



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

Submission Number: 475

Date Authorised for Publication: 19/4/18

Submission to the Select Committee on End of Life Choices in the ACT

The Secretary
Select Committee on End of Life Choices in the ACT
Legislative Assembly for the ACT
GPO Box 1020
CANBERRA ACT 2601

Dear Secretary

I wish to make the following submission for consideration by the Select Committee.

Name Victor Stevens

Address [REDACTED]
Rivett. ACT 2611

Telephone (02) [REDACTED]

Email [REDACTED]

Affiliations

Member of: Civil Liberties Australia, Health Care Consumers Association ACT, Dying with Dignity ACT, and former member of EXIT International.

Summary of my submission

Like the majority of the community I want the option of a “good death” if I am faced with a horrible one. I hope that eventually the law will change to allow this choice.

If the ACT Legislative Assembly is ever in a position to legislate for voluntary assisted dying, it should leapfrog the type of model passed in Victoria and move on to select, or develop, a more liberal model that gives more control and access to members of our community at the end of their lives.

To enable such future legislation to be effected, the ACT should only finance palliative care that will be able to adapt to accommodate voluntary assisted dying.

I explain my reasoning by responding to the terms of reference, in reverse order.

Public hearings

I am willing to appear at a public hearing.

Responses to the terms of reference (in reverse order):

5. The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change.

Two points.

Firstly, the ACT obviously cannot legislate for VAD until Federal legislators restore to the Territories the right to do so. The five Restoring Territory Rights Bills submitted to the Senate between 2007 and 2012 all failed, but Senator David Leyonhjelm's 2015 Bill is still before the Senate and the political climate may be changing. In 2016, Willmott *et al.*, in their *UNSW Law Journal* paper '(Failed) Voluntary Euthanasia Law Reform in Australia', examined fifty one (51) attempts to pass Voluntary Euthanasia Laws in Australia and wrote in their Conclusion:

"The authors predict that VE law reform is likely to occur in Australia. There is a convergence of factors that make this issue increasingly difficult for politicians to ignore: high and sustained public support for reform in Australia; an ageing and increasingly informed population seeking choices for their end-of life experience; the changing legal landscape internationally; and the media's interest in the topic and, particularly for social media, its agitation for change. These factors are evidenced by an increasing trend of parliamentary activity in this area such as through the introduction of Bills, the release of exposure drafts of Bills and the establishment of select committees. And once the first state or territory enacts legislation, others are likely to follow."

The very next year Victoria passed Voluntary Assisted Dying legislation. So I applaud the Legislative Assembly initiative in forming the Select Committee to add to the highly visible parliamentary activity described above. I hope a well-publicised report will follow at the end of the year. And later, perhaps exposure drafts of Bills (that Federal legislation would overrule) could draw attention to the fact that we are in step with the rest of the country whilst the Feds are not.

Secondly, if the ACT legislature sometime were to pass voluntary euthanasia (VE) law, it would face the same difficulty with Federal Legislation as the Victorian scheme is currently facing; that is, Federal law prohibits importation and use of Nembutal, the drug of choice for VE, except for veterinary use on animals (Victorian compounding chemists may come up with a suitable alternative drug, but this is not a trivial problem). Somewhat similar to when a Federal block on heroin prevented the ACT from implementing the Heroin Trial.

4. The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme.

For the ACT the importance of the Victorian scheme (assuming it survives a possible change of Government before it is proclaimed in 2019) is that it will be LAW and will have been operating for some period by the time the ACT has an assembly disposed to VE legislation. Transparent and (hopefully) problem-free working of the Victorian scheme should allay community concerns and allow the ACT the freedom to concentrate on designing a Bill that delivers the greatest choice, benefit and ease of access to residents at the end of life.

A luxury that the Victorian Bill, striving to be the first Australian state VE Bill to pass, did not have. Cognisant of the previous twenty failed attempts at Australian state VE legislation, the Victorian Government drafted a Bill *designed to pass through the Houses of Parliament* rather than to provide the most desirable outcomes for the most people. As Emeritus Professor Ian Maddocks AM, a member of the Ministerial Advisory Panel, wrote:

"The Minister presented the Bill to parliament in September 2017 as a comprehensive and complete package, embodying a conservative approach — its stringent, detailed requirements making it resistant to amendment. ...
The Bill disappointed many established advocates of euthanasia in its clear exclusions, its stringent and restrictive eligibility criteria, and its necessary diligent processes of

referral, reporting and oversight. *Relatively few dying persons will be eligible to access voluntary assisted dying.*” (my emphasis)

So the Victorian VAD legislation, though fit-for-purpose and successful, should not be a template for future legislation in other jurisdictions. It is legislation more suitable for presentation to Parliament in the 1990s before we had the benefit of decades of evidence from VAD schemes in real-world operation (rather than, sadly, suitable for a Parliament in a frightened little country in 2017). It is easy to forget that we had just such a scheme operating in the NT in 1995, before it was struck down in 1977 by the Andrews Bill. Philip Nitschke (who knows much more than anybody about the working of that law) writes in his book ‘Damned if I Do’ about just how difficult it was for the dying to make use of the ROTI law because of all the ‘safeguards’.

