Submission 694



Submission to the Legal and Social Issues Committee on the Inquiry into End of Life Choices

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Introduction

The Australian Christian Lobby (ACL) welcomes this opportunity to make a submission to the Victorian Legal and Social Issues Committee Inquiry into End of Life Choices.

People requiring medical treatment and care who are approaching the end of their life are often some of the most vulnerable members of society. It is essential that those nearing the end of their life are treated in a way that is consistent with the dignity of their humanity. Medical and palliative care should reflect a concern for a patient's dignity by ensuring that good health practice is carried out in any decisions that will affect them. Good public policy should ensure that our legal framework and public health resources are directed towards the good of the patient. Public health policy should reject any health care solutions that seek to intentionally end a patient's life or alternatively, deny a healthcare professional the flexibility to provide good and sound medical care.

In addressing the question of **euthanasia**, ACL acknowledges that there are many people with chronic terminal illness or disability who are facing the end of their life and feel that their suffering is unbearable. A compassionate response to such suffering must ensure that under no circumstance euthanasia is presented as a solution. The legalisation of euthanasia transmits the message that some lives are not worth living. To legalise euthanasia, even on compassionate grounds, allows individuals and society to make subjective judgements about a person's worth based on their 'quality of life'. Legalisation of assisted killing tacitly encourages patients to seek death as a way out when the only sound approach is to affirm their worth and care for them as valued members of society. A truly compassionate society will provide care and support to those in need, rather than seek to end their life. Although many advocates for euthanasia are motivated by compassion, euthanasia and assisted suicide are not 'medical options' but are in fact contrary to the spirit of health care to 'do no harm'.

Palliative care is the compassionate response to those who are approaching the end of their life and need the care and management of health care professionals. Appropriate palliative care allows those with a chronic terminal illness or disability to access pain relief and management with dignity. Nobody dealing with intense suffering and illness should be abandoned by society to cope with this struggle alone, without appropriate care and relief. There is a growing demand and awareness of palliative care that is placing increased pressure on existing services. As the population ages, further funding and investment by the Victorian Government is essential to address the needs of Victorian residents. ACL looks forward to the Victorian Government providing further support and funding to this vital area of health care. This should be a priority of the Victorian Government so as to ensure that those nearing the end of their life are treated with compassion.

Advance Care Directives have been the subject of increased attention in recent years and are but one element of advanced care planning. They can be useful towards assisting family members, decision makers and medical teams to make decisions that are consistent with the wishes of the patient. Recent research shows, however, that written directives taken by themselves are not always sufficient to ensure that patient choices about future medical treatment and care are respected.²

¹ Victorian Auditor-General's Report 'Palliative Care' April 2015 2014–15-26 Page 17.

² Cairney H, et al. 'Can community dwelling older adults complete a person based Advance Care Directive to provide useful information to substitute decision makers?' Research Results *Alfred Health*.

Good advanced care planning requires a much broader approach towards respecting patient choices. ACL is concerned by the publicly stated plans of the Labor Government in Victoria to make Advanced Care Directives legislatively binding.³ ACL opposes this approach and will explore these concerns in this submission.

Euthanasia

Legalising euthanasia puts at risk the lives of the most vulnerable members of society – the elderly, the lonely, the sick and the depressed.

ACL acknowledges that there are many who feel that their suffering is unbearable. The debate around end-of-life care and euthanasia is highly emotive, and there are people of good intent and compassion on both sides. Nevertheless, the right response to those suffering is to alleviate their pain through appropriate medical care and emotional support. To do so communicates that every life is worth caring for until natural death. The role of the medical profession does not include hastening death on request.

A system of legal euthanasia alters the relationship between the state and its most vulnerable members. It relinquishes the responsibility of the state to protect all lives equally. It also undermines the fundamental relationship of trust between doctor and patient, one of the most important relationships in society.

There is no way to ensure that all cases of euthanasia are truly voluntary. There is sufficient evidence to suggest that involuntary euthanasia is frequent in jurisdictions in which euthanasia has been legalised. Safeguards cannot be made adequate.

The swift termination of life is not the solution to suffering. On the contrary, the compassionate answer is to recognise a person's inherent dignity regardless of their physical capacity or their mental abilities or health, and to strive to provide the best possible care for those with disabilities or at the end of their lives.

Defining euthanasia

It is important to use clear definitions when discussing euthanasia. Often the word "euthanasia" is avoided by using terms such as "dying with dignity medical service". This is a cumbersome phrase, and an attempt to avoid using the controversial language of euthanasia. At other times, proeuthanasia advocates use the term "dignity" to add an illusion of compassion and divert attention away from the reality, while also ignoring that dignity is preserved by proper care for a dying patient.

