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The Secretary
Mr Todd Buttsworth
The Standing Committee on Community Development
Parliament House
HOBART TAS 7000

RE: Inquiry into Palliative Care

The Australian Christian Lobby

The Australian Christian Lobby (ACL) is a grassroots movement of over 68,000 people seeking to bring a Christian influence to politics. We want to see Christian principles and ethics accepted and influencing the way we are governed, do business and relate as a society. We want Australia to become a more just and compassionate nation. ACL is a non-party partisan, non-denominational movement that seeks to bring a credible, Christian voice for values to our national debate.

Submission

ACL welcomes this opportunity to contribute to the Standing Committee on Community Development's Inquiry into Palliative Care. Those needing medical treatment and care towards the end of their life are some of the most vulnerable members of society. Implementing good public policy in this area will ensure that both the legal framework and public health resources are directed towards the good of the patient.

Palliative Care

Good quality 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, and to die comfortably in a home or hospice setting.

According to the Grattan Institute, between 60 and 70 percent of Australians would prefer to die at home, yet only around 14 percent in fact do so.¹ In comparison to other OECD nations, Australia lags behind. We can do better.

Further support and funding to this vital area of health care is needed. Government should lead in funding and implementing policy that increases services and delivery of palliative care so that more Tasmanians can end their days as they wish: at home under palliative care.

Good principles of palliative care

The goal of health care is to assist people to sustain life and health in the context of their total well-being. Sustaining a patient's good health may mean saving a life when at risk, or curing illness, but there comes a time when death ought to be accepted. The goal then shifts towards alleviating pain and suffering where possible so that a patient can die comfortably, with full regard to the patient's dignity.

Palliative care is concerned with caring for, and accompanying, a dying person and his or her family or carers in the closing phase of life. The relief of pain and symptoms is also a strong feature of palliative care. Good palliative care upholds the patient's dignity and respects their individual needs.

Human Dignity

Human dignity is the concept that all human beings have an intrinsic worth by virtue of being a human. Every person, therefore, has inherent dignity regardless of their physical or mental capacity, or their health.

The practice of palliative care is consistent with good health care, and cannot flourish in the context of a health system that provides the option of euthanasia or assisted suicide. This is because euthanasia or assisted suicide violates the inherent dignity of human beings.

Legitimising euthanasia within the law undermines the perceived 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.

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Burdensome or futile treatment

Treatment that continues beyond a point where it is burdensome or futile is against good health principles. Treatments are futile if they provide no benefit to a particular patient.

¹ Hal Swerissen and Stephen Duckett, *Dying Well*, (Grattan Institute), 2014. p 4.

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*.

Treatments are burdensome when they cause distress and suffering, cause difficulties for the patient, or are costly to obtain or provide.

Patients have the moral right to refuse any treatment that is futile, or that the patient judges to be overly burdensome or morally unacceptable. Such refusals should always be respected by health care professionals.

Similarly, health care professionals should refrain from providing treatment that is futile or overly burdensome.

Advanced care planning and advanced care directives

Good advanced care planning can greatly assist in ensuring the patient's wishes are valued and dignity respected in the last period of a patient's life.

Advanced care directives can be useful to a point, towards assisting family members, decision makers and medical teams to make decisions that are consistent with the wishes of the patient, and are but one element of advanced care planning.

There are **limitations to written directives** that should be considered:

- they can be difficult to interpret;
- they are a snapshot of past wishes of the patient: patient preferences change as circumstances change;
- they can ignore the important distinction of intention.

Written directives taken by themselves are not always sufficient to ensure that patient choices about future medical treatment and care are respected.² Good advanced care planning requires a much broader approach towards respecting patient choices.

Should written directives be legally binding?

A holistic approach towards advanced care planning is desirable and should not make written directives legally binding.

When a person becomes incompetent, their earlier wishes and values may be a helpful guide, but are problematic for directing specific treatment and care decisions. Additional guidance from the person's representative is important.

ACL recommends that the inquiry consider the importance of ensuring written directives are not emphasised to the detriment of other advanced care planning approaches. A holistic approach to advanced care planning is needed.

