Submission No 26

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Dying With Dignity Victoria Inc

Date Received: 19 November 2021

dying with dignity victoria

respect for the right to choose

the overwhelming majority of australians believe in
the right of the terminally ill to seek and obtain
medical assistance to end their life with dignity

19 November 2021

A Submission in relation to the New South Wales Voluntary Assisted Dying Bill 2021

This submission responds to the invitation by the Parliament of New South Wales to address aspects of the Bill under debate.

Since 19 June 2019, Voluntary Assisted Dying ("VAD") legislation has been in force in Victoria.

From 1974, the organisation now known as Dying With Dignity Victoria ("DWDV") has been active in

- Seeking legislation for VAD
- Ensuring the success of its implementation
- Monitoring the efficacy of the VAD process throughout Victoria.

DWDV is a charity registered with the Australian Charities and Not-for-profits Commission. We offer opinions based on the experience in Victoria as observed by members of this organisation.

We would be pleased to respond to any questions that may arise as a result of this submission.

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Summary

In our opinion

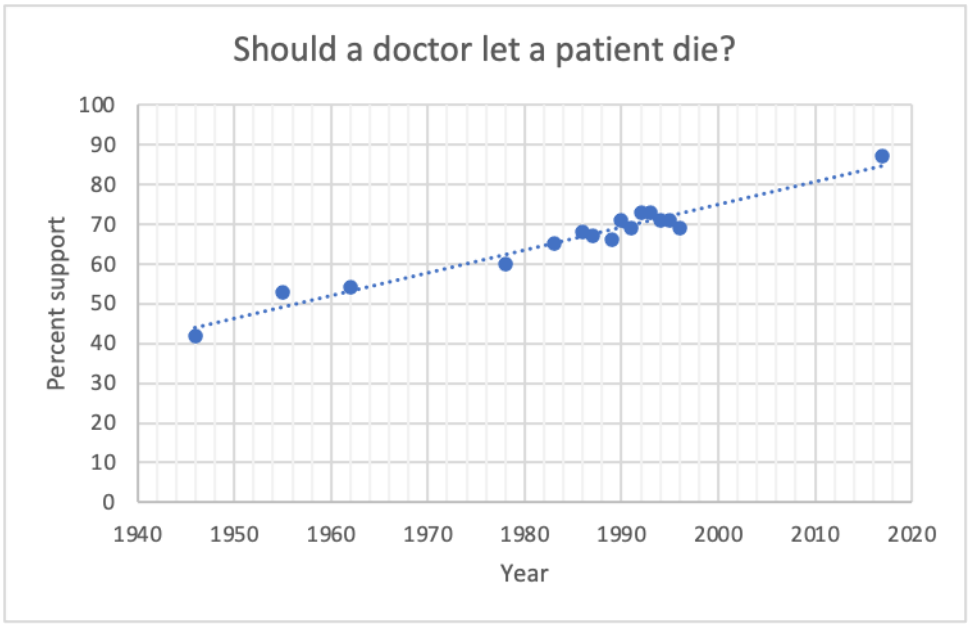
- The Australian community support for VAD is around 85%. The Victorian experience of over 2.5 years has shown VAD can be safely implemented
- The Bill presented to the NSW parliament is the best yet
- The arguments put forward by opponents are without substance and show only a bias from an undeclared origin. An assessment of a current list objections to the introduction of VAD is provided in the Appendix to this submission.

In detail:

Support from Australians for VAD

There have been so many surveys over so many years that is seems unnecessary to have to keep on referring to them. Whilst there have been some recent Vote Compass surveys of some Sydney electorates, it may suffice to show results and conclusions from Roy Morgan polls:
http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349

In summary, the Roy Morgan survey concluded "A large majority of Australians, 87% (up a significant 18% from May 1996) are in favour of 'letting patients die when they are hopelessly ill and experiencing unrelievable suffering with no chance of recovery' compared to 10% (down 7%) who say doctors should 'try to keep patients alive' and 3% (down 11%) who are undecided." A chart below tracks the level of such support since 1946, in response to the question above. A trend line is included.



It thus seems like a rejection of democratic principles, that a significant number of politicians have so little concern for the opinions of their constituents.

Experience

The argument of 'slippery slope' has been and continues to be floated as a reason not to allow for the proposed change of law, to which our response is "where's the evidence?". For evidence to the contrary we may look at what has taken effect in Victoria, and the experience since 19 June 2019.

