



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL

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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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Submission to the Select Committee on the ACT Voluntary Assisted Dying Bill (the Bill)

Submitted by: Dinny Laurence

Dear Committee

Interest in voluntary assisted dying (VAD)

As a committee member of Dying with Dignity WA (DWDWA) I was the manager of the campaign to legislate VAD in Western Australia. The *Voluntary Assisted Dying Act 2019* (the Act) was passed in December 2019 and, after an implementation period of 18 months, VAD became available as an end of life choice to those who satisfied the eligibility criteria in the Act, which has now been in operation in WA since 1st July 2021. The first review of the 'operation and effectiveness' of the Act is currently underway in accordance with section 164 of the Act (the WA Review).

Although I am no longer on the committee I have worked closely with DWDWA and with the other Dying with Dignity organisations in Australia to determine the strengths and weakness of the legislation in our respective jurisdictions. As each state has passed VAD legislation, progressive changes have been made. This is as it should be: that the laws are evolutionary, with each one building on the improvements made by the others. In an ideal world, ultimately all Australians in both states and territories should have access to very similar VAD laws, but sadly the reviews in both WA and Victoria have been constrained by arbitrary restrictions. This is an opportunity lost.

It is in this context that I respectfully make this submission.

Prognosis to death criterion and the principles of autonomy and minimising suffering

In the VAD laws of every state in Australia, the combined effect of the various prognosis eligibility criteria, and the requirement that the person seeking access to VAD must have enduring capacity throughout the process, is that many people who need it most are denied access to this compassionate law. This is in direct contradiction to the principle in section 7(c) and (d) of the Bill regarding autonomy (including in respect of end of life choices) and minimising suffering.

I will deal separately with these issues:

(1) Prognosis to death

It is very encouraging that there is no prognosis to death eligibility requirement per se in the Bill. The cogent evidence in support of its exclusion is comprehensively set out in the explanatory statement to the Bill (pp 10 -13), so there is no need to repeat it here.

My concern however is that the intention of the proponents of the Bill is not reflected in the draft legislation, in particular in the definition of 'advanced' in s. 11(4) set out below:

In this section:

advanced—an individual's relevant conditions are **advanced** if—

- (a) the individual's functioning and quality of life have declined; and
- (b) any treatments that are available and acceptable to the individual lose any beneficial impact; and
- (c) the individual is in the last stages of their life.

There is unlikely to be anything controversial about (a) above. However in my experience (b) and (c) are both problematic, particularly as – by virtue of the 'and' rather than 'or' after each sub-section - all three of the components of the definition must be satisfied in order for a person to be eligible for VAD.

I hope you will permit two personal stories that justify my use of the word 'experience' rather than 'opinion' in the paragraph above (repeated from my submission to the Panel currently reviewing the WA VAD Act).

The first is about my dad, who throughout his life had suffered from asthma. By the time he turned 80 this condition had become chronic and progressive and made his life wretched. With no end in sight he saw suicide as his only way out. He wrote a note to my mother and the family, and unplugged his nebuliser when he went to bed. He woke gasping for air and called out in panic, but by the time my mother reached him he had died. This was in South Africa, 30 years ago. It is ironic that had he lived in Australia today, there would still not have been a more humane alternative under any of the state VAD laws to end the suffering he endured as he suffocated to death that night, alone and afraid.

How would the above provisions of the Bill have assisted him in his quest for a peaceful death? It is clear that treatment was available to him that might have kept him alive for many years, so it had not lost its 'beneficial' impact. But was it beneficial given the extreme suffering he endured constantly from his breathlessness? He was very claustrophobic and

often had the sensation that he was suffocating, and this was only temporarily alleviated by his medication. He did not want to continue to live, when living caused suffering that was intolerable to him.

It is clear that his condition was terminal, because when he deliberately stopped his asthma treatment that night, he died. Would it have been enough to satisfy two medical practitioners that he was eligible for VAD merely by saying that the treatment was no longer acceptable to him? And if so, could he also have persuaded them that he was in fact 'in the last stages of his life'?

My second personal experience of the cruelty inherent in the time-based prognosis requirement was through my friendship with AB, an 83 year old man who had Parkinson's. Having watched his father die an excruciatingly slow death from the same disease, his last 12 years being spent paralysed in a hospice bed, AB was desperate to avoid the same fate.

When I first met him, AB could walk short distances, but after a few months he became permanently confined to a wheelchair: just one of the many other symptoms of his decline into helplessness and total dependence.

