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SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Weak Safeguards

An analysis of the Victorian Voluntary Assisted Dying Bill 2017 tendered as a submission to the ACT Legislative Assembly Inquiry in to End of Life Choices

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Journeying with those in need as they complete the great circle of life and death

In late 2017 the political representatives of the people of Victoria made a fundamental change to the most critical aspect of the relationship between the people and the State. About 250 years ago, key thinkers in the English, French and Spanish speaking world, started to develop ideas about how the rule of sovereigns could be replaced with a sovereignty enjoyed by the people, for the people, paving the way for the development of modern democracies. While the emergence of the modern democratic states did not occur without violence, the decisive battles were not fought with arms but with ideas. We came to the view that all people have, by their nature, created by God, certain basic rights which were inalienable: not inhering to them because of social status or invested in them as part of a polity, but rights they held by virtue of their dignity as free human persons. Whether you read John Locke or Thomas Jefferson, in this broad philosophical movement, the first and most clearly inalienable right was the right to life. While this right to life is not as well defended as we would hope, it has become the first principle of the whole democratic endeavour, is deeply entrenched in the foundational political and legislative infrastructures of most modern democratic states, and arguably stands as the greatest social achievement of the modern period.

It is in the context of this immense philosophical and political legacy that we need to look closely at what the political representatives of the people of the ACT are now considering in their Assembly Committee Inquiry into End of Life Choices looking at the arguments to legislate for a right to medically assisted suicide and euthanasia. We have to be clear about this. What Victoria has legislated is that individuals, in certain circumstances, while have the legal power afforded to them by the state to ask medical professionals to end their lives (euthanasia) or empower them to end their lives (medically assisted suicide). Medical practitioners will be asked to prescribe the lethal drug at public expense and may be asked to administer it, against the policy of the AMA, and against the Hippocratic Oath which they have taken, which has been the ethical guiding light of the medical profession for centuries. This is not a debate about the legal right to commit suicide. Whether such action is moral or not has been debated over millennia and romanticised in literature by authors like Shakespeare. What the Assembly Committee is considering is whether the ACT Legislature should be allowed to withdraw from its core ethical obligation: to do all in its power to preserve the lives of its citizens. What is being called for is a departure from fundamental ethical basis of modern democracies: to defend in law the right to life as the first obligation of the state. What is proposed is a fundamental philosophical change to the ethical obligations the people ask of the governments in the modern era. What is being asked for is a very big thing indeed.

These sorts of proposals have been put up to legislators time and time again and have on the whole been knocked back with 21 failed attempts in the US. England and New Zealand rejected it. It has been rejected in NSW, South Australia and Tasmania. Most European nations don't do it and where it has been introduced the results are generally quite concerning. There have been large increases in requests for assisted suicide/euthanasia in the jurisdictions which permit the process with average annual growth rates of over 21% in Washington State, over 19% in Belgium and Switzerland, and 13% in Holland and Oregon. If we seek to produce a simple weighted average of these growth rates based for size of the cohort of people who were killed as part of these measures using latest data, the annual growth is in order of 17%.

In Victoria, the expected initial cohort of persons who will access the procedure of 150-200 people must be seen as an unrealistically low estimate. The initial evidence from Quebec is that applications for assisted death/euthanasia are already much higher in Canada than was expected. However, even if we were to accept the initial median estimate of assisted suicide/euthanasia deaths per year of 175 in Victoria, applying the 17% indicative average growth rate in international jurisdictions over ten years would mean that in 2030 1000 people in Victoria would be killed under the assisted death/euthanasia measures. The cumulative total of these deaths by 2030 is estimated to be 5,806. An estimate of over 5,800 persons accessing the measures in ten years represents a significant cohort of persons in Victoria.

Looking at the relative size of the ACT population to Victoria this would mean that after ten years of operation 65 persons per year would end their lives under a VAD scheme operative in the ACT with a total of about 375 persons over this ten-year period.

While many reasons have been given by politicians in the debate, and commentators on the issue, the key cause of the nervousness amongst most legislators probably relates to whether such laws can adequately protect the rights of vulnerable people. A key area of concern is the extent to which any such legislation can deal with the problem of persons who have mental illness and depression, the latter being an expected condition of comorbidity for terminal patients. In Oregon, the references for a secondary psychological assessment are unrealistically low at about 4% suggesting that protections in law are difficult to enforce.

When people are in their last stages of life they are vulnerable indeed. They can be overwhelmed by the emotional burden of just another day, who of us can blame them for many of us will be in this situation when our time comes. I am not confident I would cope well. But perhaps the most important vulnerability is a sense of being a burden to others, especially those emotionally close to them. It is a profoundly emotional time for them and their loved ones. They have the vulnerability of physical frailty and they have a natural sense of fear of death. They need medication to deal with pain control. We don't have a perfect health system, but we have a reasonably good one, and while there is scope for more public investment in palliative care, this element of the medical system works fairly well to manage pain to the point where the pain itself does not press on the consciousness of the dying person in the vast majority of cases.

This gives the dying person some space, a respite before the end, to hold the hands of their children and grandchildren and even great-grandchildren and go gently, quietly and peacefully into the final frontier, cherishing intimate and precious moments of love. It allows the dying, in their current vulnerability, to receive love from those they have loved when they were young and vulnerable. Giving and receiving love, at moments of vulnerability, isn't this what the whole game of life is really about. Precious moments not to be taken away.

So why should we want to interfere with this most natural of processes? Why should we need to ask doctors to write a prescription to allow dying people to take a lethal poison, or worse, allow doctors to actually administer the poison? In the challenging situation of facing death, we Territorians are very well served by our medical professionals, palliative care doctors and nurses, who generally meet our high expectations. I believe that in this debate the public should be guided by the advice the medical profession is giving us. The AMA formally oppose this legislation. Doctor's representatives don't think it is necessary, and think it involves unwarranted risks to the welfare of

dying persons. I think that this proposed measure, to allow doctors to kill their patients, in violation of their Hippocratic Oath, is a statement of a lack of confidence in the competence as palliative care professionals and undermines confidence in the palliative care system which dying patients rely upon.

What is needed is to increase support to palliative care as the proper way to manage end of life choices. The best way to enhance the wellbeing of dying persons is to ensure that the palliative care system is adequately supported. This should be the focus of policy change in the area of end of life choices.

For many people assisted suicide is a violation of the dignity of the individual, a violation of the obligation to take all reasonable measures to sustain a person's life. Those, like myself, who hold a religious perspective believe that in death we are going back into the loving hands of the God that created us, completing the great circle of life and death, and journeying into a new and better life in peaceful serenity: a good end to a life well lived, a happy end to a new beginning. Death has meaning. Many who do not hold religious views still oppose this type of legislation. Most persons generally hold a commitment to defend vulnerable people and value above all else the right to life, and expect the state to do all in its power to defend and sustain human life. While holding compassion for those who are suffering, many persons are reluctant to permit the state the power to sanction the end of human life, feeling that such an action exceeds the boundaries the people impose of the state as part of the implicit social contract that grounds the moral basis of modern democratic life.

This is where the Victorian Act failed. It failed to provide sufficient safeguards to the vulnerable at the end of their lives. The first failure was a lack of commitment to adequately fund palliative care. The second failure was to carve out persons with mental illness from the scheme. The third failure was the inadequate response to the issue of elder abuse. The fourth failure was the inability to deal with the problem of doctor shopping. The fifth failure was the opening of the scheme to suicide tourism. However, the most important failure was the incapacity to explain to the people of Victoria what drug will be used, how it will be tested and approved consistent with Commonwealth law.

The Victorian legislation ignored the careful analysis of Dr Daniel Mulino MLC on the international experience of these schemes detailed in his minority report to Legislative Council Committee of Inquiry into End of Life Choices. He concluded that these regimes just don't work as they were set up to work. The goal was always to target a small group of people in the most difficult circumstances in their very last days. But the problem is that this small group balloons out. The legislative walls built to keep the regime tightly focused get broken down. This argument is called the problem of the slippery slope. In Belgium the annual growth rate of physician assisted deaths was 19.6% - that's 20% each year, Netherlands 13%, Switzerland 19%, Oregon 13% and Washington State 22%. Average growth, year on year, of 17%. The initial evidence from Canada is that demand for access to the scheme has dramatically exceeded the level estimated. The data speaks for itself – this rapid rise in death rates indicate that the safeguards in the legal framework are weak.

The safeguards also appear weak for persons with mental illness. In Belgium the proportion of deaths from medically assisted death involving psychiatric disorders has risen from 1.2% of cases in 2004/5 to 3.7% of cases in 2013/14: triple the reported incidence rate over the decade (with many cases of

course not being diagnosed or reported). In the Netherlands from 2012-2015 assisted death cases with mental illness have risen at an average annual growth rate of 59%. What we are seeing is the risk that dying people with mental illness will activate the assisted suicide process because of their mental infirmity rather than a decision relating solely to their primary medical condition.

The safeguards for the mental illness cohort in the Victorian Act largely reflect the Oregon model. However, from 1998 to 2012, on average only 6.2% of patients who died under the Act in Oregon had been referred for counselling to check for “impaired judgment.” In 2013-2016 this declined to less than 4%. Of 108 patients who died under the Act in 2007 and 2009, none was referred for psychological evaluation – more evidence of weak safeguards.

We also cannot ignore the inconvenient truth about the risk of elder abuse. We have recently been exposed to the problem in aged care system. For those in end of life care elder abuse can take many forms through subtle emotional pressure, to direct coercion. The interests of patients approach their final days are protected when they are relieved of any emotional pressure, or sense of guilt for still being alive, or of holding up the financial benefit they will provide when they die to the people they love. It is a complex emotional situation, and one that is very difficult to manage through a regulatory regime.

There have been some harrowing stories of coercion overseas. Dutch media reported in February the results of a case where a doctor asked the relatives of the woman, said to be aged “over 80”, to restrain her while she administered the lethal injection, and the nun with cancer who was euthanised against her will – acts of coercion not compassion.

People with disability are also worried about this policy. The English TV star Liz Carr who has cerebral palsy has said that “What terminally ill and disabled people need is an Assisted Living not an Assisted Dying Bill.” They want the supports to deal with their degenerative illnesses not the offer of lethal cocktail.

And then we come to greatest problem with the Victorian Act – the drug itself. For a start it would be nice to know what the drug is that is proposed to be used. This is important because recent evidence from the US shows that certain drug cocktails used have caused significant pain or led to very slow deaths. Secondly, we need to know how this drug is to be approved. Medications usually undergo years of testing and trials before they are considered safe for use. Some medications used by dying patients can inhibit the effects of the proposed drug cocktail possibly resulting in a more painful or protracted death. But none of this testing has taken place. There is also some uncertainty as to whether the drug is to be covered by the Federal Therapeutic Goods Act. If not, then we have essentially a completely unregulated process.

Finally, it is difficult to avoid the philosophical point made by former Prime Minister Paul Keating who stated that the bill “is a threshold moment for the country. No matter what justifications are offered for the bill, it constitutes an unacceptable departure in our approach to human existence and the irrevocable sanctity that should govern our understanding of what it means to be human.”

Executive Summary of this Submission

This submission seeks to address related to the terms of reference. The first issue relates to items 2 and 3 of the terms of reference highlighting the risks of legislating for medically assisted suicide and euthanasia in general. The second issue constitutes a discussion of the recently enacted Victorian legislation in which the author was actively engaged in 2017 as a researcher. The third issue relates to the interaction with Federal Legislation from any change to ACT law in the area of assisting dying in relation to approval of the lethal drug and overarching Commonwealth Legislation under the Therapeutic Goods Act.

Problems associated with the issue of medically assisted dying

Five key public policy problems associated with assisted suicide/euthanasia can be identified:

1. Medical professionals engaged in end of life medical treatment, palliative care doctors and nurses, generally are very uncomfortable with this proposed medical procedure. The emotional impact on them of having to be engaged in this process is a very important consideration that cannot be easily discounted.
2. The assisted suicide debate evokes similar concerns in relation to the rights of persons and the duty of the state that apply in the capital punishment debate. Public attitudes notwithstanding, the state should not be involved in a direct action to take a human life. This argument was referred to by senior Victorian political figures in speeches in Federal Parliament including Barry Jones, Lindsay Tanner and Kelvin Thompson.
3. The case presented by advocates for VAD (Voluntary Assisted Suicide) embodies an individualist rights agenda. Such a perspective emphasises the rights of an individual and ignores the wider influence of such decisions on those around them, especially their families. The death of a person impacts on those around them dramatically. A more sophisticated perspective emphasises the interconnectedness of our life decisions and is a political approach which is more in touch with the real-world situation of families where a loved one is dying. End of life decisions are not just individual decisions, they involve us all.
4. This type of legislation was rejected in the UK, Scotland and New Zealand due to concerns around the efficacy of safeguards to guarantee the intent of the Parliament. It has been rejected in Tasmanian, South Australia and New South Wales. There were concerns about unintended consequences and doubts as to whether safeguards were adequate for people with mental illness, persons with degenerative disability and the risk of elder abuse, especially inheritance impatience.
5. PAS (Physician Assisted Suicide) may have the unintended effect of increasing suicide rates.
6. There is the danger of the slippery slope. If the Victorian scheme was to grow at the same rate as other jurisdictions overseas by 2030 1,000 Victorians would be expected to end their lives each year under the regime. The corresponding figure for the ACT would be 65 persons per year.

Specific problems in the Victorian Legislation

Four key problems are focused on in this analysis of the Victorian Voluntary Assisted Dying Act 2017. It is not an exhaustive list of concerns that can be raised but are chosen by this author as being of greatest significance.

1. Failure to adequately fund palliative care services. The Victorian Parliament, through a rigorous Legislative Council inquiry process, identified gaps in palliative care and Palliative Care Victoria (PCV) has stated that there is an annual \$65m funding shortfall in service delivery. These concerns are the first priority for reform of the legislative framework for end of life choice decisions in Victoria. Funding measures announced as part of the consideration of the Victorian law failed to bridge the gaps identified in the LC Inquiry report and by PCV.
2. The question of safeguards was not dealt with adequately in the Victorian legislation. Persons with mental illness may be able to access the regime due to weaknesses in the proposed review provisions for psychological assessment. There is the risk that people with depression can activate the PAS regime due to the episodic nature of their condition. Depression is very difficult to diagnose. There is uncertainty as to how people with degenerative disability will be treated under the scheme. Indigenous persons with high disability rates are particularly vulnerable. There is a significant risk of elder abuse including through the inconvenient reality of inheritance impatience that can allow subtle emotional pressure to be placed on dying persons who feel they are a burden to their families.
3. Doctor shopping is also a significant issue. If a potential applicant for the VAD regime in Victoria receives an adverse assessment of their capacity to make an informed decision, then there is nothing to stop that person remaking their request to a series of doctors until they receive the outcome they seek. While adverse assessments are recorded in Victoria, these records will not be available to medical practitioners ask to provide an assessment. The door is fully open to doctor shopping, which is a major gap in safeguards under the Victorian legislation.
4. Suicide tourism was an issue raised in Parliamentary debate on the Victorian legislation. Legal opinion made available to legislators questioned the effectiveness of measures to enforce the definition of 'ordinarily residing' in the State for the prescribed period. No record keeping of this residency test is mandated. There is no effective measure under the act to prove residency (like evidence to being a party to a residential tenancy agreement or other proof of a sustained location of residence). There is no effective mechanism to stop an applicant to the VAD scheme in Victoria effectively residing outside the State but seeking medical approval for access to the scheme from a medical practitioner registered within the State. Given the close proximity of the ACT to NSW this is a critical issue for the ACT jurisdiction to consider. Were the ACT to approve a VAD scheme, and if the Victorian model was adopted, an applicant residing just across the NSW border could access the arrangement in defiance of legislation operative in NSW. ACT would risk becoming a very attractive site for assisted suicide applicants from NSW. This would reduce safeguards considerably in the Territory and would frustrate the legislative intent of any legal change to approve medically assisted suicide or euthanasia. The proximity of the border with NSW makes it extremely difficult to effectively enforce a VAD scheme without a complementary arrangement being operating in NSW.