The Voluntary Assisted Dying Review Board ("VADRB") is an independent and professional body who have produced reports, at regular intervals, on how the VAD process is operating. These reports are based on feedback from individuals and families that navigate the process, and Medical Professionals involved with its provision. The reports have consistently shown very high levels of compliance and have never reported any matters for concern in relation to implementation.

For example, from https://www.bettersafercare.vic.gov.au/sites/default/files/2021-08/VADRB%20August%202021%20report%20FINAL.pdf we have

- Under the Compliance section "From 1 January to 30 June 2021, 99 per cent of applications have been compliant. …"
- Under Feedback, "Overwhelmingly, applicants talk about having the choice to decide the timing and manner of their death. It gives them a sense of control at the end of their life, when many other choices are no longer available to them…"

The Bill

In our opinion this Bill provides the best set of options and controls of the five cases of VAD legislation we have seen to date, and we commend the authors for their work.

A framework
Section 4, Principles, includes under (h) "a person is entitled to genuine choices about the person's care, treatment and end of life …"

What is voluntary assisted dying?
It is important that the Bill notes (12) that Voluntary assisted dying not suicide. Whilst it seems implicit in the Victorian Act, the lack of clarity has been an issue in some cases.

Eligibility
The eligibility criteria (16) are similar to those that apply in Victoria. They are reasonable in view of community expectations at this time. The residency requirement is a great improvement on the Victorian version, which has caused a great deal of unnecessary suffering.

Administration of the substance
The provisions are similar to those of Victoria. We suggest that, if the medication to be used for self-administration in NSW is the same as that in Victoria, there then seems to be no need for a different chemical to be used for physician administered intravenous medication.

Communication of the request
Section 182 deals with the manner of communication between the person and the medical practitioner, and provides, as far as it may, the options for Audio-visual request. This option is especially important for those living far from a major centre and those whose mobility is severely impaired.

The limitation relates to the interpretation that the Commonwealth Criminal Code, that makes this means of communication an offence. We note the problems this provision has caused. These issues are referred to in the VARDB Report, under Commonwealth Criminal Code, where the authors advise "The Board continues to urge the Commonwealth to consider an exemption for those accessing voluntary assisted dying, and for it to be treated in the manner of other telehealth consultation options."

We look forward to that consideration taking place, and the obvious conclusion that it be resolved in the affirmative. "Telehealth" also permits (say) two medical attendants, and family, to be effectively present during consultations.

We will be surprised if this matter is not resolved satisfactorily before long. For now, we enclose an Opinion from Barristers Robert Richter QC and William Stark.

Safeguards

The criterion of decision-making capacity clears many of the causes of concern that the process may be open to interference. The prevention in Victoria of initiation of VAD discussion, by the physician, is considered by many to place them in breach of a professional duty of care. The provisions of Section 10(2) are a suitable solution.

Information for health professionals

The Victorian process of training by doctors, and the paperwork associated with the provision of VAD, has been widely criticised. We suggest the implementation process review the Victorian experience.

Implementation

Witnessing – Division 5

At the stage where independent individuals were required to witness a person's request for VAD, it became evident that some VAD persons found it difficult to find individuals to fill the role. DWDV implemented a 'witnessing' program, which has been extremely successful. More than two years later, witnesses have been provided on 145 occasions.

In hindsight it does appear that the role of the witness has been understated in its importance. The witness becomes privy to many personal and identifying details about the VAD person. These details include the person's name, the nature of the disease/illness/medical condition as well as the location of the person which may include details of a private residential address. Occasionally the witness may learn of the exact date that the person wishes to carry out the VAD process. Some VAD persons do not want family and friends to be aware of the choice they have made and are therefore entrusting unknown individuals, witnesses, with a lot of identifying information.

A few issues have been brought to our attention in recent times. It was reported that witnesses occasionally engaged in conversation relating to the VAD process with the VAD person and associated family. On other occasions, comments were made about the amount of time-consuming paperwork that was associated with that relevant stage of the VAD process. It is an extremely anxious time for the VAD person and often they are in extreme pain and in a state of exhaustion, just wanting to complete the process. The role of the witness is self-explanatory, they are not present to provide their personal VAD view. The Victorian VAD Act, unlike the proposed NSW VAD Act, requires witnessing to be conducted in the presence of a Health Practitioner. In fact, witnesses are advised not to present

themselves to the VAD person until the overseeing Health Practitioner is present. This safeguards against the possibility of a witness speaking inappropriately.

It appears that NSW VAD Legislation does not require the witnessing process to take place in the presence of a Health Practitioner. We suggest that consideration be given to the above points.

