



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Submissions on End of Life Choices in the ACT

To: The ACT Select Committee
LACommitteeEOLC@parliament.act.gov.au

From: Anna Walsh

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1. Thank you for the opportunity to comment on end of life choices in the ACT. I am a lawyer who has specialized in Medical Law litigation in NSW/ACT for 15 years, and an academic completing a PhD on physicians and freedom of conscience in Australia, with a Master of Bioethics from Harvard Medical School.
2. This submission focuses on terms of reference three and four, that is, the risks to individuals and the community associated with voluntary assisted dying and whether these can be managed, and the applicability of voluntary assisted dying schemes operating in other jurisdictions. It raises several key reasons as to why legislation to permit the choice to be killed at the end life ought not be considered.
3. The central premise of euthanasia and assisted dying laws such as in Victoria and elsewhere, is that an adult patient's request to be killed ought to form part of the services of the medical profession because it cures the patient's suffering. That such acts could be contemplated in a profession that abides by the maxim, 'first, do no harm', is justified by the assurance that it will be restricted to terminally ill patients, who are deemed to have capacity to make the decision, and where there is no treatment for suffering that the patient finds acceptable.
4. In Oregon, where physician-assisted suicide has occurred for 20 years, and upon which the Victorian *Voluntary Assisted Dying Act 2017* is based, statistics demonstrate that pain relief is not the primary reason people request this service. Rather, most people have anticipatory fears about loss of autonomy and dignity, and being less able to enjoy life's activities.¹ This is an important finding because when pain is the issue, palliative care physicians have the means to control it.
5. Treatment to control the pain that accompanies terminal illness but has the foreseeable consequence of shortening the patient's life has long been ethically justified in palliative care on the basis of 'double effect reasoning.' Central to this reasoning is the *intention* of the physician.² Physicians may not intend to hasten death so as to avoid suffering. The cause of death must be the disease process itself, and the physician's action that contributes to death must be good or neutral.

¹ Oregon Death with Dignity Act: 2015 Data Summary
<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>.

² See, eg, Daniel Sulmasy and Edmund Pellegrino, 'The Rule of Double Effect' (1999) 159 *Archives of Internal Medicine* 545, 545.

6. Intention acts as a restraining hand in the preservation of professionalism and integrity in the medical profession. Where a person's death is imminent, then adequate pain relief that includes the unintended but foreseeable consequences of hastening death is permissible and consistent with the ends of medicine. Prescribing lethal substances to end the patient's life runs afoul of double effect reasoning. Euthanasia and physician-assisted suicide are part of the medical care continuum.
7. The ethical justification for permitting both the direct and indirect killing of a patient is utilitarian consequentialism. For those who subscribe to this ideology, the nature of the act itself is irrelevant to whether it is permissible. What matters is the end result and the end justifies the means. Therefore, the physician's intention is irrelevant. So too is whether or not treatment is available to effectively control pain. Instead, the principle that sits beneath state interference with medical practice is the ability of patients to choose not to have to suffer in the future.
8. Whilst physicians must respect the patient's autonomy, patients do not have a right to demand treatment from a physician that goes against the physician's deeply held views on what is moral. The recent defeat of euthanasia and physician assisted suicide in New South Wales was achieved in part by the strong and organized opposition of palliative care physicians to the Bill.³ As they note, the World Health Organization and the Australian Medical Association oppose legalizing euthanasia and physician assisted dying as healthcare. To enact legislation in the face of such opposition is imprudent and does not benefit the common good.
9. If the ACT enacts laws for euthanasia and physician assisted suicide, it must consider upon whom the burden should fall to ensure there are enough physicians willing to assess, prescribe, and administer lethal drugs to patients to meet the demand created by legislation. Whilst the ACT has human rights legislation that respects freedom of conscience, the legislation permits limitations on this freedom where it is considered reasonable in a democratic society.
10. We have seen limitations on physicians' freedom of conscience with respect to abortion. The argument that a patient is harmed by not obtaining timely lawful treatment or by encountering a physician who does not morally agree with their choice, is at the heart of is mandatory referral laws which require physicians with a conscientious objection to refer patients to physicians whom they know do not have a conscientious objection, and to perform abortion in an emergency. Contrasted against this is Victoria's *Voluntary Assisted Dying Act 2017* which recognizes physicians' right to refuse to assist with a request for death, including the provision of information. This inconsistency demonstrates a lack of logic and should be a cause of discomfort for physicians.