Interaction with Federal Law

The Victorian Parliament approved the medically assisted dying regime without having chosen the lethal drug: the "medically assisted dying substance". The proposed solution is to allow pharmacists to dispense the drug under a special pathway permitted under the Therapeutic Goods Act (TGA) of

the Commonwealth where compounding pharmacists can produce a cocktail of drugs from components that are approved for other uses. This exemption to the normal TGA approval process is intended to be used in limited circumstances for persons with specific medical needs. It is not intended to be applied for a generic class of clients like those seeking access to a legislated VAD scheme. So, the Victorian Parliament has approved a scheme without research into the appropriate drug and its effectiveness, without even specifying the drug or outlining a process for its approval that is consistent with normal TGA approaches. Evidence from overseas jurisdictions is that the choice of the drug is highly problematical, and drugs have often had to be changed due to adverse effects including prolonging death and suffering in a number of cases. The failure of the Victorian scheme to adequately explain which drug will be used and how it will be tested and approved to normal TGA standards is probably the most significant failure of the Victorian medically assisted suicide model.

The submission recommends that the Assembly Committee not recommend a change to current ACT law on assisted dying.

Examination of the issues against medically assisted dying

1. The position of the medical profession.

Medical professionals engaged in end of life medical treatment, palliative care doctors and nurses, generally are very uncomfortable with this proposed medical procedure.

The AMA has stated its position in November 2016:

“The AMA believes that doctors should not be involved in interventions that have as their primary intention the ending of a person’s life. This does not include the discontinuation of treatments that are of no medical benefit to a dying patient.”

<https://ama.com.au/system/tdf/documents/AMA%20Position%20Statement%20on%20Euthanasia%20and%20Physician%20Assisted%20Suicide%202016.pdf?file=1&type=node&id=45402>

In their view there is a conflict created between their Hippocratic oath and the aims of legislation to this type.

We also need to acknowledge the emotional impact on workers of having to be engaged in this process. Active participation in a process that directly ends the life of another human being is likely to be an event with lasting impacts on a person. In this debate we need to be mindful of the psychological effects on medical personnel who will be required under law to assist in a medical procedure that directly ends a person’s life.

There is some concerning international experience in this area.

- In Canada's Ontario province, in the eight months between when assisted suicide was legalised (June 2016) and February 2017, 24 doctors had their names permanently removed from a voluntary referral list of physicians willing to help people die. Another 30 put their names on temporary hold. This was at least partly due to psychological distress, the weight of the act of helping someone decide to end their life and legal ambiguities involved.
- In a telephone survey of randomly selected United States oncologists who reported participating in euthanasia or assisted suicide, 24% regretted participating, and 16% of the physicians reported that the emotional burden of participating adversely affected their medical practice. (E. J. Emanuel et al., *The Practice of Euthanasia and Physician-Assisted Suicide in the United States: Adherence to Proposed Safeguards and Effects on Physicians*, 280 JAMA 507, 507 (1998).)
- Responses from Dutch physicians who had participated in euthanasia to questions from British House of Lords Select Committee on the Assisted Dying for the Terminally Bill in 2015 included the following statements:
 - "No physician ever likes performing euthanasia."
 - [How did you feel about participating in euthanasia?]: "Awful."
 - "It is not a normal medical treatment. You are never used to it."
- Even with the ability to opt out, other doctors report feeling intimidated and coerced by patient and family members to participate in assisted suicide.
- The first cases of legal PAS in Oregon occurred in 1998. In 2000, 35 Oregon physicians were interviewed regarding their responses to PAS requests. Mixed feelings were expressed by

the physicians. The authors noted: "Participation in assisted suicide required a large investment of time and had a strong emotional impact . . . Even when they felt they had made appropriate choices, many physicians expressed uncertainty about how they would respond to requests in the future".

2. Parallels between assisted suicide and the death penalty

There are some important parallels between the issues of physician assisted suicide and capital punishment. Both issues concern the ending of a life, sanctioned by the state and undertaken by agents of the state (as PAS is to be publicly funded). Both probably enjoy majority public support. Both involve a measure of risk associated with the state's actions. In the case of capital punishment there is risk of an innocent person being convicted of a capital crime and there are unfortunately many acknowledged cases where this has occurred. There are also risks with PAS as we learnt in the Northern Territory regime where significant doubts have been raised as to whether each of the 4 persons whose lives were ended under the measure had a terminal illness or in fact gave clear and informed consent. In the case of PAS and capital punishment there remains a risk that the original statutory intent is frustrated by administrative failure and insufficient safeguards with the gravest of consequences.

Certainly, PAS advocates would point to fact that in case of capital punishment the death is presumably not the free choice of the criminal. However, such a distinction is not a neat one. People in their last days are very vulnerable. There is a natural co-morbidity of depression associated with terminal illness. As a person's health deteriorates their capacity to be fully in command of their themselves declines and they may not have the robust capacity for free and informed decision making they may have showed at other stages of their life. Mental wellbeing can be affected. There is also the real possibility of emotional pressure from family members who may experience the dying person as a burden and may also show some impatience in relation to questions of inheritance. Assessment of a fully free and informed consent is complicated and presents real challenges for the state in administration. Mistakes will be made.

What is raised with PAS, as with capital punishment, is the role of the state in direct decisions regarding life and death. Do we believe that this is a power the state should have? Limiting the power of the state is a key feature of any successful democratic system of government. Probably the arguments for these limits are most strongly made when the question of life and death is involved. It is reasonable to conclude that this not a power the state should have. Just as with capital punishment, so also with PAS, the government should be highly reticent to exercise a legal right to actively participate in a decision that involves a person's life coming to an end.

Social democrats like Barry Jones, Kelvin Thompson and Lindsay Tanner have referred to their attitudes to capital punishment in framing their statements of reluctance and opposition in relation to these measures (see speeches in Appendix 1).

"I regard individual freedom in our society as essentially very fragile, as very vulnerable to misuse of state and bureaucratic power. Intrinsicly, the state assuming the right to sanction killing of a citizen, for whatever reason, troubles me a great deal. Even with apparent consent, it worries me." (Hon Lindsay Tanner MP, Second Reading Speech, EUTHANASIA LAWS BILL 1996, 28 October 1996).

“The resource, or utilitarian arguments for euthanasia can also be applied to the issue of capital punishment and I repudiate both.” (Hon. Barry Jones MP, Second Reading Speech, EUTHANASIA LAWS BILL 1996, 21 November 1996).

“There are important parallels between the state sanctioned killing which we call capital punishment and the state sanctioned killing which is now being called euthanasia.”

“With capital punishment and euthanasia every mistake is permanent. There is no turning back”. (Hon. Kelvin Thompson MP, Second Reading Speech, EUTHANASIA LAWS BILL 1996, 21 November 1996).

3. Physician assisted suicide embodies an individualist rights agenda

The grounding ideas of modern democratic government, formed over 200 years ago, are embodied in the legal and institutional fabric of our nation. Essentially, this means in practice that the state exists to sustain the fundamental rights of its citizens. Nothing more, nothing less. Every new right asserted embodies a set of new obligations on the state and its citizens to respect and sustain that right.

The ethical question in relation to PAS is whether there should be a right for a person to ask the state to assist them to end their life? This right has just been created in Victoria. How this is to be judged depends on your philosophical starting point. Those who lean towards political libertarianism think people should be able to do what they want, and the state exists to ensure this. But the reality is much more complicated than this. Those who favour a more communitarian approach, like social democrats, emphasise the interconnectedness of all our personal decisions. Our decisions affect us all. This is especially the case in life or death decisions. The death of a person affects those around them. The effect is more obvious the closer the people to the person who dies, like the family members. It will change their lives. However, it also affects others in the community directly.

In the case of PAS, the proposed regime will have dramatic emotional effects on health care workers engaged in palliative care, change the way health care services are provided to those approaching the end of their lives, and have impacts for taxpayers as the Government will save money from reducing expenses on caring for a person who decides to end their life before they would pass away naturally.

The point is that the way a person dies matters to those around them. To say that it is just a decision for the person themselves is an extreme individualistic rights perspective. Those who favour PAS probably place too much emphasis on the rights of the individual and fail to consider the wider implications of the state requiring others to participate in various degrees in their decision.

Here the social democrat will sound caution. Do we want to give priority to the choices of individuals, even those in most challenging situations, or do we want to judiciously balance individual rights against the obligations on others those rights impose? Australia is not, on the whole, a nation of political libertarians but more likely to be a nation that seeks to balance individual rights with social obligations. The PAS advocates seem to be more in the camp of the political libertarians. However, there is a contradiction in the libertarian viewpoint. PAS gives an immense power to the state in the area of life and death decisions. Under the guise of giving greater choice PAS actually grants the state and medical professionals operating under a PAS regime an extreme

degree of power over the lives of citizens. I submit that this power of sanctioning and actively participating in procuring the end of the life of a person is beyond the reach of the state’s remit in a social democracy and fails to recognise that such actions will impose burdens on medical professionals which, on the whole, they should never be called upon to undertake. In a social democracy individual rights are important, but individual rights must be balanced with a concern for the common good. The common good is lessened when the state actively engages in the death of a person.

4. The overseas experience on safeguards

The international experience in the operation of PAS schemes is troubling. This type of legislation was rejected in the UK, Scotland, New Zealand, Tasmania, South Australia, and most recently in NSW, due to concerns around the efficacy of safeguards to guarantee the intent of the Parliament and mitigate unintended consequences of increasing reliance on such measures for people with mental illness, persons with degenerative disability, and the risk of elder abuse especially inheritance impatience.

- **Concerns in relation to people with mental illness**

There is a strong risk that dying people with mental illness will activate the assisted suicide process as a result of their mental infirmity rather than a decision relating solely to their primary medical condition. The evidence from the overseas jurisdiction is that demand for access to PAS for those with mental illness has increased dramatically.

As stated in the Victorian Legislative Council End of Life Choices Inquiry Report (p.414)

“The proportion of euthanasia deaths involving neuropsychiatric disorders has increased sharply in Belgium over the past decade, from 1.2% of cases in 2004/05 to 2.8% in 2010/11 (58 cases) and 3.7% of cases in 2013/14 (67 cases).”

Table 4: Number of cases of euthanasia for neuropsychiatric conditions in Belgium⁷⁹

Source	Years covered by report	Number of cases of neuropsychiatric conditions
Second report	2004 and 2005	9 ⁸⁰
Third report	2006 and 2007	13 ⁸¹
Fourth report	2008 and 2009	62
Fifth report	2010 and 2011	105

And on page 415 of the same report.

“In the Netherlands, recent data from reports of the Regional Euthanasia Review Committees points to a growing number of cases of euthanasia in cases of mental illness and dementia. Table 5 contains the number of cases of mental illness and dementia over the period 2012-2015.”

“There is no reason to think that growth rates in either category will taper off given what we observe in growth rates in the overall number of cases both in the Netherlands and other major jurisdictions.”

Table 5: Number of cases of euthanasia for mental illness or dementia in Netherlands⁸²

Year	Mental Illness (Cases)	Dementia (Cases)
2012	14	42
2013	42	97
2014	41	81
2015	56	109
Growth rate: (CAGR 2012-2015)	59%	37%

Part of this growth in the mental illness cohort is due to difficulties in assessing mental capacity for patients in end of life situations. Here are quotes from respected Australian medical professionals in a paper to Palliative and Supportive Care (2015), 13, 1399–1409. Cambridge University Press, 2015 1478-9515/15.

Even when psychiatrists are involved, their capacity to confidently assess the existence and role of mental illness in EAS has been questioned (see: <http://jme.bmj.com/content/37/4/205.short>).

Assessing mental capacity, a common requirement for jurisdictions where euthanasia and physician-assisted suicide are legalised, can also be problematic for doctors”(see <https://bmcomedethics.biomedcentral.com/articles/10.1186/1472-6939-15-32>).

Mental illness is notoriously difficult to diagnose. There are two problems. The first is that it is a hidden disease. Without specialist clinical training, or a developed personal case history for the client, it is not easy for a GP to be able to distinguish mental illness from normal mood cycles or occasional aberrant behaviour. A GP faces significant challenges in distinguishing mental illness from a certain level of anxiety or depression that could be expected to be experienced by any patient facing a terminal illness. There is therefore a significant risk that a GP, when facing a referral for assisted suicide or euthanasia, may simply fail to identify latent mental illness and therefore fail to call for a psychological assessment of a dying patient who in fact seeks suicide as result of their mental illness.

Perversely, the increased prevalence of mental illness in the community may also exacerbate the difficulties with diagnosis. Data from the Australian Institute of Health and Welfare (AIHW) reveals a rapid rise in the mental illness cohort in the overall population in recent years. In Mental Health Services in Brief (2016, p.6) AIHW estimates that

“the incidence of mental health related encounters has increased by a rate of 4.4% per year between 2010-11 and 2014-15. “

This is a dramatic annual growth rate. When it becomes a daily reality in a GP clinic that clients may present with some signs of risks of mental illness, the diagnosis of psychological pathology, as distinct from an episodic mild depression, which is a natural response to diagnosis of a terminal disease, becomes a fine judgement. Many GPs will not be clinically trained to evaluate this situation. One way of determining if the mood change is a normal reaction or a pathological one is observing the patient over time, but time is not a resource available to dying person and their GP. Diagnosis of mental illness is also a function of the depth of trust in the doctor-patient relationship. It is often easy to hide depression or anxiety when it is mild or moderate. This exacerbates the risk that a GP might fail to trigger a psychiatric assessment for a terminal patient with mental illness.

When we consider the international evidence, there are increased grounds for caution. As stated above, the evidence available from Belgium and Holland, which has allowed assisted suicide and euthanasia for many years, shows a concerning rapid rise in people with mental illness seeking access to euthanasia. In Belgium the proportion of deaths from euthanasia that involved psychiatric disorders has risen from 1.2% of cases in 2004/5 to 3.7% of cases in 2013/14: triple the reported incidence rate over the decade (with many cases of course not being diagnosed or reported). In the Netherlands data is available for both dementia and mental illness.¹ From 2012-2015 euthanasia cases with mental illness have risen from 14 to 56 with an average annual growth rate of 59%. Reported cases with dementia have risen from 42 in 2012 to 109 in 2015: an average annual growth rates of 37. In addition, the Belgium and Netherlands experience is that safeguards to exclude candidates for euthanasia with mental illness and depression, through psychiatric evaluation, have proved to be weak and ineffective. Few candidates were referred and of those referred it was difficult to be objectively clear whether someone had mental illness or clinical depression. The Bill is substantially based on the model applied in Oregon State in the US. The safeguards for the mental illness cohort reflect the safeguards in the Oregon model. However, in this model only from 1998 to 2012, on average only 6.2% of patients who died under the Act in Oregon had been referred for counselling to check for “impaired judgment.” In 2013-2016 this declined to less than 4%. Of 108 patients who died under the Act in 2007 and 2009, none was referred for psychological evaluation.² This is a very low level of review.

