

TO: MEMBERS OF THE NORTHERN TERRITORY LEGISLATIVE ASSEMBLY LEGAL & CONSTITUTIONAL AFFAIRS COMMITTEE

RE: VOLUNTARY ASSISTED DYING (VAD)

Ladies and Gentlemen

I am a private citizen, presently living in Tasmania, but a one-time Darwin resident, who maintains an acute interest in the issue of VAD across Australia and throughout the world. I am neither a member of, nor affiliated with, any organisation promoting or opposing the introduction of VAD-enabling legislation in any jurisdiction.

But over time I have lodged submissions supporting the introduction of VAD legislation in Tasmania, Queensland and Western Australia, and assisted the Dying With Dignity Queensland organisation by drafting their submission supporting VAD, leading to enacting of that State's VAD legislation.

I offer these comments and observations as an informed private citizen, who feels passionately about any means by which Governments may, by their VAD legislation, show compassion for those facing intolerable deaths. This submission addresses the four questions outlined in the "Short Consultation Guide" provided on-line by your Committee.

1 Do you support making VAD legal in the NT?

I passionately support the introduction in the NT of legislation enabling VAD.

It is ironic that, the NT having been the first jurisdiction in Australia, and only the second (after Switzerland) in the world, to enact such legislation (the *Rights of the Terminally Ill Act, 1995 - ROTI*) it is now the last of the Australian States and Territories to consider re-examining such legislation, after the original Act was rendered inoperable by the Commonwealth's *Euthanasia Laws Act 1997*. It is further ironic that three persons qualified for, and died under the provisions of the NT's ROTI Act, without any of the threats and risks habitually used by opponents of VAD there and elsewhere.

The key word in any discussion of VAD is 'compassion'. In almost any conversation about the merits of VAD legislation, words like "You wouldn't do it to your dog" are raised (referencing allowing fellow human beings to die badly, compared to the routine availability of euthanasia for loved animals suffering evident distress). Those within the medical fraternity, and notably practitioners of palliative care, readily admit that, while they can currently apply measures which may control pain and manage some end-of-life difficulties, there remain circumstances where they are unable to provide comfort and relief. It is to such people that VAD holds the hope of a peaceful passing.

Examples and images of death throes which can only be described as degrading and horrific have been graphically detailed during consultations leading to VAD in other jurisdictions, and doubtless will be provided to your Committee by professionals involved in end-of-life care. Providing sufferers of conditions which threaten intolerable deaths, should they opt to take advantage of VAD, should be free from entrenched religious, social or racial impediments, since any such decision must always be demonstrably voluntary. Such provision should be the overriding goal of any VAD-enabling legislation.

2 What eligibility criteria should a person need to meet before they can access VAD?

Existing VAD legislation in other Australian jurisdictions, and elsewhere in the 8 countries and multiple States of the USA, provide templates for eligibility criteria which to this time have meant that recipients of VAD have avoided any of the alarming consequences habitually used to oppose the introduction of VAD-enabling legislation.

But in efforts to appease strident opponents, eligibility criteria in all Australian jurisdictions apply such strict conditions as mean that many worthy applicants for assistance either fail to complete the lengthy and perhaps overly complex application procedures, or die (badly) before they do: statistics detailing the numbers of people so affected are contained within periodic reviews of the operation of VAD Acts in all States and the ACT.

The NT has the luxury of learning from the unintended consequences of applying extreme levels of rigor to eligibility criteria applied in other jurisdictions, which effectively work to deny wholly worthy applicants help to avoid intolerable deaths, rather than slavishly use existing Australian legislation as a template.

One issue which the Committee may like to consider, is that of ‘mental competence’ at the time of an application for VAD is made. A number of terminal medical conditions rob applicants of their intellectual competence well before they may be deemed eligible for assistance under VAD frameworks – especially referring to timelines to death which are currently specified to varying degrees in all Australian VAD legislation. Giving effect to Forward/Advanced Health Directives, made when the applicant is of reliably sound mind, should be contained within eligibility criteria, so that when they reach a predictable end-stage, their forward wishes can be activated.

A related matter is the insistence by other jurisdictions of nominating fixed timelines to expected death. The most fervent medically-qualified supporter of VAD will readily admit that any prediction of the timing of an applicant’s death is incapable of any reliable precision, and thus should be carefully reviewed by your Committee. One possible solution would be for any eligibility assessment to require periodic reviews of the rate of an applicant’s physical and/or mental deterioration, adjusting eligibility accordingly. Or abandoning timelines altogether.

The guiding principle behind any assessment of applicants’ eligibility for assistance under the NT’s VAD-enabling legislation, should be compassion for the applicant, rather than applying rigid bureaucratic measures to accommodate the naysayers. Protection for applicants is effectively provided by using some – but not all – such provisions in existing Australian VAD Acts across Australia, but very serious consideration should be given to a review of such protections, noting (as described briefly above) that when they work against compassionate treatment of applicants, they can and do mean that many whose technical eligibility for help from VAD legislation, do not complete bureaucratic requirements before they either withdraw or die.

