LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),
Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

Submission Number: 076

Date Authorised for Publication: 14 December 2023

Submission to the Select Committee on the Voluntary Assisted Dying Bill 2023

From: Roy Harvey

1. Introduction

The ACT Legislative Assembly Select Committee on the Voluntary Assisted Dying Bill 2023 has invited submissions on this Bill.

The purpose of this submission is to ask the Select Committee to consider including three of the community priority proposals identified by the Discussion Paper survey into the Bill The three priorities were: a role for Advance Care Directives in the Bill; non-terminal conditions should be *relevant conditions* for eligibility for access to voluntary assisted dying and there should be no timeframe on the time to expected death; and the persons under 18 should be eligible for access.

I request that, on the basis of my experience during the last weeks of my wife's life, the Select Committee reviews Clause 42 (1) relating to self-administration decision, and Clause 61 (6) the role of the *assisting person*.

The Human Rights Act 2004 Compatibility Statement was a very formulaic document in the manner it went through assessing each eligibility criteria and process against all 7 related Human Rights, deciding the extent to which each criterion and process *promoted* or *limited* each human right. Then deciding which human right was the most important. Then by some unexplained process, saying whether or not the eligibility criteria or process was or was not compatible with the ACT Human Rights Act 2004. The process sounded dodgy when anything that differed from the Australian Model was not compliant, and everything that was in the Australian Model was compliant.

The Compatibility Statement was total devoid of evidence from Australia or overseas jurisdictions. At no stage was the compliance testing influenced by real world experience. Even more concerning was that many of its decisions about compliance to human rights differed from decision in the Canadian Supreme Court and the Quebec Superior Court. These court decisions have seen the Canadian Medical Assistance in Dying Act move away from the Australian model and towards the more humane models of Netherlands, Belgium, Luxembourg.

Appendix 1 contains my analysis of one of the main principles that the Compatibility Statement considered underpins the Australian Model. That principle was the *blanket rule* - 'that an individual must have decision-making capacity at key stages of the VAD process: the first assessment, consulting assessment, final assessment, and practitioner administration of the approved substance. (page 23)'. The analysis in Australian evidence and evidence from overseas jurisdictions to help decide whether this rule was, in itself, compatible with the Human Rights Act 2004. Introducing data into evaluation the *blanket rule* shows that the rule does more harm than good.

I suggest that the Human Rights Act 2004 Compatibility Statement does not provide a reliable guide to the appropriateness of the of the ACT VAD Bill to the views and values of the ACT community.

I suggest that, if the Select Committee wants the Bill to reflect the views of the ACT community, it examines the three lines of inquiry described below. Then, that it conducts a survey of the community to test how the alternate eligibility criteria and process conform to their views.

The **first line of inquiry** is to review three of the highest priority suggestions that came from the Discussion Paper survey: a role for Advance Care Directives in the Bill; non-terminal conditions should be eligible for access to voluntary assisted dying; there should be no timeframe on the time to expected death; and the persons under 18 should be eligible for access. In the Compatibility Statement, the treatment of these issues was superficial and, in some ways, disrespectful of the 900 Canberrans that provided detailed responses to the Discussion Paper survey. There is some Australian evidence, and extensive evidence from overseas jurisdictions, that gives a different picture to the conclusions of the Compatibility Statement.

The **second line** is to review Clause 159 of the Bill requires the Minister to review the operation and effectiveness of the Act, as soon as practicable, 3 years after this the commence date and every 5 years thereafter. The first review must include a review of the eligibility criteria for access to voluntary assisted dying for minors, and of the residency rules, and the use of Advance Care Directive. This means that several of the community priorities will not be reviewed for 5 years; say 6 months before the Bill is enacted, 18 months implementation period after the commencement date, and 3 years of operations. Then the mandatory review would take, 6-12 months?, legislated – 6-12 months, implementation period 6-12 months? So, some of the community priorities, as expressed through the Discussion Paper survey might be available to the community by 2031?

I suggest that the Select Committee might have a look at how things happened in Canada when the Supreme Court directed that changes should be made to the Medical Assistance in Dying Act in a specified time frame. Most of the changes were based on human rights decision of the Supreme Court or the Superior Court of Quebec. In Canada, the new eligibility criteria were included the MAID Act immediately. The new eligibility criteria were in the aACT but the implementation dates relied on Parliamentary and Professional committees to produce necessary guidelines to support the new eligibility criteria.