He made a request for VAD, and was referred to a neurologist, who said that his heart was strong and he would probably live 'at least' another five years. It seemed as though the worst was still to come, but 'fortunately' (AB's word) other health emergencies landed him in hospital a number of times, and these, as he put it, helped him over the line. I was honoured to be there as he died a peaceful death by lethal injection, surrounded by his family.

In WA, without the prognosis requirement of 12 months to death for someone with a neurodegenerative condition, AB would have qualified for VAD. He had a terminal condition that was 'advanced and progressive' based on the common meanings of those words, and his condition was causing [him] suffering 'in a way that could not be relieved in a manner he considered tolerable'. But how would he have fared under the Bill, with the word 'advanced' being prescriptively defined?

I asked him once what would happen if he stopped taking his medication, and he replied that his doctors had told him that he would not die, but that he would be 'a helpless jelly'. So the medication was *de facto* 'acceptable' to him, because he wanted to keep taking it because without it his suffering would be even more extreme. And it was not losing its beneficial impact in that he was not yet completely paralysed, as his father had been.

And was AB in the 'last stages' of his life? This expression could mean virtually anything. To someone who believes that suffering is redemptive, the 'last stages' of 'life' could last 12

years. It could be less or more than the 6 or 12 months prescribed under other VAD legislation. Whether by design or careless drafting, (b) and (c) could turn out to be way more restrictive than any actual time to death criterion. These provisions also contradict the principles of autonomy and minimising suffering, considered further below.

The doyen of VAD, Marshall Perron, also asks you to consider omitting (c), but I respectfully suggest that the alternative he proposes (set out below) is even more restrictive:

The wording “*Any medical treatment reasonably available and acceptable to the patient is confined to the relief of pain, suffering, and/or distress, with the object of allowing the patient to die a comfortable death*” assumes that the person is already in palliative care and may well have less than 6 months to live.

Similarly I would argue that the alternative wording for (c) proposed by Doctors for Assisted Dying Choice, is as confusing and uncertain as the phrase “in the last stages of life”. Is having a personal ‘opinion’ about when you are likely to die sufficient to satisfy (c), provided that opinion persists after a discussion with the assessing doctors? Or can the person’s health professionals override that opinion? Moreover it seems that the vexed issue of dementia is being introduced by the words “*or are in the last stage of their life with decision-making capacity*”. Does this mean that if the person is of the opinion that they don’t have much time left before losing capacity then this will satisfy (c)? It seems unlikely that any Parliament would accept this.

Neither Mr Perron nor D4ADC deal with (b) of the definition, which as illustrated in the personal stories above is just as problematic as (c).

I submit that defining the word “advanced” at all is unnecessary and confusing and could have the unintended consequence of making the ACT Bill more restrictive than its predecessors that include a prognosis to death eligibility criterion.

(2) Principles of autonomy and minimising suffering

It is encouraging that *The Bill commits to a review being undertaken once voluntary assisted dying has been in operation in the ACT for three years and this review will further consider the issue of whether eligibility should be broadened to include voluntary assisted dying being available to mature minors and people who do not meet residency requirements, as well as through advanced care directives*¹.

¹ In Western Australia the statutory ACD is known as an advance health directive, but I have adopted the acronym ‘ACD’ in this submission for convenience.

I have no detailed knowledge of other jurisdictions that have made VAD available to mature minors, and make no representations in this regard.

In relation to the residency requirements, is it necessary to wait 3 years for a review? Since VAD is already available in all the states of Australia, would it not be possible to include a provision that - as soon as the territories have equivalent laws - the residency requirements will fall away? There are many circumstances in which these provisions already cause much unnecessary stress and suffering.

In relation to advanced care directives (ACDs), I would argue that it is not possible to uphold the principles of autonomy and minimising suffering without making it legitimate to request VAD through an ACD.

The principle of autonomy is the same principle that underlies an ACD, which (in WA and I assume in the ACT) is at the top of the hierarchy of decision making when a person has lost the capacity to speak for him or herself, whether permanently or temporarily. It is the person's own voice that must be respected by a person's medical practitioners, even if those practitioners disagree with the directives it contains. For instance, even if appropriate treatment would (in some circumstances) almost certainly prolong or save the person's life, the person's refusal of such treatment must be respected. The refusal by a Jehovah's Witness of a blood transfusion is an obvious case in point.

What is not clear is why someone's autonomy (in person or through the proxy of an ACD) is treated as an intrinsic human right in the above circumstances, but not in the case of VAD. Requesting VAD through an ACD is not explicitly excluded by the WA Act, but it is the effect of the requirements that in order to access VAD the person must have decision making capacity *and* their request for VAD must be enduring. This in turn means that even if all the other eligibility criteria have been satisfied, and a current ACD clearly requesting VAD has been signed, VAD cannot be provided if the person loses capacity during the process. This causes particular hardship if capacity is lost between making the second and third requests, and has led some applicants for VAD to refuse pain and other relief of their suffering in case it impairs their capacity to make the final request.

