LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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Comments on Submissions to the Select Committee on Voluntary Assisted Dying

Roy Harvey

I have read the 80 submissions to the Select Committee and want to highlight a number of recurring themes in those submissions.

In some cases, these recurring arguments and propositions are either factually incorrect, are assertions for which no factual evidence is provided, or make assumptions about Australian 'values' that are not borne out by 40 years of social change and legislation.

Rather than leave these assertions stand in the public arena, it would give the Canberra community greater reassurance if the Select Committee report addressed them directly and could give some evidence based assessments of the value of these concerns.

Coercion and Bullying

Many of the above submissions state their continuing opposition to voluntary assisted dying, while others acknowledge that VAD is likely to be a reality in the ACT, and then go on to make raise coercion and bullying to further complicate an already complex process. Almost all these submission: make assertions, rather than provide evidence; or draw analogies between the abuse associated with Enduring Power of Attorneys.

In my earlier submissions I've provided an analysis of several claims about bullying and coercion, and included a paper which reported wide spread evidence. That submission also included an article that provided a rebuttal of the arguments put forward in that paper.

One of the submissions to this enquiry has provided similar evidence. I have not been able to do a comprehensive review (in part due to a faulty link in that submission but Attachment 1 gives some examples of the selective use of data in that submission, extreme extrapolations, and implausible analyses of the experience of almost every jurisdiction with VAD laws.

Since making my submission I have carried out further attempts to find documented cases of coercion and bullying. The only press report I found on this was from Canada, where there is a report of an individual who had chosen Medical Assistance in Dying being bullied to revoke their decision.

Palliative Care

Palliative care comes up in submissions in two ways: either as a panacea to all end-of-life issues and so there is no need for VAD; or that governments will underfund palliative care once VAD is in place. Palliative Care Australia, in a 2018 report[1] it commissioned, found that '*in jurisdictions where assisted dying is available, the palliative care sector has further advanced'*. In Victoria, the VAD 2022 Report noted that 81% of people seeking VAD had used community or institutional palliative care. There is no normative standard for what would be appropriate,

[1] *Experience internationally of the legalisation of assisted dying on the palliative care sector* 2018. A report prepared for Palliative Care Australia by Aspex consulting.

Many of these submissions do not acknowledge that, even if palliative care was a panacea, there are many people who do not want to end their life, in institutions or at home, receiving extensive medications, probably receiving some form of opioid sedation, having their lungs drained as a result of fluid build up, or in a coma for some days, while nature takes its course. Dying with Dignity means different things to different people.

It would do a service to the Canberra community if the Select Committee examined whether palliative care is a panacea, and made comment about the adequacy of the level of funding for palliative care. If palliative care funding is to be cut, or increased, in the ACT following the introduction of VAD, it will be you, as members of the Legislative Assembly, who will pass budgets to bring about these increases of cuts to funding.

Perhaps as part of the negotiating process for finalising this Bill, the Select Committee could seek an all-party commitment to maintaining and/or improving the level of palliative care services in the ACT.

Dementia

The widespread concern in the Australian community about Dementia and end-of-life. A 2010 survey[2] found that dementia ranked second to Cancer as the most feared health issue. More recently, the National Seniors Australia 2021 survey of 5,000 members concerning VAD found that 87% of the 3514 respondents to the survey supported VAD, and 67% strongly agreed or agreed that non-terminal conditions. In the discussion of results of the survey, dementia was the frequently raised, and it was of greater concern to people who had experience with friends or relatives with dementia. The National Seniors submission to this Select Committee did not explicitly raise dementia but did raise the issue of non-terminal conditions.

The current draft Bill effectively prevents people from requesting VAD for dementia by requiring that persons are close to death and that they still have decision-making capacity before reqeusting access. Many submissions to the Select Committee have raised this as an issue and the need to consider use of Advance Care Directives or other such measures for addressing this issue. The ACT Human Rights Commission supported consideration of the role of Advance Care Directives.

Putting this issue off the be addressed in 2030 would lead more people to make alternate, 'illegal', arrangements to address this growing concern. I know many people who have made such plans.

Hopefully the Select Committee will make recommendations that address community concerns about Dementia

Community values and Organised Religion

Most submissions to the Select Committee that are overtly anti-VAD identify themselves as either speaking on behalf of their church, or are professing Christians. Only one submission was made on behalf of Christians in Support of VAD.

