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

Via email: LACommitteeEOLC@parliament.act.gov.au

Dear Sir/Madam,

Inquiry into End of Life Choices in the ACT

The Archdiocese of Canberra and Goulburn includes almost 90,000 Catholics living in the Australian Capital Territory. The Catholic Church provides Australia’s largest non-government grouping of hospitals, aged and community care services, providing approximately 10 per cent of health care services. Catholic agency Calvary Clare Holland House is the major provider of palliative care services in the ACT.

The Archdiocese of Canberra and Goulburn appreciates the opportunity to offer a submission.

Introduction

We all want a good death. No one wants to die in pain. The evidence of palliative care practitioners is that very few people cannot have their pain or other symptoms effectively relieved as they are dying. In the rare cases where pain cannot be adequately palliated, patients can be sedated so they do not experience pain.¹

University of Melbourne palliative care specialist, Professor Jennifer Philip, points out that “requests for a hastened death ... are uncommon, about 1-2 per cent of people who referred to specialist palliative care services. That number reduces still further as pain or other concerns are effectively managed.” But evidence is that many people who need this care are not referred and in many places in Australia funding is inadequate.² How can

² J Philip, Assisted dying debate is taking the focus off the benefits of palliative care. Herald Sun, 18 October 2017.
Euthanasia is the intentional ending of a person's life by action, such as a lethal injection, or by stopping reasonable care. Catholics instead support good end-of-life care that takes away people's pain and makes them comfortable.

When euthanasia is done at the request of the patient it is referred to as voluntary euthanasia. When lethal drugs are provided to the patient to take themselves, it is referred to as assisted suicide. This submission will sometimes use these two terms interchangeably for simplicity and because both actions raise very similar concerns.

Euthanasia is not giving someone drugs with the intention of relieving their pain, even if those drugs may unintentionally hasten death. Nor is it turning off a life support machine, ending burdensome treatment nor finishing treatment that has no prospect of success.

Giving someone a lethal drug crosses the fundamental ethical line that we should not kill our fellow brothers and sisters. More than that, this submission will argue that:

- Euthanasia would endanger vulnerable people
- Acceptance of euthanasia cannot be limited, but brings pressure on boundaries and numbers over time, and
- Compassion demands that all people in the ACT should have guaranteed access to palliative care when they need it.

**Pressure on vulnerable people**

Legalising euthanasia would put pressure on vulnerable people to request a lethal dose.

Pain dominates discussion of euthanasia and assisted suicide in Australia, but does not always feature prominently in the reasons people give for seeking a lethal dose. In Oregon only 21 per cent of people who died from a lethal dose of drugs had said they were concerned about pain while 88 per cent cited being “less able to engage in activities making life enjoyable” and 87 per cent said loss of autonomy, 67 per cent loss of dignity and 55 per cent being a burden on others.³

Professors Barron Lerner and Arthur Caplan note in their paper that almost 50 per cent of people granted euthanasia in the Netherlands cited loneliness as part of their suffering.⁴ Loneliness was also a factor in at least one of the four people who died under the Northern Territory’s euthanasia laws.⁵ Surely as a community we should work to alleviate loneliness – not offer a lethal drug.

Fear, depression, loneliness, not wanting to be a burden, even pressure by family members, can all be factors in someone asking for euthanasia.

⁵ D W Kissane, A Street and P Nitschke, op. cit.
The reasons seven people sought euthanasia in the Northern Territory in 1996-97 included fear of the future, not wanting to be a burden and depression.  

Professors Annette Street and David Kissane point out that:

“Empirical studies of desire for death have highlighted the pathway that develops in which untreated symptoms, loss of meaning and pleasure, worthlessness and hopelessness fuel the development of a clinical depression. Suicidal ideation grows directly from such negative cognitive states.”

Depression is hard to diagnose and often misinterpreted, sometimes seen as a rational response to difficult circumstances. Undiagnosed depression is clearly a major danger to vulnerable people.

If euthanasia were allowed, the concern is that vulnerable people would be overwhelmed by these pressures rather than seeking help.

Just to speak of euthanasia as a treatment option would send a very strong signal to people that their life is of no great consequence and that their remaining days have no value.

Miller and Appelbaum comment in relation to mental health patients that “… a clinician’s willingness to comply with a request for physician-assisted death is countertherapeutic, since it involves an implicit endorsement of the patient’s perspective that his or her life is worthless and there is not hope for improvement.”