- **Persons of linguistically diverse background.**

People in this cohort can find it very difficult to understand the intricacies of a complex legal framework that would apply in the proposed assisted suicide regime. There is a real concern that language barriers could lead to a frustration of informed consent under the proposed regime.

- **People with disability**

Persons in this cohort facing a terminal illness of significant duration face extraordinary struggles which few of us can even imagine. There is a real risk that the assisted suicide process could exacerbate a co-morbid condition of latent depression or mental illness, with risks that persons with disability with ultimately terminal conditions might activate the assisted suicide process in an episodic moment of depression or anxiety. The other argument, for those with disability is the fear that doctors may

¹ Dutch Regional Euthanasia Review Committee: Annual Reports various years.

² <http://www.usccb.org/issues-and-action/human-life-and-dignity/assisted-suicide/to-live-each-day/upload/OR-and-WA-Safeguards-FACTSHEET.pdf>, p.2.

consider their life not worth living because of their disability and offer them PAS instead of sound medical treatment.

There is much uncertainty about whether with people with degenerative disability can or should access PAS. The condition of persons with degenerative disability is usually terminal but it is very difficult to predict their longevity. The boundary between degenerative disability and the cohort of persons potentially eligible for PAS is unclear. On one hand, the Government offers all reasonable and necessary support to these people under the NDIS and on the other it offers them a lethal drug – two opposite policy approaches. This is an area in which the PAS measures are likely to lack precision in eligibility criteria, which causes uncertainty for potential applicants and policy confusion. This concern has been raised by disability advocates, including in the ACT, (http://www.no euthanasia.org.au/disability_advocates_tell_victorian_mps_why_they_oppose_assisted_suicide_and_euthanasia).

A pivotal issue in Tasmania and South Australia that led to the failure of proposed legislation was the problem of dealing with the issue of disability. There was uncertainty as to whether disability should be an eligible ground for access to assisted suicide.

In South Australia, the bill introduced by The Hon. Duncan McFetridge MLA included a clause that said that access to the proposed process could not be made on the basis of disability alone. This was seen as being ineffective given that many people with disabilities have co-morbidities that flow from degenerative conditions. The failure to properly identify the scope of the Bill in relation to persons with degenerative disability was a critical element of the failure to secure passage.

The same problem occurred in Tasmania in 2013. There the Bill included the clause:

11 (2) For the avoidance of doubt, a person does not have an eligible medical condition solely because of the age of the person, any disability of the person or any psychological illness of the person.

The Tasmanian Law society indicated inconsistency with these provisions and definitions of disability under Tasmanian law.

This issue is not resolved in the Victorian VAD Act. There is no certainty as to the boundary conditions of access to the Victorian scheme for persons with degenerative disability where the condition is ultimately terminal. This is a critical issue which has been sidestepped.

- **Concerns in relation to elder abuse**

There is a real risk that persons who are elderly and dying might activate the assisted suicide process out of a sense of being a burden to their family. There is also the risk that some family members might encourage such a perception for financial motives. The report by the Australian Law Reform Commission (ALRC) in relation to elder abuse used data from the World Health Organisation suggesting that elder abuse can occur in 2 to 14 percent of relevant cases. (Australian Law Reform Commission, Elder Abuse –Final Report p.17, referring to WHO publication The Toronto Declaration on the Global Prevention of Elder Abuse.) <https://www.alrc.gov.au/publications/elder-abuse-report>.

Elder abuse can take many forms through subtle emotional pressure, to direct coercion. In the analysis of public policy decisions that have financial implications for individuals, there is a need to examine the incentive structures that are in place. In the case of the situation of a vulnerable person experiencing a terminal illness, the incentives of the suffering person and the beneficiaries of their estate are in direct conflict. The beneficiaries, usually family members, have a strong financial incentive to expedite release of assets that might flow from a will. The interests of the suffering persons are protected when they are relieved of any emotional pressure, or sense of guilt for still being alive, or of holding up the financial benefit they will provide when they die to the people they love. It is a complex emotional situation, and one that is very difficult to manage through a regulatory regime.

As noted in the ALRC report there is an important issue of gaining consent from older Australians.

The prevalence of cognitive impairment also increases with age. From age 65, the prevalence of dementia doubles every 5 or 6 years. 30% of people aged over 85 have dementia ...

This data seems to indicate that high levels of safeguards are required to prevent elder abuse.

The impact of PAS on suicide rates

There is some evidence to suggest that PAS might lead to an increase in suicide generally. Jones and Paton have found that in the US assisted suicide does not reduce suicide rates in the community. In relevant US jurisdictions assisted suicide “has been associated with an increased rate of total suicides relative to other states and no decrease in non-assisted suicides.” (Jones and Paton, 2015, *Southern Medical Journal*, 180 (10). pp. 599- 604).

Since euthanasia was legalised in the Netherlands in 2002 the rate of completed suicides (excluding premature death by euthanasia) has risen from 9.6 to 11.1 per 100,000 population (1,500 people in 2003 to 1,871 people in 2015).

Being exposed to suicide increases the risk of suicide by family and friends (see “Familial transmission of suicidal ideation and suicide attempts: evidence from a general population sample”, Goodwin, Renee D., Annette L. Beautrais, and David M. Fergusson, *Psychiatry Research*

Volume 126, Issue 2, 30 April 2004, Pages 159-165.)

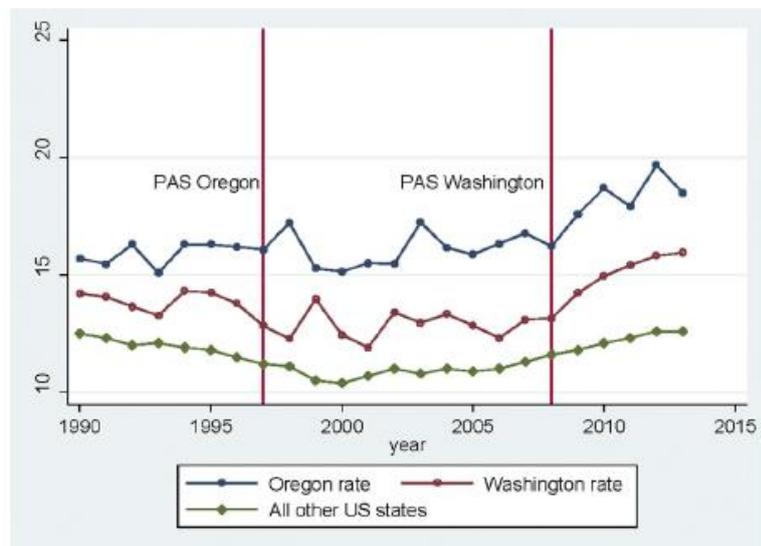


Fig. 1. Total suicide rates per 100,000 residents, PAS and non-PAS states, 1990–2013. Vermont is excluded because PAS was legalized in 2013 and no PASs were recorded in that year. Montana is excluded because PAS was decriminalized rather than legalized and as such, no data are collected on PAS. The vertical lines indicate the timing of the legalization of PAS in the two states. PAS, physician-assisted suicide.

“Exposure to the suicidal behaviour of family members has been well-established as a risk factor for youth suicidal behaviour in the professional literature.” (The Impact of Exposure to Peer Suicidal Self-Directed Violence on Youth Suicidal Behavior: A Critical Review of the Literature, M. Franci Crepeau-Hobson, and Nancy L. Leech, *Suicide and Life-Threatening Behavior* 44 (1) February 2014.)

“Risk of suicidal behaviours among those exposed to the suicide is significantly higher than those unexposed.” (Is Exposure to Suicide Beyond Kin Associated with Risk for Suicidal Behavior? A Systematic Review of the Evidence, *Journal of Suicide & life-threatening behaviour*, Maple, Myfanwy, et al. October 2016).

Providing suicide assistance for some undermines suicide prevention for everyone. There is no bright line between so-called ‘rational’ and ‘irrational’ suicide because all the same social, economic and health factors are involved (see: NZ Care Alliance <http://10questionsfordavidseymour.nz/> Question 8)

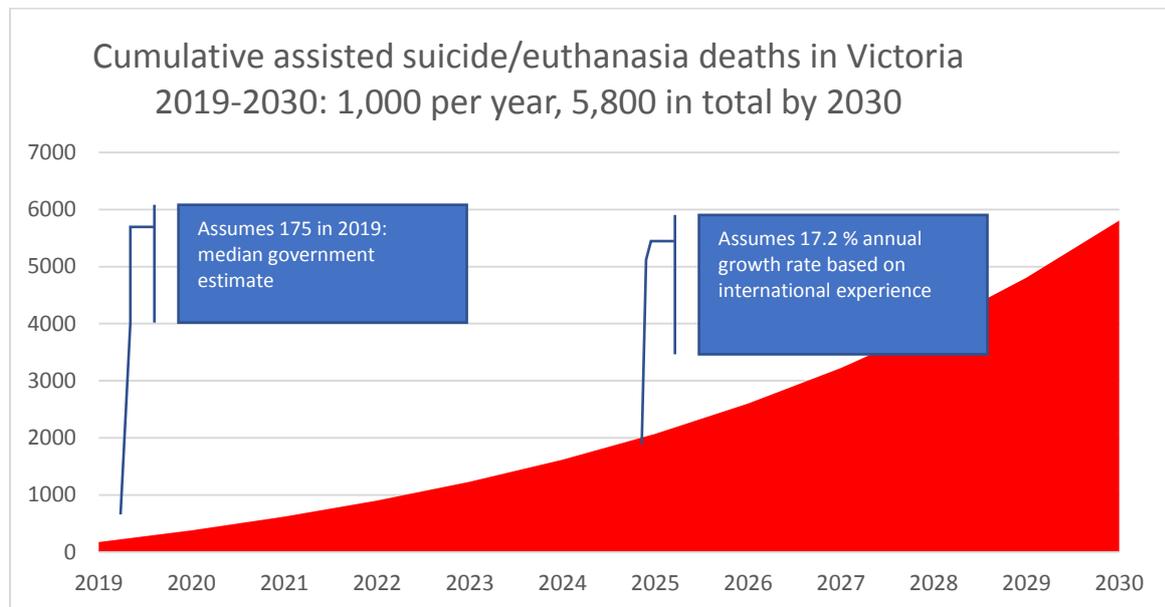
5. Evidence for ‘the slippery slope’?

When considering the issue of medically assisted suicide the issue of what is labelled the ‘slippery slope’ is a critical issue. The slippery slope argument, which is a strong argument against permitting medically assisted suicide, can be put in form of this question: has the use of legislated euthanasia or assisted suicide expanded over time through legislative change or scope creep in overseas models? From a purely statistical perspective the answer is clearly yes. The data reveal annual cumulative growth rates of about 17% for overseas jurisdictions. This annual compounding growth rate is very high indeed. It cannot be explained by the ageing of the population. Certainly, as the population ages more persons as a proportion of the total population will find themselves in the end of life situation. Infirmary increases with age, and as the proportion of aged person in the population increases the proportion of persons in the infirm and final stage of their lives must increase. However, while the population is ageing in most developed countries this process is very gradual. It cannot explain an increase in the cohort of persons in their end of life stage at anything close to a 17% annual growth rate. The only explanation that is statistically viable to explain such an extraordinary growth rate is that the medically assisted suicide regimes face surging demand to access these schemes. Medical professionals who approve access to these schemes may naturally find it difficult to deny requests earnestly made to them by persons suffering at the end of their lives. This surging demand leads to pressure to relax the original legislative constraints of the scheme either de jure or de facto. What the data suggests is that constraints to access to the schemes are modified or in practice not enforced. The international experience is one of significant scope creep for PAS regimes. Originally, tight legislative constraints become impossible in practice to enforce. The growth rates evident for PAS and euthanasia regimes in European and North American jurisdictions statistically reveal this strong scope creep and highlight that the ‘slippery slope’ effect is real.

Country	Initial PAS cohort	Latest data	growth rates
Belgium	235 (2003)	2012 (2015)	19.6
The Netherlands	2331 (2008)	5516 (2015)	13.1
Switzerland	50 (1998)	836 (2014)	19.2
Oregon	16 (1998)	132 (2015)	13.2
Washington State	64 (2009)	170 (2014)	21.6

Source: http://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf, pages 397-398.

This analysis seeks to measure the slippery slope effect operative under the new Victorian legislative model and also measure the likely impact on the ACT if the Victorian model is adopted. Applying international growth rates to the government estimate of 150-200 persons per year in Victoria leads to a figure of 1,000 Victorians ending their lives by accessing the scheme each year by 2029 and 5,800 in total.



Source: Dr Brendan Long, Australian Centre for Christianity and Culture, Charles Sturt University, 2017.

Looking at the relative size of the ACT population to Victoria this would mean that after ten years of operation 65 persons per year would end their lives under a VAD scheme operative in the ACT with a total of about 375 persons over this ten-year period. This is the gradient of the slippery slope.

Examination of deficiencies in the Victorian Legislative model.

1. The shortfall in funding for palliative care in Victoria

The Victorian Parliament, through a rigorous Legislative Council Inquiry process, identified significant gaps in palliative care service delivery in Victoria. This was the prime focus of the Legislative Council inquiry report. Of its 49 Recommendations, 29 Related to expansion of service delivery in palliative care, 19 to issues related to the process of Advance Care Planning directives to better manage end of life choices for the patient, and only one recommendation was made in relation to physician assisted suicide.

The first 48 recommendations seem to have been buried under the weight of the 49th. This is not in the public interest. Concerns about gaps in palliative care funding and service delivery, and recommendations in relation to Advance Care Planning should have been the priority for government before advancing consideration of the recommendation on PAS.

Palliative Care Victoria (PVC) conducted a recent survey which “found over 92% of Victorians support more government funding for palliative care.” PVC has also stated that there is a \$65m a year funding shortfall needed to deal with unmet need and increasing demand for palliative care services. Dealing with these concerns should be a higher priority than proceeding with this legislation (<http://www.pallcarevic.asn.au/2017/07/funding-increase-needed-improve-access-palliative-care/>)

The best way to enhance the wellbeing of dying persons is to ensure that the palliative care system is adequately supported. This should have been the focus of policy change in the area of end of life choices. Some expansion of funding to palliative care was outlined by the Victorian government as the legislation was debated (\$62 over 5 years). Still, this failed to achieve what PVC has called for. A key deficiency of the Victorian model was to proceed with legislation before palliative care services were adequately expanded (<http://www.pallcarevic.asn.au/2017/11/new-victorian-palliative-care-funding-announcements-disappointing-inadequate/>).

Can all pain and physical distress can be managed for those approaching the end of their lives?

Pain relief for palliative care is successful in 96% of cases. In these cases, the pain management is sufficient that pain does not press on the consciousness of the patient.

This medical conclusion is based on a review of 62 studies, with 4241 participants, into oral morphine for cancer pain. Where results were reported for individual participants in 17 studies, 'no worse than mild pain' was achieved by 96% of participants.

2. Weak safeguards in the Victorian legislation.

The question of safeguards was not dealt with adequately in the Victorian legislation.

Persons with mental illness may be able to access the regime due to weaknesses in the proposed review provisions for psychological assessment. There is the risk that people with depression can activate the PAS regime due to the episodic nature of their condition. The safeguards for applicants for mental illness under the Victorian Act appear to be no stronger than those in the European or US jurisdictions. As noted above, in these jurisdictions they are clearly weak. The evidence stated from medical experts and the low levels of psychological review in overseas jurisdictions highlights the difficulties in assessing informed consent for the mental health cohort of applicants under the VAD.

