



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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Submission
to the
Select Committee on End of Life Choices in the ACT
by
Dr Rachel Carling-Jenkins MLC, Member for Western
Metropolitan (Parliament of Victoria)

1. The terms of reference for your inquiry into End of Life Choices in the ACT include “*the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme*” [Terms of Reference 4].

I, along with seventeen of my parliamentary colleagues, voted against the *Voluntary Assisted Dying Bill 2017* on its third reading in the Legislative Council of the Parliament of Victoria. Sadly we needed only two more votes against the Bill to defeat it.

It may be helpful for your committee to consider the reasons why I, and so many of my colleagues, opposed a Bill to legalise assisted suicide and euthanasia.

These reasons will also address the third term of reference for your inquiry: “*risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed*”. This submission will argue that proposals for legalising assisted suicide and euthanasia, including the scheme to be established in Victoria by the *Voluntary Assisted Dying Act 2017*, pose an unacceptable risk to individuals and the community that cannot be managed because the risks are inherent in the proposed fundamental change to the law on murder and assisted suicide which currently protects everyone.

My perspective on proposals for euthanasia and assisted suicide is informed by 20 years’ experience in the disability field, a PhD in disability rights and the lived experience of disability.

Fundamental change to the law on murder and assisting suicide

Section 12 (1) (a) of the *Crimes Act 1900* (ACT) provides that “*A person commits murder if he or she causes the death of another person intending to cause the death of any person*”.

The absolute prohibition (putting aside war and self-defence) on doing any act with the intention of causing the death of any person is fundamental to a well-ordered society.

The prohibition on inciting, counselling, aiding or abetting any person to commit suicide (Section 17 of the *Crimes Act 1900*) is a necessary corollary of the law against murder.

Victoria's *Voluntary Assisted Dying Act 2017* undermines the protection the law gives to every Victorian by making lawful acts intended to directly cause the death of a person (euthanasia) or to assist a person's suicide.

Any similar legislation would do the same in the ACT.

This would be a very profound change to the law. It would divide the community into two categories - those people who would continue to have the intrinsic value of their lives reflected in the law which would prohibit them being murdered or incited, counselled or aided to kill themselves and those people whose lives were deemed "not worth living" and who could be legally killed by a doctor administering a lethal substance to them or assisted to kill themselves by self-administering a lethal substance prescribed by a doctor.

Deadly discrimination

In my second reading speech against the *Voluntary Assisted Dying Bill 2017* I addressed the deadly dangers that legalising euthanasia and assisted suicide poses to people in living with disabilities. My remarks apply to any proposal for legalising euthanasia and/or assisted suicide.

As an expert in disability with 20 years' experience in the field, a PhD in disability rights and lived experience, I feel that I must address the disability perspective of this bill. This bill sends a dark, discouraging, even disastrous message to many people with disabilities. This message is that your life — our lives — are not worth living, that we are better off dead than that kind of disabled and that the way to solve society's problems is to once again put us out of sight and out of mind, an archaic message that we have been fighting against for decades through the disability rights movement. This bill sets our movement back.

All we must do to qualify for this bill is to be in suffering. Yet this bill lacks any real definition of suffering, which is personal, subjective and above all situational. In Oregon, for example, some people who have taken up suicide have identified their suffering as coming from the financial cost of their treatment. Randy Stroup and Barbara Wagner were both told by their health insurers that the cancer treatment proposed for them by their doctors was not covered, but assisted suicide drugs were.¹ Another kind of suffering mentioned by half of all people in Oregon accessing assisted suicide is their concern about being a burden to family, friends or caregivers.² This is

¹ Susan Donaldson James, "Death drugs cause uproar in Oregon:", ABC News, August 6, 2008, <http://abcnews.go.com/Health/story?id=5517492#.Ty9-VsXy8sl> ; Dan Springer, "Oregon Offers Terminal Patients Doctor-Assisted Suicide Instead of Medical Care", July 28, 2008, <http://www.foxnews.com/story/0,2933,392962,00.html>

² Oregon Public Health Division, *Oregon Death With Dignity Act: Data Summary 2016* <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>

a very disturbing reason to choose to die. And I need to say here that people with disabilities are often led to feel guilty about the burden of their disability on others. This is a common reason to take up the offer of assisted suicide. Does anyone else see the warning signs here?