The Australian Law Reform Commission recently found that risk factors for elder abuse include disability, poor physical or mental health including depression, low socioeconomic status and social isolation. Associate professor of law at the University of Tasmania, Jeremy Prichard, commented on an attempt to prevent elder abuse in a Tasmanian euthanasia bill:

“... everything we know about crime prevention would suggest that this law will have little effect. Why? First, the chances of detection will remain very low. Secondly, multiple opportunities may present to commit the crime. Thirdly, the crime is easy to commit; it takes no planning or skill to repeatedly verbally pressure an elderly person behind closed doors. Fourthly, the crime may be attached to a reward, such as access to the victim’s assets.”

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6 D W Kissane, A Street and P Nitschke, Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. Lancet 1998; 352: 1101.
11 J Prichard, Assisted dying bill needs to be analysed. The Examiner, 24 May 2017.
Elder abuse is a particular risk in the event of assisted suicide being legalised as the population ages and as the price of housing both increases the value of the assets and locks out younger people.

The experience in Australia

The only experience Australia has had with legal euthanasia was in the Northern Territory in 1996-97. Despite claims of so-called strict safeguards:

- There was a procedure set out for patients wanting approval for euthanasia, which meant steps like a psychiatric assessment were seen as barriers to overcome rather than a key safety check;\(^{12}\)
- "... four of the 'Seven deaths in Darwin' revealed prominent features of depression, highlighting its strong role in decision-making by those seeking euthanasia";\(^{13}\)
- Fear of what might happen was a major reason given for wanting euthanasia.\(^{14}\) Frailty and fatigue also contributed to the suffering of patients, while pain was not "a prominent clinical issue";\(^{15}\)
- Some desperate people engaged in doctor-shopping as they sought a doctor willing to endorse their death;\(^{16}\) and
- Dr Philip Nitschke was involved in every euthanasia death.\(^{17}\)

After examining the Northern Territory experience, Professor Kissane concluded that:

"despite considerable legislative effort to draft safe regulations that would protect the vulnerable, review of the clinical accounts of patients that sought access to this legislation revealed blatant failure of the Act to achieve its purpose. Given the level of error rate that does occur in medical practice, this experience suggests it would be impossible to safely legislate for doctors to kill. Certainly the gatekeeping roles designed by this Act failed to protect depressed, isolated and demoralized patients. Cast in a legislative and bureaucratic stance, these gatekeepers ceased to practice the craft of medicine, to the neglect of the patients they sought to serve ... it does not appear possible to safely legislate to grant autonomy for the few, without creating danger to many other vulnerable individuals in society."\(^{18}\)

We should not put vulnerable people in that position; they deserve our unquestioning love, respect and support.

\(^{12}\) A Street and D W Kissane, op. cit.
\(^{13}\) Submission 589 from D W Kissane, Senate Standing Committee on Legal and Constitutional Affairs, Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008.
\(^{14}\) A Street and D W Kissane, op. cit.
\(^{15}\) D W Kissane, A Street and P Nitschke, op. cit.: 1102.
\(^{16}\) A Street and D W Kissane, op. cit.
\(^{17}\) D W Kissane, A Street and P Nitschke, op. cit.:1097-1102.
\(^{18}\) Submission 589 from D W Kissane, op. cit.
Acceptance of euthanasia cannot be limited

If people accept that it is all right to offer euthanasia to someone who has a terminal illness, why not also allow euthanasia for someone who is not terminally ill but who suffers from a very difficult medical condition? If it is humane to allow euthanasia for someone who requests it, isn’t it also humane for someone with the same condition even if they cannot request it? Once euthanasia or assisted suicide are accepted in some cases, there is a logical progression to expand the boundaries.

In those overseas jurisdictions where euthanasia is permitted, the boundaries have expanded over the years to include brothers who were deaf and found they would soon be blind\(^{19}\), to children with the consent of their parents\(^{20}\) to almost seven per cent of people euthanased in the Netherlands who said they were tired of living\(^{21}\) and to a prisoner who was initially granted permission to die rather than endure the suffering of prison life, although the plan was halted at the last minute without explanation.\(^{22}\)

Where euthanasia or assisted suicide have been legalised, there has been a disturbing increase in the number of people accessing lethal drugs:

