around how we support people who are often in difficult or vulnerable personal circumstances. Euthanasia provides an option which appears to be simple and straightforward but which in reality poses troubling questions about whether we value some lives more than others, about the nature of consent, and about how we frame policies which contribute to the common good in society.

There is another option which exists already, and which offers hope, empathy, and the opportunity for people to make informed choices at the end of their lives. This is the option of palliative care, and the services it is already able to offer. It is an option which more people need to be aware of.

It is also important for the committee to understand that potential legislative changes toward the legalization of physician assisted suicide pose significant challenges for religious freedom. A significant number of palliative care providers and health institutions are run by Non-Government Organisations, including many aligned to the Catholic Church. The values of many individual medical practitioners are also influenced by their faith. For many of these organisations and individuals the dignity of the human person and the inherent value of human life are central to their mission and practice. In the Catholic tradition, health care is undertaken in the context of a community; the death of an individual impacts on their family, friends, their care providers and other people they have had a relationship with.

### **It is our submission that:**

- 1. There is a clear need to focus on the options palliative care offers currently and the potential it has to offer further alternatives in the future, especially with regard to pain relief and support services.**
- 2. While the laws regarding enduring powers should be clarified, physician assisted suicide or assisted suicide should not be legalised in Western Australia.**

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<sup>36</sup> Catholic Health Australia “Consultation on End-of-Life Care in Victoria on behalf of Catholic Health Australia”, *Inquiry Into End of Life Choices* (2016) 5, Submission 937.