A good alternative to written directives is the appointment of a **health care proxy**. Durable power of attorneys act as the patient's representative and discuss treatment options with the medical staff and family. Proxies can represent the patient's interests as their illness

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*.

progresses and respond flexibly to the changing circumstances of the patient's illness, whilst respecting and upholding the values and approach discussed with the patient at an earlier stage. A static document does not provide this level of flexibility or management.

Artificial nutrition and hydration in advanced care directives

For example, one specific problem of making directives legally binding flows from the potential for some requests in advanced care directives to refuse everything, including food and water, the provision of which would normally under such circumstances keep the patient alive.

The presumption should always be in favour of the provision of artificial nutrition and hydration as long as it can be assimilated by the patient or until such time as it is futile or until the method of delivery of the nutrition and hydration imposes too great a burden on the patient.

Of course the provision should be removed once it is clear that it is no longer effective or creating a burden on the patient.

ACL submits that to cease providing nutrition and hydration that is neither futile, nor unduly burdensome, with the intention of shortening a patient's life, is ethically wrong.

Gardner; re BWV

The legal status in Common Law of the permissibility of the withdrawal of artificial nutrition and hydration was considered in the Victorian case of *Gardner; re BWV*. In that case, Justice Morris determined that the use of a percutaneous endoscopic gastrostomy (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 amount to a criminal act.

ACL submits that defining artificial nutrition and hydration as a 'medical procedure' under law 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.

ACL recommends a new statutory definition for artificial nutrition and hydration that does not define it as a 'medical procedure'. The Common Law definition established in *Gardner; re BWV* is regrettable and should be rectified through a new statutory definition.

Euthanasia and assisted suicide

Some voices in the community have called to allow euthanasia and assisted suicide, and have done so in the context of palliative care, yet the practice of euthanasia is contrary to the principles of palliative care.

Euthanasia and physician assisted suicide are not components of palliative care.

Euthanasia and assisted suicide should be distinguished from other palliative care decisions that sometimes have the unintended effect of shortening life.

The debate around end-of-life care and euthanasia is highly emotive, and there are people of good intent and compassion on both sides. There is much public confusion about the meaning of the terms euthanasia and assisted suicide. ACL hopes the following clarification may be helpful.

Defining euthanasia

A good definition was proposed by Archbishop Fisher in 2004 in a debate with euthanasia advocate Dr Philip Nitschke; the same definition was accepted by euthanasia advocate Professor Peter Singer in a debate with Fisher in August 2015.

*an act or calculated course of omission intended to shorten life with a supposedly merciful motivation.*³

Key to this definition is the inclusion of not only positive acts but also omissions, since euthanasia is not always the result of a positive act. Yet, this point also requires further clarification since some kinds of acts or omissions which can foresee the death of a patient are not euthanasia.

‘Intent’ is the differentiating moral principle that delineates good medical practice end-of-life decisions from euthanasia. Bioethicist John Fleming explained this point well in another Tasmanian inquiry:

*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.***⁴

It is, therefore, important to consider not only the act or omission, but the intent of the doctor or medical team and their judgements about the futility or burden that a treatment may have on the health of the patient.

Where pain relief is the **primary** intention of a treatment, and a secondary effect of that pain relief is that a patient’s death would be hastened (such as may be the result of administering morphine) the administration of the pain relief is not euthanasia.

³ <https://www.catholicweekly.com.au/euthanasia-the-great-debate/>

⁴ 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*.

Similarly, to cease or not commence treatment that is seen to be **overly burdensome or medically futile** is not euthanasia, it is good medical practice.

The meaning of words is important and there is a need to ensure the emotions on either side of the debate do not cloud the definitions. The words 'dignity' and 'compassion' have each only recently become a kind of vague code word for euthanasia, lacking the above definition's precision and thereby distorting the original meaning of the words, which never before included the intentional killing of a person. Terms such as 'dying with dignity medical service' are cumbersome and an obvious attempt to avoid the word euthanasia. Similarly, the use of the term 'dignity' as a code word for euthanasia is misleading since a patient's inherent dignity is best respected through good medical and palliative care, whereas it is violated when the patient's life is taken by another person.