³ See, especially <<https://www.healthprofessionalsayno.info>>

11. Not all terminally ill people experience suffering, and not all people who suffer are terminally ill. However where relief of suffering is the key to co-opting the medical profession into assisting with suicide or administering drugs that cause death, there is no clear logic as to why it should be restricted to the terminally ill adult of a particular age. Suffering – and fear of suffering – can occur at any time in one’s life, for a multitude of reasons. Legislative safeguards restricting euthanasia and physician-assisted suicide to the terminally ill adult are arguably discriminatory. It would be unjust not to provide this service to those who are perceived to be suffering but nevertheless lack capacity to make decisions, or those who are mentally ill and lack capacity, but also suffer from a terminal illness.
12. The argument that ‘scope creep’ can be kept in check by lawmakers is hardly comforting given laws can be amended or abrogated. There is evidence from overseas countries that over time, the laws for physician assisted suicide have broadened to include euthanasia of not just the terminally ill adult, but also terminally ill children, and people who suffer from other types of illnesses that are not in themselves terminal.⁴ There is no mechanism to ensure this would not happen in the ACT. To enact permissive legislation in this area is to permit the possibility of ‘scope creep’ and all that it implies.
13. The fear of ‘legislative creep’, where permitting one kind of action increases the tendency of further ethical encroachment, is often dismissed as scaremongering. The framework for the Victorian legislation on euthanasia and physician assisted dying derives from Oregon’s *Death with Dignity Act*. Whilst it has remained stable and confined in its operation, the same cannot be said for other legal frameworks that operate in Belgium and other European countries. These have undeniably succumbed to legislative creep. Like Oregon, legislation enacted in Belgium was initially confined to terminally ill adults, however today it encompasses incurable physical and mental illness and terminally ill children.⁵
14. Even the Victorian legislation exhibits scope creep from the Organ framework. Whilst the Oregon framework is restricted to physician-assisted suicide, the Victorian legislation has gone further and extends to the direct killing of the patient by a physician or nurse where the patient is physically incapable of administering the lethal substance to him or herself. Accordingly, it is not irrational to be concerned about legislative creep. Once killing a terminally ill patient on the basis of their fear of suffering and loss of dignity is justified by society and normalized in the law, there is no logical basis upon which to restrict it to the terminally ill adult.

⁴ European Institute of Bioethics, ‘Analysis of the Seventh Report of the Federal Commission for Euthanasia Control and Evaluation to the Legislative Chambers (for the years 2014-2015)’

[www.http://eib.com](http://eib.com).

⁵Ibid.

15. Having co-opted the medical profession into prescribing and administering lethal substances to certain patients in order to cause death, and creating a legal fiction whereby the acts performed by the physician are not to be taken as assisting in a suicide, concerns exist as to whether further fictions will be created such as by requiring physicians to record the cause of the person's death in their Death Certificate as the underlying terminal illness, rather than suicide or homicide.
16. The requirement for a physician to record the cause of a person's death relates to the need for them to complete a death certificate, which can be used to gain access to benefits under insurance contracts. In addition, the facts recorded on a death certificate is used for medical research that seeks to know more about immediate, underlying and contributing causes of death. An inaccurate description of the cause of death affects the accuracy of data that ultimately impacts the community.
17. In other jurisdictions, such as Orgean, the obligation to inaccurately describe the cause of death on a legal document concerning a patient who dies via euthanasia or physician assisted suicide is justified by the rationale that it will facilitate the state's social policy to assist the beneficiaries of insurance contracts. Considered in isolation, the state's intention is arguably just, but it violates the physician's obligation to act honestly and to inform their actions by scientific evidence.
18. In jurisdictions that permit euthanasia and physician assisted suicide, penalties usually exist for physicians who fail to follow the safeguards in the law. However there is usually a 'closed reporting' system, with heavy reliance upon the honesty of the physician. Unfortunately, experience from overseas demonstrates that even with the addition of penalties for failing to report, under reporting continues to occur, especially where the death involved euthanasia by the physician⁶
19. In Victoria, its legislation creates a 'Voluntary Assisted Death Review Board' that reviews each suicide or death, and has power to require people to provide information or records, make recommendations on policy and practice, and can refer the matter to any other person or body for investigation. However experience from overseas demonstrates that even with such boards, referral of physicians to the police for non-compliance with the law, rarely, if ever, occurs.⁷ Hence, simply having a Review Board is an insufficient safeguard to protect the public from harm. It lends itself to unscrupulous physicians falsifying evidence or simply failing to report such deaths.

⁶ Ibid.

