



Australian
CareAlliance

“Care and Compassion: Opposing Assisted Suicide.”

Submission to

the Royal Commission into Aged Care Quality and Safety

prepared by Richard Egan for the Australian Care Alliance

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The [Australian Care Alliance](#) was formed in March 2018 by health professionals, lawyers and community activists who had worked together informally to oppose the passage of the *Voluntary Assisted Dying Bill 2017* through the Parliament of Victoria.

It is the considered position of the Australian Care Alliance, based on all the available evidence, that [none of the sixteen jurisdictions](#) that have legalised euthanasia and/or assisted suicide have succeeded in establishing a safe and compassionate framework for assisted suicide and euthanasia.

The Alliance has identified [eleven categories of wrongful deaths](#) that have or can occur under any scheme so far proposed which legalises assisted suicide and/or euthanasia.

These categories of wrongful death include three categories of direct relevance to the Royal Commission:

- The wrongful death of elderly persons who are subtly or overtly coerced by family members or carers into requesting assisted suicide or euthanasia;
- The wrongful death of persons with dementia, who are killed by euthanasia or assisted suicide while unable to give consent.
- The wrongful death of persons with disabilities who are affirmed by family members, doctors or society as being “better off dead”.

This submission addresses risks to the safety of elderly persons and persons with disabilities in the aged care system from the coming into effect of the *Voluntary Assisted Dying Act 2017* in Victoria on 19 June 2019 and from proposals for similar legislation currently being considered in Western Australia, Queensland, South Australia and Tasmania.

Based on our analysis of these risks the Australian Care Alliance makes the following three recommendations:

Recommendation 1: The Royal Commission should recommend that regardless of the law of any State or Territory permitting assisted suicide or euthanasia the *Aged Care Act 1997* be amended to prevent any assessment directed at possible authorisation of an act of assisted suicide or euthanasia or any storage or use of a lethal substance for the purpose of assisted suicide or any act of euthanasia to take place while a person is on the premises of a residential aged care facility or as part of the provision of home care.

Recommendation 2: (if recommendation 1 is not adopted) The Royal Commission should recommend that regardless of the law of any State or Territory permitting assisted suicide or euthanasia the *Aged Care Act 1997* be amended to ensure that providers of residential or home care can effectively prevent any assessment directed at possible authorisation of an act of assisted suicide or euthanasia or any storage or use of a lethal substance for the

purpose of assisted suicide or any act of euthanasia to take place on the premises of a residential aged care facility under their control or as part of their provision of home care.

Recommendation 3:

The Royal Commission should reject any proposal that it recommend any steps towards the legalisation of assisted suicide or euthanasia as an advancement of person-centred care or allowing people to exercise greater choice, control and independence in relation to their care.

These recommendations and this submission are relevant to several elements of the Royal Commission's Terms of Reference as indicated by the bolding below:

- a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, **including mistreatment and all forms of abuse**, the causes of any systemic failures, and any actions that should be taken in response;
- b. how best to deliver aged care services to:
 - i. **people with disabilities residing in aged care facilities, including younger people**; and
 - ii. the increasing number of Australians **living with dementia**, having regard to the importance of dementia care for the future of aged care services;
- c. **the future challenges and opportunities for delivering** accessible, affordable and **high quality aged care services in Australia**, including:
 - i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - ii. in remote, rural and regional Australia;
- d. what **the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are** of high quality and **safe**;
- e. how to ensure that aged care services are **person-centred**, including **through allowing people to exercise greater choice, control and independence in relation to their care**, and improving engagement with families and carers on care-related matters;
- f. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;
- g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

Elder abuse, assisted suicide and euthanasia

- Assisted suicide and euthanasia laws usually require that a request be voluntary and free of coercion. To be truly voluntary a request would need to be not just free of overt coercion but also **free from undue influence, subtle pressures and familial or societal expectations**.
- A regime in which assisted suicide is made legal, and in which the decision to ask for assisted suicide is positively affirmed as a wise choice, in itself creates a framework

in which a person with low self-esteem or who is more susceptible to the influence of others may well express a request for assisted suicide that the person would otherwise never have considered.

- Elder abuse, including from adult children with “*inheritance impatience*” is a growing problem in Australia. This makes legalising assisting suicide unsafe for the elderly.
- Evidence from jurisdictions that have legalised assisted suicide or euthanasia shows that coercion, including the feeling of **being a burden on others, is a real problem.**
- Some supporters of assisted suicide **don’t care if some people are bullied into killing themselves** under an assisted suicide law.

Oregon and Washington

The data from [Oregon](#)¹ shows that in 2018 more than half (54.2%) of those who died from prescribed lethal drugs cited concerns about being a “*Burden on family, friends/caregivers*” as a reason for the request. For a further 14.9% of cases (nearly one in seven cases) the attending physician reported not knowing if the person who requested lethal medication and subsequently died after ingesting had a concern about physical or emotional burden on family, friends or caregivers.

