

31 October 2017

Dear Committee members

Re End of Life Choices Inquiry

Thank you for considering my belated submission. I hope my perspective provides some useful ideas the form any proposed medical assistance in dying (MAiD) framework in Western Australia should take.

Like the vast majority of Australians, I welcome any move to give compassion and choices to people at the end of life.

As you are no doubt aware, the Victorian parliament is currently debating the Voluntary Assisted Dying bill - likely and hopefully soon to be the Voluntary Assisted Dying (VAD) Act.

I have closely followed the extensive consultation and workshopping of the legislation over the past 18 months and hope some of my criticisms of the legislation will inform the drafting of any similar bill in Western Australia.

Individuals with decision making capacity should be able to determine the timing and manner of their own death.

Unfortunately this principle is not as ingrained in the Victorian VAD bill as it should be.

While decision making capacity is requisite for MAiD under the VAD bill, the following elements must also be satisfied for eligibility:

- The patient must be expected to die within 12 months or less
- The patient's pain and suffering must not be solely a product of mental illness, or solely a product of a disability (as defined in other legislative instruments)
- The patient must have decision making *throughout the whole application process*
- The patient must be over 18 years old
- The patient must be a Victorian resident and Australian citizen

While undoubtedly well intentioned, it is foreseeable beyond doubt that these barriers to MAiD access will have perverse outcomes in practice.

Indeed they betray the principle of individual autonomy and represent abandonment of patients living intolerably painful lives suffering needlessly.

The patient must be expected to die within 12 months or less

Just as a prognosis of 12 months or less to live is not to say a life is no longer worth living, a prognosis of over 12 months to live is not to say a life may not have, to a patient, because irreversibly not worth continuing.

The prognosis eligibility criteria means patients who are not imminently dying but whose lives are rendered permanently not worth living are forced to suffer for years or decades.

An illustrative example of such a condition is treatment resistant depression, which ties in with my argument that a patient suffering solely a mental illness should not be excluded from MAiD access.

The patient's pain and suffering must not be solely a product of mental illness, or solely a product of a disability

In their paper '[Treatment resistant major depressive disorder and assisted dying](#)'¹ authors Schuklenk and van de Vathorst present a convincing argument that jurisdictions establishing MAiD unfairly discriminate against individuals suffering from treatment resistant mental illness if they are excluded under the framework.

While treatment resistant mental illness may not in itself give rise to a prognosis of 12 months or less, that is not to say it cannot be as, if not more debilitating, and cause as much suffering as a solely physical illness.

Denying access to MAiD for those people whose suffering is a product of solely mental illness – as the Victorian bill does – implies mental illness is somehow less real or potentially intolerable than a physical illness.

Such a notion is absurd and any MAiD framework established in Western Australia should not establish and entrench such fallacy, and discrimination against people with mental illness.

The patient must have decision making *throughout the whole application process*

Dementia is another condition that does not usually result in death within 12 months of diagnosis. The afflicted may be kept alive for years or decades as their cognitive, physical and, critically as it applies to the Victorian MAiD framework, decision making capacity erodes.

¹ <http://jme.bmj.com/content/41/8/577>

By the time a dementia patient has a prognosis of 12 months or less, it is likely they will lack the requisite decision making capacity the Victorian MAiD bill demands.

Unfortunately, the Victorian scheme makes no accommodation for people to consent to MAiD in an advance directive, whilst they have decision making capacity.

[With 39 600 West Australians with dementia today, projected to increase to 84 161 by 2036 and 143 957 by 2056²](#), it seems a particularly careless and cruel state of affairs to deny such a large segment of the population a say in their own future.

Dementia patients are vulnerable and suffering enough insofar as they are robbed of their autonomy, not just by the disease but by the failure of the Victorian framework to make allowances for advance requests for MAiD.

The patient must be over 18 years old

Regrettably, conditions that may render an individual's life irreversibly not worth living are also not confined to those aged 18 and over.

Unfortunately, the Victorian bill establishes that an eligible person must be at least 18 years of age.

This requirement is arbitrary insofar that decision making capacity does not magically appear on the beginning of the 217th month of one's life.

According to the [WA Health Consent to Treatment Policy of 2016³](#):

²

<https://www.dementia.org.au/files/NATIONAL/documents/The-economic-cost-of-dementia-in-Australia-2016-to-2056.pdf>

³ 4.3.2.3 *Mature minors* <http://www.health.wa.gov.au/circularsnew/attachments/1135.pdf>

A minor who fully understands the nature and consequences of the proposed treatment is capable of effective consent or withholding consent.

In keeping with the principle of individual liberty and patient autonomy that underlies the legislation of MAiD, mature minors should not be disqualified from MAiD access solely on the basis of their age.

The patient must be a Victorian resident and Australian citizen

A final requirement of the Victorian bill that warrants critique, and hopefully will be avoided in any Western Australian MAiD framework is the citizenship and residency requirement.

As is the case with the over prescriptive criteria regarding the prognosis, nature of the illness/disability and age, the requirement for Victorian residency guarantees that only those interstaters with the financial means to establish Victorian residence should be afforded MAiD.

This is an inequitable outcome, as residency - and citizenship, for that matter - has no bearing on whether an individual believes their life is irreversibly not worth continuing.

There is no reason Western Australia should not become the Switzerland of the southern hemisphere and provide a peaceful, legal means for people whose lives have irreversibly ceased to benefit them to die, Australian citizens or not.

Aside from being the ethical and non-discriminatory thing to do, it would also benefit the West Australian economy

In summary, individuals with decision making capacity – that is, the ability to understand, remember, use & weight, and communicate information should be given latitude in determining the time and manner of their own death.

While something may be better than nothing in establishing a framework for medical assistance in dying, the proposed Victorian model in its current form leaves a lot to be desired.

I hope Western Australia can provide a fairer MAiD framework that avoids some of the so-called 'safeguards', that as I have articulated, are in fact just illogical and discriminatory barriers to MAiD access at the end of life.

Again, thank you for your consideration and I look forward to the release of the committee's findings and recommendations.

Kind Regards

Mark Weaver