Is it not possible for the ACT Legislative Assembly to include the community priorities into the Bill now. Then use the 18 month implementation period before the commencement of VAD program as provided in the Bill, to develop the guidelines and necessary for their implementation

Why wait until 2029 to even consider the community priorities?

The **third line** of enquiry that a review be made of clauses 42 (1) and 61 (6) of the Bill. Clause 42 (1) relates to persons who elect to self-administer the VAD substance, and 61 (6) relates to the role of *assisting persons.* The current clauses were not designed with human being in mind.

The submission consist of four parts:

Part 1: Evidence from Australia and overseas jurisdictions relevant to the Bill is discussed. This will save repetition is several sections later.

Part 2: A review of voluntary assisted dying laws in the Netherlands.

Part 3: A review of each of the community proposals derived from the Discussion Paper survey. A review of *assisting person* in Clause 61 (6)

Part 4: Implications for the existing eligibility criteria and processes in the Bill.

Part 1: Evidence from Australia and overseas jurisdictions relevant to the Bill

A consistent finding from almost every jurisdiction that permits VAD, is that people seek access to VAD because of: decreasing ability to participate in activities that made life enjoyable; loss of autonomy; loss of dignity; a desire to have some control over the timing of their own death; pain generally ranks well down the list – even for cancer patients. Another consistent finding, in Australia and overseas, is that about 30% of all people who are given VAD drugs do not use them – this is consistent with the importance to people to choose their end of life. So why does the ACT Bill have to be underpinned by *intolerable suffering* and *near death*?

Another finding from analyses of the long experience with VAD in theNetherlands, Belgium, Luxembourg, Switzerland and Oregon,) in voluntary assisted dying programs is that the median/average age at which people seek access is increasing. This is consistent with the aging of their populations. It does not support the concerns expressed by some that well defined VAD programs will undermine society values.

The rate of use of VAD is determined partly by what conditions are eligible for VAD, but more importantly by social values. The health and social security support systems are fairly uniform across the Netherland Districts but a 7 fold variation across its districts in VAD deaths as a percentage of all deaths. The VAD death rate in the Netherlands was about 5% in 2022

Similar variations are observed across Canadian Provinces. In 2022, Quebec had the highest rate of VAD deaths as a percentage of all deaths - 6.6%; Newfoundland had the lowest 1.5%. Over the four years of Medical Assistance in Dying Act statistics, the rates across all Provinces have all increased by about 150%.

Social/cultural factors play a large part in determining VAD death rates, just as murder rates and suicide rates are influenced by the same factors. Data across 6 countries showed an inverse correlation between VAD rates and murder/suicide rates.

Switzerland decriminalised altruistic assisted suicide about 70 years ago and now makes available safe drugs for people to end their life with. The medical conditions for suicide in Switzerland are pretty much the same as for countries with medical focused VAD eligibility. Cancer, Neuro-degenerative diseases account for pretty much the same proportion of suicide deaths as they do in countries with VAD. The Swiss Federal Statistics office reports often note the fall in the rate of suicide/suicides as compared to assisted suicide. This is likely to reduce trauma amongst relatives and friends and first responders, as suicide/suicide is often messy.

Part 2: Voluntary assisted dying laws in the Netherlands

Euthanasia is illegal in the Netherlands. But if a doctor follows a series of guidelines that have developed over 30 years, they are not prosecuted.

The Netherlands has very simple eligibility criteria and procedures for accessing voluntary assisted dying. To avoid prosecution a physician must

1. be satisfied that the patient's request is voluntary and well considered;
2. be satisfied that the patient's suffering is unbearable and that there is no prospect of improvement (not necessarily a terminal illness or physical suffering);
3. inform the patient of their situation and further prognosis;
4. discuss the situation with the patient and come to the joint conclusion that there is no other reasonable solution;
5. consult at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the criteria for due care; and
6. exercise due medical care and attention in terminating the patient's life or assisting in the patient's suicide.

No patient written requests are required and after meeting the requirements of (4) above the legislation does to require a repeated request. But it is usual practice to ask for a second request.

Minors 12-15 years can access euthanasia but parental consent is required. Persons 16-17 can make a request but the parents must be informed.