[ORS 127.815](#) sets out as the very first responsibility of an attending physician under the Death With Dignity Act a duty to “*Make the initial determination of whether a patient has a terminal disease, is capable, and has made the request voluntarily*”

How can a physician come to a firm conclusion that a person is voluntarily requesting lethal medication in order to end their lives without exploring whether or not the person is motivated by a concern about the physical or emotional burden on family, friends or caregivers.

Surely such a discussion is necessary to exclude any possibility that the person is making the request under duress, subject to coercion or undue influence from a family member or caregiver.

Additionally, in the absence of such a discussion there may be a missed opportunity to relieve the person’s concern about being a burden by arranging respite for family caregivers or additional care or support.

If the 14.9% of cases where the attending physician does not even bother exploring this issue with a person before writing a prescription for lethal medication are added to the 54.2% of cases in 2018 where the attending physician reports knowing that the person had a concern about the physical or emotional burden on family, friends or caregivers then in nearly seven out of ten cases (69.1%) concern about being a burden is or maybe a factor in a request for lethal medication.

¹ <https://www.australiancarealliance.org.au/oregon>

Similarly in the State of [Washington](#)² in 2017 significantly more than half (56%) of those who died by assisted suicide cited concerns about being a burden on family, friends or caregivers as a reason for requesting assisted suicide.

Does the concern about being a burden originate from the person or is it generated by subtle or not so subtle messages from family, friends and caregivers - including physicians - who find the person to be a burden or a nuisance or just taking too long to die?

[Elder law expert Margaret Dore comments:](#)

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 behavior 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.³

Belgium

Claire-Marie Le Huu-Etchecopar is a French nurse who has worked in Belgium since 2008. She [has written about her experience with euthanasia in Belgium](#).

She describes the actions of the friends of a patient:

Those close to her are locked in the emotion of seeing their friend disabled. They cannot bear to see her different. Any other solution than euthanasia seems unimaginable to them. In a small notebook where they leave her messages while

² https://www.australiancarealliance.org.au/washington_state

³ <http://scholarship.law.marquette.edu/elders/vol11/iss2/8>

she's sleeping, the question of euthanasia is on every page. You can read words such as:

Do not forget your euthanasia, it is your right, you have to ask the doctors or they'll never do it for you...⁴

Elder abuse in Australia

Undue influence is increasingly being seen as a relevant factor in the financial abuse of elders.

Seniors Rights Victoria provides [a useful summary of case law and best practice on undue influence](#) in the financial abuse of elders.⁵

It is clear from this summary that undue influence can easily be missed and may be difficult to identify. Of course, the courts can apply the remedy of rescission if it is established. In the case of assisted suicide a failure to spot undue influence before writing a prescription for a lethal dose will be incapable of remedy once the lethal dose is ingested.

A [parliamentary report on Elder Abuse in New South Wales](#) also referenced the failure of professionals to identify undue influence and so unwittingly facilitate elder abuse.⁶

It cites the Council on the Ageing NSW as observing that the *NSW Interagency policy on preventing and responding to abuse of older people*:

does not address the more common cases where elder abuse is perpetrated by a family member or carer 'in an environment of isolation, dependence and undue influence'. (para 5.13 on p. 54)

The report also notes that:

Capacity Australia observed that financial abuse is often fueled by ignorance and family conflict, as well as 'inheritance impatience'. It further noted that undue influence by one family member over another is commonly facilitated by legal professionals because of their failure to detect when an older person is struggling to manage their financial affairs, that is, when they lack financial capacity. (para 6.6 on p. 80)

As long ago as 1885 in what is still cited in Australian law as the leading case on undue influence, [Sir James Hannen described some of the kinds of subtle coercion](#) that a frail, elderly or ill person may be subjected to that could be hard for any outside person to detect.

⁴ <http://alexschadenberg.blogspot.com.au/2014/05/lifting-veil-on-euthanasia-what-really.html>

⁵ <https://assetsforcare.seniorsrights.org.au/relationship-breaks-down/equity/undue-influence-unconscionable-dealing/>

⁶ <https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%252044%2520-%2520Elder%2520abuse%2520in%2520New%2520South%2520Wales.pdf>

*The coercion may of course be of different kinds, it may be in the grossest form, such as actual confinement or violence, or a person in the last days or hours of life may have become so weak and feeble, that a very little pressure will be sufficient to bring about the desired result, and it may even be that the mere talking to him at that stage of illness and pressing something upon him may so fatigue the brain, that the sick person may be induced, for quietness' sake, to do anything. This would equally be coercion, though not actual violence.*⁷

Victoria

The *Voluntary Assisted Dying Act 2017 Act* requires the two assessing doctors, as well as the witness to an administration request in the case of euthanasia, to certify that the person requesting assisted suicide or euthanasia is *“acting voluntarily and without coercion”*.