⁷ J. Ezekiel, D. Emanuel Bregje, John W. Onwuteaka-Philipsen et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Europe and Canada' (2016) 316(1) *Journal of American Medical Association* 79, 81. The authors note that in over 10 years of physicians assisted suicide, only one case as been referred to the police prosecutor in Belgium and in the Netherlands, whilst 75 cases have been forwarded to the Public Prosecutor for non-compliance with legal safeguards, none have proceeded to prosecution to date.

20. In Victoria's legislation, as with Oregon, there is no requirement as to when the patient must self-administer the lethal substances. Whilst in Victoria, physicians can administer the substances to the patient unable to do so due to infirmity, it is also open to a third party to do so, given it requires no particular medical skill. Coercion is a real issue that seems impossible to protect against.
21. For a healthcare option enshrined in the law, it is reasonable for the community to expect that the drugs used to cause death are safe and efficacious. The Victorian Legislation will come into effect in July 2018. It has deferred the making of regulations for the use of drugs for euthanasia and physician assisted suicide, as well as the training of doctors and medical students to perform this 'health service'.
22. The approval of new drug combinations for suicide, or indeed the development of new drugs intended to kill people, is subject to federal and state legal legislation as well as stringent ethical guidelines.⁸ The Therapeutic Goods Administration is an arm of the Department of Health and Ageing and ensures that drugs supplied, imported, exported, manufactured or advertised for use are appropriate for health.⁹ Drugs appropriate for health are those intended for diagnosis, cure, mitigation, treatment or prevention of disease, ailment, defect, or injury.¹⁰
23. Accordingly if approved, drugs intended to cause death would broaden this definition of health. For prescribed drugs, the TGA must be satisfied that there is sufficient data from trials on human that prove the drugs do what they are intended to do. Ethical guidelines require that drug trials be approved and overseen by a medical facility's Human Research Ethics Committee.¹¹ Theoretically, for a death drug trial, participants must be aware that death from taking the drugs cannot be assured, let alone a quick and painless death from taking the drugs. It is hard to imagine that clinical trials on humans to develop death drugs would meet ethical guidelines.
24. The alternative for physicians is prescribing 'off-label', meaning to prescribe drugs to the patient that have been approved by the TGA, but not for the purpose intended by the physician. Despite the common practice of prescribing 'off-label', there is little guidance for physicians. An 'off-label' prescription for any drug must still be based on reasonable evidence, and the physician must have fully informed consent from the patient. The pharmacokinetics and pharmacodynamics of drugs varies significantly between people. A painful, slow death caused by the drug is unconscionable. Without the benefit of data from clinical trials, knowledge that certain drugs will kill the particular patient humanely is limited. A physician's immunity from liability for acts carried out in good faith to fulfill a lawful suicide request places the public at risk and there is no way to rectify this flaw.

⁸ See, *Therapeutic Goods Act 1989* (Cth); *Poisons and Therapeutic Goods Act 1966* (NSW); National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007).

⁹ *Therapeutic Goods Act 1989* (Cth) s 4(1).

¹⁰ *Therapeutic Goods Act 1989* (Cth) s 3.

¹¹ National Health and Medical Research Council, 'National Statement on Ethical Conduct in Human Research (2007)' General Guidance Section 2, see especially 2.33-2.38, 2.44, 12.

Conclusion

25. Euthanasia and physician assisted suicide cannot operate merely as a narrow exception in the law. An unavoidable consequence of re-defining suicide is its flow on effects regarding the broadening of the terms health, harm and injury in medicine and other areas of the law that regulate medical practice. As such, justice demands that lawmakers be made aware, and consider, the wider impact of such laws on healthcare in the community.
26. There are many other concerns not addressed in this submission about legalizing the ability to not just choose a quick death at the end of life, but to embed it into the practice of medicine as ‘standard of care’. Suffice it to say, it is unrealistic to assume that legalizing euthanasia and physician-assisted suicide can be placed in a special, controlled box in order to appease those frightened of suffering associated with ill health or terminal illness. Even were it not to be used with frequency, its legalization would create a massive shift in the principles and practice of medicine, and what affects medicine, affects the community.
27. Changes to principles, once embedded into the law, and normalized in society, provide a platform for future reforms that can easily broaden the content and scope of the law to encompass the notions of voluntary and involuntary euthanasia, which has been the general trend in Europe. Physician-assisted suicide and euthanasia are moral and medical issues. Putting aside the emotion that accompanies this discussion, your recommendations should be cast for an ideology you believe will best serve the medical profession, that will produce good fruit in terms of its consequences, and that promotes the kind of moral positions you believe will help society flourish.

Dated: 26 March 2018

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