There is a protocol for severely disabled infants not expected to live more than a year. The Groningen protocol was developed by the Paediatric Association of the Netherlands and if this is followed no prosecutions have occurred – but it is not law.

There is a special protocol that enables persons with mental illness as the sole underlying cause to access euthanasia, but it here are more complex requirements for assessment and approval. The number of persons who did go through the process was 83 in 2017 (in a total population of 18 million people) or 1% of total deaths. The numbers of euthanasia deaths associated with mental illness has decline for a couple of years after. A significant proportion of applicants commit suicide before completing the process.

In the Netherlands a doctor can assist a person to end their life on the basis of Advance Care Directives, even if the person no longer had decision-making capacity and could not give informed consent at the time. The person making the Directive must be assessed as having decision-making capacity and the Directive must be updated/re-affirmed at regular intervals. Persons over 12 can make an Advance Care Directive subject to parental involvement.

Only one case of euthanasia has ever gone to court to test this law in its twenty years of operation. That case, in 2016 'involved a woman who had advanced dementia, had very limited mental capacity, created difficulties for staff and other patients and frequently told anyone around that she wanted to die. As well as her Advance Care Directive, her desire for ending her life if this situation arose, had been known to family for many ears. In that case, the doctor was found to have acted according to law.

The euthanasia law in the Netherlands retains a high level of public support. It is unlikely that if the coercion that most opponents of the euthanasia law did occur, it would have resulted in declining support of the program.

There is a high level of scrutiny by regional assessment boards which screen every application and post death return. Between 2013 and 2019, 4 to 12 cases each year have failed to meet that statutory duty of care standard. That is 4 to 12 out of about 6000 cases a year. So there is a very high level of compliance with the duty of care regulations.

Compared to the bureaucratic Australian Model, the Netherlands system has very few requirements for reviews, and no multiple consent processes. Decision-making capacity is required when making Advance Care Directives, and when initiating discussions with doctors about accessing VAD, but not required at the time of administering the VAD drug. This 'light touch' system has had only one significant court case in its 22 years of operation. I don't know what it tells us about the Dutch society. What does the Australian Model tell us about Australian society?. Who are all the 'safeguards' protecting us from? The Netherlands experience raises questions about the narrow eligibility criteria and extensive regulation in the Australian model.

The Netherlands system is the most liberal in terms of process and has the widest range of eligibility criteria. No issue seems to be put in the 'too hard basket' in the Netherlands.

Access to euthanasia for Dementia is quite low. About 1% of euthanasia deaths are associated with Dementia. This is less than the proportion of all deaths associated with euthanasia.

The number of persons under 18 who access euthanasia is also very small – 1 in 2021.

Quebec, which has a much more restrictive process and eligibility criteria, quite close to the Australian Model, has a 20% higher rate of voluntary assisted dying than did the Netherlands.

Despite the attention that euthanasia in the Netherlands attracts, it has provided access to euthanasia for 'hard cases' than most other countries avoid.

If the Select Committee is interested in an evidence based model for VAD, there is a lot to be learned from the Netherlands. It was be of use in reviewing the ACT Bill, if the evidence from the Netherlands would be very informative were focus group tested here. The ACT community might accept something less severe that the Australian Model.

Part 3: A review of each of the community proposals

Part 3.1 The role of Advance Care Directives

3.1.1 Incorporating VAD into Advance Care Directives – some background issues.

All Australian jurisdictions encourage people to make Advance Care Directives to record a person's preferences for medical treatment including end-of-life care. At present end-of-life options include stopping life support systems or medical services, and voluntarily stopping eating and drinking (VSED). VSED raises some of the same ethical issues as VAD. VSED often has to be carried out in institutional settings because it often requires support activities (toileting, hygiene, pain relief) and sometimes clinical interventions that may not be able to be provided in a home setting, even with Community and/or Palliative Nursing support. There are still ethical issues associated with institutions and access to VSED, which according to a QUT Australian Centre of Health Law report, are not well addressed by current laws. With the legalisation of VAD in all Australian states, soon the ACT, and the Northern Territory at the enquiry stage, Advance Care Directives will have to be modified to consider the how preferences or VAD will be incorporated.

