Submission Cover Sheet

End of Life Choices in the ACT

Submission Number: 442
Date Authorised for Publication: 19/4/18
23 March 2018

Dear Sir/Madam

Inquiry into End of Life Choices in the ACT

This submission from the Australian Catholic Bishops Conference (ACBC) has been prepared by the Bishops Commission for Family, Youth and Life (BCFYL).

The ACBC is the assembly of Catholic Bishops of this country and the means by which the Bishops act nationally and address issues of national significance. The BCFYL is one of the commissions established by the ACBC to address important issues both within the Church and the Australian community. The BCFYL has responsibility for life issues such as euthanasia.

As well as a long-respected source of reflection on bioethical questions, the Catholic Church is the oldest and largest provider of healthcare, aged care, palliative care and healthcare professional education, in the world. Across Australia, Catholic providers operate Australia’s largest non-government grouping of hospitals, aged and community care services, providing approximately 10 per cent of healthcare services in Australia. This includes 42 Catholic specialist palliative care services. This care is delivered in accord with best practice technically and ethically.

The ACBC appreciates the opportunity to make a submission on how best to honour the human dignity of people at the end of their life. As Catholics, we affirm that every human being possesses an intrinsic dignity and worth. This dignity can never be diminished or taken away, because we believe that the human person is made in the image of God and is eternally loved by Him.

The ACBC believes that a radical change to civil society’s most foundational law, overturning the prohibition on the intentional killing of citizens, is ethically unjustifiable,
cannot ensure the legal protection of the vulnerable, and would fail to uphold the dignity of the dying.

World-leading Australian expert in medical law and ethics, Professor Margaret Somerville, points out that “euthanasia is special (among ethical debates) because there’s nothing new about it. We’ve always got old, suffered, become terminally ill, been dying and somebody could have killed us, and we said ‘No, that is wrong. We don’t do that.’ So that’s why euthanasia is so important because if we change that, we’re changing the very roots of our society. I think we’re changing the essence of what it means to be human if we start killing each other.”¹

Euthanasia refers to deliberately ending someone’s life in order to relieve their suffering.² When it is done at the request of the person it is referred to as voluntary euthanasia. Euthanasia can be achieved by a lethal injection or by intentional neglect. Euthanasia is not turning off a life support machine where there is no prospect of recovery. It is not ending treatment that is overly burdensome. It is not giving someone pain relief that might unintentionally hasten their death. In good palliative care such pain relief will rarely if ever shorten life, but many people still believe this is the case.

Assisted suicide is a variation of euthanasia and refers to when someone is provided with a lethal dose of drugs which they can take later, at a time of their choosing, to end their own life.

These ways of ending people’s lives are sometimes referred to by terms which seem designed to obscure meaning and avoid referring to the deliberate ending of a human life, like ‘voluntary assisted dying’ or ‘medical assistance in dying’.

Community attitudes are often gauged today through opinion polls which may give higher or lower numbers of support depending on how the question is framed. In one instance, support for euthanasia fell away by up to 20 per cent if the words “assisted suicide” were used in the question. Furthermore, when participants in polls were exposed to counter arguments to legalisation, support wavered even further, in one poll from 73 per cent to 43.³ Polling needs to be framed correctly to get an accurate understanding of public opinion.

The ACBC will argue the best way to improve care and respect for the human dignity of people at the end of life and to dignify people as they are dying is to:

• Affirm the inherent and absolute value of every person’s life at their most vulnerable;
• Reject attempts to legalise the deliberate killing of citizens at the hands of others;
• Encourage people to discuss and plan for their end of life care; and

¹ Professor Margaret Somerville, presentation at The University of Notre Dame, Sydney. 30 June 2015
² Suffering may be physical, such as pain, or ‘existential’, such as fear of loss of control.
³ Jones, D, Assisted Suicide and Euthanasia: a Guide to the Evidence, Anscombe Bioethics Centre, August 2015, page 5.
• Increase government investment to provide adequate palliative care, respite care and psychosocial support for carers, to back up the strong community commitment to supporting the care of people as their life comes to an end.