Assessing doctors are required to complete training approved by the Secretary of the Department of Health on *“identifying and assessing risk factors for abuse or coercion”*.

This training is part of an online module and is relatively brief and basic. Merely completing this online training cannot guarantee that assessing doctors never miss the signs of coercion or abuse given the well-documented evidence of failure by professionals in Australia to identify elder abuse as cited above.

Furthermore, the training module actually suggests that if a patient indicates that *“becoming a burden on family, friends and caregivers”* is their reason for seeking assisted dying this could be the *“patient’s expression of suffering experienced from the loss of autonomy”*.

There is no provision for anyone to seek a review at VCAT of an assessment by the two doctors that a person is acting *“voluntarily and without coercion”* in requesting assisted suicide or euthanasia.

A family member or friend who becomes aware that a person is being coerced has no formal recourse under the Act at all.

For example, if one adult child becomes aware or concerned that her mother has been unduly influenced by a current partner or by another adult child (perhaps because of inheritance impatience or carer fatigue) to request assisted suicide and that this coercion has not been identified by either of the assessing doctors then there is simply no provision for the assessment that the request was voluntary to be re-examined.

The Victorian law allows both assisted suicide and euthanasia.

In the case of assisted suicide the assessment that the person requesting it is acting *“voluntarily and without coercion”* takes place at the start of the process. Once the final request is made there is no subsequent assessment. The person is given the lethal

⁷ <https://swarb.co.uk/wingrove-v-wingrove-1885/>

substance in a metal box with a key. The lethal substance is kept by the person with no time limit for its use. There is no requirement that a health care provider or indeed any other witness be present when the lethal substance is ingested.

The law, therefore, is entirely lacking in any mechanism for ensuring that when the lethal substance is actually ingested the person is acting voluntarily and without coercion.

It would be quite possible for a person to be cajoled, bullied, tricked or, indeed actually forced to ingest the lethal substance by a family member, carer or predator.

Thomas Middleton died in Oregon on 22 July 2008 after ingesting a lethal dose of drugs prescribed for him under the Death with Dignity Act. Earlier that month he had moved into the home of real estate broker Tami Sawyer after making her the trustee of a trust to which he then deeded his house. In October 2008 Sawyer sold the house and transferred the profits to her own businesses. Sawyer was charged with taking custody of Middleton for the purposes of fraud.⁸ It is quite possible that she was the one who administered the lethal drugs or that she “encouraged” Middleton to take them. Who would know?

Indeed in [Oregon](#) between 2001 and 2018 in 59% of cases there was no health care provider known to be present when the lethal substance was ingested.⁹

Conclusion

It is clear from this evidence that simply requiring a physician to tick a box stating the person requesting assisted suicide is doing so voluntarily and without coercion is no guarantee that the physician has the competence or has undertaken the extensive and careful inquiries necessary to establish that the person is not subject to undue influence or subtle pressure (albeit unwittingly) from family, friends or society to request assisted suicide so as not to burden others.

No jurisdiction that has legalised assisted suicide has even made any serious effort to establish a genuinely safe framework in this regard. Indeed no such framework is possible because so much coercion and undue influence takes place in private; victims often fail to disclose relevant matters that might enable it to be detected; and the more subtle forms of undue influence and coercion are by the nature intangible and not susceptible to easy identification.

Therefore any law permitting assisted suicide or euthanasia will inevitably result in wrongful deaths from coercion.

⁸ <https://choiceisanillusion.files.wordpress.com/2016/10/sawyer-arraigned-a-63.pdf> ;
<http://www.ktvz.com/news/crime/sawyers-go-to-prison-victims-see-justice-but-money/68441556> ;
<http://www.ktvz.com/news/crime/state-dropping-tami-sawyer-fraud-case/68314086>

⁹ Oregon Public Health Division, *Oregon Death With Dignity Act: 2018 Data Summary, Table 1*, p.12
<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>

Dementia, capacity, consent and euthanasia

There is evidence that legalising euthanasia based on an explicit request by the person results in a significant number of cases of euthanasia without such an explicit request.

It seems that these acts of euthanasia **without any explicit request** are carried out by doctors who have grown used to the practice of ending their patients' lives.

In one case from the Netherlands a doctor actually euthanased a woman with dementia who was actively resisting (see below).

Netherlands

In [2015](#) there were 431 cases of euthanasia without explicit request, representing 6.06% (or more than one out of sixteen) of all euthanasia deaths.¹⁰

More than 1 in 200 (0.52%) of all deaths (other than sudden and expected deaths) of 17-65 year olds in the Netherlands are caused intentionally by euthanasia without an explicit request from the person being killed.

In [Case 2016-85](#) the Review Committees found that a doctor had not acted with due diligence in administering euthanasia to a woman with Alzheimer's disease. The woman had made a general reference in a living will to wanting euthanasia at the "right time". At the time the doctor euthanased her she was incompetent to voluntarily request it.