ACL opposes *active euthanasia*. Active euthanasia is defined by the Australian Medical Association (AMA) as:

³ Farrah Tomazin, 'Victorians to get a greater say in dying with dignity under Labor reforms', *The Age* (Melbourne), 16 November 2014, http://www.viclabor.com.au/wp-content/uploads/2014/1115-11nelp.html, and Victorian Labor Platform 2014 http://www.viclabor.com.au/wp-content/uploads/2014/05/Victorian-Labor-Platform-2014.pdf page 38-39.

giving a patient a treatment or action that **directly** and **deliberately** results in their death.⁴

This does not include medical practices used in end-of-life care that may hasten death. Such practices are sometimes mistakenly referred to as euthanasia, or may be referred to as *passive euthanasia*. ACL agrees with the AMA's statement:

The AMA believes... that if a medical practitioner acts in accordance with good medical practice, the following forms of management at the end of life **do not** constitute euthanasia or physician assisted suicide:

- not initiating life-prolonging measures;
- not continuing life-prolonging measures;
- the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death.⁵

This is an important distinction. Medical practice at the end of life will often focus on managing and relieving pain in order to increase comfort, rather than on prolonging life. This is consistent with upholding the inherent dignity of a human being and flows from a desire to provide compassionate care. It is also quite different to taking measures which *directly* and *deliberately* result in death.

Withholding or withdrawing futile treatment or administering pain relief that may have the secondary but unintended effect of shortening a person's life is not illegal or unethical if the doctor does so on the basis of good medical practice and has regard to the patient's best interest.

The Tasmanian Community Development Committee report, on the Need for Legislation on Voluntary Euthanasia, drew attention to the submission of Dr John Fleming, Director, Southern Cross Bioethics Institute, in order to provide a key insight into understanding this distinction. Dr Fleming's submission pointed out that 'intent' is the differentiating moral that delineates medical end-of-life decisions from euthanasia.

What is morally and legally relevant in medical decisions at the end of life is whether in withholding or withdrawing the treatment the physician intends to kill his patient, or whether his non-treatment decision is based on his best clinical judgement that that treatment would either be futile or burdensome disproportionately to benefit.⁶

Because of the public confusion about this distinction, which is no doubt reflected in public opinion polls, it is also important that it be made clear in public discussion. Current heath practice emphasises the dignity of the person, not only by providing care and relieving pain but also by refusing to present the intentional death of a patient as a solution to suffering. Further distinction between the terms 'euthanasia' and 'assisted suicide' can be a helpful exercise toward understanding the similarities and differences between the two types of intentional killing.

• Euthanasia is administered by a doctor to "directly and deliberately" result in death.

⁴ Australian Medical Association (2007), *Position Statement on the Role of the Medical Practitioner in End of Life Care*, p 2. Emphasis added.

⁵ Australian Medical Association (2007), *Position Statement on the Role of the Medical Practitioner in End of Life Care*, p 2. Emphasis in original.

⁶ Dr. John I. Fleming, Director, Southern Cross Bioethics Institute, submission 311, Tasmanian Community Development Committee (1998), *Report on the Need for Legislation on Voluntary Euthanasia*.

• Assisted suicide is performed by the patient himself with the assistance of another.

Assisted suicide is similar to euthanasia in that it is a deliberate and direct act which causes death. ACL is strongly opposed both to the legalisation of euthanasia and to the legalisation of assisted suicide.

Tasmanian inquiries into euthanasia

The Tasmanian Parliament held an inquiry into euthanasia in 1998. In its report, the Community Development Committee made several findings, including the following:

- whilst individual cases may present a strong case for reform the obligation of the state to
 protect the right to life of all individuals equally could not be delivered by legislation that is
 based on subjective principles;
- the codification of voluntary euthanasia legislation could not adequately provide the necessary safeguards against abuse; and,
- the legalisation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and that the obligation of the state to protect all its members equally outweighs the individual's freedom to choose voluntary euthanasia.⁷

More recently, Tasmania rejected the Greens' Dying with Dignity Bill 2009. A Parliamentary inquiry into this bill reiterated the Community Development Committee's concerns about inadequate safeguards.⁸

Euthanasia bills

Australian parliaments have repeatedly rejected attempts to legalise euthanasia. In addition to the 2009 bill, the Tasmanian Lower House voted 13-11 against the Voluntary Assisted Dying Bill 2013. Earlier in 2013, the NSW upper house also defeated, by 29 votes to 11, a euthanasia bill, the Rights of the Terminally III Bill 2013. Victorian upper house members voted 25-13 against a euthanasia bill in 2008. Western Australia voted 24-11 against a proposed euthanasia bill in 2010. In 2010, South Australia rejected its third euthanasia bill since 2003. Two more South Australian bills were introduced in 2013 and since lapsed.

It is significant that euthanasia has been repeatedly and consistently voted against in Australia.

⁷ Community Development Committee (1998), *Report on the Need for Legislation on Voluntary Euthanasia*, Parliament of Tasmania, p 6,

http://www.parliament.tas.gov.au/ctee/old_ctees/reports/Voluntary%20Euthanasia.pdf.

⁸ Joint Standing Committee on Community Development (2009), *Report on the Dying with Dignity Bill 2009*, Parliament of Tasmania, p 6,

 $[\]underline{http://www.parliament.tas.gov.au/ctee/REPORTS/Dying\%20with\%20Dignity\%20Final\%20Report.pdf.}$

⁹ Tasmania, *Parliamentary Debates*, House of Assembly, 17 October 2013.