Safeguards for persons with disability were not adequately dealt with in the VAD Act. There is no certainty as to the boundary conditions of access to the Victorian scheme for persons with degenerative disability where the condition is ultimately terminal. This is a critical issue which has been sidestepped.

There is a significant risk of elder abuse including through the inconvenient reality of inheritance impatience that can allow subtle emotional pressure to be placed on dying persons who feel they are a burden to their families. The Victorian Act relies upon criminal sanctions to prevent coercion to mitigate against the risk of elder abuse. Where such sanctions are applied overseas they are rarely activated and the burden of proof is high. It is argued that such sanctions will be unlikely to be legally effective. The Victorian Act could have included more pro-active intervention mechanisms where the risk of elder abuse was deemed high. One option could have been involving mandatory reporting by social workers in hospital environments in suspected cases of elder abuse.

3. The problem of 'doctor shopping' was not addressed

Doctor shopping is also a significant issue. If a potential applicant for the VAD regime in Victoria receives an adverse assessment of their capacity to make an informed decision, and the applicant is committed to activating the VAD regime, they can seek out another medical practitioner, or a series of practitioners, until the application is finally approved. While adverse assessments are recorded in Victoria, there is no process under the legislation for doctors to access these assessments when they consider an application for access to the scheme. These records will not be immediately available to medical practitioners asked to provide an assessment. This means the door is fully open to doctor shopping in order to access the scheme. This is a significant design flaw in the safeguards regime under the Victorian legislation.

The scheme could have been approved by amendment to require that the 'coordinating medical practitioner', the doctor who supervises the application process, to be either:

- 1) a practitioner working for or at a health facility providing treatment for the patient at the time of the patient's diagnosis, or
- 2) a practitioner who has been treating the person for at least three months before the person makes a first request.

Such an amendment would have effectively eliminated the reduction in safeguards caused by the risk of doctor shopping.

The problem of 'suicide tourism' was not adequately addressed

Suicide tourism was an issue raised in Parliamentary debate on the Victorian legislation. The legal advice of P Willis distributed in the debate indicated that the current test under clause 9 of the Act states that the applicant must be 'Ordinarily resident' in Victoria. This is defined in legal terms to include some notion of permanence of residence, but this is not tested under the bill. There is no requirement that the person applying for assisted suicide procedure produce documentary evidence that this test is met. This legal opinion questioned the effectiveness of measures to enforce the definition of 'ordinarily residing' in the State for the originally prescribed 12-month period, ultimately reduced to 6 months by Legislative Council amendment to the Bill. However, as the legal advice attested, no record keeping of this residency test is mandated. There is no effective measure under the Act to prove residency (like evidence to being a party to a residential tenancy agreement

or other proof of a sustained location of residence). There is no effective mechanism to stop an applicant to the VAD scheme in Victoria effectively residing outside the State but seeking medical approval for access to the scheme from a medical practitioner registered within the State.

The close proximity of the ACT to NSW makes this a critical issue for the ACT jurisdiction to consider. Were the ACT to approve a VAD scheme, and if the Victorian model was adopted, an applicant residing just across the NSW border could access the arrangement in defiance of legislation operative in NSW. ACT would risk becoming a very attractive site for assisted suicide applicants from NSW. This would reduce safeguards considerably in the Territory and would frustrate the legislative intent of any legal change to approve medically assisted suicide or euthanasia. There are costs associated with accessing such a scheme to the Territory Budget and cost savings to NSW from having to provide palliative care services. Introduction of a VAD scheme in the ACT would lead to a cost shifting of end of life care services from the NSW to the Territory Budget. This cost shifting would be significant at a per client level. It can be asked whether the taxpayers of the ACT are willing to bear costs of end of life care for NSW taxpayers and earn the reputation as a location of choice for those seeking to end their lives. The proximity of the border with NSW makes it extremely difficult to effectively enforce a VAD scheme without a complementary arrangement being operating in NSW, or some cost sharing arrangement negotiated which would be difficult to administer

There are also some risks associated with control of the lethal drug to be taken – the ‘Voluntary assisted dying substance’ – as labelled under the Victorian Act. Under this ACT a person could travel to Victoria to access the regime, take the drug out of the state, and sell it on the black market as an illegal substance. The drug, then procured illegally, would have a market value. Given that there is no real tracking of the lethal drug once prescribed and given that it will not really ever be known how much of the prescribed drug is actually administered by the person, there is a risk the drug will be sold to persons outside the jurisdiction for whom it is not prescribed. While the Victorian Act seeks to address these concerns through criminal penalties, sadly, the evidence on the extent of illicit trade in pharmaceutical products indicates that such criminal penalties are not particularly effective. Residents of the ACT might reasonably be concerned about the risk of a black market for the lethal substance being created by any VAD scheme introduced in the Territory.

Interaction with Federal Law: the lack of clarity on testing and approval processed for the lethal drug

Probably weakest element of the Victorian assisted dying model relates to problems and uncertainties surrounding the use of the legal drug called the “medically assisted dying substance” in Section 3 of the Act. The Government has not chosen the drug and has not outlined how it will be tested or approved. This is a significant concern particularly as the choice of the lethal drug remains highly problematical.

Consideration of side effects of drugs used in other jurisdictions

The lethal pharmacological substance used in Washington and Oregon medically assisted suicide regimes was made up of phenobarbital, chloral hydrate and morphine sulphate. Phenobarbital, the critical life ending agent, was taken in 107 (44.6%) of medically assisted suicides carried out in 2016

under Washington State's Death With Dignity Act and in 39 (29.3%) of medically assisted suicides carried out in 2016 under Oregon's Death With Dignity Act.

Kaiser Health News reported in December 2016 on problems with mixture that was being used experimentally as no approved drug mixture was then available.

- "...the combination turned out to be too harsh, said Dr. Robert Wood, a volunteer medical adviser for End of Life Washington.
- "The chloral hydrate mixture was too caustic for some folks and our volunteers didn't like using it," because some patients became distressed, Wood said.
- Most doses of lethal medication are bitter, often requiring patients to take anti-nausea drugs. But the new mixture was not only bitter but also caused a burning sensation in the mouths of some patients, said Glennon. "There was some profound burning," she said. "We didn't like working with it. As a volunteer, you want to reassure people. We're about a peaceful, dignified death."

Another cocktail used by doctors in these jurisdictions was a three-drug mixture that includes diazepam, digoxin, and morphine. However, a new problem emerged, as reported in the Seattle Times in March 2017:

"[Twenty percent] of the cases were three hours or more before death, which we think is too long," said Robert Wood, a retired HIV/AIDS researcher who volunteers with the advocacy group End of Life Washington, in an email. "The longest was 31 hours, the next longest 29 hours, the third longest 16 hours and some eight hours in length."

Patients and families are told to expect sleep within 10 minutes and death within four hours. When it takes far longer, family members get worried, even distressed, said Dr. Carol Parrot, a retired anaesthesiologist who has prescribed drugs for dozens of aid-in-dying patients in Washington.

The Oregon data shows that in 2016, for those for whom information is available, some 11.1% of people ingesting lethal drugs regurgitated them. Some six people in Oregon have regained consciousness after initially going into a coma, one of them after 3 days and 16 hours.

The interval from ingestion of lethal drugs to unconsciousness has been as long as one hour while the interval from ingestion to death been as long as 4 days and 8 hours.

The Washington data shows that in 2016 one person took 11 hours to lose consciousness after ingesting the lethal dose and one person took 22 hours to die after ingesting the lethal dose. Seven people regurgitated the lethal medication. In 2014 one person suffered seizures after ingesting the lethal medication.

It is very concerning that vulnerable persons seeking to access medically assisted suicide did not enjoy the protection of a drug that was tested appropriately under supervised clinical trials before being used on human beings. Without the benefit of knowing what the drug is, we cannot access research into the risks the drug may involve of causing increased suffering and prolonged death, and we don't know the process by which such risks are even to be assessed.

Drug Approval processes under the Therapeutic Goods Act

The Victorian Government is proposing to apply an exemption pathway under the TGA where compounding pharmacists can produce a cocktail of drugs from components that are approved for other uses. Schedule 5 of the TG Regulations lists certain categories of medicines which, pursuant to regulation 12, are exempt from the registration requirements in Part 3-2 of the TGA. Notably, Item 6 of Schedule 5 provides “medicines that are dispensed, or extemporaneously compounded, for a particular person for therapeutic application to that person” are exempt from the requirements of Part 3-2 of the TGA.

However, there are number of risks with this approach. Firstly, this exemption to the normal TGA approval process is intended to be used in limited circumstances for persons with specific medical needs. It is not intended to be applied for a generic class of clients like those seeking access to a legislated VAD scheme. By activating this approach, the Victorian government effectively sought to bypass the safety and testing regime the TGA requires and which the Victorian government enforces in its jurisdiction. The Therapeutic Goods Authority und the Act must have regard to the quality, safety and efficacy of any proposed drug on the register of approved drugs. This is good public policy as it acts as a protection of members of the public against drugs that are judged to be too severe relative to the condition being treated and/or may lead to side effects that are uncertain and that may vary significantly across people. The question can be asked as to why the Victorian government did not seek to activate the protections, the safeguards, embodied in the TGA regime? The likely conclusion is that this would have involved considerable delays in the approval process.

The process of drug compounding can also involve a range of systemic difficulties. The Pharmacy Board of Australia: “Guidelines on Compounding Medicines” state

“Compounding should only be carried out by pharmacists and other staff involved in compounding medicines if education and training in the types of compounding they undertake has been completed, and they have demonstrated competence in the relevant compounding techniques.”

The Guidelines outline appropriate competence for “simple compounding” in section 3 and for “complex compounding” in section 4. However, in the Victorian legislation there is no mechanism to ensure that the “professional practice profile for pharmacists undertaking complex compounding” is complied with and how the prescribed compounding protocols are developed, monitored and enforced? The Victorian Act does not require appropriate education or training or demonstrated competence in the relevant technique.

There a range of complications in the context of assisted suicide in ensuring that the drug cocktail will be suitable for the physiology of each patient. The lack of information in relation to this drug provides little ground for optimism that such complications will be properly dealt with. There is the risk that existing medical conditions will interact with the “voluntary assisted dying substance” and reduce its effectiveness. More research is required on this issue. The Guidelines also make reference to the need for an evidence base – and state that, “when compounding medicines, pharmacists must ensure that there is good clinical and pharmaceutical evidence to support the quality, stability (including appropriate expiry periods), safety, efficacy and rationality of any extemporaneous formulation.” Given the difficulties in Washington State and Oregon in settling on

a drug or cocktail of drugs, we can reasonably be concerned as to how will this evidence base is to be established. For example, the “voluntary assisted dying substance” will need to be stable for months. This might lead to concerns in relation to expiry periods for some compounded drugs.

So, the Victorian Parliament has approved a scheme without research into the appropriate drug and its effectiveness, without even specifying the drug or outlining a process for its approval that is consistent with normal TGA approaches. Evidence from overseas jurisdictions is that the choice of the drug is highly problematical, and drugs have often had to be changed due to adverse effects including prolonging death and suffering in a number of cases. The failure of the Victorian scheme to adequately explain which drug will be used and how it will be tested and approved to normal TGA standards is frankly an astounding policy outcome. If the ACT proceeds with VAD legislation it should seek to avoid this poor policy position. Any drug chosen under a VAD scheme in Australia should meet TGA standards for testing and approval.

[Failure to comply the Charter on Human Rights and Obligations.](#)

In a number of ways, the Victorian Legislation failed to meet the criteria for compliance with the Victorian Charter on Human Rights and Obligations. This issue was raised by this author in a submission to the Scrutiny of Acts and Regulations Committee of the Victorian Parliament which is included in Appendix 3. Much of the material in the latter submission is repeated in this submission to ACT Assembly Committee.

Appendix 1: Selected Speeches of politicians on Andrews Bill

LINDSAY TANNER'S SPEECH TO THE ANDREWS BILL IN 1996

Monday, 28 October 1996

Page: 5916

EUTHANASIA LAWS BILL 1996

Second Reading

Mr TANNER (5.25 p.m.) —Like other members of this House, I sadly have seen my share of death and of people dying of terminal illnesses—AIDS, leukaemia, cancer in various forms—and it is something that has affected me, as I am sure it has affected those in the House who have also had the same experience. I have seen the extreme pain, the loss of dignity, the loss of quality of life that often goes with such circumstances, but also I have seen the enormous courage, the enormous hope, the refusal to give up hope, the refusal to accept defeat that is so much part of the human condition and so much part of the strength of the will to live in these circumstances.

I accept that on occasion there are situations where it is clear that death is inevitable; that the person has a terminal condition against which nothing can be done to prevent death; and, that the person concerned is suffering so badly and is in such extreme circumstances that they desire death, they hope for death and that somebody does assist them—a doctor or another medical professional—in attaining release. It is very difficult for any of us to regard that as in some way morally wrong.

But there is a very different question at stake here; that 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. This debate should not be about one or two individual experiences, not about our own experiences, but about the broader social question. Just as the question of capital punishment cannot be determined by one or two murders, by one or two gross and appalling examples of killing, neither should our view on euthanasia 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.

I first approached this issue a couple of years ago when writing a newspaper column. I worked my way through the issue and came to the conclusion that I was opposed to euthanasia and, if anything, the debate that has ensued subsequently has strengthened my view. I think our views on this issue very much come from our own individual natures, our own characteristics, our own perspectives; and our response very much depends on how we look at things, the angle from which we come at any particular issue. I do not have a particularly absolutist view on this issue; I am open to further debate. But faced with the option of the status quo or legalised euthanasia in the form that is proposed in the Northern Territory, then I prefer the status quo.

It has been argued that this bill put forward by the member for Menzies (Mr Andrews) is about the separation between church and state. I would disagree with that analysis. I think it is also worth noting that just because the churches take a particular view does not therefore make it wrong. Most of us would probably agree with the churches on a few fundamental issues like murder, rape, assault and so forth. So whether the churches take a position is really neither here nor there.

To me this is an issue about the relationship between state and citizen—not between church and state. It is interesting that the context of the debate has in some ways presented this bill as unusual. What is unusual is the Northern Territory legislation. The Andrews bill is unusual procedurally, but the substance of the issue—which is what we should be really about—is that it is the Northern Territory legislation that is unusual.

I am troubled by euthanasia because I think it is virtually impossible to draw safe boundaries, because I think it is virtually impossible to prevent abuses and mistakes and because I think it is virtually impossible to justify offering the option of assisted suicide to one category of people when you deny it to others. That is a necessary implication of the Northern Territory legislation.

I regard individual freedom in our society as essentially very fragile, as very vulnerable to misuse of state and bureaucratic power. Intrinsicly, the state assuming the right to sanction killing of a citizen, for whatever reason, troubles me a great deal. Even with apparent consent, it worries me. I refer those in my part of the political spectrum, most of whom have a different point of view from me, to debates that have occurred on issues like the Australia Card, where the same sorts of concerns about fears of misuse—obviously not on the same life or death scale, but fundamentally the same framework—occurred. Others laughed and said, 'You are paranoid, it is excessive,' and the like, but many on the Left had the same sorts of concerns there.