The doctor put medication in her coffee to reduce her consciousness deliberately so as to avoid her resisting being given drugs. Nonetheless she physically struggled against the administration of an intravenous lethal injection. She was physically restrained by family members while the doctor completed the administration of the lethal drugs.¹¹

On 13 June 2018 the Regional Disciplinary Court for Healthcare in The Hague considered a complaint against the doctor brought by the Inspectorate for Health Care and Youth. The [decision](#) was published on 24 July 2018.¹²

The Court found that the written declaration of intent was not sufficiently clear to justify euthanasia in this case. It also found that the doctor should have tried to discuss the execution of euthanasia with the patient beforehand.

¹⁰ <https://opendata.cbs.nl/statline/#/CBS/en/dataset/81655ENG/table?ts=1525401083207>

¹¹

https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2016/april/12/jaarverslag-2016/RTE_jaarverslag2016.pdf

¹² <https://www.tuchtcollege-gezondheidszorg.nl/binaries/tuchtcolleges-gezondheidszorg/documenten/publicaties/documentatie-procedures/uitspraken/uitspraken-van-persberichten/beslissing-euthanasie-bij-dementie/2018-033bes.pdf>

In view of the irreversibility of termination of life and the ethical aspects connected with the deliberate ending of the life of a fellow human being, a written euthanasia declaration must be unambiguous, not needing any further interpretation.

The Court did not completely ruled out that ambiguities in a written declaration of intent could be removed (even in the case of a demented patient) if a patient is later unambiguous, consistent and tenacious (verbally or non-verbally) in his statements about wanting death. However, with this patient this was not the case because she sometimes said she wanted to die and sometimes not.

Despite its finding that the doctor had seriously breached the requirements for euthanasia it only imposed a reprimand on the doctor.

On 9 November 2018 it was [announced](#) that a criminal investigation into this case by the Board of Public Prosecutors had concluded and that the doctor would be prosecuted.¹³

This is the first time that the Dutch Public Prosecution Service (OM) will prosecute a doctor for euthanasia since the introduction of the Act on Termination of Life on Request and Assisted Suicide in 2002.

*After extensive investigation, the public prosecutor came to the conclusion that the nursing home doctor had not acted in accordance with the legal standards. The public prosecutor considers it important **that the court assesses whether the doctor was entitled to rely on the living will completed by the woman**. In addition, the OM reproaches the physician that she assumed that the woman still wanted to die without verifying this with the woman. Although the woman had regularly stated that she wanted to die, on other occasions she had said that she did not to want to die. In the opinion of the OM, **the doctor should have checked with the woman whether she still had a death wish by discussing this with her**. The fact that she had become demented does not alter this, because according to the Public Prosecution, the law also requires the doctor to verify the euthanasia request in such a situation. **These two legal questions on the termination of life of people suffering from dementia justify the submission of this case to the criminal court judge.***

It is not yet known when the case will be heard by the District Court of The Hague.

Victoria

The *Voluntary Assisted Dying Act 2017* requires that an assessment of decision-making capacity be made by both the co-ordinating medical practitioner and the consulting medical practitioner before a request for assisted suicide or euthanasia is submitted for approval.

¹³ <https://www.om.nl/vaste-onderdelen/zoeken/@104443/nursing-home-doctor/>

Sections 18 (1) and 27 (1) of that Act provide respectively that if the co-ordinating medical practitioner or the consulting medical practitioner:

is unable to determine whether the person has decision-making capacity in relation to voluntary assisted dying as required by the eligibility criteria, for example, due to a past or current mental illness of the person, [he or she] must refer the person to a registered health practitioner who has appropriate skills and training, such as a psychiatrist in the case of mental illness.

It is entirely up to the assessing doctors to form their own view as to their expertise in assessing decision-making capacity. This provision is weaker than the [corresponding provision in Oregon](#) which refers to “*impaired judgement*”¹⁴ rather than a lack of “*decision-making capacity*” which is defined in section 4 in purely cognitive terms, taking no account of the effects, say, of depression or demoralisation on a person judging what is truly in his or her best interests.

The evidence from Oregon shows that even with this stricter approach “[as many as 150 people with depression may have been helped to commit suicide without any such referral](#)”.¹⁵

Under section 36 of the Act the two people witnessing the signature on the written declaration must certify in writing “*that, at the time the person signed the declaration, the person appeared to have decision-making capacity in relation to voluntary assisted dying*”. This hardly adds any extra assurance to the process as the witnesses do not need to have any expertise or prior knowledge of the person.

There is a provision in section 68 of the Act for a person who is considered by VCAT (Victorian Civil and Administrative Tribunal) to have “*a special interest in the medical treatment and care of the person*” assessed as eligible for assisted suicide or euthanasia to apply to VCAT for a review of the decision that the person has decision-making capacity.