 $^{^{\}rm 10}$ New South Wales, $\it Parliamentary \, \it Debates$, Legislative Council, 25 March 2013, 20784.

¹¹ David Rood (September 11, 2008), 'State MPs vote down euthanasia bill', *The Age*, http://www.theage.com.au/national/state-mps-vote-down-euthanasia-bill-20080910-4duu.html.

¹² ABC (September 23, 2010), 'Chapple's voluntary euthanasia bill defeated', *ABC*,

http://www.abc.net.au/news/2010-09-23/chapples-voluntary-euthanasia-bill-defeated/2270956.

13 ABC (November 26, 2010), 'Another euthanasia bill rejected in SA', ABC, http://www.abc.net.au/news/2010-11-25/another-euthanasia-bill-rejected-in-sa/2350152?section=justin.

It is also significant that very few countries in the world allow euthanasia. Currently only the Netherlands, Belgium, and Luxembourg have legislation permitting euthanasia.

The limited extent of legalised euthanasia is not surprising. The United Nations has expressed serious concern about the situation in the Netherlands, ¹⁴ meanwhile, as recently as 2012, the Council of Europe stated:

Euthanasia, in the sense of the intentional killing by act or omission of a dependent human being for his or her alleged benefit, **must always be prohibited**. ¹⁵

Can safeguards protect against abuse?

One of the main concerns about euthanasia is the inability to ensure adequate safeguards. No euthanasia law can provide adequate protection for the vulnerable.

The UK Select Committee on Medical Ethics report in 2005 cited an earlier report by the same Committee:

'it would be next to impossible to ensure that all acts of euthanasia were truly voluntary...'
[there is] also concern that 'vulnerable people – the elderly, lonely, sick or distressed – would feel pressure, whether real or imagined, to request early death'. ¹⁶

The 2005 report then discussed "a number of developments" since its earlier 1993/94 report. This included the enactment of euthanasia legislation in other jurisdictions, as well as the citation of opinion polls. ¹⁷ ACL submits that opinion polls are irrelevant to whether the statement in the 1993/94 report stands true. Opinion polls are no basis for public policy, particularly in life-and-death matters of this magnitude.

Likewise, the legalisation of euthanasia in other jurisdictions is not an argument to legalise it in our own. It can, however, offer insight into the effects of legalised euthanasia. As shown below, this strengthens the case against euthanasia, showing that safeguards cannot be made adequate.

Another development cited in the report is that the "ability of medicine as a whole to defeat life-threatening illnesses and of specialist palliative care to relieve the suffering of terminal illnesses has continued to improve". This is a strong argument against euthanasia. If life-threatening illnesses can be defeated, and suffering can be relieved, there is little validity in the arguments that euthanasia is necessary to defeat suffering and life-threatening illnesses.

ACL submits that the Select Committee's statement remains valid today.

¹⁴ Concluding Observations on the Netherlands (2001) Un doc. CCPR/CO/72/NET, para 5(b), http://www.unhchr.ch/tbs/doc.nsf/0/dbab71d01e02db11c1256a950041d732.

¹⁵ Council of Europe Parliamentary Assembly (January 25, 2012), 'Protecting human rights and dignity by taking into account previously expressed wishes of patients', [5], http://assembly.coe.int/Main.asp?link=/Documents/AdoptedText/ta12/ERES1859.htm#P16 146. Emphasis added.

¹⁶ Select Committee on Assisted Dying for the Terminally III Bill (2005), *First Report*, [2], http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8604.htm.

¹⁷ Select Committee on Assisted Dying for the Terminally III Bill (2005), *First Report*, [3], http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8604.htm.

¹⁸ Select Committee on Assisted Dying for the Terminally III Bill (2005), *First Report*, [3], http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8604.htm.

The inadequacy of safeguards is demonstrated by data from Belgium and the Netherlands.

Belgium

Euthanasia is legal in Belgium. One study of the Flanders region of Belgium found that nearly 32% of euthanasia deaths had occurred without explicit request or consent. ¹⁹ Although this has decreased, the prevalence of unrequested euthanasia deaths shows that the safeguards are not working as intended.

Another study in Belgium found that only 52.8% of euthanasia deaths were reported to the authorities. ²⁰ The study notes that reported cases are dealt with "carefully and in compliance with the law", but "concerns exist that only cases of euthanasia that are dealt with carefully are being reported. Whether cases that are not reported to the official review system are dealt with equally carefully is uncertain". ²¹

Nurses as well as doctors are often involved in euthanasia. One study found that in 12% of euthanasia deaths, the life-ending drugs had been given by nurses, despite Belgian law prohibiting this.²² This same study's interpretation of the findings was that:

By administering the life-ending drugs in some of the cases of euthanasia, and in almost half of the cases without an explicit request from the patient, the nurses in our study operated beyond the legal margins of their profession.²³

As recently as 12 June 2015, news broke of a study that showed that Belgian GPs have been killing patients who have not asked to die. ²⁴ The study found that "one in every 60 deaths of a patient under GP care involves someone who has not requested euthanasia." ²⁵

The Netherlands

A 2012 report found an estimated 23% of euthanasia deaths in the Netherlands are still not reported, after 8 years of legal euthanasia. ²⁶ The report also states that ending of life "without an

¹⁹ Chambaere, Bilsen, Cohen, Onwuteaka-Philipsen, Mortier, Deliens (May 17, 2010), 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey', *Canadian Medical Association Journal*, p 2, http://www.cmaj.ca/content/early/2010/05/17/cmaj.091876.full.pdf.