While extreme caution has been exercised by all Australian VAD legislation with regard to applicant eligibility, your Committee is encouraged to think laterally about the conditions under which an applicant may seek relief to end what may become intolerable lives.

Current laws list an expectation of death within a specified period.

Yet many folk face and must endure unbearable pain and suffering from conditions for which there may be no reliable prognosis to death. Examples are those suffering from unbearable and untreatable pain from skeletal deterioration due to advanced age; those whose breathing or ability to communicate are restricted to such a degree as robs them of enjoyment of life; and those whose human dignity is compromised by such widespread enfeeblement as denies them completing such daily routines as toileting themselves, or such limited movement and flexibility that they only function thanks to the ministrations of others.

The Swiss example is illustrative of how a broader interpretation of assistance for relief of intolerable, yet not necessarily fatal, human conditions can be addressed. The Swiss Criminal Code allows for voluntary euthanasia where applicants self-administer lethal medication, without any requirement that their condition is predictably terminal. While commending such an approach to consideration by your Committee, any suggestion of commercialising voluntary deaths (such as the *Dignitas* organisation in Switzerland) or “death tourism” to those countries whose allowance of assisted deaths is relatively accommodating, is not being recommended, and rather should be deplored.

3 How could the NT make sure that an eligible person can access VAD in a safe and effective way, including people living in remote areas and Aboriginal and Torres Strait Islander people?

Existing Australian VAD Acts provide valuable templates for mechanisms enabling safe and effective access to VAD, even though some of their measures are so restrictive that they may work against the applicant seeking assistance under their Act.

Limiting factors currently include a shortage of medical practitioners who are required under those Acts to play roles in the VAD process. Quite rightly, their inclusion in the process is and must remain entirely voluntary, but the NT should address the means of promoting the community value of them enlisting in the VAD process, while ever honouring their right to their personal views.

Another is the current prohibition on other than face-to-face discussion between medical practitioners and aspiring applicants for help to die, an issue whose review is under active consideration at Commonwealth level. Lifting of such restrictions is of particular interest in the NT, where so many of its residents are located away from major population and medical centres. Such folk should not be denied or the ability to discuss with medicos their options for relief, via telephone or electronic communication media, from potentially intolerable deaths.

4 How could the NT monitor the process to ensure VAD is delivered safely and effectively?

Once again, existing Australian State and Territory VAD Acts offer templates for monitoring and reporting mechanisms which, to this time, are providing informative performance data on the operation of the respective Acts, and supply indicators of where revision to requirements under those Acts may be desirable.

Of particular value to your Committee are the statistics in (for example) the Victorian Act's periodic reviews, giving numbers of those applicants for whom the length and complexity of the application approval procedure works against the likelihood they would ever be able to avail themselves of help under the Act. Any such review should allow for revision of such provisions under the Act as may unwittingly deny applicants the relief they seek, rather than enshrining such provisions in ways which are incapable of change.

5 *Conclusions*

- (i) With all Australian VAD legislation (other than in the NT) now in place, the negative, alarming, sensational and catastrophic outcomes predicted by opponents of VAD have been proved comprehensively wrong: there have been no such consequences. As mentioned above, that may at least be in part due to excessively cautious and restrictive demands placed on eligibility and practices relating to operation of the scheme, which I urge the Committee to not replicate without very careful review of the extent to which they may, therefore, be serving to unreasonably discourage worthy aspiring applicants from submitting to what in most cases are lengthy, overly-bureaucratic and complex procedures.
- (ii) The Committee should address the current denial of those suffering such intellectual deterioration as may/will risk ineligibility for VAD assistance, on the basis of their mental competence at the time they request help. Mandating the validity of Forward/Advanced Health Directives would be the means by which such people could specify the conditions under which they would wish to activate their request for VAD, rather than be denied assistance due to their already-deteriorated mental competence.
- (iii) The currently universal reliance on varying predictions of a time to death from the date of application is unreliable and ignores medical evidence of advancing debilitation of the applicant, and deserves review. The present requirement of support for relief from more than one medical professional may be expanded to their assessment of current rather than predicted levels of pain and suffering, allowing access to VAD without specifying a period to death.
- (iv) Members of the Committee are warmly encouraged to place themselves in the shoes of those facing any form of intolerable death, when framing conditions attaching to processes leading to approval and implementation of assistance for relief through VAD. The principal motive behind any such legislation should ever be compassion for those facing unbearable life, and death, rather than appeasing critics of the means such people may wish to take to alleviate their suffering. The immutable condition must always be protection of the applicant from any form of influence over their decision to seek relief via VAD: such decisions relating to that process must be sacrosanct to the applicant alone.

SUBMITTED BY BRUCE M LINDSAY, TASMANIA ████████.