As explained above, in the case of assisted suicide the assessment that the person requesting has decision-making capacity takes place at the start of the process. Once the final request is made there is no subsequent assessment. The person is given the lethal substance in a metal box with a key. The lethal substance is kept by the person with no time limit for its use. There is no requirement that a health care provider or indeed any other witness be present when the lethal substance is ingested.

The law, therefore, is entirely lacking in any mechanism for ensuring that when the lethal substance is actually ingested the person has decision-making capacity.

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<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/statute.pdf>

¹⁵ https://www.australiancarealliance.org.au/mentally_ill_at_risk

A person may well experience dementia to the extent of lacking decision-making capacity for such a profound and irreversible decision as ingesting a lethal substance in order to end one's life between the time the person is issued with the locked box containing the lethal substance and the time it is ingested.

It would be quite possible for a person lacking such decision-making capacity to be induced into ingesting it without an understanding of what the result will be.

At the Voluntary Assisted Dying Implementation Conference held in Melbourne on 9-10 May 2019 questions were asked about this issue. The answers given by presenters were unsatisfactory and, in some cases disturbingly flippant.

For example in answer to a question from the point of a view of a manager of an aged care facility what should be done if a resident known to have a locked box with the lethal substance in her possession has developed dementia the presenter, a member of the Voluntary Assisted Dying Implementation Taskforce replied that there was no need to do anything as if the person had dementia they were unlikely to remember how to open the box and ingest the substance!

The Victorian law simply lacks any provision for dealing with this issue.

Disability and assisted suicide

- In the Netherlands and Belgium disability – both physical and intellectual – is accepted as a reason to euthanase a person.
- In Oregon the **five main reasons** given for requesting assisted suicide **all relate to disability** issues.
- People with disabilities are often seen in our society as “*better off dead*”.
- Depression is less likely to be diagnosed and treated in a person with disability.
- The boundary between physical disability and terminal illness is fuzzy, not clear.

Netherlands and Belgium

A [2018 paper examines nine case reports](#) on euthanasia in the Netherlands between 2012 and 2016 of people with an intellectual disability or an autism spectrum disorder.¹⁶

The case reports make for chilling reading, illustrating how once euthanasia becomes normalised in a society it becomes the go-to, accepted, “*final solution*” for “*difficult*” patients.

A man in his 60s with Asperger's, described as “*an utterly lonely man whose life had been a failure*”, was euthanased because he was “*horrified at moving into sheltered accommodation*”. Although he had been diagnosed with “*severe and probably chronic*”

¹⁶ <https://bmcomedethics.biomedcentral.com/articles/10.1186/s12910-018-0257-6>

depression with a persistent death wish” another psychiatrist, after seeing him just once, certified that he was free of depression in order to facilitate his euthanasia.

Another man in his 30s, also with Asperger’s, was euthanased based on his distress at “*his continuous yearning for meaningful relationships and his repeated frustrations in this area, because of his inability to deal adequately with closeness and social contacts”*.

A third case was of an intellectually disabled woman in her 60s who was euthanased for tinnitus despite a finding that:

the patient had indeed gone through many treatments in the past, but also, that often the wrong treatments had been instigated. It had also become clear to the physician that the patient often wanted to abandon the treatments, and that the treating practitioners had not encouraged her to try and persevere with these treatment(s) a bit longer.

In [Case 2016-44](#) the Netherlands Review Committees approved the action of a doctor who euthanased a man aged between 80 and 90 years of age on the sole ground of having progressive loss of vision due to macular degeneration with his lack of capacity to read being accepted as unbearable and hopeless suffering.¹⁷

In Belgium, in December 2012 [identical twin brothers were euthanased on the grounds of their psychological distress at learning they were both going blind](#). The brothers were reportedly distressed that they would not be able to see each other.¹⁸

[Commenting on this case, Dr. Marc Maurer](#), President of the [US] [National Federation of the Blind](#),¹⁹ said:

*“This disturbing news from Belgium is a stark example of the common, and in this case tragic, misunderstanding of disability and its consequences. Adjustment to any disability is difficult, and deaf-blind people face their own particular challenges, but from at least the time of Helen Keller it has been known that these challenges can be met, and the technology and services available today have vastly improved prospects for the deaf-blind and others with disabilities. That these men wanted to die is tragic; that the state sanctioned and aided their suicide is frightening.”*²⁰

¹⁷

https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2016/april/12/jaarverslag-2016/RTE_jaarverslag2016.pdf

¹⁸ <http://www.telegraph.co.uk/news/worldnews/europe/belgium/9798778/Belgian-identical-twins-in-unique-mercy-killing.html>

¹⁹ <http://www.facebook.com/NationalFederationoftheBlind>

²⁰ <https://nfb.org/national-federation-blind-comments-belgian-euthanasia-deaf-men-losing-sight>

Disability issues accepted as leading reasons for assisted suicide

Assisted suicide proposals usually would require two doctors to agree to a person's request for a prescription for a lethal dose to be used to end the person's life. To do so the doctors essentially need to agree that the person would "be better off dead" or at least that it is reasonable for a person in that position to consider that he or she would be better off dead.