²⁰ Smets, Bilsen, Cohen, Rurp, Mortier, Deliens (2010), 'Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases', *British Medical Journal*, p 1, http://www.ncbi.nlm.nih.gov/pmc/articles/pmc2950259/pdf/bmj.c5174.pdf.

²¹ Smets et al (2010), 'Reporting of euthanasia in medical practice in Flanders, Belgium", p 1.

²² Inghelbrecht, Bilsen, Mortier, Deliens (2010), 'The role of nurses in physician-assisted deaths in Belgium', *Canadian Medical Association Journal*, p 905, http://www.cmaj.ca/content/182/9/905.full.pdf.

²³ Inghelbrecht, Bilsen, Mortier, Deliens (2010), 'The role of nurses in physician-assisted deaths in Belgium', *Canadian Medical Association Journal*, page 1

²⁴ Steve Doughty, 'Belgian GPs 'killing patients who have not asked to die': Report says thousands have been killed despite not asking their doctor' Daily Mail (Australia) 12/06/2015, http://www.dailymail.co.uk/news/article-3120835/Belgian-GPs-killing-patients-not-asked-die-Report-says-

thousands-killed-despite-not-asking-doctor.html>
²⁵ Paper: First do no harm: intentionally shortening lives of patients without their explicit request in Belgium J Med Ethics medethics-2014-102387Published Online First: 3 June 2015
http://jme.bmj.com/content/early/2015/06/03/medethics-2014-102387.abstract

²⁶ Bregje D Onwuteaka-Philipsen, Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen JF de John-Krul, Johannes J M van Delden, Agnes van der Heidi (July 11, 2012), *The Lancet*, 'Trends in end-of-life practices

explicit request of the patient had decreased, albeit not significantly" – 0.7% of all deaths in 2001, 0.4% in 2005, and 0.2% in 2010.

A survey of GPs in 2011 found that nearly half had "felt pressured by patients or their relatives" to use euthanasia. 20% said they were willing to euthanise a patient who is merely "tired of life", despite the law requiring unbearable pain as a condition for euthanasia. ²⁷

Oregon

Oregon legalised physician assisted suicide in 1997. Patients reported the concern of being a burden to family and friends in 57% of cases in 2012, up from 42% in 2011. ²⁸ This figure has varied from year to year but has not been lower than 24%, in 2001, except in 1998 when it was first reported, at 12%. Although not all of these cases involve a euthanasia request primarily due to this concern, it does reveal an alarming aspect of legalised euthanasia. Where euthanasia is a legal option, people who already feel like they are a burden on family and friends will inevitably feel that added pressure to opt for life-ending treatment.

The Northern Territory

Australia's failed experiment with euthanasia in 1998 found the safeguards to be entirely ineffectual. As Professor Robert Goldney of the University of Adelaide said:

[E]ven with ostensibly strict guidelines embodying most issues considered by proponents of euthanasia to be important, as a result of the clinical details provided there exist reservations about what occurred with two of the four persons who died under the Northern Territory legislation. This is hardly a reassuring record for examples of euthanasia.²⁹

The slippery slope - the gradual relaxing of strict conditions

The Belgium-based European Institute of Bioethics released a report after ten years of euthanasia in Belgium. They commented:

Initially legalized under very strict conditions, euthanasia has gradually become a very normal and even ordinary act to which patients are deemed "to have a right"... ³⁰

The Institute expressed concern about the "trivialization of euthanasia in Europe where, let us not forget, Belgium, the Netherlands and Luxembourg are the exception". ³¹

These concerns are well founded. Earlier this year Belgium passed laws to allow euthanasia for terminally ill children of any age. ³² Paediatricians in the Netherlands, where euthanasia is already

before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey', http://press.thelancet.com/netherlands_euthanasia.pdf, p 6.

²⁷ DutchNews.nl (29 July, 2011), 'One third of doctors have refused a euthanasia request', http://www.dutchnews.nl/news/archives/2011/07/one third of doctors have refu.php.

²⁸ See Hannah Graham and Jeremy Prichard (October 2013), 'Volunatry Euthanasia and 'Assisted Dying' in Tasmania: A Response to Giddings & McKim', http://www.bestcare.com.au/documents/reports/Voluntary-Euthanasia-and-Assisted-Dying-in-Tasmania-A-Response-to-Giddings-and-McKim-Oct2013.pdf, p 15.

Robert Goldney (2001), Euthanasia: The Australian experience, in D. De Leo, (Ed.) Suicide and Euthanasia in Older Adults: A Transcultural Journey, pp. 172-179.

