LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),
Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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A SUBMISSION TO THE ACT PARLIAMENTARY SELECT COMMITTEE ON THE VOLUNTARY ASSISTED DYING BILL 2023.

BY MARSHALL PERRON **4th December 2023**

Having tracked the progress of voluntary assisted dying (VAD) legislation in Australia for over 20 years, I conclude that there are many combinations of provisions that establish a safe regime, but few that establish an effective one.

The VAD laws in all Australian states have been passed with trepidation by well-intentioned MP's who opted to minimise the numbers of people that might choose to exercise the option of VAD. The view seemed to be that success would be demonstrated by how few people used the law to die. The contrary is true.

The driving objective in allowing a citizen access to the means of a tranquil death is to relieve unbearable suffering.

At the end of the day, when all the states and territories permit VAD, the judgement of which has the best law will not be the one with the most restrictive regime, or the most safeguards. It will be the one which has the most liberal, least complicated access for those deemed eligible. It will also prevent anyone who is not eligible from unwillingly or inadvertently gaining access and enshrine the right not to participate without penalty.

This submission addresses only the subject of eligibility, on the basis that it is the primary criteria that is of concern to anyone who believes VAD should be an end-of-life option. Other subjects, such as application processes, monitoring and enforcement, protections of the vulnerable and for medical personnel etc., are matters of administration. While they are a necessary part of any responsible legislation, they are not addressed here.

I commend the researchers and decision makers who drafted the ACT Voluntary Assisted Dying Bill 2023. The bill more closely reflects the views of the broader Australian community and draws from the learned experience of the states that allow VAD. If passed in its current form, the law would be the most effective in respecting individual autonomy and relieving suffering that exists in Australia.

With one important caveat.

ELIGIBILITY is the factor that permits or limits who can access the means to a tranquil death. If the objective of VAD legislation is to allow relief from unbearable suffering,

then the law should provide a wide gate to those who are mature, informed, acting voluntarily and without coercion.

While failing to prevent legislation to permit VAD, state campaigns by opponents have been successful in making eligibility restrictive, and the whole process more complex than it needs to be. The imposition of time periods predicting life left is the most serious and harmful obstruction.

There is something not right when we say, "We know you are an adult with a disease that will kill you. You are competent, informed, acting voluntarily and without coercion, but we also want to know that you do not intend to shorten your life by more than we think you should. If that involves you suffering a while longer – so be it."

This cruel stance is also reflected in the 'cooling off' periods included in State laws. To demand that a person who considers the burden of living exceeds their fear of death should endure a period of reflection on their decision, is callous.

The above is simply to support the absence of time limits and a cooling off period in the Bill before the committee. I believe this initiative will eventually flow to all state VAD laws as it is a serious flaw in current legislation.

The law should be structured to encourage individuals to live as long as their suffering is endurable. Creating an arbitrary period within which an applicant is expected to die establishes a dreaded objective which must be met. One has to 'achieve' a short death sentence to qualify for assistance.

There is growing evidence in the USA of people declining medical treatment to meet the required prognosis. Fostering unnecessary suffering should not be part of any VAD legislation.

Instances have been recorded where VAD applicants have lost competence or died before they had completed the application process. Given the complexity of disease, the physical and mental resilience of individuals and their environment, predicting when death is likely to occur has been described by doctors as a 'guess'. Claims that patients often live much longer than predicted are countered by research showing that the contrary is true. The majority of patients die before the predicted period.**

The Bill before the select committee avoids this problem by encouraging inquiry early after a terminal diagnosis is confirmed, to explore all end-of-life options. Although it needs to be confirmed, Section 9 in the Bill provides for a person to ask for assessment and delay the process at different stages. It would be beneficial if an applicant could be assessed as meeting the eligibility criteria before the suffering became intolerable, making the final request when (if) the suffering did become too much to bear.

This ‘slow’ two stage process would allow unhurried assessments with less patient stress, but most importantly, encourages the patient to get on with living to the best of their abilities knowing VAD was available if it was needed. There is ample evidence that the terminally ill experience a renewed determination to live when they know a peaceful death is available.

THE CAVEAT

Having applauded the decision to exclude predictions of life left in the bill, I flag a potentially serious flaw in the Bill.

I am concerned the eligibility criteria in the Bill S11 (4) (c) “*the individual is in the last stages of their life*” could negate the benefits of not specifying life left times.

The words “*the individual is in the last stages of their life*”, it can be argued, introduces some of the same issues the 6/12 time limits do. Although it is intended to discourage VAD applicants from ending their lives ‘too early’, it actually encourages them to exacerbate their condition in order to meet the criteria. In fact, it might be argued that ‘last stages of life’ means even less than 6/12 months.

Worse than that, requiring the individual to be in the last stages of their life will leave individuals with diseases that have long physical decline trajectories, like dementia, Parkinsons etc; likely to lose competence before they reach the last stages of life. That is the case now under the state laws.

What to do about it?

The preferred option is to simply drop S11 (4) (c) completely. I urge the committee to seriously consider this option. I contend that legislation should not demand that a competent, suffering individual, who considers death preferable to their daily existence, endure more, solely to reach a greater state of physical and mental decay.

If the committee rejects omitting the offending sub section, I suggest the following be considered to replace it.

“*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.”*

This provision would reinforce the decision not to stipulate a life expectancy period in the law. The terminally ill patient has reached a stage where all medical treatment seeking to cure the disease has ceased, and all treatment is aimed at keeping them comfortable.

It is very hard for opponents to argue against this proposition. The patient is clearly going to die. The only uncertainty is how long it will take and how 'bad' a death it will be. There is no incentive for the patient to aggravate their condition to meet a timeline.

IN CONCLUSION

The ACT Assisted Dying Bill, if passed into law and **subject to the caveat above**, will be a significant step forward in easing futile suffering by the terminally ill. Having accepted advice from permissive jurisdictions the authors of the bill have given the ACT the opportunity to lead Australia in this important law reform.

While ideally the Bill would have extended eligibility to adults with unbearable suffering from incurable but non terminal conditions and VAD via an advance directive, that does not diminish the important advances proposed by this Bill.

I wish the committee well in its deliberations.

Marshall Perron

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*** At the Forefront. UChicago Medicine. Doctors Overestimate Survival Times for Terminal Patients. Feb 17th 2000**

The Author

Marshall Perron was a member of the NT Legislative Assembly 1974 to 1995.
NT Chief Minister for 7 years.
He was the architect and sponsor of the *Rights of the Terminally Ill Act 1995.*