The [five main reasons given for requesting assisted suicide in Oregon in 2017](#) are **not primarily to do with pain (only 21%)** but rather with concerns about decreasing ability to participate in activities that made life enjoyable (88.1%), loss of autonomy (87.4%), loss of dignity (67.1%), physical or emotional burden on family, friends, or caregivers (55.2%) and the loss of control of bodily functions, such as incontinence and vomiting (37.1%)²¹. **These are all disability issues.**

Any assisted suicide proposal that includes a subjective notion of suffering as part of the eligibility criteria would allow assisted suicide for a similar set of concerns.

This set of concerns reflects the day to day realities of life for many people living with disabilities of various kinds.

If we legalise assisted suicide for incontinence, a loss of ability to engage in one's favourite hobby, a need to have other's take care of your physical needs, a loss of mobility and so forth what is the take home message for those who live with these challenges every day?

Are we saying they would also be better off dead?

Stella Young

The late Stella Young, comedian, writer and disability activist, [wrote on the implications of legalising assisted suicide for people living with disabilities](#):

As a disabled person, I'm accustomed to conversations about quality of life and dignity. Specifically, I'm accustomed to assuring people that my life is worth living. I'm short statured, a wheelchair user, and I frequently have bone fractures. All the visual cues that make me 'the other' are front and centre.

People make all sorts of assumptions about the quality of my life and my levels of independence. They're almost always wrong.

I've lost count of the number of times I've been told, "I just don't think I could live like you," or "I wouldn't have the courage in your situation," or, my favourite one to overhear (and I've overheard it more than once), "You'd just bloody top yourself, wouldn't you?". What we as a society think we know about what it means to live as a disabled person comes from cultural

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<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>

representations of disability seen through a nondisabled lens. And we, as people with disability, rarely get to tell our own stories.

Also, social attitudes towards disabled people come from a medical profession that takes a deficit view of disability. This is my major concern with legalising assisted death; that it will give doctors more control over our lives. As a disabled person who has had a lot to do with the medical profession, I can tell you that this is the space in which I've experienced some of the very worst disability prejudice and discrimination. Doctors might know about our biology, but it doesn't mean they know about our lives.

Media reports on assisted dying feed these misconceptions. ABC News reported this week on the case of Barbara Harling, a Queensland woman with motor neurone disease who said that she would consider moving to Tasmania if the Voluntary Assisted Dying Bill had passed. Harling is quoted as saying: "Well, let's put it this way. I can use my left hand, my right hand is just about useless. If I can't use my left hand to wipe my bottom, then I can do nothing else for myself. That means someone has to do everything for me. I couldn't bear to live like that."

The thing is, a lot of people do live like that. I know many, many people who depend on personal assistants for all of their daily living tasks, some of them requiring 24 hour care. Having to rely on someone else to wipe your bum may not be something anyone aspires to, but I'm quite sure it's never killed anyone.

Perhaps our discomfort with this kind of thing is why we don't hear the counter view in reports about assisted dying. Often we hear supporters of euthanasia and assisted suicide talk about wanting to avoid the pain and suffering that often comes with imminent death. But more often, we hear stories like Barbara Harling's, which are more about wanting to avoid a loss of autonomy and independence.²²

Screening for depression or coercion

Proposals for assisted suicide offer require assessing doctors to screen for depression or other mental health conditions that may be affecting the person's decision making capacity. Similarly the assessing doctors are supposed to determine that the request is voluntary and not the result of coercion.

Doctors are less likely to identify depression in people with disability, simply by assuming that it is normal for a person with disability to show signs of depression such as sadness and lack of hope.

Doctors may also easily miss the particular vulnerability of a person living with disability to overt or subtle coercion from family or caregivers who reinforce a feeling that the person is a burden, "too much trouble", "life is too hard" and so forth.

²² <http://www.abc.net.au/rampup/articles/2013/10/18/3872088.htm>

Terminal condition or disability?

Proposals for assisted suicide may suggest making assisted suicide available to people with a specified length of time to live, such as six or twelve months or use some vaguer term such as where death is reasonably foreseen.

However, such proposals generally indicate that the prognosis should take account of which treatments are “acceptable to the person”. On this basis various condition that are not in themselves terminal may be considered as terminal for the purpose of offering assisted suicide if the person decides to forego an effective, available treatment for whatever reason.

This approach poses a severe risk to people following an initial acquisition or diagnosis of a condition that may involve a considerable level of disability.

Marilyn Golden writes :

Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in our lives.

However, the adaptation usually takes considerably longer than the mere fifteen-day waiting period [generally] required by assisted suicide proposals. People with new diagnoses of terminal illness appear to go through similar stages. In that early period before one learns the truth about how good one’s quality of life can be, it would be all too easy, if assisted suicide is legal, to make the final choice, one that is irrevocable.