**Euthanasia is not compatible with good medical care**

Lethal injections are not compatible with good medical care because:

- Euthanasia or assisted suicide cannot be made safe;
- There is no dignity in giving sick people a lethal dose;
- Where euthanasia has been legalised, it has been disastrous for the vulnerable;
- Euthanasia undermines true autonomy.

**Euthanasia or assisted suicide cannot be made safe**

The clear conclusion of reason and experience is that euthanasia or assisted suicide cannot be made safe, because no law can prevent vulnerable people from abuse. Legalised euthanasia endangers the lives of people who are seriously ill, elderly, have a disability, have low self-esteem or are otherwise vulnerable. Vulnerable people must continue to have our care and the protection of our laws.  

Where people are suicidal and want to end their life, the community should offer care and treatment, not a lethal injection.

The evidence from places that have attempted to legalise and regulate euthanasia is that it is not possible to draft safeguards that would effectively protect vulnerable people from subtle or overt pressure to request euthanasia.

Professor Margaret Somerville, points out that “physician-assisted suicide and euthanasia involves taking people who are at their weakest and most vulnerable, who fear loss of control or isolation and abandonment – in a state of intense ‘pre-mortem loneliness’ – and placing them in a situation where they believe their only alternative is to kill themselves.”

It is not possible when euthanasia is legal to prevent someone from feeling or being made to feel they are a burden. It is not possible when euthanasia is made socially acceptable to prevent other people deciding that certain patients would be better off dead. What such vulnerable people would hear from the community – from euthanasia laws and a legal system which permits deliberate killing or assisted suicide – is that they are thought to be better off dead or that the community thinks it would be better off if they were dead.

Euthanasia advocates argue that giving someone a lethal dose is a private decision, but allowing euthanasia would make a person’s death a public act, necessarily involving, in addition to the sick person, medical professionals, law-makers and regulators, as well as

---


family and the wider community.\textsuperscript{6} It therefore has an impact not just on how one person dies but on how all of us will live out our last days and will die.\textsuperscript{7}

Once a community accepts the idea that doctors or others can end people’s lives for one reason or another, it is difficult to argue that those people’s lives might not be ended for some other reason or that other people’s lives should not also be ended.

Legal euthanasia would also put at further risk suicidal people, who deserve help rather than assistance to kill themselves. The Australian Bureau of Statistics reported 2,866 deaths from intentional self-harm in 2016.\textsuperscript{8} This is much higher than the 1,295 road deaths in Australia in 2016,\textsuperscript{9} but receives much less attention. Legal euthanasia would clearly signal there are some people who would be better off dead. There are already media reports on how the euthanasia movement’s detailing of methods of suicide is leading to the deaths of young people, who could otherwise have been helped.\textsuperscript{10}

There is no dignity in giving sick people a lethal dose

Human dignity, as understood in international human rights instruments, sound secular ethics, as well as the Christian tradition, is at the centre of our common humanity. It is the basis of our equality at law, our human rights including the right to life, and the care we have a right to expect from others. No matter our personal circumstances, our dignity as unique and irreplaceable human beings cannot be lost or volunteered away. Our dignity does not depend on whether we are useful, healthy or wanted, or even whether we appreciate ourselves and our rights. Whatever the motive, killing someone is no way of recognizing their inalienable dignity or their inviolable right to life.

Doctors can either affirm the dignity of their patients by offering them ongoing care, or add to their sense of hopelessness by words or actions that imply their life is not worth living. We do not demonstrate respect for the dignity of others at their most vulnerable by telling them by our words or actions that we think they would be better off dead or that others would be better off if they were dead. Especially where care is insufficient and symptoms are not adequately addressed, people can experience a loss of meaning and hope, even depression. Undiagnosed depression is, in fact, very common in the terminally ill.\textsuperscript{11}

Speeding someone’s death also dishonours the very important remaining part of their life and deprives people of a valuable and special time, even when confronted with suffering