It must be remembered that current good health practice already 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. The introduction of euthanasia would be a clear break with current good health practice since it would turn this upside down and begin to provide the death of the patient as a solution, something that is at odds with the doctors oath to 'do no harm'. The role of the medical profession has never before included hastening a patient's death as a solution to suffering or illness.

The question is never whether the patient's life is worthwhile, but whether a treatment is worthwhile.

Distinction between 'euthanasia' and 'physician assisted suicide'

Whilst both terms refer to intentional killing, euthanasia usually refers to an act or calculated course of omission by a doctor or member of a medical team that is intended to shorten a patient's life.

Physician assisted suicide (PAS), on the other hand, is performed by the patient himself or herself with the assistance of another, such as when a doctor prescribes a lethal substance which the patient later ingests.

The distinction between PAS and euthanasia is essentially about who actually does the killing. PAS cannot be by omission and, normally understood, it is an act intended to provide the means to shorten life.⁵

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 medical practitioners contains the phrase "I will maintain the utmost respect for human life."

⁵ <http://noeuthanasia.org.au/blog/2297-the-great-debate-fisher-vs-singer.html>

The role of the medical profession, therefore, does not include hastening death on request. Euthanasia undermines the fundamental relationship of trust between doctor and patient, one of the most important relationships in society.

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.*⁶

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

State-citizen relationship

The first responsibility of the state is to protect its citizens. 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. 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.*⁷

How should policy makers approach the problem of the suffering patient?

At the heart of the conversation around euthanasia is the question of how to deal with suffering. 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 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 terminal sickness and disabilities toward the end of their life.

Previous 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;*

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

⁷ 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.

- *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.*

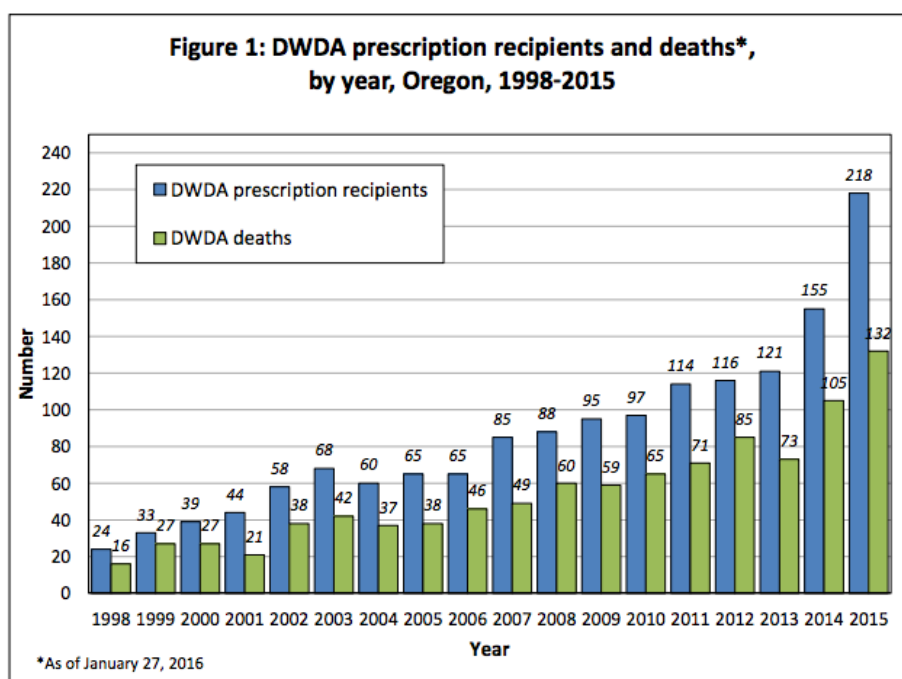
The Tasmanian enquiry into euthanasia gave positive focus to the importance of palliative care as the better alternative to addressing the suffering of terminally ill or disabled patients. The committee found that in the majority of cases palliative care was able to provide optimum care for suffering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

Euthanasia and Assisted Suicide in other jurisdictions

Oregon

Oregon's legalised physician assisted suicide came into force in 1997, allowing terminally-ill adult Oregon residents to obtain and use prescriptions from their physicians for self-administered, lethal doses of medications.