Dr. Richard Radtke, a well-known retired academic oceanographer in Hawaii, provides one such example. Dr. Radtke has had a very disabling form of muscular sclerosis for over 25 years. In the period after his diagnosis, doctors often classified him as terminally ill. He experienced severe depression for two years. Had assisted suicide been legal, he acknowledges that he would have chosen it and died long ago. Today, still with an extremely limiting disability, he has retired from a successful academic career, is a happily married father, remains the president of a charitable foundation, and is grateful for the length and varied experiences of his life.

How many such individuals is our society prepared to sacrifice as the collateral damage from the legalization of assisted suicide? ²³

Victoria

²³ <https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/>

Section 9 (3) of the *Voluntary Assisted Dying Act 2017* provides that “A person is not eligible for access to voluntary assisted dying only because the person has a disability, within the meaning of section 3(1) of the **Disability Act 2006.**”

The key word is “*only*”.

Nothing precludes a person with a disability – physical or intellectual – from accessing assisted suicide or euthanasia provided the person meets the other eligibility criteria.

Nothing precludes the person’s disability from being considered as “*a disease, illness or medical condition*” expected to cause death within 6 months.

There are no explicit provisions to protect people with disability from discriminatory assessment under the required processes by doctors who would consider a person with a particular disability as “better off dead”.

People with disability [are more likely to experience undiagnosed depression](#) especially following initial acquisition of a disability or adverse developments in their physical, psychological or social condition.²⁴

The Act explicitly provides for requests for assisted suicide or euthanasia to be made by gestures. It is not made explicit in the Act whether or not an accredited interpreter is required in this case. A [recent court case in the Netherlands](#) determined that “*hand squeezes, nods, eye blinking and crying were all sufficient signs of*” a request for euthanasia.²⁵

Conclusion

The Victorian *Voluntary Assisted Dying Act 2017* and any scheme that legalises assisted suicide or euthanasia poses a direct threat to the lives of some people with disabilities who may be assessed as eligible to request it. Doctors are more likely to agree that they are “*better off dead*” and to miss signs of depression or coercion.

Legalising assisted suicide or euthanasia for being a burden, incontinence or loss of ability to enjoy activities trivialises issues faced daily by persons living with disability and demeans their courage in facing the challenges of life.

This risk to the lives of persons with disabilities is likely to be even greater for those young persons with profound disabilities who are living in aged care facilities due to the lack of suitable alternatives.

The example of Roger Foley is instructive. Roger is a Canadian who has a crippling brain disease and who has been seeking support to live at home. He is currently in an Ontario

²⁴ https://www.australiancarealliance.org.au/better_off_dead

²⁵ https://www.australiancarealliance.org.au/euthanasia_consent_by_gestures

hospital that is threatening to start charging him \$1,800 a day. The hospital has told Roger that his other option is euthanasia or assisted suicide under Canada's medical assistance in dying law.²⁶

No person with a disability should be faced with a choice between assisted suicide and living in an unsatisfactory or unaffordable care facility.

Recommendation 1: The Royal Commission should recommend that regardless of the law of any State or Territory permitting assisted suicide or euthanasia the *Aged Care Act 1997* be amended to prevent any assessment directed at possible authorisation of an act of assisted suicide or euthanasia or any storage or use of a lethal substance for the purpose of assisted suicide or any act of euthanasia to take place while a person is on the premises of a residential aged care facility or as part of the provision of home care.

²⁶ https://www.australiancarealliance.org.au/canada_assisted_suicide_not_assisted_living

Guaranteeing the right to non-participation in assisted suicide and euthanasia

Proponents of physician assisted suicide and euthanasia often seek to normalise these exceptions to the criminal laws prohibiting murder and aiding suicide to the extent that requesting and receiving assisted suicide or euthanasia is seen as simply another “medical treatment” or even a “right to die”.

For example in Hawaii, although the [Our Care, Our Choice Act](#) contains explicit provisions protecting the right of a health care facility to prevent health care providers in its employ or on its premises from “participating” in the provision of assisted suicide there may be gaps in this provisions.

The American Civil Liberties Union is already [threatening a law suit against Kahala Nui](#),²⁷ a continuing care retirement community, which is run by a non-profit organisation and is situated on land owned by the Catholic Church, [to force it to repeal a provision](#) in its residents agreement which makes it clear that acts of assisted suicide under Hawaii’s new law are not permitted in the community.²⁸

The proponents of assisted suicide bitterly and aggressively object to any organisation seeking to preserve a life-affirming ethos.