\textsuperscript{6} Ibid.
\textsuperscript{7} Boudreau, JD and Somerville, MA, Euthanasia and assisted suicide: a physician’s and ethicist’s perspectives. \textit{Medicolegal and Bioethics}, 2014; 4:7
\textsuperscript{9} Department of Infrastructure and Regional Development, \textit{Road Trauma Australia: 2016 Statistical Summary}. DIRD, Canberra, Australia.
and pain. Laws allowing euthanasia effectively say to people at a very low ebb: “we do not regard the rest of your life as valuable; in fact you might well be better off dead.” Legalising euthanasia makes frail and ill people more likely to feel they are a burden on their families or the community and can add the extra dimension of making them feel they are somehow selfish for not ‘volunteering’ to die.

If euthanasia were to be regarded as ‘a medical service’ (which it is not by definition), treating doctors would be required to offer it among the various treatment options. This is already the case in the small number of jurisdictions that allow euthanasia. Where patients are incompetent but have given someone power of attorney to make decisions on their behalf, euthanasia would become a form of killing to which the appointed guardian could consent on the patient’s behalf. This is an unacceptable responsibility to place on the shoulders of guardians, carrying grave risks for abuse.

For us to continue to trust doctors, it is necessary to be confident that they will refuse to kill people. In a similar way, the mutual respect and trust that we share as a community is dependent upon our continued refusal to allow people to be killed.

The experience of legal euthanasia

Amongst those jurisdictions that have experimented in legal euthanasia are Belgium and The Netherlands.

In Belgium, where euthanasia has been legal since 2002:

- There are more than five deaths by euthanasia every day;
- Almost one third of cases of euthanasia in Flanders are now without explicit consent;
- Only half the euthanasia cases are reported as legally required;
- The law was changed in 2015 to remove any age limit so competent children can request euthanasia with their parents’ consent;

---

13 Tonti-Filippini, N, About Bioethics: Caring for people who are sick or dying (Ballan: Connor Court, 2012), p. 106
16 Caldwell, S, Five people killed every day by assisted suicide in Belgium as euthanasia cases soar by 25 per cent in last year alone. Daily Mail, 29 May 2014.
• Life-ending drugs are administered by nurses in almost half the cases of assisted
death without an explicit request.\(^{20}\)

In the Netherlands, where euthanasia has also been legal since 2002, but was tolerated
under guidelines even before that:

• 23 per cent of deaths by euthanasia are not reported to authorities;\(^{21}\)
• There were 310 euthanasia deaths without explicit consent in 2010;\(^{22}\)
• Euthanasia, once tightly restricted to consenting adults with terminal illness, is
now permitted from 12 years of age with parental consent and from 16 years of age
without parental consent;\(^{23}\)
• The Groningen protocol allows for the euthanasia of newborns with poor
prognosis, in agreement with the child’s parents.\(^{24}\)

Professor Theo Boer, a former supporter of euthanasia and member of a Dutch
euthanasia Regional Review Committee since 2005, warned the United Kingdom not to
legalise euthanasia, saying “beginning in 2008, the numbers of these deaths show an
increase annually, year after year... Euthanasia is on the way to becoming a ‘default’ mode
of dying for cancer patients.”\(^{25}\)

The risk of “bracket-creep” is confirmed by a study\(^{26}\) published in August 2015, which
found in The Netherlands 3.3 per cent (one in thirty) of deaths were by euthanasia in
2013, three times the percentage in 2002, while in Flanders, Belgium the study showed
4.6 per cent (one in twenty two) of deaths were by euthanasia in 2013, up from 1.9 per
cent in 2007.

In summary, public records in the Netherlands and Belgium indicate the situations where
euthanasia may be applied have been progressively extended beyond the relief of the
suffering of the terminally ill under the loose guidelines applied in these countries. This
should give Australians, especially the most vulnerable and their loved ones, real cause for
concern about the perils of going down this dangerous path.