The ACT VAD Bill has slated a review of role Advance Care Directives in VAD laws for the 2029 review.

The ethical issues associated with VAD may not be as complex as the Human Rights Act 2004 Compatibility Statement thought. There are many similarities between the ethical issues surrounding VAD and those associated with 'fertility' services – some institutions and individual health practitioners have strong objections to having to be involved with abortion.

People can experience traumatic accidents that result in them relying on their Advance Care Directives to guide medical care if they do not have decision-making capacity. VAD will have to be one of the issues addressed.

Medical ethics and the law require clinicians provide information to enable that patients can make informed choices. With legalised VAD, information to patients will have to include informing people about VAD as an option. Some clinicians do not want to be involved with abortions or other fertility services, but they must take steps to inform their patients of the issues. So VAD is another hard issue for the medical profession to come to terms with.

3.1.2 Possible uses of Advance Care Directives in VAD.

Reports on voluntary assisted dying provided by State regulatory agencies record concerns by at least 3 states about the number of people who die before the request processes are completed. The proposed solutions involve better patient information and better IT systems. There was no suggestion of simplifying the review process.

A recently written Advance Care Directive could be counted as a written 'request' for access to VAD and so shorten the current 3 request time.

The ACT Billl requires that if someone loses decision-making capacity part way through Request process, they are not eligible for VAD. The role of Advance Care Directives should be examined in this context.

In Canada, as noted in the Human Rights Act 2004 Compatibility Statement, there is a 'consent waiver' by which someone who has been assessed as eligible but wants to continue living as long as they are capable, can make an agreement with a doctor to end their life if they lose decision-making capacity. This seems a humane provision. A British Columbia Ministry of Health consent waiver is at *https://www2.gov.bc.ca/assets/gov/health/forms/1645fil.pdf*.

The Select Committee could consider whether a current Advance Care Directive could replace a consent waiver.

The Netherlands experience suggests that vulnerable people are well protected with many fewer processes and rules than in the ACT VAD Bill

The Joint Ministerial media release of 31 October said that the VAD Bill was '*'our evidence-based model'*. The Select Committee could well recommend a simpler system that places less stress on applicants for voluntary assisted dying and on those close to them. Clearly, Advance Care Directives

could play a role in simplifying the request procedures and make the system less risky for people already '*suffering intolerably'*. '*experiencing diminishing quality of life*', and *'close to death'* as the current Bill requires.

3.2 Non-terminal conditions and no time limit on time to death

The Voluntary Assisted Dying Survey Report combined a number of related suggestions together in the summary results report. 13% of respondents suggested that non-terminal conditions should be included in the Bill and that there should be no timeframe for death. Chronic untreatable pain and Dementia/Alzheimer's were mentioned as examples of community concern. No timeframe for death was grouped with the non-terminal conditions. Presumably the text accompanying the questionnaire linked these to items. I propose to include in this discussion, the three conditions, a disability, mental disorder or mental illness, that were excluded from relevant conditions by Clause 11 (2) of the Bill.

The common factors that link chronic untreatable pain, disability, mental disorder or mental illness, are that they are all associated with high suicide rates and they all have significantly reduced life expectancy. The shortened life expectancy reflects, in part, that people with these conditions frequently have behaviours shorten life – including physical inactivity, smoking, and being overweight or obese.

These conditions all involve 'intolerable suffering' and 'diminishing quality of life', but are currently excluded from *relevant conditions* because people with the conditions are not necessarily near the end of life.

In 2021, the eligibility criteria for Medical Assistance in Dying Act in Canada were changed. In 2019, the Superior Court of Quebec found 'the reasonable foreseeability of natural death' eligibility criterion in the Canadian Criminal Code, as well as the 'end-of-life' criterion from Québec's Act Respecting End-of-Life Care, to be unconstitutional.

The original Canadian Medical Assistance in Dying Act was very similar to the Australian Model. But As a result of Court decisions on eligibility criteria , the Canadian Criminal Code, of which is a MAID is a part, has been changed. The medical eligibility criteria for MAID are now:

- have a serious and incurable illness, disease or disability (excluding a mental illness until March 17, 2024)
- be in an advanced state of irreversible decline in capability
- have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable

This moves Canada away from the Australian Model, which requires nearness to death, intolerable suffering, and decline in capability. Health Canada says that the Canadian system has moved towards the model in Netherlands, Belgium, Luxembourg. The Canada laws still has all the complex 'request for access' processes that we have here, but it allows non-terminal conditions to be *relevant conditions*.