Others cite a decreasing ability to participate in activities that make life enjoyable, like, 'I can't play golf anymore' or 'I can't cook for my family anymore', and the loss of control of bodily functions such as incontinence or needing assistance to eat. These can all be part of the lived experience for people with disabilities. The late Stella Young, the comedian and disability activist who was a fierce opponent of euthanasia and assisted suicide laws, said this:

Before we can talk about death with dignity, we need to ensure that all people, regardless of age or disability, can live with dignity. We're not there yet.³

I agree with Stella Young. We are not yet there yet. In fact we are a long way from there.

On 10 August this year a group of women with disabilities visited our Parliament and met with MPs to express their grave concerns about this bill.⁴ Kelly Cox, a woman with muscular dystrophy, described how she cannot even access regular Pap smears due to the physical inaccessibility of beds and how she is at greater risk of dying of cancer because of this disparity. She posed the question: should she be happy because if she does get cancer, she has an equal right to assisted suicide? Kelly also shared the testimony of a person with cystic fibrosis, who for family reasons wished to remain anonymous. This person said, and I quote:

"In my experience — as a person with a lifelong terminal condition and a transplant recipient who was given 12 months to live while on the waiting list — there are no clear lines around ideas of choice, of dignity, of pain, of coercion, even of suffering.

Cultural attitudes to terminal illness are underpinned almost entirely by benign pity, and our default discourse both reflects and reinforces this: unbearable, helpless, without hope, suffering, inevitable, tragic, and incurable.

These are the words I have heard my whole life to describe my life and prospects.

They also, without coincidence, form the technical language of qualifying criteria for the euthanased.

Until our culture can stop defining my life — my healthy, thriving life — with the same terms as it uses to justify reasons to choose death, I will not feel safe from social and internalised coercion to make free choices. Until we look deeply at our attitudes

³ Stella Young, "Disability a fate worse than death?", Ramp Up, 18 Oct 2013, <http://www.abc.net.au/rampup/articles/2013/10/18/3872088.htm>

⁴ Disability advocates tell Victorian MPs why they oppose assisted suicide and euthanasia http://www.no euthanasia.org.au/disability_advocates_tell_victorian_mps_why_they_oppose_assisted_suicide_and_euthanasia

towards disability and terminal illness, I do not yet feel ready to have this legislation imposed upon me."⁵

*This testimony profoundly illustrates just how dangerous this bill could be for people living with disabilities. They may at various stages in their lives meet the criterion of having less than 12 months to live. Life with a disability can often be repeatedly precarious. It is unthinkable that every time a Victorian living with a disability faces such a precarious phase in their life journey they should be presented with the choice of state-sanctioned suicide or euthanasia.*⁶

I note that the Victorian Bill was amended to reduce the eligibility criteria from “*not less than 12 months to live*” to “*not less than 6 months to live*”. In my view this remains insufficient to protect people living with disabilities from the dangers I addressed in my second reading speech.

Whether proposed legislation applies as in Oregon only to people with less than 6 months to live, or as in Belgium and the Netherlands to any person suffering unbearably, people with disabilities, as well as people with mental illnesses, remain at risk.

I note that in Belgium and the Netherlands euthanasia has been performed on the grounds of a person suffering from autism, anorexia, borderline personality disorder, alcoholism, bipolar disorder, diminished vision, deaf-blindness, post-traumatic stress disorder following sexual abuse, and failed “gender reassignment”.