[2] Dementia is the second most feared condition among Australian health service consumers: results of a cross-sectional survey. Rochelle Watson1,2*, Robert Sanson-Fisher1,2, Jamie Bryant1,2 and Elise Mansfield1,2
Watson et al. BMC Public Health (2023) 23:876 https://doi.org/10.1186/s12889-023-15772-y

The submissions from organised churches are generally more nuanced than those of professing Christians. Church spokemen/persons acknowledge that a VAD law will come into force in the ACT and seek to introduce more 'checks and balances' to protect the vulnerable (as discussed earlier) or to strengthen protection of the freedom of conscience of religious individuals and usually government funded religious organisations from providing support and assistance who want to access VAD.

The submissions from professing Christians and some of their voluntary organisations are frequently less nuanced, with arguments ranging from Old Testament condemnations of the Bill to predicting the introduction of compulsory euthanasia for a wide range of people.

These submissions ignore that significant social changes that have occurred over the last 50 years: legalising divorce, regulating and publicly funding abortions, abolition of criminal penalties for homosexuality, introduction of same-sex marriage laws. In all of the cases, the major churches have generally opposed them. Most Australian and Canberrans choose not to be marriage in churches and are most do not have church funerals. In all of these cases, surveys have found that the position of the churches do not reflect the views of people who identify with their churches. This is the case with attitudes towards VAD, where surveys have found that a large majority of ACT residents, regardless of the religious affiliations, support VAD.

In all of these big social changes the rights of persons who have conscientious objections to them have been recognised and protected. There is no compulsion for persons with religious views to get divorced, have abortions, or become gay. This freedom of conscientious was not permitted under the old, frequently religious based, laws.

The laws on these social issues have often followed social attitudes but in the case of VAD, legal practice has reflected changing social attitudes faster than governments have. In Australian courts, since 2000, persons who come to trial as a result of 'mercy killings' are generally found guilty of the offences for which they are charged, but are generally given suspended sentences - even in circumstances where the person killed did not have decision-making capacity[3].

England does not permit voluntary assisted dying, but the English Crown Prosecutor Service has issued guidelines to regional Crown Prosecutors to help them decide if it is in the public interest to prosecute cases of 'mercy killings' and 'failed suicide pacts'.

As the Explanatory Memorandum to the VAD Bill said 'the purpose of introducing VAD is to promote the human rights of individuals who are suffering and dying by enabling an eligible individual to both 'enjoy a life with dignity' and 'die with dignity',[4] and by providing choices for a person about the circumstances of their death.

[3] ASSISTED SUICIDES AND 'MERCY KILLINGS': VOLUNTARY REQUESTS, OR VULNERABLE ADULTS? A CRITIQUE OF CRIMINAL LAW AND SENTENCING *University of New South Wales Law Journal, Vol. 45, No. 2, 2021*

[4] UN Human Rights Committee (HRC), *General comment no. 36, Article 6 (Right to Life)*, 3 September 2019, CCPR/C/GC/35, accessed 28 October 2023, available at: https://www.refworld.org/docid/5e5e75e04.html

Aa a Canberra resident, I urge the Select Committee to make a statement supporting the right to conscience of individuals in respect to VAD whether or not they oppose or support voluntary assisted dying.

Attachment 1: Comments on Evidence in Submission 26 or abuses of VAD law in other countries.

As stated in the foregoing text, I have not had time to do a comprehensive analysis of the evidence presented in submission 26. Below are three examples of evidence in that submission or referred to in that submission, that suggests that caution should be exercised in accepting its conclusion.

Selective quotations

In the attachment on Bullying and Coercion to that submission the following quotation is provided.

> **OREGON AND WASHINGTON (STATE)**
>
> The data from Oregon and Washington shows that in 2017 more than half (55.2% in Oregon; 56% in Washington) of those who died from prescribed lethal drugs cited concerns about being a "*Burden on family, friends/caregivers*" as a reason for the request.
>
> Does the concern about being a burden originate from the person or is it generated by subtle or not so subtle messages from family, friends and caregivers - including physicians - who find the person to be a burden or a nuisance or just taking too long to die?

The table in the Oregon 2017 Report on Dying with Dignity from which the above information is quote is shown below.

While it is true that 55.2% of persons who requested VAD cited 'burden on family' as a reason for seeing access to VAD, it was the fourth most commonly cited reason. 87.4% of people cited loss of autonomy, 88.1% cited Less able to engage in activities making life enjoyable, and 67.1% cited loss of dignity. Clearly, most of those people who cited concerns about a 'burden on family' also cited loss of autonomy and loss of dignity. In fact, loss of autonomy and burden on family are two sides of the same experience.