I am very conscious of human fallibility, very conscious of the fact that euthanasia inevitably focuses on the most vulnerable members of our community. For those who think that 'voluntary' amounts to an unimpeachable protection, I ask them to look at one or two examples where capital punishment has been meted out to people who have actually confessed to crimes they did not commit. The case of Timothy Evans in Britain in the early 1950s is a very good example of how, in certain circumstances, the protection of a person having to ask to be killed may not quite be as strong as you think. It is very notable that the parliamentary inquiries that have examined these issues have very much focused on these concerns as a basis for rejecting euthanasia.

I am also concerned at the nature of the boundary. Why is it that it is only the terminally ill? Why shouldn't it also be the severely disabled? For example, why shouldn't somebody who has been rendered quadriplegic have the opportunity to opt for assisted suicide? Why not somebody with an incurable mental illness that perhaps makes their life as unbearable or as difficult as a terminal physical illness makes life for the sort of people who are supposedly the subject of this legislation? Why not children who are terminally ill? Why shouldn't they have their guardian make the decision on their behalf, as we do, in so many circumstances in our society, allow an adult to make a decision on behalf of a child?

Once this principle is established, it becomes very hard to draw lines. If you look at the detail of the legislation, for example, you will see that it is possible for somebody

with a condition as relatively uncomplicated in modern terms as diabetes, if they refuse treatment, to then have that as a basis for achieving assisted suicide. I am not suggesting that that will necessarily happen, but I am using it as an illustration of how difficult it is to draw boundaries around these things which are safe.

Why is it that, on one hand, we put so much effort and concern into telling some people, 'Don't kill yourself,' and we have so much concern now about youth suicide, yet on the other hand we are now shifting into a pattern where we are going to help certain other people, in effect, to commit suicide? There is an inherent subjectivity in all of this, and that is about the quality of life for people. It involves a subjective judgment which says that certain people in certain circumstances of a particular nature inherently have a lesser quality of life and therefore we are going to permit assisted suicide for those people, but not for other people.

If you look through the list of criteria in Marshall Perron's little flow chart which he sent around, you will see things which, when you read them carefully, are inherently subjective. 'Have the implications been considered by the patient? Has the proper information been provided by the medical practitioner?' Any decision to opt for assisted suicide cannot be taken in isolation from the current mental state of the person, the quality of the care they are receiving, the attitudes of the carers, the attitudes of the family and friends whom they are with every day and, ultimately, the financial imperatives in the health system.

It is impossible, in my view, to guarantee a genuinely pure decision to die based purely on the factors that are beyond human control, namely, the terminal illness. It will be inevitable that other factors which are within human control may impinge on such a decision. The emphasis on palliative care in our health system may be subtly altered as a result of the distorting signal that support for euthanasia sends through. Individuals may succumb to subtle pressure, or even imagined pressure, to do the right thing by relatives or even the system.

It is interesting that throughout this whole debate nobody has actually asked the question: what about the terminally ill who don't want to die? What impact does this have on those people who say, 'No, I want to live, I want to hang in there and I want every bit of assistance I can have'? The message that this sends to those people is: you are downgraded in some way; you are devalued.

We could even see situations where changes in health funding, changes to Medicare, could insert a substantial financial part into this equation which currently is not there. That is a big worry, in my view. If people ultimately are faced with choices such as, 'Do I have to spend my children's inheritance to maintain my care?' then all of a sudden you have got a real problem with an equation that has got a capacity for assisted suicide there.

Anyone who scoffs at these concerns—the concerns about distorting signals being inserted into a bureaucratic organisational structure—and thinks they will have no impact should read some of the aviation safety reports that have been going around recently as a good illustration of what can happen when you have got some sort of subtle cultural change being inserted into a system that is designed to protect, to care, to preserve life, and see what can happen.

These may be exaggerated fears. They may come from my own personal views, personal perspectives, but everybody's view in this debate will ultimately come from that gut level set of values, which will be the base from which we approach these things. My concern is that you will get these distortions—not overnight, maybe not next year or in two years time, but eventually you will get them.

The argument in favour of euthanasia in this debate essentially rests on three key themes: individual rights, states rights and the fact that it happens anyway. In this great age of individualism, it is perhaps not surprising that the line of individual choice scores very well in opinion polls and that euthanasia is getting 75 to 80 per cent in the opinion polls. I think it is worth pointing out to some of those behind me, including some in my own faction, that the same theme also ensures that there are lots of people out there from whom, when you put the proposition to them, 'Should individual workers have the right to negotiate their contract with their boss,' you get the same sort of result. It depends very much on what question you ask.

If we went to a referendum, I suspect, as was the case with the Communist Party Dissolution Bill in the early 1950s, that majority in the polls would shrink very quickly and you would get a very hard fought and difficult contest. There are many areas in our society where we inhibit individual freedom. I refer, for example, to the ability to contract out of workers' compensation obligations. We do not let people do that. The honourable member for Menzies mentioned the ability to allow someone to commit grievous bodily harm to oneself. We do not permit people the individual right to do that. There are a whole range of things there.

What this is ultimately about is the balance between the individual and the community in our society. I do not believe, in this debate or in any other, that we should start with the premise that the individual is supreme. That is the underlying logical effect of the starting point for the pro- euthanasia position.

The weakest line in the argument in favour of euthanasia in this debate is the states rights line. It is an absolute absurdity that we are now in a position where the same set of conduct in Darwin is legal but in Mount Isa it is illegal. The same set of conduct in Broken Hill is illegal but it is legal in Alice Springs. It is absurd that a parliament that represents roughly one per cent of Australians should, in effect, make a decision that affects all Australians on an issue of such fundamental importance. For those who push this line, I would like to ask them: where were you a couple of years ago when this parliament legislated to overrule the Tasmanian parliament on the question of personal privacy? Exactly the same issues were there. This parliament had the constitutional power, and it used it.

Where would you be if this were not about euthanasia but about capital punishment? I suspect that there would be some who would be only too happy, too ready, to join in overruling the Northern Territory parliament should it decide to reintroduce capital punishment. I support a uniform national position, whether it be by referendum, by legislation in this parliament in concert with the states or whatever. We should have a single uniform national position.

On the question of 'It happens anyway' this is the strongest argument, I must concede, on the part of the supporters of euthanasia . It is a difficult one for me because on other issues, for example the drug question, I think it is a very powerful point. But I think you have to look at these things on an issue by issue basis. The status quo may be

unsatisfactory, but I believe that full legalisation in the case of euthanasia would lead to a worse situation. In some respects I would say the same of heroin. The status quo is unsatisfactory. The criminal law being involved is the core part of the problem with heroin use. But if we went to complete legalisation I think in many respects we would have a worse situation.

It is difficult to know what the intermediate point in how you deal with these things is but, faced with a choice of the status quo or legalisation, I will stick with the status quo. I have had some dark warnings of: 'This is all a Lyons Forum conspiracy' and the Catholic Right and so forth and what am I doing on board with all these people. The spectrum in this community that is opposed to euthanasia is much wider than just the so-called Catholic Right. Other churches—for example, the Anglican Church—have taken the same position. It is also notable if you look internationally that euthanasia, unlike abortion, is illegal virtually throughout the world. What that ought to tell us is that, regardless of religion, regardless of orientation, there is a very wide spectrum of opinion opposed to euthanasia across the world.

I seek leave to table the Hughes advice that the member for the Northern Territory referred to. If his advice is not correct, there is one simple way of solving it, and that is mutual repeal. If this parliament passes this act then the Northern Territory parliament has a simple solution to those alleged problems. It could then repeal the right to die act and we will then consequentially repeal this act. So there is a simple way to solve those problems.

My final concern is that the Northern Territory law is a clear indication that there are two types of people, that there is not equality before the law with respect to these issues, that society values some citizens differently. If you are terminally ill then you are permitted access to assisted suicide but not if you are in another category. I think this fits in with a pattern that is extending right across our whole polity, right across many decisions to reduce people to atoms, to individuals, to take decisions that are not based on the society as a whole. I believe we should support the bill of the member for Menzies. (*Time expired*)

Mr BARRY JONES(10.30 a.m.) —In the course of my 25-year parliamentary career, I have only exercised two conscience votes. The first, in 1975 in the Victorian Legislative Assembly was to abolish the death penalty and I had no doubts at all on the issue. On the second, in the House of Representatives in 1978, the Lusher motion to take away medical benefits for abortion, I had very real doubts. So it will be with the third, on the private member's bill to overturn the Northern Territory's euthanasia law.

A debate in which the outcome is uncertain and depends on the quality of the discussion itself is of the greatest rarity—an occasion when this parliament itself can take a lead. How appalling then that this debate has been shunted off to a committee room with a 10-minute limit on speeches, without members actually listening to each other. In this debate, it is my conscience that I must follow—a conscience shaped by knowledge, analysis and, I hope, compassion. I adopt the words of Edmund Burke in his celebrated address to the electors of Bristol in 1774:

Your representative owes you, not his industry only, but his judgment; and he betrays instead of serving you if he sacrifices it to your opinion.

I see both sides of the euthanasia debate all too clearly. No other issue has troubled me so much because I am not sure that I am correct. Nevertheless, I have a moral obligation to vote—to choose. I cannot abstain—indeed, not to choose is to choose. The contribution of Sir Gustav Nossal to the collection of essays entitled *The last right?* puts the position with compassion and clarity and I adopt his words:

Dying with dignity and in peace should be everyone's right, particularly in an industrialised country with high standards of health care. Nevertheless, I am against the formal legalisation of euthanasia. A well-ordered society is a very fragile thing, as recent history (Hitler, Pol Pot, Rwanda) shows. I believe there are grave dangers in a society giving to anyone, no matter how well intentioned, the right to terminate a human life. However, I do believe that those who are terminally ill should come to the end as free of pain as possible and with as tranquil a state of mind as possible. This may necessitate the use of strong drugs in doses that imperil life. I certainly do not believe that fear of possibly fatal consequences should limit the dosage of narcotics, tranquillisers or other medications in such circumstances. It seems to me that the crucial thing here is intent. The intent to relieve pain and suffering is good; the intent directly to kill breaches what I consider to be societal norms. Enshrining a right to terminate life in legislation would, I believe, do more harm than good, although I totally support the right of others to disagree with this view.

The valuable contributions of Mr Justice Michael Kirby and Sir Ninian Stephen are along parallel lines. I support the Victorian Medical Treatment Act 1988 and would commend it to the legislature of the Northern Territory. At the consideration in detail stage of the bill, after the passage of the second reading of the Andrews bill, I propose to move some amendments to the three schedules of the bill to incorporate the broad thrust of the Victorian act. The Victorian act, now adopted in South Australia as well, was introduced by a Labor government, drafted, as it happened, by Mr Kevin Andrews, who was later to become the federal member for Menzies, and endorsed by Archbishop Sir

Frank Little. However, on several points my amendments would go further than the Victorian act.

I know very well that the practical outcome of the Victorian legislation has led to a good death—literally, in the Greek, euthanasia—for very many terminally ill patients, but where death is the side effect of heavy sedation, a corollary of the treatment of acute and chronic pain, not the result of direct intention to terminate life, death by timetable, death by appointment. The practical outcome probably differs very little—merely a delay of hours or days—but the moral implications are completely different. It does not force a physician to pass over the Rubicon—to transform his or her role from a preserver of life to a terminator of life. There have, of course, been no prosecutions under the Victorian law. To the best of my knowledge, the law is working well.

I have been following recent decisions in the US Supreme Court where a bare majority of judges is now re-defining limits to privacy—whether rights over matters involving the most intimate and personal choices a person may make in a lifetime are central to the 14th Amendment to the Constitution, guaranteeing equal protection under the law. Justice Anthony Kennedy said:

At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life.

These words first used in *Planned Parenthood v. Casey* in 1992, an abortion case, have been adopted by other courts in euthanasia and assisted suicide cases.

The US Supreme Court majority may be moving towards a distinction between the realms of 'private law' and 'public law'. Such private law would include sexual orientation, contraception, which used to be illegal in some American states, abortion—the great philosophical divide being on whether a foetus is to be regarded as a person—and assisted suicide. Some state courts have struck down assisted suicide laws, but these cases are yet to go on appeal to the Supreme Court.

One could not imagine a more central illustration of privacy than choosing the way we die, and this includes assisted suicide or 'assisted passage', as I have called it. In matters of life, death and sexuality, the realm of public law remains in the areas where there are identifiable victims—where there is no consent, or where children and the incompetent are, correctly, deemed to be incapable of consenting. I am increasingly drawn to this division between private and public law and I would prefer less rather than more state intervention by way of regulation.

At a time when economic rationalism is the dominant paradigm, with its obsession that all values have a dollar equivalent, the medical system will come under increasing pressure to speed up the turnaround time in hospital beds. In the Northern Territory, the fear of Aboriginal groups about how the law might be applied in practice is understandable, although, I hope, misplaced.

I felt distinctly uneasy about Bill Hayden's view that 'utilitarian judgments . . . cannot be totally ignored' as if loss of productive capacity was a prelude to elimination in a brave new world. I have always thought that the key element of civilisation is that we preserve at infinite cost elements of life and experience which cannot be justified on purely utilitarian grounds.

When this bill is carried, will the Howard government put more resources into palliative care? I hope so, but I could be permitted some scepticism. I have real difficulty with the idea of institutionalising euthanasia by setting up legislative protocols. A very highly qualified House of Lords Select Committee on Medical Ethics 1994, chaired by Professor Lord Walton of Detchant, a neurologist, was repelled by its observation of Netherlands practice. The committee concluded that there was a high risk of involuntary euthanasia being applied and where terminally ill patients are under a burden of guilt, as well as disease, and feel they must relieve and end the suffering of family and friends and the drain on resources. This guilt pressure may prove to be the thin end of the wedge.

The resource, or utilitarian arguments for euthanasia can also be applied to the issue of capital punishment and I repudiate both. I am well aware that passive euthanasia occurs already and will continue. On balance, I have more confidence in the role of medical practitioners operating under existing moral and ethical constraints within the profession, and with the provision for 'living wills' and the appointment of agents, than providing an institutionalised code, supervised by a state or territory.

The great British judge Patrick Devlin, in his 1985 book *Easing the Passing*, quotes his summing up in the famous trial in 1957 of Dr John Bodkin Adams:

If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life. This is not because there is a special defence for medical men but because no act is murder which does not cause death. We are not dealing here with philosophical or technical cause, but with the common sense cause. The cause of death is the illness or the injury, and the proper medical treatment that is administered and that has an incidental effect on determining the exact moment of death is not the cause of death in any sensible use of the term. But . . . no doctor, nor any man, no more in the case of the dying than the healthy, has the right deliberately to cut the thread of life.

With all due respect to the Legislative Assembly of the Northern Territory, I had not thought of it as providing moral leadership for the rest of the world, especially as there is a deep division between those members who are committed to the principle of euthanasia per se and those, such as the honourable member for the Northern Territory, who feel obligated to support the Rights of the Terminally Ill Act as an assertion of territorial sovereignty, a position shared by the legislators of the ACT and Norfolk Island. Cocos Island and Lord Howe Island are silent on either issue.

Oddly, the Northern Territory's remonstrance does not refer to section 122 of the Commonwealth constitution which gives this parliament a specific head of power over legislation passed in territorial legislatures. Until the Northern Territory becomes a state, or until the constitution is revised, there can be no moral, legal or political objection to the Commonwealth parliament exercising its functions.