A disturbing recent development has been preparation of a cost analysis in Canada of the
 savings to be made to public health budgets from legalised euthanasia. A 2017 study
estimated that medical assistance in dying could save the Canadian health budget

\(^{20}\) Inghelbrecht, E, et al, The role of nurses in physician-assisted deaths in Belgium, CMAJ 2010; 182(9):905-
10.
\(^{21}\) Onwuteaka-Philipsen, BD, et al, Trends in end-of-life practices before and after the enactment of the
euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. The Lancet, 2012;
\(^{22}\) Statistics Netherlands, see: http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=
SLen&PA=81655ENG&LA=en
\(^{24}\) Ibid.
\(^{25}\) The Daily Mail, 10 July 2014.
\(^{26}\) Lerner, B and Caplan, A, Euthanasia in Belgium and the Netherlands: On a Slippery Slope? JAMA Intern
between $34.7 million and $138.8 million. Such studies suggest economic imperatives too may drive a widening of those considered eligible for euthanasia.

In Oregon USA, which is often held up as an example of a place where euthanasia laws are working “well”, disturbing trends have developed toward treating euthanasia as a preferred option for certain categories of patients, particularly terminal cancer sufferers. As Barbara Wagner, a terminally ill cancer patient, put it when she was refused life extending drugs under Medicaid but offered euthanasia as an option, “We’ll pay for you to die, but not pay for you to live.”

It is state policy in Oregon to reimburse for assisted suicide but not for treatments which may sustain a terminally ill patient’s life, particularly a patient whose life expectancy is assessed as short.

In Oregon, reporting to the state is done solely by the physician prescribing the lethal drugs, who is not present in 90 per cent of cases when the drugs are ingested. Eighty per cent of patients accessing lethal drugs in Oregon now die without a health care provider of any kind present according to state records. In 2016, the lethal drugs are known to have taken as long as nine hours to cause death. At least 30 patients (three in 2016) regurgitated the drugs with some regaining consciousness before dying, others dying from their illness and some not dying.

Death certificates in Oregon routinely report the underlying illness as the cause of death, “in order to avoid autopsy or other scrutiny”. Lethal drugs may be ingested many months after prescription, making a nonsense of the Oregon law’s requirement that patients must be “mentally capable” and without depression or other mental disturbance at the time of ingestion. There are, perhaps most disturbingly, no meaningful barriers in the Oregon regime to prevent a carer or other person coercively administering the lethal drugs to a vulnerable patient against their wishes.

Euthanasia undermines true autonomy

The autonomy of people who are sick, frail, have a disability or who are dying is commonly already compromised by their condition. By legalising euthanasia the community adds to their sense of being a ‘burden’ and ‘expendable’ and to the pressures upon them ‘to end it all’. In the name of autonomy, euthanasia actually reduces the freedom of such persons.

John Keown argues “the fact that, through depression or pain or loneliness, some patients may lose sight of their worth is no argument for endorsing their misguided judgement that their life is no longer worth living. Were the law to allow patients to be intentionally

---

28 Cook, M, We’ll pay you to die, but not to live. Bioedge, 30 July 2008.
killed by their doctors, it would be accepting that there are two categories of patients: those whose lives are worth living, and those who are better off dead. What signal, moreover, would that send out to people who are sick, elderly, have a disability, or who are dying?”

No serious-minded doctor would give a lethal dose to a patient just because the patient asked: the doctors would have to come to his/her own judgment that this person was an appropriate candidate for euthanasia. In the end it is the doctor, not the patient, who decides whether to grant or administer a lethal drug or not. Thus in the name of autonomy euthanasia further undermines patient autonomy by potentially giving doctors arbitrary power of life and death over their patients.

There is compelling evidence that doctors themselves suffer serious emotional and psychological effects from their involvement in the euthanasia or assisted suicide deaths of their patients, and from pressure to participate in these acts once they are made lawful.

Having accepted that doctors may sometimes decide that certain patients are ‘better off dead’ or are appropriate candidates for euthanasia, a next logical step is that a doctor would make that decision on behalf of someone not able to request death. Why should a patient be denied what the doctor may regard as good treatment – euthanasia – just because she or he is not able to request it? The slide from voluntary to non-voluntary euthanasia has already demonstrably occurred in some jurisdictions and some euthanasia advocates themselves see voluntary euthanasia as the first step towards providing this ‘mercy killing’ to others who do not or cannot ask, such as children, people who have a severe disability or who are unconscious. Once again, euthanasia endangers the autonomy of these people.