- In Oregon “from 1998 through 2013, DWDA (Death with Dignity Act) deaths increased an average of 14% annually; from 2013 through 2015, DWDA deaths increased by 36% annually, but they levelled off in 2016.”\(^{23}\) This levelling may only temporary, as happened in 2013.\(^{24}\)
- “In the Netherlands, the percentage of euthanasia of the total mortality rate tripled from 1.3% in 2002 to 4.08% in 2016. During that same period, the suicide numbers did not go down. From 1,567 in 2002, they went up to 1,894 in 2016, a rise of 20.8%.”\(^{25}\)
- “One (3.3%) in 30 people in the Netherlands died by euthanasia in 2012, roughly triple the percentage in 2002 when the practice was first decriminalized ... Whereas 1.9% of all deaths in Flanders, Belgium, in 2007 were by euthanasia, the percentage increased to 4.6% by 2013; this represents 1 in 22 deaths—even higher than the 1 in 30 deaths in the Netherlands.”\(^{26}\)

\(^{19}\) Euthanasia twins ‘had nothing to live for’. The Telegraph, 14 January 2013, see: https://www.telegraph.co.uk/news/worldnews/europe/belgium/9801251/Euthanasia-twins-had-nothing-to-live-for.html
\(^{25}\) T A Boer, Does Euthanasia Have a Dampening Effect on Suicide Rates? Recent Experiences from the Netherlands. Journal of Ethics in Mental Health, 10: 6.
\(^{26}\) B H Lerner and A L Caplan, op. cit.
• A study of several US states where assisted suicide is legal found “... legalizing PAS [physician assisted suicide] was associated with a significant increase in total suicides (including PAS) and no reduction in rates of nonassisted suicide”.27

These significant increases in the number of people dying by assisted suicide or euthanasia are occurring without significant changes in the legal framework.

Compassion and palliative care

Legal euthanasia would undermine the human dignity of all people by allowing us to think that death is a solution to serious and difficult conditions such as cancer, depression or Alzheimer’s.

Compassion involves walking with people in their suffering, attending to their needs and helping them to live the rest of their lives in the best comfort possible.

It requires commitment and focus to understand a patient’s fears and needs, so that they can be addressed. Tragically, that commitment and focus will not always be there if there is an option to end a patient’s life.

Good end-of-life care can help people to both live and die well but it only works if we recognise the human dignity of all, not just those who are strong enough to insist on their right to live.

Sometimes slow, hard dying can exhaust both the person dying and their families. We need to be so much better at finding ways to support not only patients but also their families. Good care should go beyond what is offered in medicine and in institutions to broader models of good community support. That sort of support is sometimes provided by family and friends, but not everyone has that blessing.

As a community, how can we better support families through the often physically and emotionally exhausting time of a long dying period of a loved one?

We are very fortunate in Canberra to have the excellent Clare Holland House hospice. Operated by Little Company of Mary Health Care, the hospice offers expertise in end-of-life care to promote human dignity. Catholic hospitals have championed palliative care in this country to ensure Australians can have a good death. No one should be denied palliative care when they need it. It is an absolute outrage that this care is not available to all Australians.

Is there adequate funding to ensure all people in the ACT and surrounding areas have access to the hospice when they need it?

The Grattan Institute report Dying Well makes the point that while 70 per cent of Australians would prefer to die in their own home, only 14 per cent get their wish.28

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27 D Jones and D Paton (2015), How does legalization of physician assisted suicide affect rates of suicide? Southern Medical Journal, 180 (10), pp. 599-604
28 H Swerissen and S Duckett, Dying Well. Grattan Institute, September 2014, pages 26-27.
Are their adequate community palliative care services to ensure all ACT residents have the support to live their last days at home, if they wish?

It is not hard to imagine that funding for palliative care would suffer in a time of budget restraint if euthanasia were an alternative.

**Conclusion**

The church has an obligation and a responsibility to participate in important public debates, such as the debate over euthanasia. We argue our case in the public square in terms that can be understood and accepted by all people of good will. This is not a matter of faith but a matter of social justice.

Introducing a policy of euthanasia or assisted suicide would cross a fundamental ethical threshold that we should not kill our fellow sisters and brothers. It would be dangerous for vulnerable people in our community. Allowing euthanasia is a policy that cannot be effectively limited over time, with pressure for changes in boundaries and increases in numbers inevitable. Finally it would threaten to overwhelm the crucial obligation our community has to ensure all dying people have guaranteed access to the best of care, including palliative care.

We should never forget that vulnerable people such as the elderly are relying on us to affirm their value, to share our lives with them and resist the pressure to legalise euthanasia.

Yours sincerely,

Archbishop Christopher Prowse
Catholic Archbishop of Canberra and Goulburn Archdiocese