The Canadian changes were made on the basis of human rights considerations. The end of life/foreseeable death eligibility criteria were found to be in breach of Canada Charter of Rights and Freedom:

> 7 Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.
>
> And
>
> 15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Do these rights sound familiar? The Canadian Charter 7 is almost identical to Section 18 of the ACT Human Rights Act, and Canadian Charter 15 (1) is almost identical to Section 8 of the ACT Human Rights Act.

This supports my earlier comments that the analysis of the human rights implications of some section of the ACT VAD Bill, given in the Human Rights Act 2004 Compatibility Statement, is inconsistent with real world human rights decisions.

Another test of the value of the three community proposals is to ask, if these a changes were made to the ACT VAD Bill, who would be harmed, and by how much, and who would gain and by how much?

Giving access to voluntary assisted dying for people with disability and mental health issues appears to raise quite a few issues. However, if the eligibility criteria refer only to intolerable suffering, and diminishing quality of life, it should not matter what the clinical cause was. So disability and mental should not be excluded from access to VAD. It would be prudent and humane to require some additional assessment, and to provide additional support for such groups processes.

The ACT Bill contains the requirement a person to be close to death – but, the Canadian Supreme Court judgements would indicate that this 'close to death' requirement, is probably inconsistent with the ACT Human Rights Act 2004.

If this is removed from the Bill, then there would be no reason to exclude persons with non-terminal conditions from accessing VAD, if all other eligibility criteria were met.

3.3 Access for persons under 18

Netherlands and Belgium both give access to children under 18, with parental consent being necessary for children 12-16 and that parents are informed for 16-18. The arguments for allowing this are on Human Rights Grounds, but with parents having a role in the process to 'protect life'.

There was only 1 child who accessed euthanasia in the Netherlands in 18 million people. The Select Committee is best placed to decide whether the rarity of the events make it harder or easier to get community support.

3.4. The role of an *assisting person* (Clause 61 (6)) and self-administer the preparation

Under Clause 41 (1) of the VAD Bill a person who has been approved for access to voluntary assisted dying may elect to self-administer the drug provided. Clause 61 (6) allows for that person to nominate another person to assist with some parts of the self-administration process – an *assisting person.* The roles of an *assisting person* can be to receive the substance for the individual and *give* the substance to the individual. *Give* does not include administer - Clause 61 (7).

So if something happens so that the person approved for voluntary assisted dying cannot self-administer then what? The *assisting person* cannot administer it on pain of a maximum 7 year prison sentence (70 (a)) unless that persons is also the authorised administering doctor. The Bill does not say directly what happens. The next section Clause 62 (1) says what happens if the individual changes their administration decision.

If the person can't self-administer then they would be forced to change the self-administration decision and wait for the processes to permit health practitioner administration. If the individual had reached the stage where they were about to end their life, they are not going to want to wait for the wheels of the voluntary assisted dying process to grind on. Also, if the *assisting person* is a spouse/family member, which is the most likely situation, they are not going to tell their partner to hold off dying until I get the doctor. Putting myself into the situation of the *assisting person,* I would administer the substance and risk imprisonment. In my own experience, my wife and I had agreed to assist the other when the time came and Voluntary assisted dying was not legal.

Even worse, if the approved individual had lost their decision-making capacity, at the same time as they lost their capacity to self-administer, they would be no longer eligible for health practitioner administered dying.

I recommend that the Select Committee propose that the *assisting person* be allowed to administer as well as prepare the substance. The current Bill creates the same maximum 7 year prison term for a spouse/family member administering the substance as it does for someone who *'dishonestly or by coercion, induces an individual to self-administer an approved substance*'. (71 (1)).

Part 4: Implications for the eligibility criteria and processes in the ACT VAD Bill.

4.1 The role of Advance Care Directives

The discussion in Part 3.1.2 shows that the community proposal that Advance Care Directives be into the VAD Bill has merit. The discussion shows that Advance Care Directives will have to be adjusted to allow for VAD as it is now a legal end-of-life choice. Many of the ethical and clinical issues that concerned the Human Rights Act 2004 Compatibility Statement will have to be addressed so they VAD can be recognised within the framework of Advance Care Directives.