Though the ‘right to be killed’ has been unknown to international human rights instruments and thinking, were there really such a right, it would imply a duty on the part of health professionals and others to collaborate in killing, whatever their conscientious beliefs. Thus euthanasia is not only about the rights of the suffering person: it inevitably affects the freedom of medical professionals who are asked to assist or turn a blind eye, of by-standers, of regulators and others.

Euthanasia is not compatible with good medical care and would in fact undermine both the good care of people as they reach the end of their life and the autonomy which euthanasia purports to offer.

---

34 Ibid.
Planning for end-of-life care

It is very important that people speak with their family, friends and health care professionals about how they may like to be treated in the event of illness and to develop that understanding over years, rather than in an isolated conversation or when it is too late for considered thought.

The Grattan Institute's study *Dying Well* argues that discussing an advance care plan is vital:

“The hard discussions about end of-life care are delayed and sometimes avoided altogether. People and their families then do not have the opportunity to prepare for death. Often treatment that has little benefit is provided and they die in hospital rather than at home.”

The Catholic Church has set out a clear approach to advance care planning with resources for patients, residents and health care professionals provided by Catholic Health Australia (CHA) and the ACBC on the My Future Care website [http://myfuturecare.org.au/](http://myfuturecare.org.au/).

The guides recommend appointment of a representative or proxy who can make decisions on the patient's behalf in the event they can no longer make decisions themselves.

There is more than one approach to advance care planning.

The CHA/ACBC documents were prepared partly in response to concern over the usefulness of written advance care plans like the Respecting Patient Choices program, which can put too much emphasis on trying to define outcomes a patient wants rather than more usefully focusing on the patient indicating an appropriate approach to care.

The problems of advance care plans, sometimes also called living wills or advance directives, were well documented in a study published in the *Hastings Center Report*. The authors pointed out that despite significant efforts and funds expended over many years to promote the use of advance care plans, most people do not have them. For those who do have plans, many have not given sufficient thought to the instructions that will direct life and death decisions; the nature of the directives mean it is difficult to clearly communicate preferences; the documents often do not get to the relevant medical staff; and the documents do not help health care proxies better represent the preferences of the patient.

Other problematic aspects of advance directives are that:

---

• they are difficult to interpret because illnesses and the course of illness are unpredictable and medical staff need to discuss the burdens and benefits of treatments with the patient or proxy before a decision is made;
• they are a snapshot of past wishes of the patient and can be given more weight than a contemporary assessment of reasonable care. They also do not recognise that patient preferences change as circumstances change. What might seem unacceptable to a healthy patient might become more than acceptable in a life threatening situation;
• written directives can ignore the important distinction of intention. There is a great difference between a patient refusing treatment that is burdensome or futile and refusing treatment for the sole intention of ending life.  

A more useful approach is to appoint a health care proxy, such as someone who has been given a durable or enduring power of attorney, who can act as the patient's representative and discuss treatment options with the medical staff and family, making informed judgements on the relative usefulness or burden of treatment options as the patient's illness progresses. But proxies need help and support from the palliative care team in what is often a very confronting and unfamiliar situation, dealing with life and death questions.

Palliative care

The Catholic Church has a long tradition of caring for the ill and dying and for their families. It does so in accord with the classical healthcare ethic that holds that every human person is made in the image of God and so their life is precious. The terminally ill should never be made to feel that their lives are “unproductive”, “futile” or “burdens” upon society, but be loved and supported in their final journey.

Our dying, in all its mysterious and puzzling dimensions, is a unique measure of our lives: it is part of what defines us as human beings. Why then, as euthanasia advocates would have it, eliminate the humanity of our dying? Wouldn’t it be better to accompany someone as they are dying; to be with them in their pain; to fight for them in their suffering; to allow their humanity to shine forth? Rather than eliminating the lives of suffering persons, how about acknowledging and respecting their lives with good palliative care and personal accompaniment. Confronting the pain and suffering of a dying person calls for a human solution, not a medical fix.