Lack of participation by doctors

The Victorian Voluntary Assisted Dying Act 2017, did not make provision for nurses to act in the role of 'Administering Practitioners', specifically stating that only doctors, who were deemed eligible, could fulfill this position.

The 6-month report released by the Victorian Voluntary Assisted Dying Review Board (1) indicated that 33% of VAD registered medical practitioners were located outside of Metropolitan Melbourne with this figure increasing to more than 36%, in the 18-month VAD Review Board report (2). It was also noted in this latter report that "*There remain limited numbers of medical practitioners participating in voluntary assisted dying in eastern and western Victoria."*

A 2017 cross sectional survey of clinicians from 7 Victorian Hospitals, conducted after VAD Legislation had been passed in the Parliament but not yet implemented, concluded that about 73% of those surveyed supported VAD however only a small number of medical specialists stated that they would be willing to participate in the process (3). This study also reported that a great majority of nurses expressed support for VAD compared to medical specialists who were more evenly divided. Furthermore, nurses appeared far more willing to participate in a VAD death, a majority indicating they would be prepared to insert an IV canula for the necessary VAD medication, than the comparable small number of medical specialists.

Perhaps the consideration of the utilization of specialized nurses, in the VAD procedure, may have helped counter the inadequate numbers of VAD medical providers in the Victorian rural areas mentioned.

DWDV is therefore supportive of the New South Wales Bill's **Section 55 Eligibility to act as administering practitioners** that allows qualified nurses to act in this role.

Opponents

Some of those who oppose VAD are vocal and present what they call 'arguments'. Our own definition of an argument requires that the statements made be based on data, and then proceed using laws of logic to reach a conclusion.

We see little evidence of this in what has emerged to date. An analysis of some offerings is included as an Appendix to this submission.

We view the VAD Bill, that is being presented to the NSW Parliament, as the best bill yet to be presented to an Australian State Parliament. It has taken into consideration many of the impediments and difficulties faced by the Victorian Voluntary Assisted Dying Act 2017.

Other

Additional relevant information may be found at:

1. Voluntary Assisted Dying report of operations (June to December 2019)
2. Voluntary Assisted Dying report of operation (July to December 2020)
3. Support for and willingness to be involved in voluntary assisted dying: a multisite, cross-sectional survey study of clinicians in Victoria, Australia.

Appendix

We have the opposition group Care Alliance providing what it calls “Articulate and persuasive arguments against legalising assisted suicide …” at https://www.australiancarealliance.org.au/why_i_am_opposed
In our opinion these so-called arguments are pitiful, and devoid of substance.

In detail:

My Opposition
Senator Pat Dodson

"If we give one person the right to make that decision—that is, to assist in committing suicide—we as a whole are affected. If we give one family that right, we as a whole are affected. If we give one state or territory that right, we as a country are affected. If we give one nation the right to determine life, our common humanity is affected. I cannot support this legislation."

The argument provides no evidence for whether the ‘right’ concerned is a good or a bad one.

My Opposition
Adrian Dabscheck

"I would like to question if the possible consequent good of allowing a highly selected population of privileged people the ability to request and be administered medical assistance in dying is sufficient to overturn millennia of accepted medical practice."

Having questioned it, we may note that millenia of practice is of itself no recommendation. Many aspects of medical practice have changed, even in recent decades, as a result of discoveries and changes in public perception. The implication that the ‘good’ is available to only a selection of the public is ridiculous where the legislation makes not such distinction.

My Opposition
Paul Kelly

"Crossing the threshold to euthanasia is the ultimate step in medical, moral and social terms. A polity is never the same afterwards and a society is never the same. It changes forever the doctor-patient bond. In brutal but honest terms, more people will be put at risk by the legislation than will be granted relief as beneficiaries."

Change is, of itself, not necessarily bad. If it were, we would not have modern medical practice. The modern doctor-patient bond is primarily a commercial one. Claims to the contrary are a medical fiction. And there is no evidence to back the claim of people being at risk.

My Opposition

Stella Young

"Social attitudes towards disabled people come from a medical profession that takes a deficit view of disability. This is my major concern with legalising assisted death; that it will give doctors more control over our lives."

To the contrary. VAD legislation places control with the person, not the doctor. All, including those with disabilities, need to demonstrate decision-making capacity before any Assistance can be provided.

My Opposition
Julian McMahon

"Legalising assisted suicide immediately places the elderly sick, and the most vulnerable under intolerable pressures. Over time, despite its intent to assist a few rational people to die, the changes in attitude it signals will undermine society's support for the lives of the voiceless and those most in need. It should be rejected."