Ironically, terminal palliative sedation (TPS) is a 'treatment option' that could be requested in an ACD, and could be provided by a doctor if clinically justified. This form of euthanasia is lawful without the person's consent, provided that (1) the primary purpose of the TPS is to alleviate suffering, even if it inevitably also hastens death; and (2) that the fatal drugs are administered slowly, instead of by lethal injection that causes a quick death.

Dementia

The position statement of Dementia Australia states that it neither supports nor rejects VAD, but advocates for “choice and a greater engagement with people impacted by dementia to understand how to best empower them to make decisions about their life and death”.

Until his death in October 2021, Dr Rodney Syme was one of the best known and most highly regarded advocates for dementia sufferers to have choice over their options at the end of life. He continues to advocate for this in his posthumously published book entitled *A Completed Life*.

In Western Australia there is immensely strong support in the community for access to VAD by dementia sufferers and it is the issue most frequently raised by the members and supporters of DWDWA. Both the former and current Premiers have advocated for a national conversation about dementia.

The very first recommendation in *My Life, My Choice*, the report based on the WA Joint Select Committee’s inquiry into end of life choices, was that an expert panel on advance health directives be appointed to consider (inter alia) that people with dementia might “have their health care wishes, end of life planning decisions and advance health directives acknowledged and implemented once they have lost capacity”. That panel was appointed but its recommendation on this issue was the only one of 23 not to be implemented.

Similarly a Ministerial Expert Panel (MEP) was established to consider what principles would be appropriate for inclusion in the WA VAD legislation. In its extensive consultations throughout the state the MEP found two main themes that emerged from the consultation. The first was the community expectation of being able to access voluntary assisted dying when dementia is present; the second the expressed wish to be able to request voluntary assisted dying by ACD (while still having decision-making capacity) in the event of a dementia diagnosis. The MEP acknowledged the depth and breadth of such views, and the intensity of feeling that accompanied many of them.

The government at the time – no doubt advisedly – decided that tackling two of the toughest and harshest issues – dementia and the time to death prognosis criterion - might cause the entire bill to be derailed. But these issues aren’t going away and should not be deferred just because they are complex and difficult.

As the law stands at present, an ACD can go some way to prevent prolonging the intense psychic and physical pain and distress that often accompanies dementia, by specifying

clearly what treatment the person wants or refuses and the circumstances in which those decisions are to apply. The person could for instance under a valid ACD refuse treatments designed to sustain or prolong life, such as assisted spoon feeding, antibiotics for infections, artificial (or forced) nutrition and hydration etcetera, but request and consent to treatments that would alleviate pain, distress and discomfort with analgesics, oral mouth care, and sedation as appropriate.

As argued above, it makes little sense for an ACD to be effective to refuse treatment that will prolong life, but not to request VAD. If the Act were to require death to be reasonably foreseeable rather than time-based, a person with dementia could use an ACD with 'dementia specific provisions' to request VAD once they had satisfied all the other relevant eligibility criteria. Of course those provisions would need to be carefully drafted to ensure adequate safeguards against duress or coercion, and that the life of someone with dementia could not be ended against that person's will.

As outlined in the explanatory statement to the Bill, this issue is being courageously grappled with in other jurisdictions, most notably in Canada. In particular the new provisions of legislation in Quebec outline a process that ensures the use of a tailor-made and suitably expressed ACD for a person who has lost capacity. This model is worthy of consideration as it would go a long way in resolving the intractable and complex issues that arise in relation to dementia, and balance safeguards with access.

Your Bill has introduced a plethora of improvements to VAD legislation, which may lead to welcome changes in other Australian jurisdictions when their laws come up for review.

I note also that the Bill "commits to a review being undertaken once voluntary assisted dying has been in operation in the ACT for three years ... [to] further consider the issue of whether eligibility should be broadened to include voluntary assisted dying being available ... through advanced care directives".

This begs the question, 'why wait for another three years'? The WA VAD Act has been in operation for two and a half years, and during that time the number of people and families affected by the relentless scourge of dementia has increased. Provisional data show that this disease will likely soon be the leading cause of death for all Australians.

If the review mentioned above could begin *now*, is it possible that in 3 years' time your Parliament might be ready to introduce, debate and legislate the reform so desperately needed?

Thank you for taking the time to consider my submission.

Yours sincerely
Dinny Laurence