Rather than buying into the dishonest euphemism of ‘dying with dignity’, we would do better – and be more human – by dignifying the lives of the dying. Palliative care is one key way we can dignify the dying.

---

39 Tobin, B (2008), More talk, less paper! Why health care proxies are a better means of extending traditional morality than are living wills. *Bioethics Outlook*, Vol 19(3), September, page 5.
40 Tobin, B, *op cit*, page 5.
Compassion is never merely giving people what they say they want or looking for quick fixes to problems. Rather it involves sharing in the suffering of others – literally suffering-with them – and so standing by and investing ourselves in them and in the demanding task of caring well for them. True compassion for the dying means offering to help them live the rest of their lives, however long or short that time may be, in the best comfort possible and with every sign that they are loved and respected. There are always ways to help a patient, even if a cure is not possible. Euthanasia points in a very different direction.

Pope John Paul II wrote “...euthanasia must be called a false mercy, and indeed a disturbing "perversion" of mercy. True "compassion" leads to sharing another's pain; it does not kill the person whose suffering we cannot bear.”

Good palliative and pastoral care, not killing, is the answer to relieving pain and suffering for the dying. Palliative Care Australia says that good, well-resourced palliative care gives people the ability not only to live well in their illness, but to die well too. Pastoral experience suggests that people’s sense of meaningless or hopelessness in suffering can also be addressed. Families also speak of how this time with a person they love who is well cared for and supported, can be very special – a gift – both to them and to the person who is dying.

The Grattan Institute wrote of the importance of improving investment in home-based palliative care in Australia, noting that “… while 70 per cent of people say they want to die at home, only about 14 per cent do so” and “to reach this number will require a major increase in the availability of community-based palliative care.”

If compassion were our real motive we would ensure that everything possible was being done to address people’s physical, psychological and spiritual pain before entertaining more drastic measures.

Any community that legalises euthanasia is likely further to neglect the provision of good palliative and other care for elderly, sick and dying people. Where euthanasia is legalised it becomes a competing option with palliative care, with all the dangers of economic and other considerations affecting which ‘option’ is promoted. By introducing the idea that not all people have lives worth living or deserve our help and care, the practice of euthanasia undermines such care even for those who do not want euthanasia.

Legalised euthanasia would mean that respect for the lives of people is no longer assumed, but depends on whether they have the will to defend their life or have others willing to stand up for them.

---

42 Ibid, p. 98.
44 Swerissen, H and Duckett, S, Dying Well. Grattan Institute, September 2014. Pages 26, 27.
45 Tonti-Filippini, N, About Bioethics: Caring for people who are sick or dying (Ballan: Connor Court, 2012), p. 98.
46 Ibid, p.102.
Conclusion

The ACBC does not believe that radical changes to civil society’s most foundational law, prohibiting the intentional killing of citizens, are necessary to provide good care for people at the end of their life and to dignify the dying.

What is needed is a firm commitment from governments and the broader community to:

- Affirm the value of people at the end of their lives and reject attempts to introduce deliberate killing;
- Encourage people to discuss and plan for their end of life care; and
- Increase government investment to provide adequate palliative care, respite care and psychosocial support for carers – particularly extra home-based palliative care - to back up the strong community commitment to supporting the care of people as their life comes to an end.

Most importantly, as Catholics, palliative care carries a special significance, for we ‘see in the dying person, as in no other, the face of the suffering and dying Christ calling out for love’.\(^{48}\) Our faith enhances our commitment to caring for and accompanying the dying, but this commitment is also a deeply human value which is shared by people of all faiths and none. We implore you to reject the indignity of euthanasia and to do all that you can to help provide readily accessible palliative care, support and companionship that the terminally ill need and deserve.

I would be happy to answer any questions the Committee may have. I can be contacted via Mr Jeremy Stuparich, Public Policy Director at the ACBC on 02 or at

Yours sincerely

Most Rev Peter A Comensoli

Bishop of Broken Bay

For the Bishops Commission for Family, Youth and Life

---