

A submission to the Expert Advisory Panel on Voluntary Assisted Dying legislation in the Northern Territory.

By Marshall Perron

6th February 2024

PREAMBLE

I commend the NT Government for acting to consult the community on Voluntary Assisted Dying (VAD) following the period where the Territory Legislative Assembly was denied the authority to consider the subject.

As noted in the Expert Advisory Panel terms of reference, the NT has the benefit of the work done by each Australian state in recent times when each moved to devise their own model permitting VAD. The inquiries by State Parliamentary Committees and subsequently Parliament itself, makes VAD possibly the most comprehensively examined law in Australian history.

Five states conducted parliamentary inquiries and one commissioned a review by a university. In total, the reports contain 2,262 pages crystallising 9,954 submissions and evidence presented by 888 witnesses*. Additionally, many public forums and meetings with stakeholders were held.

Although the subject of VAD has always invoked a high participation rate when debated by Members of Parliament, it is clear that members are still behind the desires and aspirations of their constituents regarding VAD. In particular, the public want a less restrictive approach when it comes to eligibility.

Having been an advocate for legalising VAD for 28 years and involved in campaigns when each state Parliament debated the issue, I observe that there are a number of VAD models that will work to relieve futile end of life suffering. However, some combinations are clearly more effective than others.

Put simply, the law specifies strict rules governing the relationship between a patient and their medical advisers and authorises the prescription and administration of lethal drugs. Everyone involved must be willing participants.

The obvious starting point for the NT will be to combine the most progressive elements contained in each state law, which it appears the Australian Capital Territory has done, and then add new provisions which broaden access.

The Northern Territory demography makes it unique. A small population, less elderly residents, a large percentage of ABTSI people retaining cultural traditions, a relatively small number of qualified health professionals. These factors are relevant when considering the nature of a VAD regime.

There were 1300 deaths in the NT in 2002. Approx 50% were ATSTI. VAD deaths in Australia are between 0.5% to 2%. If, as some predict, ATSI who retain cultural traditions are unlikely

to seek VAD, the number of applicants may be around 10 to 15 pa. (If eligibility is restricted to the Terminally Ill.)

The figures of usage under the Rights of the Terminally Ill Act (4) are no guide, as there was a concerted campaign to prevent participation by the medical profession during the 9 months the Act was in operation.

Legalising VAD should not be at significant cost to the NT taxpayer.

With such small numbers of potential applicants for VAD, the NT can minimise administration by using existing departments and agencies for education, monitoring and oversight. These include the Department of Health, Attorney Generals, the Police, DPP, Births Deaths and Marriage Registry, NTCAT, Coroner as well as professional medical registration boards.

The following remarks are limited to those subjects I feel are crucial to an effective regime.

ELIGIBILITY EXPANSION

Considering the option to end unbearable suffering is the principal reason for permitting VAD, eligibility is, therefore, the most important provision required to achieve the objective. It is the gate to access.

The positive opportunity which arises from a small number of applicants for VAD is that the Territory can broaden the eligibility criteria for VAD without being overwhelmed.

Consideration can be given to people who are accommodated in The Netherlands, Belgium and Canada but prohibited in the USA, NZ and Australia.

The case to extend eligibility beyond terminal illness to individuals with an advanced incurable illness, and individuals with dementia who have completed an advance directive while competent, is strong.** Despite submissions to the State Parliamentary inquiries advocating for these changes and clear support from the community, no state Parliament was prepared to extend coverage to these areas.

It was only after decades of advocacy and lobbying that state politicians finally acceded to the will of the overwhelming majority of citizens, and legalised VAD. Unfortunately, the subject was approached reluctantly with a focus on how to minimise the number of people who would be able to access VAD. The Victorian Premier boasted how their law had the most safeguards in the world. A gauntlet designed to ensure only those close to death would comply. The presumption being, the fewer people who opted for VAD, the greater success it would be, when the reverse is true.

The principles of autonomy, dignity and self-determination were lost in the fog generated by those who wanted no law and worked hard to make it arduous for everyone.

Before the NT passed the RTIA in 1995, the subject of providing a person suffering from a terminal illness the ability to hasten their death peacefully was simply 'too hard'. Today, hundreds of millions in democratic jurisdictions across the world have a right to VAD in

varying circumstances. In some of those places, the criteria is based on unbearable suffering, not longevity, and it is within the capacity of the NT to join them.

Legislating a safe regime to permit VAD for incurable but not terminal conditions and to provide an advance directive process in the event of lost competence is feasible.

A “Waiver of Final Consent” for patients deemed by their coordinating doctor to be at risk of losing competency after being found eligible (both assessments) but before administration of the medication, is a logical first step. The Canadian Parliament passed such a provision in March 2021. The Quebec National Assembly passed an Act allowing a request for MAID via an advance directive in June 2023. The provisions follow a long period of consultation and consideration.

It is noteworthy that the former President of National Seniors of Australia, John McCallum, advocates VAD access for dementia sufferers via an advanced care process while competent. Dementia Australia (DA), the national peak body and advocate for people impacted by dementia, “supports the right of every person, including those living with dementia, to exercise choice over end-of-life care options, including VAD measures.”