Advance Care Directives have a recognised role in the VAD law of most jurisdictions. The role assigned to Advance Care Directives varies significantly. In Canada they are of limited role since legislation recognise them as a legal consent. But the Consent Waiver, a very limited care directive has just been introduced. Also, according to the Alzheimer Society of Canada, the Special Joint Parliamentary Committee on Medical Assistance in Dying (AMAD) has resumed its review of MAiD –

including advance requests. The Alzheimer Society 'believes that people living with dementia should have personal autonomy in making decisions about their care – including the right to make an advance request for medical assistance in dying'. So the role of Advance Care Directives is likely to be extended in Canada. The role of Advance Care Directives in the Netherlands is very important, sometimes being the only patient written document that is required to access voluntary assisted dying.

The ACT can make Advance Care Directives an important part of its VAD request process, and simplify the process as suggested earlier.

4.2 Inclusion of non-terminal conditions as *relevant conditions*

The discussion in Part 3.1.2 showed that the inclusion of a wide range of non-terminal conditions would be consistent with the ACT Human Rights Act 2004.

The discussion of VAD in the Netherlands shows that after that after 22 years experience, the concerns about coercion of vulnerable groups have not manifested. Nor did my literature find any jurisdiction where it was. The operations of the Netherlands Regional detect very high rates of compliance with the Duty of Care guidelines with respect to voluntary assisted dying processes.

If he ACT believes it up holds the human rights in its Human Rights Act, there is no evidence that allowing access to voluntary assisted dying for non-terminal conditions would harm anyone, and it would reduce the trauma of suicide to families and first responders.

So, what reason is there for excluding the non-terminal conditions discussed here from access to voluntary assisted dying?

4.3 . The role of an *assisting person*

The position of *assisting persons* in the current Bill would almost certainly result in some people acting against the provisions of the Bill, but acting with kindness and compassion to their loved ones. Do Canberrans want to criminalise kindness and compassion?

I hope that the Select Committee will ensure that these section of the Bill are scrutinised with the real world in mind.

Appendix 1 The *blanket rule* – is it proportionate?

The Human Rights Act 2004 Compatibility Statement states that:

> The Bill provides that an individual must have decision-making capacity at key stages of the VAD process: the first assessment, consulting assessment, final assessment, and practitioner administration of the approved substance. (page 23). (Underlining added)

The Compatibility Statement uses the term *blanket rule* as shorthand for 'an individual having decision-making capacity at key stages of the VAD process'. (*Italics* are used for direct quotes from source documents)

This Compatibility Statement formulation of the *blanket rule* is slightly different to that given in the Discussion Paper. It says:

> All Australian states require that a person must have decision-making capacity throughout the entire voluntary assisted dying process. (page 10) (Underlining added).

The Discussion Paper statement is probably a more accurate statement, given the penalties in Section 61 of the Bill surrounding self-administration of the *substance.* But this is discussed later.

The Compatibility Statement makes frequent reference to the *blanket rule* in accepting or rejecting eligibility criteria and processes for inclusion in the Bill. The *blanket rule* is stated in slightly different ways through the Compatibility Statement.

Justifying the *blanket rule* - Compatibility Statement method

The justification of the *blanket rule* is that it is necessary to achieve the purpose of the VAD Bill

> The (legitimate) 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', and by providing choices for a person about the circumstances of their death. (page 21)
>
> There is a rational connection between the use of eligibility requirements and the legitimate purpose. (page21)
>
> Restricting access to individuals who have decision-making capacity serves two legitimate purposes. (page 24)
>
> Firstly, it seeks to promote the right to life by protecting individuals who have lost capacity from arbitrary deprivation of life. 'Arbitrariness' includes elements of inappropriateness, injustice, lack of predictability, and due process of law as well as elements of reasonableness, necessity, and proportionality.
>
> Secondly, it seeks to ensure that health practitioners are protected from liability for ending the life of a person who did not have capacity to consent.
>
> The Bill's *blanket rule*, that individuals without capacity cannot access VAD, will achieve the Bill's legitimate purposes...by ... operating effectively to protect individuals who have lost decision-making capacity from arbitrary deprivation of life (page 24)