Of 128 sections in the Commonwealth constitution, I estimate that there are 32 which are either irrelevant, anachronistic or purely transitional—without counting those sections relating to the exercise of monarchical power. Section 44 which led to the Lindsay by-election is one of them; section 122 is another.

I am singularly unimpressed by the argument that, because public opinion polls support euthanasia, the Northern Territory's law should be allowed to stand. If the Northern Territory decided to restore the death penalty, that too might generate rousing support as indicated in public opinion polls, but I would not hesitate to vote to overturn it if it was brought before this parliament under section 122. I am very conscious that, having been constrained by the clock, I delivered the early part of my speech with excessive speed, but it will read well.

Mr KELVIN THOMSON(10.49 a.m.) —In my view, the debate on euthanasia should not be being held here. This chamber was set up to hear the least controversial, least contentious pieces of legislation. What we have instead is one of the most controversial, most significant, pieces of legislation coming here. It is the only bill this year where we have had a conscience vote, the only bill where the outcome is not predetermined, the only bill where the debate is not set piece and could actually change votes. As Michael Gawenda said:

The debate on the Andrews Bill should not be shunted off to a Committee Room. Instead, it should be shown on national television so that all Australians can see and hear their political representatives wrestling with their consciences on this life-and-death question.

For me this is a tough call. There are strong arguments on both sides. I understand the force of Bob Dent's message. I understand the force of the argument that people should be allowed to determine what they do with their lives. I do not personally think that suicide or attempted suicide should be a criminal act, although I do find it hard to work up any sympathy for those who leave children behind or, even worse, take them with them. But, as they say in the law, hard cases make for bad law, and I will come to that later.

This is a fascinating debate because you find people in all political parties on different sides of the debate. If we examine why this is, I think it tells us quite a lot about our attitudes not only on ethical and moral questions but also on what we see the role of the states and the government as and what government is actually there to do and not to do. While most conservative politicians are quite comfortable with free market economics—although, interestingly, some commentators like Gerard Henderson and Robert Manne are awake to its shortcomings; I have even heard this bill's author speak against privatisation—quite a few are uncomfortable about libertarian social policy, support censorship and have problems with, for example, abortion, homosexuality and euthanasia .

That seems to be the basis for the different factions now springing up in the Liberal Party, such as the Lyons Forum, which has the view that government should intervene in these questions, and the John Stuart Mill Society, which has the view that it should not. I do not feel the need to address the views of either the Lyons Forum or the John Stuart Mill Society. I want to talk to those in my electorate, close to 300 of whom have written and some of whom came to see me about this issue. I want to explain to people like the member for Werriwa (Mr Latham), for whom I have immense admiration, good friends like Gary Jungworth and Eva Jones, who are Labor Party members, and one or two members on my staff, who think differently about this issue, why I believe that the progressive position is to support the Andrews bill and to oppose euthanasia .

I believe that the state plays an important role in making our community better. I am not attracted to anarchy. I do not like the economic law of the jungle which leads to beggars in the streets and the dogs and armed guards patrolling the estates of the rich

and powerful. That is how it is in some countries. I hope that the free market fetish of the Liberal Party does not bring it here.

I do not think anything goes. I do not have any problem about government getting in there and outlawing things which diminish us as a society. It ought to be understood that euthanasia is, first and foremost, a contract between a doctor and a patient. The Labor Party has never believed in unlimited freedom of contracts. We do not believe in freedom of contracts that exploit workers, particularly children. We do not believe in freedom of contracts between heroin dealers and buyers. We do not believe in freedom of contracts between gun dealers and buyers. So the question is not about the freedom of contracts. The question is: what is the social impact of euthanasia ?

To answer this question, we first need to clear up some misunderstandings. The European Association for Palliative Care points out that there is a lot of misunderstanding of the difference between dying with dignity and euthanasia . `Dying with dignity' has become a slogan of opposition to useless and degrading prolongation of life when a patient's organs, or those still minimally functional, can no longer support or permit the exercise of self-fulfilling personal control over life's events. The association says:

A time comes in the course of a disease when it is wrong to continue to prolong life aggressively and when it is right to honour informed patient's refusal of treatments that only prolong suffering.

I agree with them. I was proud to be associated with the Victorian Labor government's dying with dignity legislation. I think that the Northern Territory government should now look to this as a model for its own situation. The association also says that the legalisation of euthanasia , the active intervention which kills a patient, is unnecessary and dangerous. With the development of modern methods of palliative medicine and palliative care they say that the civilised solution rests with a rapid implementation of programs of palliative medicine and palliative care not with the resignation to pressure for euthanasia .

We have all received a lot of correspondence on this issue, but the letter which had more impact on my position than any other came from Father John Brosnan, who has been the Pentridge Prison chaplain for 30 years and is a famous opponent of capital punishment, which is a position I share. Father Brosnan said:

There are important parallels between the state sanctioned killing which we call capital punishment and the state sanctioned killing which is now being called euthanasia .

First, he said:

If someone's life appears to be worthless, allowing that problem to be addressed by killing the person allows society to avoid having to take the harder and more expensive road of actually providing resources for a more supportive, interesting and caring way of life.

Secondly, he said:

Many of the opponents of capital punishment are not so much opposed to capital punishment in principle, but were most concerned at the possibility—indeed the certainty—that innocent people would be killed.

That is my position also. As Father Brosnan pointed out, mistakes are inevitable. He said:

With capital punishment and euthanasia every mistake is permanent. There is no turning back.

In his letter he also said:

The fanfare which accompanied the first lethal injection in the Northern Territory will not be around for those who will be the victims of pressure or abuse.

Of course, the evidence from the Netherlands, where euthanasia has been allowed, is quite disturbing. I have got to say that the reports that 52 per cent of all euthanasia there is non-voluntary is so alarming that I find it difficult to believe. Irrespective of whether that figure is right or wrong, the British House of Lords concluded after an analysis of the Netherlands situation that it had been impossible to set safe limits to euthanasia.

I have also been influenced by the writing of Robert Manne, who expressed his concern. He said:

Family pressure will be applied which will suggest to someone who is terminally ill that no good can come from their purposeless clinging to life, that they have become a mere burden, and that they owe it to their suffering family to request an officially sanctioned death.

I certainly do not want my parents or anyone else to have to ask themselves that kind of question. I regard every breath of air I get on this earth as a privilege. There will not be much dignity about the way I go: I will fight for every last gasp. I will be dragged out kicking and screaming. I think that is the way most of us are made. I do not think that we should become disposable or be asked to consider at what point we are a burden and should be giving it away. Robert Manne also said:

Nor is it merely from family pressure that abuse may occur. We live, notoriously, at a time where the population is ageing, where our health systems are under great pressure, and where an economic rationalist view of the world is emerging triumphant in one sphere after another.

In such circumstances, once the cultural bridge leading to officially sanctioned killing has been crossed, is there anyone who can seriously doubt that, in the long term, social pressures will build for cutting costs by rationalising the process of death in the case of the terminally ill?

There you have it. Euthanasia is the economic rationalists' solution; it is the efficient solution. While we are productive, well and good. But, when we start to break down, stick us on the scrap heap. That is why I will be voting for the Euthanasia Laws Bill 1996 .

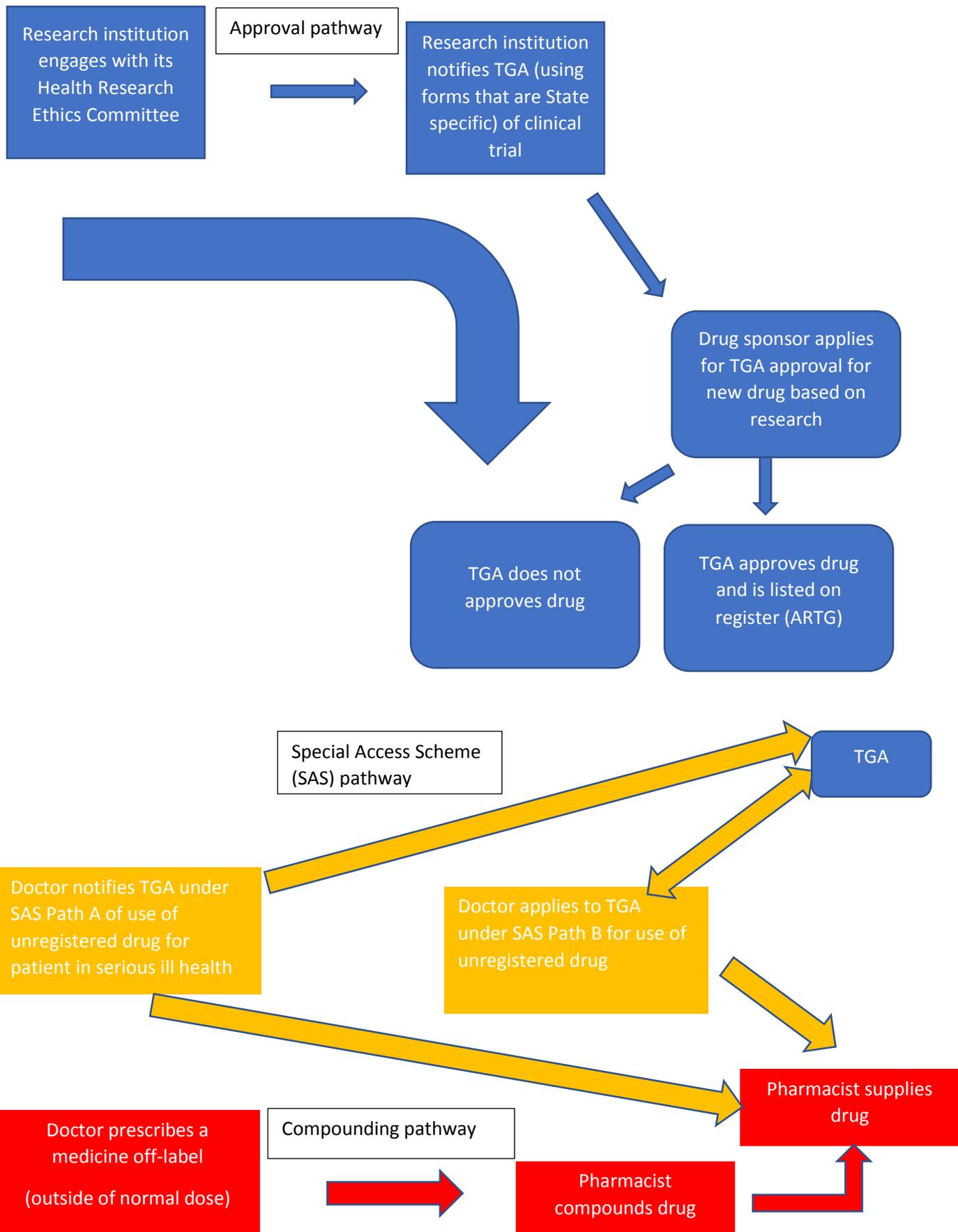
I will respond to a couple of the arguments raised against the Andrews bill . Some people say this is an issue about states' rights. Jeff Kennett says that the Northern Territory is a duly constituted democracy. I have got to say that in Victoria he has sacked councillors and installed commissioners to run cities with a larger population than the Northern Territory, so I think that is really a joke. The Commonwealth has often

intervened—without regard to states' rights—to set national standards, to protect world heritage, to combat racial discrimination, and to provide for sexual privacy. It should again here. Let us not in future have any cant or hypocrisy from those Liberal and National Party members who vote for this bill about states' rights.

Some also say that the legislation does not reflect the reality of what happens in hospitals and that it subjects doctors to criminal liability for acts of kindness they commit every day. If that were the case, you would expect the AMA to be opposed to the Andrews bill . In fact, the AMA has indicated that it believes that doctors should not be involved in acts of euthanasia. (*Time expired*)

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Appendix 2: TGA approval and exemption processes



Therapeutic Goods Act 1989

The TG Act regulates the availability of therapeutic goods in Australia, and is administered by the Therapeutic Goods Administration (TGA).

A “*therapeutic good*” is relevantly defined under the TG Act as a good that is represented, or likely to be taken, to be for therapeutic use.

In turn, the definition of “*therapeutic use*” under the TG Act relevantly includes use in or in connection with:

- (a) preventing, diagnosing, curing or alleviating a disease, ailment, defect or injury in persons; or*
- (b) influencing, inhibiting or modifying a physiological process in persons ...*

Use of a substance for the purpose of ending a person’s life – in the circumstances set out in the Bill – is likely to be considered therapeutic use, as the above definition tends to be construed broadly. For example, use in this context might be characterised as use in or in connection with:

- (a) the alleviation of pain and suffering; or
- (b) the influencing, inhibition or modification of physiological processes (*i.e.*, modifying or inhibiting a person’s physiological function for the purpose of ending that person’s life).

Regulation of therapeutic goods

Under Part 3-2 of the TG Act, therapeutic goods which are used in the treatment of serious medical conditions (or, in the case of medicines used for the purpose of voluntary assisted dying, used in the context of serious medical conditions) require registration in the Australian Register of Therapeutic Goods (ARTG) prior to supply, unless they are exempt goods. The TGA stringently assesses an application for registration of a medicine, having regard to its quality, safety and efficacy for the purposes for which it is to be used.

Therapeutic goods are registered at the product level, rather than at the level of individual active ingredients or substances (for example, two medicines containing the same active ingredient must be separately registered). No medicines containing either pentobarbital or secobarbital are currently registered in the ARTG. However, there are registered products which each contain one of the constituents of the combination product (*i.e.* there are products containing phenobarbital, products containing chloral hydrate and products containing morphine sulphate registered in the ARTG).

These products are thus able to be commercially supplied by their sponsors for the indications for which they are registered. However, a doctor is able to exercise his or her clinical judgement to prescribe a product for an indication which is not registered (*i.e.* for off-label use) and a pharmacist is able to dispense that product following receipt of a valid prescription.

In addition to the use of registered products off-label, there are exemption schemes under the TG Act and *Therapeutic Goods Regulations 1990* (TG Regulations) which permit the supply of unapproved therapeutic goods in certain circumstances. The schemes which are most relevant in the context of voluntary assisted dying are:

- (a) the compounding exemption in Item 6 of Schedule 5 to the *Therapeutic Goods Regulations 1990* (Cth) (TG Regs); and
- (b) the Special Access Scheme (SAS).

Compounding exemption

Schedule 5 of the TG Regulations lists certain categories of medicines which, pursuant to regulation 12, are exempt from the registration requirements in Part 3-2 of the TG Act. Notably, Item 6 of Schedule 5 provides “*medicines that are dispensed, or extemporaneously compounded, for a particular person for therapeutic application to that person*” are exempt from the requirements of Part 3-2 of the TG Act.

Pharmacists who extemporaneously compound medicines in reliance on the above exemption are also exempt from the manufacturing requirements in Part 3-3 of the TG Act by virtue of regulation 18 and Item 2 of Schedule 8 of the TG Regulations, provided that the medicines are compounded at and supplied from:

- (a) a pharmacy open to the public;
- (b) a dispensary operated by a Friendly Society; or
- (c) the premises of a private hospital.

Special Access Scheme – Category A

Regulation 12A of the TG Regulations provides that all medicines (except for substances in Schedule 9 to the Poisons Standard) are exempt from registration requirements when provided to a “*Category A patient*”, who has given informed consent, on the prescription of a medical practitioner issued in accordance with good medical practice. This exemption is colloquially known as Category A of the SAS.

Category A patients are defined as patients who are “*seriously ill with a condition from which death is reasonably likely to occur within a matter of months, or from which premature death is reasonably likely to occur in the absence of early treatment*”.