I strongly believe that it is simply a matter of time before the community desire for these initiatives will be met. The question is, will the NT parliament advance the case?

AGE

It could be argued that an arbitrary age limit to access VAD amounts to child abuse. The young can be inflicted with some of the same diseases as adults and suffer no less.

In my view the concept of ‘mature minor’ should be developed to allow persons under 18 years old to access VAD where they are otherwise eligible, subject to additional provisions. Such provisions could include parental approval and evaluation by an appropriate specialist of the applicant’s psychiatric and psychological state.

REQUEST AND ASSEMENT

There are many combinations of procedures for applicants and involved professionals to access VAD that will work. The general mechanism that has evolved in state laws involving two medical practitioners, specialists only where considered necessary, nurse practitioners, navigators and witnesses is quite satisfactory, with the following exceptions.

There should be no requirement demanding an applicant be assessed as having a predicted life left of 6 or 12 months. These provisions are a serious flaw in all State laws. This arbitrary figure is thought to have been drawn from the Oregon DWD Act where it related to access to palliative care in that state.

Predicting life left longer than a few days or hours is so inexact that it is little more than 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.***

VAD cases in Victoria and WA have shown the timeframe is problematic. Some applicants have died before their application was finalised.

The will to live is the strongest force in nature. If a competent adult is diagnosed with a terminal disease that causes, or will cause, unbearable suffering such that the person chooses to hasten their death, no limiting time period should apply. There is abundant evidence showing that after receiving the means to die peacefully, a competent person usually experiences a renewed determination to live as long as they can endure.

The prohibition on doctors initiating discussion on VAD is ridiculous. How can it be OK for one's neighbour, friend, family or the local butcher to suggest VAD as an option but not a doctor? If discussion on options like voluntary starvation, terminal sedation and removing life support can be initiated by a doctor, why not VAD?

The requirement in some states for a permit to be issued before a prescription is issued is bureaucratic overkill. The paper-trail required by most state laws is more than necessary to monitor VAD applications as they occur. The permit provision is another example of opponents to VAD successfully complicating the process without a valid reason. Even a short period of delay in accessing VAD can be an eternity for a person living in agony. WA and QLD laws do not demand a permit. Neither should the NT.

Cooling off periods should not be included, if they are they should be kept to a minimum and waivable if there is a risk of the applicant losing competence. Considering the period involved when a person is diagnosed with a terminal disease by a minimum of two doctors and likely specialists in the hope of a cure, requiring them to 'reflect on their decision' for days or longer before granting their request for relief through death, is patronising and demeaning.

ADMINISTRATION

I advocate that the presence of a doctor when VAD is administered be the default position. An exception should be permitted where the applicant intends self-administration and requests privacy, and the doctor believes the person is capable. (refer; Tasmanian Act S83)

The obvious advantages are that the doctor can explain the process to persons who are present, administer the VAD substance or ensure self-administration goes smoothly and comfort witnesses after the death if necessary. The doctor would also issue the death certificate. A doctor would deliver the necessary drugs and retain any unused for disposal. This would eliminate the messy, unnecessary regime contained in all state laws regarding the prescription, packaging, delivery, retention, use, handling and disposal of unused drugs.

The obsession for control reflected in state laws ignores the fact that doctors prescribe potentially lethal drugs every day for which the patient has full control. The same has been practice in Oregon for over 20 years. I have not read that it has been an issue.

The method of administration should not be specified in legislation. Considering the myriad of possible circumstances, it should be a matter agreed between the doctor and applicant.

Intravenous self-activated administration should be allowed. **** Although this method is probably not currently practiced in Australia, I predict that it will emerge over time to be the most preferred method. The advantages over doctor administration are obvious. Patient self-administration is the ultimate safeguard.

I commend the uniquely Tasmanian provision whereby a doctor can intervene in the administration process if unexpected complications arise. (Tasmanian Act S88)

OVERSIGHT

All current state VAD laws in my opinion are overly bureaucratic and more costly to administer than necessary.

There is no need for the multi stage application/ approval/ oversight process demanded in some state laws. Curiously, refusing life-saving medical treatment is permitted with no approval process.

An independent body that reviews reports submitted by a health professional after a VAD death would be appropriate. As would other points of data collection on applications, successful or not, in the interest of the national data base. These should not however delay the application process in any way.

FINALLY

Should the NT move boldly to meet the community desire for a more liberal VAD regime, there will certainly be yells of 'slippery slope'. They should be ignored. The so-called slippery slope is a myth. The implied unstoppable slide toward an undesirable place is actually a hard uphill climb to a better, more compassionate society.

I recommend a law superior to the current Australian state laws by accommodating the needs of a broader range of prospective applicants, shortening timeframes and reducing complexity.

I urge this committee to recommend so.

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*.

* State Inquiries schedule attached.

** VAD for advanced incurable illness.

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

**** Ref Vic VAD Review Board report July 2021-June 2022. Page 31.