To present the 55.2% of persons concerned about burden on family as a standalone fact, does not give a full picture of why people choose VAD. Similar results are found in almost every jurisdiction where VAD is permitted.

Characteristics	2017 (N=143)		1998–2016 (N=1,132)		Total (N=1,275)	
DWDA process						
Referred for psychiatric evaluation (%)	5	(3.5)	57	(5.1)	62	(4.9)
Patient informed family of decision (%)[3]	139	(97.9)	982	(93.1)	1,121	(93.7)
Patient died at						
Home (patient, family or friend) (%)	129	(90.2)	1,052	(93.4)	1,181	(93.1)
Long term care, assisted living or foster care facility (%)	13	(9.1)	55	(4.9)	68	(5.4)
Hospital (%)	0	(0.0)	4	(0.4)	4	(0.3)
Other (%)	1	(0.7)	15	(1.3)	16	(1.3)
Unknown	*0*		*6*		*6*	
Lethal medication						
Secobarbital (%)	71	(49.7)	676	(59.7)	747	(58.6)
Pentobarbital (%)	0	(0.0)	386	(34.1)	386	(30.3)
Phenobarbital (%)	6	(4.2)	57	(5.0)	63	(4.9)
Morphine sulfate (%)	66	(46.2)	6	(0.5)	72	(5.6)
Other (%)	0	(0.0)	7	(0.6)	7	(0.5)
End of life concerns[4]	**(N=143)**		**(N=1,132)**		**(N=1,275)**	
Losing autonomy (%)	125	(87.4)	1,029	(91.4)	1,154	(90.9)
Less able to engage in activities making life enjoyable (%)	126	(88.1)	1,011	(89.7)	1,137	(89.5)
Loss of dignity (%)[5]	96	(67.1)	769	(76.9)	865	(75.7)
Losing control of bodily functions (%)	53	(37.1)	526	(46.8)	579	(45.7)
Burden on family, friends/caregivers (%)	79	(55.2)	475	(42.2)	554	(43.7)
Inadequate pain control or concern about it (%)	30	(21.0)	297	(26.4)	327	(25.8)
Financial implications of treatment (%)	8	(5.6)	39	(3.5)	47	(3.7)

Slippery Slope arguments

One of the references[5] in Submission 26 is to an article from Marquette University in the USA. It raises quite a few issues relating to access to VAD but, as with many such articles engages in the slippery slope argument which, by analogy and innuendo, links VAD to elder abuse and murder. See box below.

It doesn't help informed debate make such unsubstantiated allegations.

Elsewhere in that submission an example is given of one case where a person did encourage a person to VAD with the intention of financial gain, but that person was prosecuted and jailed. With Enduring Power of Attorney, it is known that elder abuse occurs associated with them, but there is no move to ban EPOAs – but to try detect and limit the extent of the abuse.

[5] Dore, Margaret K. (2010) ""Death With Dignity": A Recipe for Elder Abuse and Homicide (Albeit Not by Name)," *Marquette Elder's Advisor*: Vol. 11: Iss. 2, Article 8. Available at: http://scholarship.law.marquette.edu/elders/vol11/iss2/8

In Oregon and Washington, the annual reports (*of the State Agencies reporting on VAD – added by R Harvey*) do not track income or net worth. They do, however, show that the majority of people who have died under the Acts have been well-educated and covered **by** private insurance. 60 Typically, people with these attributes would be those with money, *i.e.,* the middle class and above. The statistics also show that the majority of persons dying have been age sixty-five or older. **61** These statistics can be explained **by** older persons with money feeling a "duty to die" so as to pass on funds to their heirs. The statistics are also consistent with elder abuse. **A** recent MetLife Mature Market Institute Study states that "[e]lders' vulnerabilities and larger net worth make them a prime target for financial abuse **. . .** [v]ictims may even be murdered **by** perpetrators who just want their funds and see them as an easy mark." 6

Flawed Experiments

Another attachment to Submission 26 asserts that every one of the 27 jurisdictions that have introduced VAD legislation over a period of 25 years are all Flawed Experiments. I haven't examined every jurisdiction, but of the 6 that I have, there is continued public support for their VAD programs, and there is no evidence in either their own presses or courts to support these assertions.

In most countries, as in Australia, there have been 20 years or more public debate before VAD is introduced, and almost every jurisdiction conducts periodic reviews of their programs. Countries as socially conservative as Italy, Spain, Germany have recently introduced, or are in the process of, introducing VAD.

With 27 years experience of the operation of VAD laws to draw on, governments continue with their VAD programs and more governments are introducing them. The assertions in submission 26 fail the pub test.