Special Access Scheme – Category B

Under subsection 19(1) of the TG Act, the Secretary of the Commonwealth Department of Health may grant approval to a person for the importation or supply of unregistered goods for use in the treatment of a specified person. This access pathway is colloquially known as Category B of the SAS.

Access to medicines under Category B of the SAS requires prior approval by the TGA, and the TGA usually requires applicants (medical practitioners seeking approval for their patients) to provide evidence of the patient’s condition, as well as of the quality, safety and efficacy of the medicine for

the purpose for which it is to be prescribed (although to a significantly lower standard than would apply in an application for registration). Generally, applications under Category B of the SAS will not be approved unless the TGA is satisfied that there is proper clinical justification for the use of an unregistered product over any registered alternatives.

Notably, more than the other avenues discussed above, Category B of the SAS involves administrative overhead and delays arising from the TGA's assessment of the application.

Customs (Prohibited Imports) Regulations 1956

Regulation 5 of the *Customs (Prohibited Imports) Regulations 1956* (Cth) (CPI Regulations) provides that the importation into Australia of drugs is prohibited unless the importation is in accordance with a licence and permit issued by the Office of Drug Control (ODC) to the importer. For the purpose of regulation 5, "drug" includes the substances listed in Schedule 4 to the CPI Regulations, as well as isomers, derivatives, precursors, and mixtures of those substances.

Generally speaking, under regulation 5, customs import licences and permits must be granted to any applicant who meets the fit and proper person test and who has appropriate security and transportation arrangements in place – that is to say, the nature and purpose of the goods to be imported is not enquired into in any detail (save for the applicant's legal authority to possess and supply those products).

Appendix 3: Submission to the Scrutiny of Acts and Regulations Committee of the Victorian Parliament

Ms Lizzie Blandthorn MP

Chair

Scrutiny of Acts and Regulations Committee

Parliament of Victoria Spring Street

East Melbourne VIC 3002

By email: [REDACTED]

12 October 2017

Dear Ms Blandthorn,

The Voluntary Assisted Dying Bill 2017

As provided for in section 17(a)(viii) of the Parliamentary Committees Act 2003, the Scrutiny of Acts and Regulations Committee can consider and report on any Bill introduced into the Assembly which is inconsistent with:

“The Charter of Human Rights and Responsibilities (hereafter the Charter) is outlined in Charter of Human Rights and Responsibilities Act 2006.”

I tender this submission to the Committee as an independent academic at the Australian Centre for Christianity and Culture, Charles Sturt University.

Summary of the submission

It is argued that the questions of incompatibility exist between the Voluntary Assisted Dying Bill 2017 (hereafter the VAD) and 9 and 10(c) of the Charter. The Minister’s Statement of compliance with the Charter in relation to s13 and s21(1) is also contested.

Section 9 of the Charter states that:

‘Every person has the right to life and has the right not to be arbitrarily deprived of life’

It is claimed that:

The purpose of the VAD is to vacate the right enjoyed under s9 of the Charter for persons deemed to eligibility criteria of the VAD;

That there are grounds to assert that the VAD would operate in such a manner that eligible persons would be ‘arbitrarily deprived of life’;

Specifically, the VAD breaches s9 of the Charter for persons who are vulnerable to risks of misadministration of safeguard measures outlined in the VAD in the areas of mental illness, degenerative disability and elder abuse on the basis that the safeguards are insufficient to meet the requirements of the Charter based on international experience and scientific studies.

There are also grounds to assert incompatibility of the VAD with the Charter in relation to section 10(c) of the Charter that states that a person must not be 'subjected to medical ... treatment without his or her full, free and informed consent'. It is argued that the test of informed consent in the VAD is deficient on the basis of international experience and scientific studies.

The Minister's statement of compliance with Charter asserts that s13 and s21(1) of the Charter require that persons who meet eligibility requirements under the VAD have a right to privacy which should allow them to make a free choice to end their life according to their preferences (s13) and that the right to personal liberty and security under s21(1) also encompasses the principle of autonomy which should similarly allow them to make this free choice. This is contested on the basis that this expansive interpretation of the Charter is speculative and not in the public interest. The Charter should be interpreted strictly in its plain reading.

It is argued that the VAD should not proceed for consideration of the Parliament until fundamental human rights concerns listed above are addressed or alternatively should be addressed in the Parliament's consideration of the VAD.

A handwritten signature in blue ink, appearing to read 'B Long', with a horizontal line extending to the right.

Dr Brendan Long

Senior Research Fellow

Australian Centre for Christianity and Culture

Charles Sturt University

October 2017

UnSafeguards

Submission to the Scrutiny of Acts and
Regulations Committee of the Victorian
Parliament in relation to the Voluntary Assisted
Dying Bill

Dr Brendan Long,

Senior Research Fellow,

Australian Centre for Christianity and Culture,

Charles Sturt University

October 2017

Functions of the Scrutiny of Acts and Regulations Committee in relation to this submission

The functions of the Scrutiny of Acts and Regulations Committee (hereafter the SARC) are set out in section 17 of the *Parliamentary Committees Act 2003*. This Act under s17(a) states that it is the function of the SARC:

“to consider any Bill introduced into the Council or the Assembly and to report to the Parliament as to whether the Bill directly or indirectly –

- (i) trespasses unduly upon rights or freedoms;
- (ii) makes rights, freedoms or obligations dependent upon insufficiently defined administrative powers;
- (iii) makes rights, freedoms or obligations dependent upon non-reviewable administrative decisions;
- (iv) unduly requires or authorises acts or practices that may have an adverse effect on personal privacy within the meaning of the *Privacy and Data Protection Act 2014*;
- (v) unduly requires or authorises acts or practices that may have an adverse effect on privacy of health information within the meaning of the *Health Records Act 2000*;
- (vi) inappropriately delegates legislative power;
- (vii) insufficiently subjects the exercise of legislative power to parliamentary scrutiny;
- (viii) is incompatible with the human rights set out in the *Charter of Human Rights and Responsibilities ...*”

The *Charter of Human Rights and Responsibilities* (hereafter the Charter) is outlined in Charter of Human Rights and Responsibilities Act 2006. This submission makes particular reference to s9 and s10(c) of this act as outlined below:

9. Right to life

Every person has the right to life and has the right not to be arbitrarily deprived of life.

10. Protection from torture and cruel, inhuman or degrading treatment

A person must not be—

- (a) subjected to torture; or
- (b) treated or punished in a cruel, inhuman or degrading way; or
- (c) subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent.

The submission also responds to the Minister statement of compliance with the Charter in relation to sections 13 and 21(1) of the Charter.

13. Privacy and reputation

A person has the right—

- (a) not to have his or her privacy, family, home or correspondence unlawfully or arbitrarily interfered with; and
- (b) not to have his or her reputation unlawfully attacked.

21. Right to liberty and security of person

(1) Every person has the right to liberty and security.

Arguments presented in relation to the impact of Voluntary Assisted Dying Bill 2017 on The *Charter of Human Rights and Responsibilities* as outlined in Charter of Human Rights and Responsibilities Act 2006.

Summary

It is argued that the questions of incompatibility exist between the Voluntary Assisted Dying Bill 2017 (hereafter the VAD) and 9 and 10(c) of the Charter. The Minister's Statement of compliance with the Charter in relation to s13 and s21(1) is also contested.

Section 9 of the Charter states that:

'Every person has the right to life and has the right not to be arbitrarily deprived of life'

It is claimed that:

1. The purpose of the VAD is to vacate the right enjoyed under s9 of the Charter for persons deemed to eligibility criteria of the VAD;
2. That there are grounds to assert that the VAD would operate in such a manner that eligible persons would be 'arbitrarily deprived of life';
3. Specifically, the VAD breaches s9 of the Charter for persons who are vulnerable to risks of misadministration of safeguard measures outlined in the VAD in the areas of mental illness, degenerative disability and elder abuse on the basis that the safeguards are insufficient to meet the requirements of the Charter based on international experience and scientific studies.

There are also grounds to assert incompatibility of the VAD with the Charter in relation to section 10(c) of the Charter that states that a person must not be 'subjected to medical ... treatment without his or her full, free and informed consent'. It is argued that the test of informed consent in the VAD is deficient on the basis of international experience and scientific studies.

The Minister's statement of compliance with Charter asserts that s13 and s21(1) of the Charter require that persons who meet eligibility requirements under the VAD have a right to privacy which should allow them to make a free choice to end their life according to their preferences (s13) and that the right to personal liberty and security under s21(1) also encompasses the principle of autonomy which should similarly allow them to make this free choice. This is contested on the basis that this expansive interpretation of the Charter is speculative and not in the public interest. The Charter should be interpreted strictly in its plain reading.

It is argued that the VAD should not proceed for consideration of the Parliament until fundamental human rights concerns listed above are addressed or alternatively should be addressed in the Parliament's consideration of the VAD.

Response to the Minister's Statement of Compliance with the Charter

- **Judgements of Parliaments in the UK, Scotland and New Zealand.**

The Minister has stated in her Statement of Compliance with the Charter that the right to life as defended in s9 of the Charter is protected due to the prevalence of adequate safeguards in the Bill. This is contested in relation to the following areas of concern.

This type of legislation was rejected in the UK, Scotland and New Zealand due to concerns around the efficacy of safeguards to guarantee the intent of the Parliament. Such safeguards were not judged to sufficiently mitigate against the risk of unintended consequences associated with reliance on such measures for people with mental illness and persons with degenerative disability against the intent of the Parliament and the risk of elder abuse including inheritance impatience.

- The House of Commons in the UK rejected a euthanasia bill in September 2015 by a vote of 330 against to 118 in favour (see <https://www.ft.com/content/f791f80c-58a0-11e5-9846-de406ccb37f2>)
- In Scotland in May 2015 Holyrood rejected a euthanasia bill by a vote of 82 to 36 (see <http://www.bbc.com/news/uk-scotland-scotland-politics-32887408>)
- In New Zealand euthanasia bills were rejected in 1995 and 2003 with David Seymour's new Private Member's Bill not gaining a Second Reading in the life of the current New Zealand Parliament.

While many reasons were offered in opposition to these bills the lack of confidence in the safeguards for vulnerable persons was a critical consideration that led to their defeat. On this issue the views of medical professional were valued highly.

In the UK in a 2015 survey of 1,000 doctors only one in seven doctors indicated that would be prepared to consider a request for assisted dying. (<http://www.telegraph.co.uk/news/uknews/assisted-dying/11857701/Assisted-suicide-or-assisted-dying-has-no-place-in-our-healthcare-system-doctors-dont-want-it.html>).

While no survey of doctors is available in Victoria there is little reason to expect a widely different conclusion. The concerns held by politicians in the UK, Scotland and New Zealand have not been addressed in the current Bill in Victoria.

The Bill does not appear to provide greater safeguards than the bills which were rejected in the UK, Scotland and New Zealand.

- **Concerns for people with mental illness**

There is a strong risk that dying people with mental illness will activate the assisted suicide process as a result of their mental infirmity rather than a decision relating solely to their primary medical condition. The evidence from the overseas jurisdiction is that demand for access to PAS for those with mental illness has increased dramatically.

As stated in the End of Life Choices Inquiry Report (p.414)

“The proportion of euthanasia deaths involving neuropsychiatric disorders has increased sharply in Belgium over the past decade, from 1.2% of cases in 2004/05 to 2.8% in 2010/11 (58 cases) and 3.7% of cases in 2013/14 (67 cases).”

Table 4: Number of cases of euthanasia for neuropsychiatric conditions in Belgium⁷⁹

Source	Years covered by report	Number of cases of neuropsychiatric conditions
Second report	2004 and 2005	9 ⁸⁰
Third report	2006 and 2007	13 ⁸¹
Fourth report	2008 and 2009	62
Fifth report	2010 and 2011	105

And on page 415 of the same report.

“In the Netherlands, recent data from reports of the Regional Euthanasia Review Committees points to a growing number of cases of euthanasia in cases of mental illness and dementia. Table 5 contains the number of cases of mental illness and dementia over the period 2012-2015.”

“There is no reason to think that growth rates in either category will taper off given what we observe in growth rates in the overall number of cases both in the Netherlands and other major jurisdictions.”

Table 5: Number of cases of euthanasia for mental illness or dementia in Netherlands⁸²

Year	Mental Illness (Cases)	Dementia (Cases)
2012	14	42
2013	42	97
2014	41	81
2015	56	109
Growth rate: (CAGR 2012-2015)	59%	37%

Part of this growth in the mental illness cohort is due to difficulties in assessing mental capacity for patients in end of life situations. Research from respected Australian medical professionals in a paper to Palliative and Supportive Care (2015), 13, 1399–1409. Cambridge University Press, 2015 1478-9515/15 highlights the problem.

"Even when psychiatrists are involved, their capacity to confidently assess the existence and role of mental illness in EAS has been questioned (see: <http://jme.bmj.com/content/37/4/205.short>). Assessing mental capacity, a common requirement for jurisdictions where euthanasia and physician-assisted suicide are legalised, can also be problematic for doctors (see <https://bmcomedethics.biomedcentral.com/articles/10.1186/1472-6939-15-32>)."

Mental illness is notoriously difficult to diagnose. There are two problems. The first is that it is a hidden disease. Without specialist clinical training, or a developed personal case history for the client, it is

not easy for a GP to be able to distinguish mental illness from normal mood cycles or occasional aberrant behaviour. A GP faces significant challenges in distinguishing mental illness from a certain level of anxiety or depression that could be expected to be experienced by any patient facing a terminal illness. There is therefore a significant risk that a GP, when facing a referral for assisted suicide or euthanasia, may simply fail to identify latent mental illness and therefore fail to call for a psychological assessment of a dying patient who in fact seeks suicide as result of their mental illness.

Perversely, the increased prevalence of mental illness in the community may also exacerbate the difficulties with diagnosis. Data from the Australian Institute of Health and Welfare (AIHW) reveals a rapid rise in the mental illness cohort in the overall population in recent years. In *Mental Health Services in Brief* (2016, p.6) AIHW estimates that

“the incidence of mental health related encounters has increased by a rate of 4.4% per year between 2010-11 and 2014-15. “

This is a dramatic annual growth rate. When it becomes a daily reality in a GP clinic that clients may present with some signs of risks of mental illness, the diagnosis of psychological pathology, as distinct from an episodic mild depression, which is a natural response to diagnosis of a terminal disease, becomes a fine judgement. Many GPs will not be clinically trained to evaluate this situation. One way of determining if the mood change is a normal reaction or a pathological one is observing the patient over time, but time is not a resource available to dying person and their GP. Diagnosis of mental illness is also a function of the depth of trust in the doctor-patient relationship. It is often easy to hide depression or anxiety when it is mild or moderate. This exacerbates the risk that a GP might fail to trigger a psychiatric assessment for a terminal patient with mental illness.