At the Voluntary Assisted Dying Implementation Conference held in Melbourne on 9-10 May 2019 a claim was advanced by presenters during a workshop on aged care and voluntary assisted dying that under the provisions of the Commonwealth's *Aged Care Act 1997* as it and its subsidiary regulation *User Rights Principles 2014* will stand as amended from 1 July 2019 by the *User Rights Amendment (Charter of Aged Care Rights) Principles 2019* recipients of either residential or home care will have a right to access assessments for assisted suicide or euthanasia and to keep and use a lethal substance supplied under the *Voluntary Assisted Dying Act 2017* on the premises of the residential aged care provider or while receiving home care and that this right is not subject to any refusal by the provider of care.

It was claimed that items 2.7 and 2.8 of the Charter of Aged Care rights apply to assisted suicide and euthanasia under the *Voluntary Assisted Dying Act 2017*.

7. have control over and make choices about my care, and personal and social life, including where the choices involve personal risk

8. have control over, and make decisions about, the personal aspects of my daily life, financial affairs and possessions;

It was further claimed that access to assisted suicide and euthanasia under the *Voluntary Assisted Dying Act 2017* and the storage and use of a lethal substance supplied under that

²⁷ <https://www.aclu.org/news/aclu-hawaii-calls-kahala-nui-retirement-community-stop-religious-discrimination>

²⁸ <http://www.tribtown.com/2018/11/01/us-retirement-home-medically-assisted-suicide-the-latest/>

Act are all covered by the phrase "*legal and consumer rights of care recipients*" as used in new sections 9AA and 19A of the Users Rights Principles 2014 as amended, therefore prohibiting providers from acting inconsistently with these rights by prohibiting residents or recipients of home care from accessing an assessment for assisted suicide or euthanasia or storing or using a lethal substance supplied under the *Voluntary Assisted Dying Act 2017* while receiving residential or home care.

Further it was claimed that the list of reasons for terminating tenure set out in Section 6 (2) and Section 17 (2) [as amended] of the *User Rights Principles 2014* are exhaustive and that none of the specified reasons would cover provider objections (conscientious or practical) to the storage and use of a lethal substance supplied under the *Voluntary Assisted Dying Act 2017* by a care recipient.

When asked why this differed from hospitals - which everyone accepted could object to all aspects of *Voluntary Assisted Dying Act 2017* - the answer was that aged care is under the Aged Care Act 1997 (Commonwealth) and not the Health Services Act (Victoria).

Regardless of whether or not this view is a correct interpretation of the law it is profoundly disturbing that Victorian providers of residential or home aged care are being told that, regardless of either faith-based objections or practical considerations such as the risk to other residents from a resident storing a lethal substance on the premises or the impact of an assisted suicide on the premises on the psychological well-being of other residents and of staff they cannot prevent such acts on their premises.

If the Royal Commission does not adopt Recommendation 1 above then it should at least ensure that no provider of residential aged care or home care is prevented from effectively prohibiting any assessments for assisted suicide or euthanasia or any storage or use of a lethal substance for the purpose of assisted suicide or any act of euthanasia on its premises or as part of its provision of care.

Recommendation 2: The Royal Commission should recommend that regardless of the law of any State or Territory permitting assisted suicide or euthanasia the *Aged Care Act 1997* be amended to ensure that providers of residential or home care can effectively prevent any assessment directed at possible authorisation of an act of assisted suicide or euthanasia or any storage or use of a lethal substance for the purpose of assisted suicide or any act of euthanasia to take place on the premises of a residential aged care facility under their control or as part of their provision of home care.

Autonomy and assisted suicide/euthanasia

Term of reference (e) requires the Royal Commission to consider "*how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care*".

Proponents of assisted suicide and euthanasia often present access to these life ending acts as the ultimate exercise of choice and control in a person-centred approach to care.

At the Voluntary Assisted Dying Implementation Conference held in Melbourne on 9-10 May 2019 the keynote speaker, Canadian physician James Downar, who on his own admission has participated in 40 or more cases of euthanasia, described the typical euthanasia case as involving a “captain of industry, self-willed, no longer feeling in control [due to the diagnosis of a terminal illness] so wants to control the time and manner of his death”.

As set out in earlier parts of this submission the evidence is that no scheme for assisted suicide and euthanasia can guarantee that in every case there is an informed, voluntary request and a voluntary act involved in ingesting a lethal substance.

Some proponents acknowledge that this is the case but argue that securing the right of some to exercise the ultimate act of autonomy is worth sacrificing the lives of others.

For example, Dr Henry Marsh, a British neurosurgeon and proponent of legalising assisted suicide and euthanasia, has acknowledged the possibility of coercion and elder abuse leading to wrongful deaths under such a law but he simply doesn't care:

*"Even if a few grannies get bullied into [suicide], isn't that the price worth paying for all the people who could die with dignity?"*²⁹

Recommendation 3:

The Royal Commission should reject any proposal that it recommend any steps towards the legalisation of assisted suicide or euthanasia as an advancement of person-centred care or allowing people to exercise greater choice, control and independence in relation to their care.

²⁹ <https://www.medscape.com/viewarticle/879187>