In relation to Oregon, A Swedish researcher, Fabian Stahle, recently elicited from the Oregon Health Authority confirmation that although the Oregon Death With Dignity Act refers to “*an incurable and irreversible disease*” this phrase is interpreted as taking account of a person’s treatment decisions, and even of the unavailability of a treatment that could cure or reverse the disease due to its cost or a refusal by a health insurer to fund it.⁷

The 2016 Oregon annual report confirms, for example, that diabetes has been given as the grounds for assisted suicide.⁸

⁵ Disability testimony – No clear lines

http://www.no euthanasia.org.au/disability_testimony_no_clear_lines

⁶ [http://hansard.parliament.vic.gov.au/?IW_INDEX=Hansard-2017-2&IW_FIELD_TEXT=SpeechIdKey%20CONTAINS%20\(2-11-2017_council_40\)%20AND%20OrderId%20CONTAINS%20\(0\)&LDMS=Y](http://hansard.parliament.vic.gov.au/?IW_INDEX=Hansard-2017-2&IW_FIELD_TEXT=SpeechIdKey%20CONTAINS%20(2-11-2017_council_40)%20AND%20OrderId%20CONTAINS%20(0)&LDMS=Y)

⁷ Fabian Stahle, *Oregon Health Authority Reveals Hidden Problems With the Oregon Assisted Suicide Model*, Jan 2018,

<https://drive.google.com/file/d/1xOZfLFrvuQcaZfFudEncp2b18NrUo/view>

⁸ Oregon Public Health Division, *Oregon Death With Dignity Act: Data Summary 2016* footnote 2 on p.11,

Undermining suicide prevention

I note that, like Victoria, the ACT currently has a program that aims to prevent suicide for all Canberrans – Let’s Talk – For Suicide Prevention. It’s key message is that there is always hope. The program recognises poor physical or mental health as a risk factor for suicide that needs to be addressed not as a reason to offer to help a person kill themselves.

In Victoria, prior to the passage of the *Voluntary Assisted Dying Bill 2017*, the suicide prevention strategy applied to all Victorians who may be contemplating suicide. After 19 June 2019, when the Act is scheduled to come into full effect, the suicide prevention strategy would only apply to Victorians who are ineligible for assisted suicide.

Legalising assisted suicide or euthanasia in the ACT would similarly narrow the focus of your positive suicide prevention initiative.

Death by mistake

Unless you believe that medical practitioners are infallible then it is self-evident that legalising euthanasia and assisted suicide must of necessity lead to deaths by mistake.

That is to say, some Canberrans will be killed by euthanasia following a mistaken diagnosis. Evidence from both New Zealand and Australia suggests an error rate of at least ten percent.⁹

In other cases the prognosis may be mistaken.

We all know people who have outlived a prognosis of death by a year or more. Jeanette Hall who was assessed in Oregon in 2000 as having less than six months to live and therefore eligible for assisted suicide is still alive today and happy to be alive.¹⁰

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>

⁹ Stacey Kirk, “Euthanasia too final when the risk of error is too great – Doctors”, Stuff, 14 Sep 2016, <http://www.stuff.co.nz/national/politics/84252580/euthanasia-toofinal-when-the-risk-of-error-is-to-great-doctors> ; Alice Uribe, “Doctors mis-diagnose 1 in 10, says insurer”, Australian Financial Review, 28 Aug 2017, <https://amp.afr.com/business/insurance/insurance-companies/mlc-life-to-expand-best-doctors-service-20170827-gy4zfk>

¹⁰ Kenneth Stevens “Doctor helped patient with cancer choose life over assisted suicide”, *Missoulian*, 27 November 2012, http://missoulian.com/news/opinion/mailbag/doctor-helped-patient-with-cancer-choose-life-over-assisted-suicide/article_63e092dc-37e5-11e2-ae61-001a4bcf887a.html

Jeanette’s Story: 15 Years Later, <https://www.youtube.com/watch?v=84SsQef3B7E>

Treatment may be available but not offered to the person because the medical practitioners assessing the person for euthanasia or assisted suicide are not specialists in the person's medical condition.

In still other cases a person could have been helped to live their last months or weeks of lives without unbearable suffering but they were not given gold standard palliative care.

Certainly in the Victorian context this is a major issue as Palliative Care Victoria has estimated that 10,000 Victorians die each year without receiving appropriate palliative care.¹¹

Death by malice

As well as deaths by mistake any system of legalised euthanasia and assisted suicide is wide open for abuse by those with malicious motives for causing the premature death of a person.