Where's the evidence? All Australian VAD legislation places great emphasis on the absence of pressure, and the VADRB reports to date show no sign of coercion. Who are the voiceless? There are many support groups for the elderly.

My Opposition
Kevin Yuill

"The most serious case made by advocates for assisted suicide is autonomy. Yet what stands out for this most recent toleration of at least some suicides is the lack of autonomy; to be legitimate, it seems, suicide must be sanctioned by that new priesthood, medical authority."

Evidence, please , for the 'lack of autonomy'.

My Opposition
John Anderson

"We open this door at the peril of all future generations as we move one step closer to a heartless and expedient society where everything is expendable, including the lives of all those whom we, others, or even the state deem 'unsatisfactory'".

This statement shows a complete lack of understanding of how VAD is legislated in Australia. It is the individual concerned who decides if the suffering is intolerable. As for future generations, if VAD were deemed so bad, they could repeal the laws.

My Opposition
Richard Stith

"A culture of disdain for disabled and elderly persons is more likely to come about if we embrace a right to assisted suicide. Each endorsement of suicide endangers not only the lives but also the human dignity and quality of support relationships of persons with burdensome infirmities."

The right to assisted dying for an individual has nothing to do with the 'culture' of others. It become a choice for the individual. There is no evidence of danger to lives. Dignity, or rather the loss of it, can be a strong motivating factor. Support, and of a quality that the professions can provide, is there so long as people want it.

My Opposition
Lindsay Tanner

The question at stake here is, not whether in some individual circumstances there is something morally wrong, but whether the state should legalise and indeed can safely legalise such practices. Our view on euthanasia should not be determined by our own experiences of one or two personal tragedies. We must look beyond those experiences to the broader view of the interests of society at large and the interests of the individuals who make up society.

It has been a 'broader view of the interests of society at large and the interests of the individuals who make up society' that has driven the move to bring in VAD. If democracy means anything, then - given that it can be safely legislated – such assisted dying is precisely what the state should legalise.

My Opposition
Paul Keating

"The culture of dying, despite certain and intense resistance, will gradually permeate into our medical, health, social and institutional arrangements. It stands for everything a truly civil society should stand against. A change of this kind will affect our entire community not just a small number of dying patients."

Content-free. Permeation does not imply a negative result – see e.g. immunisation. There is no evidence here to justify the claim that a truly civil society should stand against VAD. If assisted dying is suitable for even a small number of dying people, then it should be available to the whole of the community under the terms of the law.

My Opposition
Ian Haines

"I have received many euthanasia requests from patients and families over my 34 years in full-time oncology practice, some very passionate, but I have invariably found that they quickly disappear as reassurance and adequate medication doses provide the comfort that is desired"

Presumably a strangely select clientele. The doctors of the Victorian Community of Practice report differently.

My Opposition
Dominic Perrottet

"Doctors will make mistakes. Victims will be pressured. Judgments will be clouded, and among all the arbitrary rules and safeguards, only one thing is absolutely certain: innocent people will die at the hands of these laws."

There is a need for two independent doctors to be involved, and a review process – the chance of a mistake seems outweighed by the likely benefit. As a community, we do not refuse to drive cars even though people sometimes die as a result. And there is no evidence that people are being pressured and that the 'innocent' will die. Much more often the family does not want to lose a loved one.

My Opposition
American College of Physicians

"Some individuals might view themselves as unproductive or burdensome and, on that basis, as candidates for assisted suicide, especially if a physician raises it or validates a request"

The involvement of two independent doctors, with the inclusion of a psychiatrist if there is doubt regarding mental health, reduce such a risk. There is no consideration here of risk-benefit.

My Opposition
Noel Pearson: The choice to die was not one that society ever sanctioned

"The choice to die was not one that society ever sanctioned"

No reasons why provided.

My Opposition
World Medical Association

"The WMA reiterates its strong commitment to the principles of medical ethics and that utmost respect has to be maintained for human life. Therefore, the WMA is firmly opposed to euthanasia and physician-assisted suicide"

Respect for human life can mean control over it, for the individual concerned. There is no consideration here for relief of suffering, which is supposed to be at the front of why have doctors at all.

My Opposition
John Buchanan

If the message conveyed is that 'your life is not worth living', ill people pick upon it very quickly.

In Australia it is for the individual to decide whether or not their life is worth living. They do not need to be led. As one applicant said 'I do not want to die. But I cannot go on living like this.'