Source: Oregon Public Health Division, Oregon Death with Dignity Act: 2015 Data Summary, February 4, 2016⁸

The graph shows the most recent data released by the Oregon Public Health Division. Whilst the increase for both prescriptions and deaths has been gradual for most years (from 1998 through 2013, the number of prescriptions written annually increased at an average of 12.1%), **there has also been a sharper increase in 2014, and 2015** (in 2014 and 2015 the number of prescriptions written increased by an average of 24.4%).⁹ Since the law was passed, 991 patients have died from ingesting the poisons prescribed under the Death with Dignity Act (DWDA).

There are serious holes in the reporting of details around patient deaths under the Oregon law.

- Ingestion status is unknown for 43 patients prescribed DWDA medications in 2015 alone. Five of these patients died, but they were lost to follow-up or the follow-up questionnaires have not yet been received. For the remaining 38 patients, both death and ingestion status are pending.¹⁰
- For about 80% of the 132 deaths from 2015 there is no information on how long it took the patient to die or whether there were complications resulting from the poison. There is information on only 27 of the 132 deaths, showing that 4 patients had complications; meaning that for 105 patients it is unknown if there were any complications following the ingestion of the poison. The number of patients with information available about the amount of time it took the patient to die is also limited with only 25 deaths having this information recorded.¹¹ This lack of reporting on the details around the deaths of patients under the Oregon scheme is clearly unacceptable, yet advocates of the Oregon law want to bring something similar to Australia.

Oregon: Reasons provided by those committing assisted suicide

Although uncontrolled pain is often seen as sufficient justification for legalised assisted suicide, and the Oregon law is held up by some euthanasia advocates as a means to address those suffering pain, **relatively few patients in Oregon mentioned pain as the reason behind why they were committing assisted suicide.** The three main reasons provided in 2015 were 'less able to engage in activities making life enjoyable' (96%); 'losing autonomy' (92%); and 'loss of dignity' (75%). **Only 28.7% said they were suffering from 'inadequate pain control or concern about it'.**¹²

Patients reported the concern of being a burden to family and friends in 57% of cases in 2012, up from 42% in 2011.¹³ This figure has varied from year to year but has not been

⁸ <http://www.worldrtd.net/sites/default/files/newsfiles/Oregon%20report%202015.pdf>

⁹ <http://www.worldrtd.net/sites/default/files/newsfiles/Oregon%20report%202015.pdf> p 2.

¹⁰ <http://www.worldrtd.net/sites/default/files/newsfiles/Oregon%20report%202015.pdf> p 2, 3.

¹¹ <http://www.worldrtd.net/sites/default/files/newsfiles/Oregon%20report%202015.pdf> p 5-7

¹² Ibid. p 6

¹³ See Hannah Graham and Jeremy Prichard (October 2013), 'Voluntary 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.

lower than 24%, in 2001, except in 1998 when it was first reported, at 12%. This points to an alarming aspect of the Oregon law. It is clear that people who already feel like they are a burden on family and friends see the Oregon law as a way of 'resolving' this.