In my second reading speech on the *Voluntary Assisted Dying Bill 2017* I addressed the issues of elder abuse, undie influence and coercion.

Seniors Right Victoria has on its website some useful information for lawyers to assist older clients at risk of financial abuse.

Relevant to this Bill, they make the point that "A person may be subject to undue influence or unconscionability whether or not they have the capacity to make their own decisions."¹²

It is difficult to see how a doctor will identify signs of undue influence in a single assessment, perhaps meeting the person for the first time, and never seeing the person with the family members or others who may be exerting the undue influence.

¹¹ Palliative Care Victoria, "Estimated Need and Unmet Need for Palliative Care in Victoria , 9 October 2017, <https://dr892t1ezw8d7.cloudfront.net/wp-content/uploads/2017/10/Unmet-Need-for-Palliative-Care-PCV-9-October-2017.pdf>

¹² <https://assetsforcare.seniorsrights.org.au/lawyers-role/professional-duties/re-capacity-and-influence/>

Interestingly Seniors Rights Victoria identifies illness and infirmity as factors that leave elderly people more vulnerable to undue influence.

Additionally, being physically or emotionally dependent on another person or relying on a family member for the basic necessities of life are listed as vulnerabilities.

In Oregon and Washington the annual reports on assisted suicide for 2016 each report that about half of those who are prescribed lethal drugs for assisted suicide cite concerns about "being a physical or emotional burden on family, friends, or caregivers" as a reason for committing suicide.¹³

Elder law expert from Washington State, Margaret Dore comments on this data:

"In both Washington and Oregon, the official reporting forms include a check-the-box question with seven possible "concerns" that contributed to the lethal dose request. These concerns include the patient's feeling that he was a "burden." The prescribing doctor is instructed: "Please check 'yes,' 'no,' or 'don't know' depending on whether or not you believe that a concern contributed to the request."

In other states, a person being described as a "burden" is a warning sign of abuse.

For example, Sarah Scott of Idaho Adult Protection Services describes the following "warning sign": "Suspect behaviour by the caregiver . . . [d]escribes the vulnerable adult as a burden or nuisance." The recommendation is that when such "warning signs" exist, a report should be made to law enforcement and/or to the local adult protective services provider.

Washington and Oregon, by contrast, instruct its doctors to check a "burden" box. Washington and Oregon promote the idea that its citizens are burdens, which justifies the prescription of lethal drugs to kill them.

Washington's and Oregon's Acts do not promote patient "control," but officially sanctioned abuse of vulnerable adults."¹⁴

If undue influence is found to have led to the financial abuse of an elderly person then there is a legal remedy of rescission where the contract is nullified and the parties restored to the positions they would have had if the contract had not been made.

¹³Oregon Public Health Division, *Oregon Death With Dignity Act: Data Summary 2016*

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>

Washington State Department of Health *2016 Death with Dignity Act Report*, p. 9, <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2016.PDF>

¹⁴ Dore, Margaret K. (2010) "'Death With Dignity': A Recipe for Elder Abuse and Homicide (Albeit Not by Name)," *Marquette Elder's Advisor*: Vol. 11: Iss. 2, Article 8. <http://scholarship.law.marquette.edu/elders/vol11/iss2/8>

*There is no remedy for the victim of undue influence who is led to commit suicide.*¹⁵

British neurosurgeon Henry Marsh has argued that “*if a few grannies get bullied into it [assisted suicide/euthanasia] isn't that the price worth paying for all the people who could die with dignity?*”¹⁶

I reject categorically the idea that we can accept the bullying to death of elderly, sick, disabled and mentally ill people as collateral damage necessary to allow less vulnerable people fixated with a sense of entitlement the indulgence of arranging their deaths at a time of their choosing.

State authorised killing reintroduced

Victoria abolished the death penalty in 1975. I note that there has never been an execution in the Australian Capital Territory and the death penalty was abolished by the Commonwealth's *Death Penalty Abolition Act 1973*.