³⁰ European Institute of Bioethics (April 2012), *Euthanasia in Belgium: 10 years on*, p 7, http://www.ieb-eib.org/fr/pdf/20121208-dossier-euthanasia-in-belgium-10-years.pdf.

European Institute of Bioethics, Euthanasia in Belgium, p 8.

legal for children from the age of 12,³³ and which already allows euthanasia for children under one under the Groningen protocol,³⁴ are now also pushing for allowing euthanasia for children of any age.³⁵

Another example of the trivialisation or normalisation of euthanasia is the case of the Belgian Verbessem twins, Marc and Eddy. ³⁶ The twins, born deaf, were 45 years old when they were euthanised, having been told they would also go blind. It took them two years to find a doctor willing to perform euthanasia, not surprising as neither was terminally ill or in physical pain. Under Belgian law, a doctor must judge that a patient is suffering unbearable pain before euthanasia can be performed.

Recently a new scheme called "Life End" was launched, sending "mobile euthanasia units" around the country to euthanise patients whose own doctors refuse to do so. ³⁷

Psychiatric patients are also being euthanised in the Netherlands. Thirteen psychiatric patients were euthanised in 2011, while a further 49 patients in the early stages of dementia were euthanised.³⁸

Some major concerns with euthanasia

Elder abuse

One serious concern about euthanasia is that it may create an environment in which the elderly are vulnerable to abuse. This abuse could be in the form of pressure, real or imagined, to die when an elderly person feels he has become a burden on his loved ones. It could also be in the more direct form of the elderly being taken advantage of, euthanised without requesting it, and even having euthanasia authorised by carers who no longer want to give the time or the effort or the money to caring for their elderly patients. In extreme cases, relatives who stand to gain through inheritance, or those seeking vengeance, could take advantage of the laws.

Although these latter cases may be rare, it is inevitable that legalising euthanasia will create a culture which accepts that some people will end their lives when their "quality of life" has decreased to some subjective level of an individual's choosing. Even with supportive families, many elderly or disabled people will be aware of the "burden" they place on their loved ones, financially or emotionally. The figures from Oregon, cited above, are evidence of this being a consideration for

³² Robert-Jan Bartunek (February 14, 2014), *Sydney Morning Herald*, 'Belgium allows euthanasia for terminally ill children', http://www.smh.com.au/world/belgium-allows-euthanasia-for-terminally-ill-children-20140214-hvcb9.html.

³³ See Article 2, sections 2 and 3, of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*.

³⁴ Eduard Verhagen and Peter JJ Sauer (March 10, 2005), *The New England Journal of Medicine*, 'The Groningen Protocol – Euthanasia in Severely III Newborns', http://www.nejm.org/doi/full/10.1056/NEJMp058026.

³⁵ Anneke Stoffelen (July 7, 2014), *Volkskrant.nl*, 'Physicians 'Make euthanasia possible child up to 12 years'', http://www.volkskrant.nl/vk/nl/2672/Wetenschap-Gezondheid/article/detail/3684922/2014/07/07/Artsen-Maak-euthanasie-mogelijk-bij-kind-tot-12-jaar.dhtml (article in Dutch).

³⁶ See Bruno Waterfield (January 15, 2013), 'Euthanasia twins 'had nothing to live for'', *Sydney Morning Herald*, http://www.smh.com.au/world/euthanasia-twins-had-nothing-to-live-for-20130115-2cq9z.html.

³⁷ Kate Connolly (March 1, 2012), 'Dutch mobile euthanasia units to make house calls', *The Guardian*, http://www.guardian.co.uk/world/2012/mar/01/dutch-mobile-euthanasia-units.

³⁸ DutchNews (September 25, 2012), '13 psychiatric patients were helped to die last year', *DutchNews.nl*, http://www.dutchnews.nl/news/archives/2012/09/euthanasia case rise steeply.php.

many patients who "choose" euthanasia. The most supportive and loving family may still have their lives affected practically by their elderly relatives at the end of their lives. In an age when many people move away from their families, this stage has the potential to cause significant disruption and cost. Although most people may willingly bear this cost, most patients would be aware of the lengths their families go to through these times.

While in the immediate future this pressure may not be felt on the current older generation, future generations who are currently healthy, and often supportive of euthanasia, may feel this pressure acutely should they become infirm in their old age.

Even if most people withstand any perceived pressure, a culture accepting of a medical profession which will, at times, assist the death of its patients will inevitably create this pressure.

Furthermore, the strength to fight this pressure, even if it is imaginary, will be more difficult to those who are otherwise in physical pain or mental anguish.

A UK survey conducted in 2011 found that 70% of people with a disability would be concerned that legalising euthanasia would place pressure on other disabled people to "end their lives prematurely", while over a third feared they would face such pressure personally.³⁹

A compassionate society should leave its vulnerable members in no doubt that they are valued. Prohibition of euthanasia within the legal system sends a positive message to the elderly and the disabled that their lives matter.