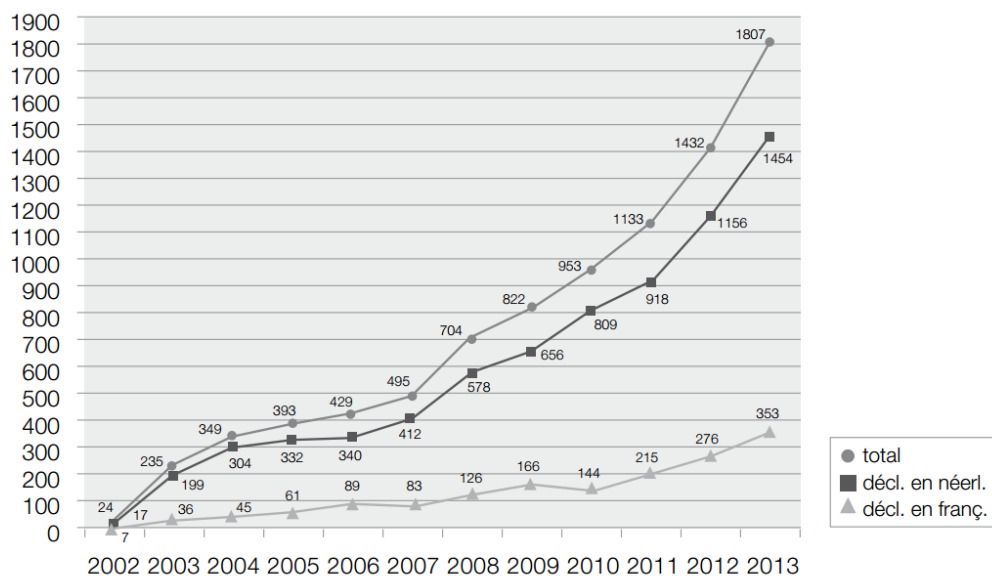
Oregon: Mental Illness

The law requires that patients be referred for psychological examination if the doctor suspects they have depression or mental illness, yet the frequency of the role of mental illness or depression in the decision to end one's life under the Oregon law is unclear, since **only 5 individuals who died by assisted suicide in 2015 were referred for psychiatric evaluation to ensure that was not their motivation.**

Belgium

The Belgian act legalizing euthanasia for competent adults and emancipated minors became law in 2002. Belgium legalized euthanasia by lethal injection for children in 2014. The graph below shows the startling increase in total number of reported euthanasia. There has been an 89% increase between 2010 (953) and 2013 (1807).

Evolution du nombre annuel d'euthanasies légales



Source: Commission Fédérale De Contrôle et D'évaluation De L'euthanasie Sixieme Rapport Aux Chambres Législatives (Années 2012-2013)¹⁴

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Various studies have reported:

- Nearly 32% of euthanasia deaths in Flanders, Belgium, occurred without explicit request or consent.¹⁵
- Only 52.8% of euthanasia deaths were reported to the authorities.¹⁶ 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”.¹⁷
- In 12% of euthanasia deaths, the life-ending drugs had been given by nurses, despite Belgian law prohibiting this.¹⁸

The Netherlands

- A 2012 report found an estimated 23% of euthanasia deaths in the Netherlands are not reported.¹⁹
- A survey of GPs in 2011 found that nearly half had “felt pressured by patients or their relatives” to use euthanasia.
- 20% of GPs surveyed said they were willing to euthanize a patient who is merely “tired of life”, despite the law requiring unbearable pain as a condition for euthanasia.²⁰
- The United Nations has expressed serious concern about the situation in the Netherlands.²¹

Conclusion

ACL hopes that palliative care will be strengthened in Tasmania. The government should provide further resources in order to allow more people to end their lives at home with appropriate palliative care in accordance with their desires.

¹⁵ 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>.

¹⁶ 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>.

¹⁷ Smets et al (2010), ‘Reporting of euthanasia in medical practice in Flanders, Belgium’, p 1.

¹⁸ 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>.

¹⁹ 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 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.

²⁰ 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.


²¹ Concluding Observations on the Netherlands (2001) Un doc. CCPR/CO/72/NET, para 5(b), <http://www.unhchr.ch/tbs/doc.nsf/0/dbab71d01e02db11c1256a950041d732>.

It is essential that good principles of health and palliative care be followed; principles that uphold the dignity of the human person in all care situations.

Any solution that intentionally seeks to end a patient's life, as a solution to suffering must be rejected as such solutions violate the inherent dignity of the patient.

ACL thanks the committee for considering this submission.

Regards,

A handwritten signature in dark ink, appearing to read 'Mark Brown', with a stylized flourish at the end.

Mark Brown
Tasmanian Director
Australian Christian Lobby