One of the reasons for abolishing the death penalty is the consideration that it is not possible to create an error-free judicial system. This necessarily means that in a legal system with the death penalty there is a real risk that innocent people will be put to death.

It should be obvious that the very same consideration should be applied to proposals for legalised euthanasia and assisted suicide.

It is not possible to create an errorfree health system. This necessarily means that in a health system with legalised euthanasia and assisted suicide there is a real risk that people will wrongly be put to death (wrong diagnosis, wrong prognosis, suffering that was relievable, request was not voluntary).

Another reason for abolishing the death penalty is the notion that it is simply wrong for a civilised state to authorise the direct killing of a person in cold blood (that is outside of the context of a defensive war).

If Victoria's *Voluntary Assisted Dying Act 2017* comes into effect as scheduled on 19 June 2019 then from that date a medical practitioner will be empowered to apply to the Secretary of the Department of Health and Human Services (or any public servant to whom the Secretary has delegated the relevant power) for a VADPAP - a voluntary assisted dying practitioner administration permit.

¹⁵ [http://hansard.parliament.vic.gov.au/?IW_INDEX=Hansard-2017-2&IW_FIELD_TEXT=SpeechIdKey%20CONTAINS%20\(2-11-2017_council_40\)%20AND%20OrderId%20CONTAINS%20\(0\)&LDMS=Y](http://hansard.parliament.vic.gov.au/?IW_INDEX=Hansard-2017-2&IW_FIELD_TEXT=SpeechIdKey%20CONTAINS%20(2-11-2017_council_40)%20AND%20OrderId%20CONTAINS%20(0)&LDMS=Y)

¹⁶ Z. Chustecka, “Renowned Neurosurgeon on Assisted Dying and His 'Suicide Kit'” Medscape, Apr 27, 2017, <http://www.medscape.com/viewarticle/879187>

A VADPAP will specify the name of the person to be killed, the name of the doctor who will do the killing and the specific deadly means to be used.

It will, by then, have been over 52 years since the State of Victoria last authorised the direct killing of a person, when the State Executive Council, led by Sir Henry Bolte, authorised the death by hanging of Ronald Ryan on 3 February 1967.



BERLIN, den 1. Sept. 1939.

Reichsleiter Bouhler und
Dr. med. Brandt

sind unter Verantwortung beauftragt, die Befugnisse wesentlich zu bestimmender Ärzte so zu erweitern, dass nach menschlichem Ermessen unheilbar Kranken bei kritischer Beurteilung ihres Krankheitszustandes der Gnadenstich gewährt werden kann.

Das Bescheid mir
übergeben am 28.8.40
Dr. Gierke

The VADPAP will be the first official government permit authorising the euthanasia of a particular person by a particular doctor since those issued by Reich Leader Bouhler and Dr Brandt under the decree of 1 September 1939, signed by Reich Chancellor Adolf Hitler which reads:

Reich Leader Bouhler and Dr Brandt are charged with the responsibility for expanding the authority of physicians, to be designated by name, to the end that patients considered incurable according to the best available human judgement of their state of health, can be granted a mercy death.

I am ashamed and appalled that Victoria is heading down this path.

If the assisted suicide or euthanasia were ever to be legalised in the ACT then the first Canberran to die under that law would be the first person to be killed with the approval of the government of the ACT.

Section 23 (1A) of the Australian Capital Territory (Self-Government Act) 1988

This section reads:

The Assembly has no power to make laws permitting or having the effect of permitting (whether subject to conditions or not) the form of intentional killing of another called euthanasia (which includes mercy killing) or the assisting of a person to terminate his or her life.

This is a very fine provision as it reflects the truth that no elected assembly has an inherent right to make a law permitting the intentional killing of those we are elected to govern.