Euthanasia 2.0

Just as poorer parts of Africa are by-passing older technologies, such as fixed-line telephones and coal-fired power, and jumping straight to mobile phones and renewable energy, the ACT should by-pass a conservative, restrictive, VAD and jump straight to a more inclusive, liberal, euthanasia 2.0 model – more aligned with the spirit expressed by Michael Moore when introducing his Voluntary and Natural Death Bill to the ACT Assembly in 1993: “Active euthanasia takes the prime decision making process out of the hands of the doctor and returns it to where it rightly belongs, to the individual.”

For example, on page 58 of his submission to the Parliament of Western Australia joint Select Committee (EOLC Sub 642), Neil Francis lists five broad options for End of Life Choices. The Victoria legislation is based on option A, except that a doctor may assist as in option B.

I personally think only options D and E should be considered for ACT euthanasia legislation. Ten times more people are able to use VAD law in the Netherlands (D) than are able to in Oregon (A). Of course E is not possible without changes to the Crimes Act.

A. A restrictive approach (Oregon/Washington model)

A new statute allows only the terminally ill to potentially qualify, via an arduous process, for self-administration only.

B. A conservative approach

A new statute allows those with a terminal illness or the advanced stage of a degenerative disease causing intolerable and unrelievable suffering to potentially qualify, via a rigorous process, for self-administration *unless the individual is incapable of doing so*, in which case a doctor may directly assist but only if the individual is currently mentally competent to confirm the request.

C. A moderate approach

A new statute allows those with terminal illness, an advanced degenerative disease, or incurable mental illness causing intolerable and imrelievable suffering to potentially qualify, via a rigorous process, for self- or doctor-administration while mentally competent.

D. An inclusive approach (Benelux model - Belgium, the Netherlands and Luxembourg)

A new statute allows those with a terminal illness, an advanced degenerative disease, incurable mental illness, or old-age multiple morbidities causing intolerable and imrelievable suffering to potentially qualify, via a rigorous process, for self- or doctor-administration. Request for an assisted death in certain circumstances may be made in advance through an Advance Care Directive.

E. A liberal approach (Swiss model)

An exception is added to the criminal code on assisted suicide to allow any person to assist another to die, provided he or she does so for purely altruistic and compassionate reasons. Reasonable proof of the deceased's request, and grounds for altruism and compassion must be provided to the satisfaction of the coroner.

White, B & Willmott, L, 2012, *A background paper: How should Australia regulate voluntary euthanasia and assisted suicide?* Australia 21 and QUT, gives details of the legislation in five permissive jurisdictions and is easily accessed.

3. Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.

There are no risks, only *perceptions* of risk.

Even the most liberal VAD laws are responsibly regulated.

When the early attempts at legislation were proposed in the 1990s, in addition to their religious/moral objections, opponents expressed concerns about risks such as: depriving palliative care of funds [nonsense, as VE Bills always came with a bucket of money for palliative care], ruining the doctor/patient relationship, and the SLIPPERLY SLOPE whereby, regardless of any safeguards, inevitably vulnerable people would be euthanized without consent.

Back in those days these seemed reasonable concerns, as it was difficult to say with certainty that there would not be any slippery slope movement. But with the benefit of decades of data, all recent reports in reputable journals or from government bodies conclude that there is no evidence of a slippery slope. Several also point out that even in theory it is a faulty argument. These comments from the comprehensive report of The Royal Society of Canada Expert Panel: End-of-Life Decision Making (November 2011) are typical.

“Slippery slope arguments are ubiquitous in public debate. This Report canvasses empirical evidence on this issue in Chapter Four.* Academics arguing about controversial moral and policy issues are not immune to the lure of such arguments. ... The ubiquity of such arguments, especially among academics, is surprising. After all, they are, in almost all cases, *logically invalid arguments*. When slippery slope arguments are invoked, it is almost always to change the subjects.”

*Chapter Four concludes with:

“Despite the fears of opponents, it is also clear that the much-feared slippery slope has not emerged following decriminalization, at least not in those jurisdictions for which evidence is available. Nor is there evidence to support the claim that permitting doctors to participate in bringing about the death of a patient has harmed the doctor/patient relationship. What has emerged is evidence that the law is capable of managing the decriminalization of assisted dying and that state policies on this issue can reassure citizens of their safety and well-being.”