Elsewhere, Compatibility Statement says that the *blanket rule* promotes individual rights by: safeguarding individuals from undue influence and coercion; that it protects people with disabilities and other vulnerable people from abuse and exploitation; and protects vulnerable groups from arbitrary deprivation of life. The *rule* and associate processes stops people 'falling through the cracks'

Limitation of rights by the *blanket rule*

The Compatibility Statement acknowledges that, by limiting access to VAD to people with decision-making capacity, the *blanket rule* 'limits' the rights of many individuals and groups. It mentions, on page 23, 'because many terminal conditions, such as advanced dementia, impair an individual's decision-making capacity while the person is experiencing intolerable suffering'. Elsewhere the Compatibility Statement acknowledges that people who choose physician-administered substances can be denied access to VAD if, having completed the three requests process successfully, they lose decision-making capacity before being administered the substance, they will not be able to access voluntary assisted dying.

The Compatibility Statement does not give a summary of the ways the *blanket rule* promotes rights and how it limits rights. It makes no summary of how many people's rights are limited by denying them access to voluntary assisted dying, nor the severity of the suffering they incur. There is no summary of the expected numbers of people who experience arbitrary deprivation of life as a result of the application of the *blanket rule*.

What is the evidence that there is coercion, abuse or exploitation associated with VAD?

I have used Google to try to identify media coverage of abuses of VAD. The most frequent hits are individuals and groups expressing concern about the possibility of abuse and coercion. Many organisation and groups representing people with disabilities, with mental health problems, with Dementia/Alzheimer, have raised concerns about the pressure being put on their members to access voluntary assisted dying to relieve the 'burden' on family members or for the family members financial benefit if the person does access voluntary assisted dying.

Elder abuse has been a focus of public attention, research and policy in Australia for some years now. There has been extensive coverage in the media of abuse of old people by their families through the exercise/abuse of Enduring Power of Attorney. This is a real issue. However, no one suggests that the use of Enduring Powers of Attorney should be scrapped.

Much to the press coverage of concern about abuse of voluntary assisted dying comes from religious groups who oppose it.

ScholarGoogle searches of the research literature on the topic of abuse of VAD generally turns up articles of about potential abuse and the ethical issues raised. Following through on references in these articles has not found anything significant.

I found three concrete 'real' abuse examples concerned court cases. Two cases (one in the Netherlands, the other in Belgium) related to doctors who administered lethal substances to persons who had lost decision-making capacity but had very clear written Advance Care Directives authorising voluntary assisted dying. In at least one case, the family requested the doctor to act on their mother's written Advance Care Directive and on her frequent requests to them that she be

given access to voluntary assisted dying. In both cases several levels of courts found that the doctors had behave correctly according to the law and the wishes of the patients. VAD has been legal since 2002 in both jurisdictions and these cases in 2017-18 were the first ever court cases relating to VAD.

The other case was that of 'mercy' killing in England. This led to the extensive legal case literature. The English Crown Prosecutor Service conducted public consultation in 2021 on manslaughter/murder/mercy killing and identified factors that should be considered when to prosecute people who had admitted to 'mercy' killing and when it was not in the public interest.

I did not followup on the Australian literature on this topic but several of the often quoted (in the Compatibility Statement) authors have written on this subject, including making suggestions for how the England Crown Prosecutors Office guidance on 'mercy' killing could be interpreted in the context of Australian law.

My Conclusions: there is great concern about the potential for abuse, but very little evidence that is widespread coercion with respect to voluntary assisted dying. This does NOT prove the effectiveness of the *blanket rule* since many of the jurisdictions that have extensive experience with voluntary assisted dying do not have the *blanket rule*.

What is the evidence of the harm that the *blanket rule* might cause

As acknowledged earlier, the Compatibility Statement identified that the *blanket rule* harmed a lot of people who were did not have decision-making capacity for a variety of reasons; rapid onset of a condition, made application too late, was granted access to VAD but lost capacity before the substance was administered. There are probably a lot of people in that category.

But the Compatibility Statement did not acknowledge that there are a small number of cases where family members assist a person to end their life, by much less reliable and humane ways than voluntary assisted dying provides. 'Mercy' killings are rare, but not as rare as court procedures suggest. Several studies have found that in almost every country where studies were conducted there were quite many cases of 'mercy' killings that never were investigated. In all countries people knew that they were liable for prosecution and in some countries severe penalties.