When the Western Australian Legislative Council debated the *Voluntary Euthanasia Bill 2010*, Australian Labor Party MLC, the Hon Helen Bullock succinctly said:

The Voluntary Euthanasia Bill raises the question of whether our election to Parliament gives us the right to sanction the killing of other human beings in circumstances other than self-defence or the defence of the nation. This is not a difficult question. The

*answer is simple. No. We do not have such a right. We do not have the right to sanction the killing of our fellow human beings. For that reason alone, I oppose the bill.*¹⁷

Some submissions to your inquiry may suggest that, regardless of one's views on assisted suicide or euthanasia in themselves, the introduction of Section 23 (1A) into the *Australian Capital Territory (Self-Government) Act 1988* by the passage of the *Euthanasia Laws Act 1997* through the Commonwealth Parliament was an affront to the ACT's right to self-government and should be removed from the *Australian Capital Territory (Self-Government) Act 1988* on that ground alone.

A similar issue arose in the famous debates between Abraham Lincoln and rival candidate for the Senate for Indiana, Judge Douglas, who supported the "right" of territories seeking admission to the union to choose to have laws permitting slavery. In the sixth debate Lincoln said:

*When Judge Douglas says that whoever or whatever community wants slaves, they have a right to have them, he is perfectly logical if there is nothing wrong with the institution; but if you admit that it is wrong, he cannot logically say that anybody has a right to do wrong.*¹⁸

Lincoln believed that slavery was wrong and so refused to agree with Judge Douglas that a territory could have the right to choose to have laws permitting slavery.

The question then is whether a law permitting euthanasia or assisted suicide can ever be a good law. If such a law can never be a good law but would always be wrong then no one can logically say that the ACT Legislative Assembly has an inherent right to make such a law.

Section 23 (1A) does not offend against the ACT's right to self-government as it simply expresses a truth that every elected assembly of legislators should acknowledge, as the Hon Helen Bullock did, – "*we have no right to make a law sanctioning the killing of other human beings in circumstances other than self-defence or the defence of the nation*".

Conclusion

I concluded my second reading speech on the *Voluntary Assisted Dying Bill 2017* as follows:

¹⁷ WA Legislative Council, Hansard, 22 Sep 2010, p. 7028, [http://parliament.wa.gov.au/Hansard/hansard.nsf/0/F4D0DAF694383D55482577AC002FC52B/\\$file/C38%20S1%2020100922%20All.pdf](http://parliament.wa.gov.au/Hansard/hansard.nsf/0/F4D0DAF694383D55482577AC002FC52B/$file/C38%20S1%2020100922%20All.pdf)

¹⁸ Lincoln A, Sixth Joint Debate with Judge Douglas, Quincy, October 13, 1858, <http://www.bartleby.com/251/61.html>

This bill immediately places the elderly, sick and the most vulnerable, under intolerable pressures. Over time, despite its current intent to assist a few rational people to die, the changes in attitude it signals will undermine society's support for the lives of the voiceless and those most in need. It should be rejected.

So where does this leave us? People will die unnecessarily if this bill passes. People will die prematurely if this bill passes. People will die unnaturally if this bill passes. People will die. I will end with the quote [from Martin Luther King Jr] I started with at the beginning:

“Injustice anywhere is a threat to justice everywhere ... Whatever effects one directly, affects all indirectly.”

To pass this bill would be a grave injustice to all Victorians, especially the vulnerable.

To pass this bill would be a betrayal of our responsibility to uphold the common good.

To pass this bill would be a tragedy of unimagined proportions.

I do not commend this bill to the house, and I will not be voting for this bill.¹⁹

With the same sentiments I strongly urge the committee to recommend that the ACT do nothing to pursue legalising assisted suicide or euthanasia.

¹⁹ [http://hansard.parliament.vic.gov.au/?IW_INDEX=Hansard-2017-2&IW_FIELD_TEXT=SpeechIdKey%20CONTAINS%20\(2-11-2017_council_40\)%20AND%20OrderId%20CONTAINS%20\(0\)&LDMS=Y](http://hansard.parliament.vic.gov.au/?IW_INDEX=Hansard-2017-2&IW_FIELD_TEXT=SpeechIdKey%20CONTAINS%20(2-11-2017_council_40)%20AND%20OrderId%20CONTAINS%20(0)&LDMS=Y)