Nevertheless (and I have been following these events for twenty years) every time a VE Bill is announced the opposition plays the slippery slope fear card, as well “risks” to specifically named “vulnerable groups”. Whenever a subsection of the population finds voice and gains sympathetic traction with the general public, such as senior citizens, women’s movement, indigenous Australians, people with disabilities, *etc*, the opposition adds them to the list of “vulnerable groups” into which they can engender fear and cynically exploit. Even though, in the jurisdictions which have VE laws, the peak organisations of the “vulnerable” groups rubbish the idea that they are at risk, here in Oz the constant repetition of the lies leaves the *impression* of a real risk. Attempting to allay these fears, those proposing VAD legislation react by putting in more safeguards.

This ritual of the usual suspects rehashing the same old arguments, played out numerous times in Oz over the past twenty years, is clearly a reinventing-the-wheel game that always leads to the same sort of restrictive VAD model. And until Victoria 2017, an unsuccessful one.

I submit that the ACT not waste time, or any other resources, on such a crazy 1990s game when designing VAD legislation but instead move on to one of the more inclusive models, secure in the knowledge that the superior scheme comes with no extra risk (as numerous evaluative reports show). The positive aspects of the scheme should be touted and an education campaign used to promulgate the evidence that shows the supposed slippery slope, or risks to “vulnerable” groups to be the lies that they are. Many VE friendly groups would assist in this.

Handy Information Sources

[If any legislators want to get up to speed on debunking the lies (or misinformation if you don't like plain talk) then pages 25 to 55 of Neil Francis' submission to the Parliament of Western Australia joint Select Committee (EOLC Sub 642) is an easy and informative read.

For those that can't emulate the Victorian Ministerial Advisory Committee and visit the VE law countries, I highly recommend the Andrew Denton podcasts 'Better off Dead' available from the Wheeler Centre. However you may feel about Denton, or whatever your bias about euthanasia, the great value of the podcasts is that Denton has interviewed the principal anti-euthanasia spokespeople, then taken their statements to the various jurisdictions which have VE law and put the statements to the people about whom the statements were made and asked them for their responses. Denton then returned to the spokespeople he first interviewed and asked them to comment on the responses. The great thing about this is that Denton recorded all the statements and responses and counter-responses; so that you can hear it all straight from the mouths of the protagonists and spokespeople, all of whom are clearly identified, and so make up your own mind about the validity and strength of their positions. There is nothing like going to primary sources!]

2. ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.

Surveys by reputable pollsters over the past forty years have shown that about three-quarters of the population support VAD legislation and that there is no evidence that the ACT population is significantly different.

But of course this is just support for the general principle. Community views on the desirability of *a particular model* have never been properly canvassed.

VE is legally available in several jurisdictions, each using a different model (some with only minor differences) so that the aforementioned five VE models have been operating for years, decades for some. This has provided a natural experiment which has generated ample data for researchers to analyse – not only to evaluate the operation of the schemes, but to compare them as well. It has been found that regardless of which scheme was operating, the population of each jurisdiction was equally comfortable with their laws; and that the jurisdictions with more permissive laws were not more open to abuse than those with conservative schemes – in fact all schemes operated responsibly.

But because Oz commentators, including former ACT Minister for Health Michael Moore, have described us as a “death-denying society” I suspect that most of the community have not investigated end of life practices thoroughly and so would find those scientific findings counterintuitive – instead naively believing that the more liberal schemes would carry more chance of abuse. Thus, without further education, a majority would probably think conservative VAD legislation was more desirable. Especially if they thought each of them allowed similar access to VAD.

However if the ACT was free to legislate for VAD and it looked as though there was a real chance in the immediate future of such legislation being debated in the Assembly, I think that minds would be concentrated and people would absorb and discuss information about the scheme(s) being considered. I believe that then an inclusive VAD scheme would gain the greatest acceptance.

A portion of the community already strongly supports legalising VE. I belong to three organisations that campaign for it. Indeed, in the absence of such law, some of us in EXIT have made our own arrangements, as have others that have accessed EXIT information.

In a 2016 *Journal of the American Medical Association* article (doi:10.1001/jama.2016.8499) these facts were reported:

Between 0.3% to 4.6% of all deaths are reported as euthanasia or physician-assisted suicide in jurisdictions where they are legal.

More than 70% of cases involved patients with cancer. Typical patients are older, white, and well-educated. Pain is mostly not reported as the primary motivation.

The 0.3% end of the scale is from Oregon (restrictive) type jurisdictions; the 4.6% end from Switzerland (liberal). Somewhere along the scale, about 3% in the Netherlands (inclusive);

The demographic described is the type making up the membership of the groups to which I belong. We get access to assisted death in all of the VE models, and make up pretty much all of the 0.3% group. Members of other demographics get access in the more liberal models, which get the numbers up towards the 4.6%. This is why I think we should always go for the most liberal model possible.