Culture of death

Legitimising euthanasia within the law undermines the inherent dignity of human beings. It attempts to make value judgements about quality of life or standard of living. It says that these subjective measures can overrule the ancient ethical requirement of medical practitioners to protect life. It undermines the value of human worth. A compassionate and just society affirms the inherent worth of humans, and seeks to provide care for those who are suffering. It does not offer death as a solution to suffering.

Legalisation of euthanasia sends a powerfully negative and dangerous message to society: that some lives are worth more than others. Instead of valuing the intrinsic dignity of life, life becomes subjectively valued according to a personal "quality of life" standard.

Doctor-patient relationship

Over millennia of medicine, doctors have had a deep obligation to preserve life. Doctors taking the Hippocratic Oath were required to swear "I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect". The ethical obligation of doctors to preserve the life of their patients is fundamental to the doctor-patient relationship. The declaration of Geneva, currently recited by graduating Victorian medical practitioners contains the phrase "I will maintain the utmost respect for human life."

³⁹ ComRes (9 March 2011), *Scope NDPP Survey February-March 2011*, p 58, http://www.comres.co.uk/polls/DPP Assisted suicide tables March 2011.pdf.

Professor John Wyatt, a specialist in neonatal paediatrics, commented in the context of a proposed euthanasia law in the UK, that euthanasia would:

toss away, almost in a casual way, two thousand years of a tradition that doctors would only be dedicated to healing.⁴⁰

Euthanasia would erode this trust between doctors and patients, a fundamental pillar of medicine as well as a deeply important relationship in society.

Common arguments for euthanasia

Shouldn't people be allowed to die with dignity?

Yes. This argument does not favour legalising euthanasia. On the contrary, it supports giving more attention to palliative care at the end of life. Using this as an argument in favour of euthanasia makes the assumption that dignity is inseparable from physical capacity. Society should affirm that through disability, whether physical or mental, and through pain and suffering, humans maintain their inherent dignity.

Using this argument also implies that those who do not choose to "die with dignity" will therefore die without dignity. What does this then say about the experience and death of those who choose to live through suffering? Refusing to kill someone does not mean refusing to provide the best possible care, even if administering that care may result in hastening death as a secondary effect.

Shouldn't people have a choice?

This argument can be used to justify suicide and other harmful activities which society does not accept, such as using addictive drugs or self-mutilation. Society does not afford individuals complete or absolute autonomy. Choice is subject to other considerations, such as protection of the vulnerable and care for the elderly and the disabled.

The state has an obligation to protect all its members equally, which outweighs the claimed right to choose euthanasia. A parliamentary inquiry in Tasmania found:

the legalisation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and that the obligation of the state to protect all its members equally outweighs the individual's freedom to choose voluntary euthanasia.⁴¹

In addition to this, it is apparent that euthanasia will often not be truly "chosen" by those who receive it. Either it will be administered without a direct request, as occurs frequently in those jurisdictions in which euthanasia is legal, or it will be "chosen" in response to direct or indirect pressures.

⁴⁰ Care Not Killing (6 June, 2008), 'Specialists talk about the dangers of legalising assisted suicide', carenotkilling.org.uk, http://www.carenotkilling.org.uk/medical-opinion/doctors-speak-out/.

⁴¹ Parliament of Tasmania Community Development Committee (1998), *Report on The Need for Legislation on Voluntary Euthanasia (Report no 6)*, finding number 10, http://www.parliament.tas.gov.au/ctee/old ctees/euth.htm.

Palliative Care

The concept of "intolerable pain" is rarely experienced in practice if good palliative care is applied. In most cases, pain can be treated. For some patients this may mean sedation or it may mean administering pain relief which hastens death as a secondary effect. This is not euthanasia; this is good medical practice.

In cases in which physical pain is not the main reason for seeking euthanasia, the real issues should be addressed. Mental pain, whether in the form of depression, loneliness or other mental illness, are genuine problems in society that need to be addressed in the medical profession and in wider society. Society and its government should seek to help alleviate mental suffering. It should not regard mental suffering as a legitimate reason to commit suicide.

Tasmanian Enquiry

The Tasmanian enquiry into euthanasia gave positive focus to the importance of palliative care as the better alternative to addressing the suffering of terminally ill or disabled patients. The committee found that in the majority of cases palliative care was able to provide optimum care for suffering patients. Some key statements of the enquiry were:

The Committee recognises that in a small percentage of cases palliative care is ineffective in relieving all pain; however, whilst regrettable, this is not sufficient cause to legalise voluntary euthanasia.

The Committee found that there is a need for greater resources to expand and improve the quality of palliative care services.

There was a demonstrated need for increased education on several levels to improve the delivery and efficacy of palliative care.

- To provide for greater public awareness of the services available and their benefits;
- To familiarise general practitioners with the availability of specialist palliative care and encourage them to access it for their patients; and
- To provide greater palliative care training for health care workers in undergraduate and postgraduate settings.

The committee's findings in relation to palliative care are worth considering in the context of this enquiry.