Does the *blanket rule* pass the proportionality test

The amount of protection provided by the *blanket rule* is unquantified and probably unquantifiable. But while the potential is real, there is little evidence that it exists at all. Some of the Harm done by the *blanket rule* is quantifiable: several State VAD Reports have expressed concerns about the number of people who die before they complete the request/assessment cycle. There ae also studies that found that there is stress generated in the person waiting for access and in their carers and families. Then there a few reports of 'mercy' killings and probably quit a few mor unreported. I know quite a few people who have a substance that they and/or their spouse/partner intend to use.

Finally, the VAD Bill is a little vague about what happens if a person who has been provided with a substance to self-administer loses decision-making capacity before taking it. It is an offence for someone to *administer* a substance to someone, whether they have decision-making capacity or not. My reading of the Bill is that the person would have to hope they regained decision-making capacity to self-administer. They could not apply for a physician to administer the substance, because they no longer had decision-making capacity. I would expect that a carer/family member, knowing the

persons intention, would administer the substance thereby exposing themselves to possible prosecution.

Any objective assessment of harms and benefits of the *blanket rule* would have to conclude that the requirement to have it causes more harm than good.

Appendix 2: Process leading to the four community proposals.

The development of the ACT Voluntary Assisted Dying Bill 2023 followed from an apparently exemplary process; the distribution of a Discussion Paper; survey; submissions from individuals, community groups and stakeholder groups; Workshops and roundtables with key stakeholder groups. Feedback on progress through the YourSay website.

The Discussion Paper said *we are seeking the community's guidance on several key aspects of the various Australian models. We are also interested in lessons learned internationally, where access to voluntary assisted dying has been in operation over many years.* (words in *italics* are direct quotes from source documents). The Discussion Paper included a survey of 7 eligibility criteria and 9 processes likely to be included in the Bill.

There were nearly 3000 replies to the survey of which about 900 gave suggestions related to the 16 issues, and 750 people offered general comments on the design of the Bill. The most common suggestion, 14% responses, was that Advance Care Directives should be a legal way of recording a person's preference for voluntary assisted dying. The next most common suggestion, 13%, was that people with non-terminal (including untreatable chronic pain, Dementia) conditions should be eligible for voluntary assisted dying. Then, 13%, suggested that persons requesting voluntary assisted dying should have a mental assessment; next, 11%, that a person's decisions should respected; and, 9%, to ensure no coercion on persons requesting VAD. Access to persons under 18 is included in this submission. It was ranked 8th in the frequency list but is included for reasons to be discussed later.

Of the top five suggestions, two (mental assessment and no coercion) were already key elements in the Australian Model law that was the starting point for the discussion. The other three suggestions: use of Advance Care Directives, access to persons with non-terminal conditions, and respecting choice of requesters, were not included in the Australian Model. The use of Advance Care Directives was supported by three key stakeholder groups: Disability and mental health communities, Health professionals, and Clinicians Grand Rounds Session. the Conversation Snapshot of the First Nations Roundtable recorded no opinion on the issue.

The three most common new proposals, and the access by minors, were not included in the final Bill. In fact, with one minor variation, the Bill is identical to the Australian Model. The Australian Model is the most restrictive VAD law of any jurisdictions where VAD is legal, requiring individuals seeking access to experience *intolerable suffering* and be near death, and have diminishing quality of life; and be close to death, and exclude significant medical conditions from being *relevant conditions'.* Almost all other jurisdictions do not require *intolerable suffering* – only the expected death within 6 or 12 months. Some other jurisdictions exclude the same conditions that the ACT Bill does, while some do not make those exclusions. Canada's Medical Assistance in Dying Act is moving from the Australian Model to be more closely aligned with the Netherlands, Belgium, Luxembourg. Switzerland has no legal prohibition on altruistic assisted suicide and make safe end-of-life drugs available. Germany has just legislated to follow the Swiss model.

The Joint Ministerial media release of 31 October said *'our evidence-based model … responds to the known issues in other jurisdictions and reflects the ACT's unique circumstances, together with the Canberra community's views'.*

It is to align the Bill with the findings of the community survey and recommendation of the Stakeholder Roundtables.