Yes, pain is not the primary motivation. Most people want dignity and control over their own life and death (so far as is possible). That is why there is such high support for voluntary euthanasia, and why everyone needs access to VAD, whether or not they use it. Choice.

1. Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care.

I want to comment on just two things, both related to possible future VAD law in the ACT, Advanced Care Directives (ACDs) and Palliative care (PC).

Advanced Care Directives (ACDs)

Currently people who complete a legally binding Health Directive know that most health professionals will appreciate knowing the patient's wishes and be happy to abide by the directive, but they also fear that there is the odd clinician who won't.

Of course a court order can be taken out to compel a recalcitrant medical professional to comply with the ACD, but by the time this is done it is too late – the inappropriate actions would long since have been done. Likewise if a doctor is later sued, or charged with assault, it would all be too late. And in any case, people here just don't seem to sue doctors for, say, resuscitating in contravention of a Health Directive.

Compliance will be more likely if these clinicians realise that they face automatic consequences if they disregard Health Directives. The ACT should investigate establishing institutional sanctions, such as were introduced by the General Medical Council in Great Britain in 2010, whereby doctors would have to show cause why they should continue in their present position if they disregarded a Health Directive.

People are entitled have complete confidence in ACDs. This will be even more important when, or if, we get inclusive VAD legislation incorporating ACDs.

Palliative care

Professor Ian Maddocks, in a *MJA InSight* article (Issue 7 / 26 February 2018) wrote:

“Throughout Australia, Catholic hospitals, hospices and aged care facilities provide the majority of inpatient beds available for palliative care, and also promote associated community home care programs. Church spokespersons state that assisted dying cannot occur within Catholic facilities and that their staff will not provide it, which raises significant difficulties for both assisted dying and palliative care. Other care options such as a public hospital or home care placement will need to be sought if a person receiving care in a Catholic facility requests assisted dying.”

This clearly is an unsatisfactory situation for a patient in distress.

If or when the ACT legislates for VAD, I think the community would (and be entitled) to expect that the full range of EoL options – including VAD – would be available to them. In the future, if ACT VAD legislation starts to look like a realistic possibility, then contracts to manage Claire Holland House should be awarded only to organisations prepared to accommodate VAD.

More immediately, any new palliative care facility should be staffed with palliative care specialists attuned to community expectations, specialists that see the value in having VAD as a (rarely used) part of the PC toolkit, as it is in the Integral PC Belgium model where attitudes have evolved with the times. Competence in Integral Palliative Care could be a performance standard in any new facility.

Unfortunately the majority of Australian PC specialists have attitudes more suited to the 1960s pre-VAD world, when Dame Cicely Saunders started the modern hospice movement, largely to oppose

attempts to legalise euthanasia (no doubt they think of themselves as defenders of tradition and “pure” PC) but the world has changed a lot in the past half century and those attitudes also need to evolve.

For example, in a 2016 survey of Australian PC specialists (doi:10.1111/imj.13009) Dr Linda Sheahan found that 30% of respondents felt uncomfortable when patients asked for physician assisted dying. Sheahan comments, “This response to such a fundamental question in clinical practice raises an issue for consideration in training of junior doctors in palliative medicine.” Indeed, that attitude needs changing.

75% were opposed to physician assisted suicide, and 80% to voluntary euthanasia.

In response to: Which of these values is MOST IMPORTANT to you in determining your PERSONAL opinion regarding the legalisation of physician assisted suicide and/or voluntary euthanasia? (ONE answer only), the top four answers, in order, were:

1. Traditional professional obligation as a doctor to do no harm, and its effect on the doctor-patient relationship (28%)
2. Community interest in protecting life and not intentionally taking life (29%)
3. Spiritual belief in the intrinsic value or sanctity of human life (16%)
4. Relief of the patient's suffering AS DEFINED BY THE PATIENT (8%)

From my point of view as a patient I don't like to see relief of my suffering limping along, at 8% in fourth place, behind some high-sounding principles.

Dr Sheahan also seemed surprised at this result, as she felt obliged to comment that “It... may reflect a belief by palliative care specialists that suffering in dying can generally be relieved by best practice palliative care.” But this would only make it an unimportant consideration if *all* suffering could be relieved. Importantly, as Professor Michael Ashby, director of palliative care at the Royal Hobart Hospital (and who has had first-hand experience with the Belgium Integral Palliative Care model, “a very good one” for Australia) notes: “We know that it is the long deterioration with chronic diseases, especially in people over 80 years old, and in chronic neurodegenerative and related conditions, including for younger people, that demand [for assistance to die] is strong and growing.”

If we ever get VAD in the ACT we will need to have already employed palliative care staff that are willing and able to give effect to the legislation. They will have come from the 8% that put ‘Relief of the patient's suffering as defined by the patient’ as their most important value. That's who I want looking after me.