The recent April 2015 Victorian Auditor-General's Report on Palliative Care provides considerable detail on the state of Palliative Care in Victoria and is sure to be helpful in framing some of the issues around future funding of Palliative Care in Victoria. ACL welcomes further increased investment in palliative care services across the state.

Advanced Care Directives

Reform agenda of Victorian Labor

Victorian Labor's policy position on Advanced Care Directives is included in the 2014 Victorian ALP Platform document, which states:

Labor will: ... Support the introduction of statutory recognition so competent Victorians can use an Advanced Healthcare Directive to refuse or request treatment for a future condition. These arrangements should be subject to appropriate checks and balances, including regular reviews⁴²

During the lead up to the 2014 election, this intention was given media coverage in The Age⁴³ and the Sydney Morning Herald. ⁴⁴ Presumably, such legislation would provide legal rights to patients with Advanced Care Directives and provide some kind of legal penalty or liability for health care professionals who fail to carry out the requests of the written documents. Presumably, it would also protect healthcare professionals from liability arising from carrying out an Advanced Care Directive. ⁴⁵

In principle, ACL welcomes increased support for patients to plan their end of life medical treatment and care through advanced care planning, however ACL has particular concerns with moves towards making Advanced Care Directives legislatively binding on health care professionals. A number of serious issues could potentially arise from this move, and need to be considered.

Problems with relying too heavily on written directives

Research into the success of advanced care planning models, and their effectiveness in ensuring that care is carried out according to patient choices, shows that Advanced Care Directives by themselves are not sufficient in ensuring that care outcomes are consistent with patient desires. Research conducted by Alfred Health, titled 'Can community-dwelling older adults complete a person based Advanced Care Directive to provide useful information to substitute decision makers?', compared two Advance Care Directives in order to establish whether they accurately reflected the wishes of the consumer and met the needs of all stakeholders involved in the Advance Care Planning process. ⁴⁶ The findings indicate that directives alone can guide decision making, however they aren't always enough in complex medical scenarios to ensure that an individual's choices are respected. ⁴⁷ As the uncertainty of the medical scenario increased the agreement between consumers and their substitute decision makers fell significantly (88%-42%). The same trend occurred between consumers and their doctors (90%-48%). A recommendation from the study was:

Individuals should be encouraged to have conversations with families and loved ones about their values and preferences for quality of life and supported by clinicians to have discussions

⁴² 2014 Victorian ALP Platform < http://www.viclabor.com.au/wp-content/uploads/2014/05/Victorian-Labor-Platform-2014.pdf> page 39.

⁴³ Farrah Tomazin, 'Victorians to get a greater say in dying with dignity under Labor reforms', *The Age* (Melbourne), 16 November 2014, http://www.theage.com.au/victoria/state-election-2010/victorians-to-get-a-greater-say-in-dying-with-dignity-under-labor-reforms-20141115-11nelp.html.

⁴⁴ Farrah Tomazin, 'Andrews to reform medical treatment laws, but won't back voluntary euthanasia' *Sydney Morning Herald (Sydney)*, 21 June 2015 < http://www.smh.com.au/it-pro/andrews-to-reform-medical-treatment-laws-but-wont-back-voluntary-euthanasia-20150620-ghsya4?skin=dumb-phone.

treatment-laws-but-wont-back-voluntary-euthanasia-20150620-ghsya4?skin=dumb-phone>.

45 AMA Press Release AMA Vic welcomes Labor's proposed changes to Medical Treatment Act 1988 (Vic) ,

https://amavic.com.au/page/News/AMA Vic welcomes Labor s proposed changes to Medical Treatmen
t Act 1988 Vic/>.

⁴⁶ Alfred Health 'Advanced Care Planning' Accessed 22 July 2015 http://www.alfredhealth.org.au/Page.aspx?ID=733#2.

⁴⁷ Cairney H, et al at above n 2.

around preferences for medical treatment. Both these discussions should be documented on a directive however the type of this directive is less relevant than the discussions.⁴⁸

The research document goes on to say:

The writing down of wishes is only one step in the advance care planning process. The conversation about these wishes is a fundamental part of the process. ⁴⁹

These results point to the need for a holistic approach to advanced care planning. Any move towards further regulation of written directives should be part of a holistic approach towards advanced care planning that not only includes patient choices but also includes good health care principles. ACL does not believe that making directives legislatively binding will assist towards that goal.

Burdensome or futile treatment

It is foreseeable that situations may arise where patients write legally binding advanced directives requesting treatment that is overly burdensome or futile. Decision makers and medical teams need the flexibility to discontinue treatment where it is contrary to good medical practice.

Defining artificial nutrition and hydration

One risk of making directives legally binding flows from the potential for some requests in advance directives to be in fact suicidal. This might occur if a directive refused everything, including food and water that would keep the patient alive. The legality of the withdrawal of artificial nutrition and hydration under Victorian Common Law was established in *Gardner; re BWV*. In that case, Justice Morris determined that the use of a PEG for artificial nutrition and hydration was a 'medical procedure', because it involves "protocols, skills and care which draw from, and depend upon, medical knowledge", and careful choice and preparation of materials to be introduced into the body, dosage rates, and measures to prevent infection and regular cleaning of conduits and thus it fell within the scope of the term found in the *Medical Treatment Act 1988* (Vic). By defining artificial nutrition and hydration as a 'medical procedure', rather than 'palliative care', it was held that the withdrawal of artificial nutrition and hydration, under the medical circumstances of that case, would not to amount to a criminal act.

Defining artificial nutrition and hydration as a 'medical procedure' is highly objectionable. The alternate and better policy position for defining the provision of nutrition and hydration, is that it is a "natural" means of care and not a medical procedure or treatment; this is the case even when it is provided by artificial means such as a naso-gastric or PEG tube. Accordingly, the presumption should always be in favour of the provision of artificial nutrition and hydration. Artificial nutrition and hydration should be provided to a patient as long as it can be assimilated by the patient or until such time as it is futile to sustain the life of the patient or until such time as the method of delivery of the nutrition and hydration imposes too great a burden on the patient or the patient's family or healthcare resources.

ACL submits that to cease providing nutrition and hydration that is neither futile, nor unduly burdensome, with a view to shortening a patient's life, would be **euthanasia by omission**.

⁴⁹ Ibid.

⁴⁸ Ibid.

A new statutory definition that does not define artificial nutrition and hydration as a 'medical procedure' is needed. The common law definition established in *Gardner; re BWV* is regrettable. Any new statutory definition that sets out the kind of medical treatment options that can be withdrawn, should ensure that artificial nutrition and hydration is not included in that definition.

Freedom of conscience thought and belief

If the parliament makes advanced care directives legislatively binding it risks violating the right to freedom of conscience, thought and belief. Directives that request the removal of artificial nutrition and hydration when it is neither futile, nor unduly burdensome, would be against many doctors' consciences. Conversely, directives that request that treatment continue beyond a point where it is burdensome or futile, would also be against the good health principles of many doctors. If there is any further regulation of advanced care directives it is essential that any statutory definitions of the kinds of treatment that may be withdrawn do not cause a situation where doctors are forced to choose between violating their consciences or risk incurring liability.

The threat to freedom of conscience of thought and belief is very real. The Guardianship: Final Report, authored by the Victorian Law Reform Commission, recommended that:

- 1. Advanced care directives (referred to in the report as 'instructional directives') should be made legally binding.
- 2. A new offence of medical trespass be applied to health providers who do not comply.
- 3. Conscientious objectors whose views or beliefs prevented them from complying with the directives should be required to refer the patient to another health professional. ⁵⁰

Implementation of these recommendations would create the same kinds of dilemmas for health professionals and health institutions as those that were created as a result of Section 8 of the *Abortion Law Reform Act 2008* (VIC).

Conscientious objectors refuse to participate in activities because they see such participation as cooperation in evil. The proposed requirement that doctors refer patients to other compliant doctors means they would still be participating in the act. This would not resolve the problem for the conscientious objector. Clauses that appear to give conscientious objectors a way of avoiding participation but still require the doctor to give a referral to a compliant doctor are unacceptable.

Directives should not be made legislatively binding. Any further regulation of advanced care planning should ensure that a doctor's right to practice medicine according to good health care principles is protected.

⁵⁰ Victorian Law Reform Commission, Guardianship: Final Report, (18 April 2012), <http://www.lawreform.vic.gov.au/projects/guardianship-final-report>, chapter 11, paragraphs 11.115, 11.116 and Recommendation 143, paragraph 11.101.

Conclusion

This submission has focused on three important areas that are relevant to end of life decisions.

The evidence presented in this submission shows that legalising euthanasia would be a grave mistake. Legalising euthanasia has serious ethical implications. It sends a devastating message about the value of life, and perhaps even more strongly about the way society values life. It legitimises suicide as a way out of suffering, and it relegates compassionate care to a mere option among others. It undermines important ethical principles, including that doctors should not kill their patients.

As the UK Select Committee on Medical Ethics said in their 1993/94 report:

the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death but should assure them of our care and support in life.⁵¹

This statement, now twenty years old, is as important and as relevant as ever.

Legalising euthanasia can also have unintended consequences. Although apparently pursued in the name of choice, in many cases it is done without any request by the patient. It may result in "choice" which is made not freely but under pressure, either direct or indirect.

The better way for the government to provide support to those who are suffering at the end of their life is to facilitate widespread access to palliative care. ACL calls on the government to continue to improve and adequately fund access to palliative care across Victoria. Those who seek to end their life are not limited to those with terminal illness or disability, but also include those who feel alone and abandoned by the community and suffer from mental illness. It is also essential that the government seeks to improve and develop greater mental health care to assist such people.

Good advanced care planning can greatly assist in ensuring the patients dignity is respected in the last period of a patient's life. Increased knowledge and uptake of advanced care planning is a positive move, however this submission has raised ACL's objections with making directives statutorily binding.

Yours Sincerely,



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⁵¹ Cited in Select Committee on Assisted Dying for the Terminally III Bill (2005), *First Report*, [2], http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8604.htm.