When we consider the international evidence, there are increased grounds for caution. As stated above, the evidence available from Belgium and Holland, which has allowed assisted suicide and euthanasia for many years, shows a concerning rapid rise in people with mental illness seeking access to euthanasia. In Belgium the proportion of deaths from euthanasia that involved psychiatric disorders has risen from 1.2% of cases in 2004/5 to 3.7% of cases in 2013/14: triple the reported incidence rate over the decade (with many cases of course not being diagnosed or reported). In the Netherlands data is available for both dementia and mental illness.³ From 2012-2015 euthanasia cases with mental illness have risen from 14 to 56 with an average annual growth rate of 59%. Reported cases with dementia have risen from 42 in 2012 to 109 in 2015: an average annual growth rates of 37. In addition, the Belgium and Netherlands experience is that safeguards to exclude candidates for euthanasia with mental illness and depression, through psychiatric evaluation, have proved to be weak and ineffective. Few candidates were referred and of those referred it was difficult to be objectively clear whether someone had mental illness or clinical depression. The Bill is substantially based on the model applied in Oregon State in the US. The safeguards for the mental illness cohort reflect the safeguards in the Oregon model. However, in this model only from 1998 to 2012, on average only 6.2% of patients who died under the Act in Oregon had been referred for counselling to check for “impaired judgment.” In 2013-2016 this declined to less than 4%. Of 108 patients who died under the Act in 2007 and 2009, none was referred for psychological evaluation.⁴ This is a very low level of review.

In summation the safeguards for applicants for mental illness under the Bill appear to be no stronger than those in the European or US jurisdictions. In these jurisdictions they are clearly weak. In relation to the cohort of applicants with mental illness the Minister’s statement of compliance with the Charter seems in conflict with research and available data on the application of PAS regimes overseas. Furthermore, s10(c) of the Charter that states that a person must not be ‘subjected to medical ... treatment without his or her full, free and informed consent’. The evidence stated from medical experts and the low levels of psychological review in overseas jurisdictions highlights the difficulties

³ Dutch Regional Euthanasia Review Committee: Annual Reports various years.

⁴ <http://www.usccb.org/issues-and-action/human-life-and-dignity/assisted-suicide/to-live-each-day/upload/OR-and-WA-Safeguards-FACTSHEET.pdf>, p.2.

in assessing informed consent for the mental health cohort of applicants under the VAD. Compliance with s10(c) of the Charter is therefore open to question.

- **Concerns for persons of linguistically diverse and indigenous background.**

People in these cohort can find it very difficult to understand the intricacies of a complex legal framework that would apply in the proposed assisted suicide regime. There is a real concern that language barriers or poor literacy could lead to a frustration of informed consent under the proposed regime. S10 of the Charter emphasises the need for informed consent. For the sake of prudence, s10 should be strictly interpreted. The Minister has not fully informed the Parliament as to how informed consent will be secured for persons of a linguistically diverse background or persons with limited literacy. S13 and s21(1) of the Charter have been invoked by the Minister to support the Bill. For a free choice to be effectively made language and cultural barriers need to be adequately dealt with. The Minister in her Statement of Compatibility with the Charter has not addressed this issue and makes no reference faced by these important cohorts of potential applicants under the VAD.

- **Concerns for people with disability**

Persons in this cohort facing a terminal illness of significant duration face extraordinary struggles which few of us can even imagine. There is a real risk that the assisted suicide process could exacerbate a co-morbid condition of latent depression or mental illness, with risks that persons with disability with ultimately terminal conditions might activate the assisted suicide process in an episodic moment of depression or anxiety. The other argument, for those with disability is the fear that doctors may consider their life not worth living because of their disability and offer them PAS instead of sound medical treatment.

There is much uncertainty about whether with people with degenerative disability can or should access PAS. In the Bill disability alone does not provide access to the measures proposed. The condition of persons with degenerative disability is usually terminal but it is very difficult to predict their longevity. The boundary between degenerative disability and the cohort of persons eligible for PAS under the Bill is unclear. On one hand, the Government offers all reasonable and necessary support to these people under the NDIS and on the other it offers them a lethal drug – two opposite policy approaches. This is an area in which the Bill lacks precision, causes uncertainty and policy confusion.

A pivotal issue in Tasmania and South Australia that led to the failure of proposed legislation was the problem of dealing with the issue of disability. There was uncertainty as to whether disability should be an eligible ground for access to assisted suicide.

In South Australia, the bill introduced by The Hon. Duncan McFetridge MLA included a clause that said that access to the proposed process could not be made on the basis of disability alone. This was seen as being ineffective given that many people with disabilities have co-morbidities that flow from degenerative conditions. The failure to properly identify the scope of the Bill in relation to persons with degenerative disability was a critical element of the failure to secure passage.

The same problem occurred in Tasmania in 2013. There the Bill included the clause:

11 (2) For the avoidance of doubt, a person does not have an eligible medical condition solely because of the age of the person, any disability of the person or any psychological illness of the person.

The Tasmanian Law society indicated inconsistency with these provisions and definitions of disability under Tasmanian law.

This issue is not resolved in the VAD. There is no certainty as to the boundary conditions of access to the Victorian scheme for persons with degenerative disability where the condition is ultimately terminal. This is a critical issue which has been sidestepped. It needs to be resolved for the sake of those with these conditions. Failure to adequately address this issue presents another basis of concern in relation to the Minister's Statement of Compliance with the Charter. In relation to the requirements of s13 and s21(1) of the Charter the Minister argues that the Charter requires that the free decision of a dying person in relation to their end of life choice should be protected. However, the uncertainty in relation to the scope of the Bill for persons with degenerative disability which is terminal deprives these persons of the capacity to make such a decision. The capacity of persons with degenerative disability to access the VAD needs to be clarified before any adequate assessment can be made of compliance with the Charter for persons in this health cohort. Until, this clarification is made a significant question lies in relation to the compliance with the Charter for this critical cohort.

- **Concerns in relation to elder abuse**

The report by the Australian Law Reform Commission (ALRC) in relation to elder abuse used data from the World Health Organisation suggesting that elder abuse can occur in 2 to 14 percent of relevant cases. (Australian Law Reform Commission, Elder Abuse –Final Report p.17, referring to WHO publication The Toronto Declaration on the Global Prevention of Elder Abuse.) <https://www.alrc.gov.au/publications/elder-abuse-report>.

Elder abuse can take many forms through subtle emotional pressure, to direct coercion. In the analysis of public policy decisions that have financial implications for individuals, there is a need to examine the incentive structures that are in place. In the case of the situation of a vulnerable person experiencing a terminal illness, the incentives of the suffering person and the beneficiaries of their estate are in direct conflict. The beneficiaries, usually family members, have a strong financial incentive to expedite release of assets that might flow from a will. The interests of the suffering persons are protected when they are relieved of any emotional pressure, or sense of guilt for still being alive, or of holding up the financial benefit they will provide when they die to the people they love. It is a complex emotional situation, and one that is very difficult to manage through a regulatory regime.

There is an important issue of gaining consent from older Australians.

The prevalence of cognitive impairment also increases with age. From age 65, the prevalence of dementia doubles every 5 or 6 years. 30% of people aged over 85 have dementia ...

This data seems to indicate that high levels of safeguards are required to prevent elder abuse. The Bill relies upon criminal sanctions to prevent coercion to mitigate against the risk of elder abuse. It is argued that full compliance with the Charter requires more than this. Where such sanctions are applied overseas they are rarely activated and the burden of proof is high. It is argued that such sanctions will be unlikely to be legally effective. The Bill would more fully comply with the Charter if more pro-active intervention mechanisms were facilitated where the risk of elder abuse was deemed high, possibly involving mandatory reporting by social workers in hospital environments in suspected cases of elder abuse.

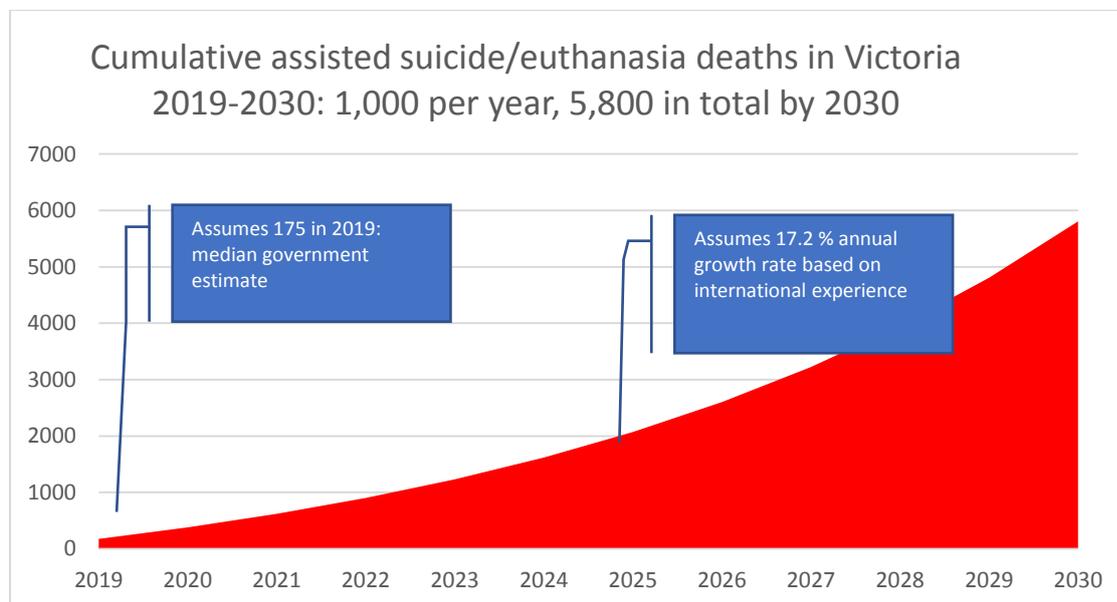
- **Statistical evidence in relation to the efficacy of safeguards in relevant overseas jurisdictions.**

Data in relation to the growth rates of deaths under PAS procedures in relevant international regimes reveals very concerning trends. Research by this author has indicated that these growth rates on average are approximately 17% per year on average.

Country	Initial PAS cohort	Latest data	growth rates
Belgium	235 (2003)	2012 (2015)	19.6
The Netherlands	2331 (2008)	5516 (2015)	13.1
Switzerland	50 (1998)	836 (2014)	19.2
Oregon	16 (1998)	132 (2015)	13.2
Washington State	64 (2009)	170 (2014)	21.6

Source: http://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf, pages 397-398.

Applying these growth rates to the Victorian initial estimate of 150-200 persons per year in 2030 1,000 Victorians would be expected to end their lives under the regime.



Source: Dr Brendan Long, Australian Centre for Christianity and Culture, Charles Sturt University, 2017.

Looking at the statistics alone, it is difficult to avoid the conclusion that there has been significant scope creep in PAS regimes overseas. The originally intended restrictions on access to PAS through safeguards mechanisms have not proved to be effective. Average growth rates of 17% per annum cannot be explained by the increasing of the age of the population or by administrative amendments made to access the regimes. The data simply evinces the strong conclusion that in the international experience the safeguards have not been proved to be effective. This data tends to undermine the claim of the Minister in her compliance statement that the Bill is consistent with the Charter under s9 due to the mandating of safeguards. The safeguards in the Bill are not radically different to those that have been ineffectively applied in relevant overseas jurisdictions.

- **Concerns of medical professionals**

Medical professionals engaged in end of life medical treatment, palliative care doctors and nurses, generally are very uncomfortable with this proposed medical procedure.

The AMA has stated its position in November 2016:

“The AMA believes that doctors should not be involved in interventions that have as their primary intention the ending of a person’s life. This does not include the discontinuation of treatments that are of no medical benefit to a dying patient.”

<https://ama.com.au/system/tdf/documents/AMA%20Position%20Statement%20on%20Euthanasia%20and%20Physician%20Assisted%20Suicide%202016.pdf?file=1&type=node&id=45402>

There is also some concerning international experience in this area.

- In Canada's Ontario province, in the eight months between when assisted suicide was legalised (June 2016) and February 2017, 24 doctors had their names permanently removed from a voluntary referral list of physicians willing to help people die. Another 30 put their names on temporary hold. This was at least partly due to psychological distress, the weight of the act of helping someone deciding to end their life and legal ambiguities involved.
- In a telephone survey of randomly selected United States oncologists who reported participating in euthanasia or assisted suicide, 24% regretted participating, and 16% of the physicians reported that the emotional burden of participating adversely affected their medical practice. (E. J. Emanuel et al., The Practice of Euthanasia and Physician-Assisted Suicide in the United States: Adherence to Proposed Safeguards and Effects on Physicians, 280 JAMA 507, 507 (1998).)
- The first cases of legal PAS in Oregon occurred in 1998. In 2000, 35 Oregon physicians were interviewed regarding their responses to PAS requests. Mixed feelings were expressed by the physicians. The authors noted: "Participation in assisted suicide required a large investment of time and had a strong emotional impact . . . Even when they felt they had made appropriate choices, many physicians expressed uncertainty about how they would respond to requests in the future”.

Medical professionals in Victoria are the strongest practical servants of the Charter in relation to medical issues. That medical professionals do not support the VAD seems to speak against the claims of the Minister that VAD is consistent with the Charter in relation to s9,10,13, and 21(1).

- The shortfall in funding for palliative care in Victoria

The Parliament, through a rigorous Legislative Council Inquiry process, has identified gaps in palliative care. This was the prime focus of the Legislative Council inquiry report. Of its 49 Recommendations, 29 Related to expansion of service delivery in palliative care, 19 to issues related to the process of Advance Care Planning directives to better manage end of life choices for the patient, and only one recommendation was made in relation to physician assisted suicide.

Palliative Care Victoria (PVC) conducted a recent survey which “found over 92% of Victorians support more government funding for palliative care.”

PVC has also stated that there is a \$65m a year funding shortfall needed to deal with unmet need and increasing demand for palliative care services. <http://www.pallcarevic.asn.au/2017/07/funding-increase-needed-improve-access-palliative-care/>

It can be argued that the Charter implicitly embodies a right to fully funded palliative care service delivery. The Minister has argued that the Charter embodies a right to personal autonomy which is to be taken as being included in the rights provided for in the Charter in s21(1). Although such an expansive interpretation of s21(1) is contested, were it to be accepted, it would seem also to involve a right to adequate service delivery in palliative care. Only if such services are adequately funded can the rights of personal autonomy in decision making in end of life choices be really protected. Any argument that the VAD protects the rights of individuals to a free choice on end of life issues seems moot until the prevailing choice – that of accessing adequate palliative care services – is guaranteed through adequate funding. Until the funding shortfall for palliative care services is addressed it can be argued that the Minister’s statement of compliance for the Bill in relation to the Charter is deficient. It is argued that any Bill in relation to end of life choices that is not accompanied by a budget decision to fully fund palliative care services required by the Charter fails to meet the standards set by the Charter.

- **Questions in relation to the interpretation of s13 and s21(1)**

There are also grounds to assert incompatibility of the VAD with the Charter in relation to s13 and s21(1) of the Charter. S13 relates to the question of privacy and reputation. On a plain reading, the provision is intended to protect private information and reputation. However, the Minister in her compliance statement indicates that:

The fundamental values which the right to privacy protects include physical and psychological integrity, individual and social identity, and the autonomy and inherent dignity of the person. In my view, the bill promotes the right to privacy by allowing Victorians who are suffering at the end of their life, in very limited circumstances, to choose to end their life according to their own preferences.

The mischief s13 seeks to protect is the abuse or theft of personal information. To interpret this section of the Charter as permitting a person to choose a specific medical procedure (PAS) over another (palliative care) is a courageously expansive reading of the scope of s13. On the surface such an interpretation of s13 is not sustainable.

S21(1) of the Charter states ‘Every person has the right to liberty and security’. The Minister in her Statement of Compliance with the Charter states “The right to liberty and security of the person also encompasses the principle of autonomy”. However, it is clear that s21 relates to freedom from unjust or unlawful detention. To justify this very exceptional reading of s21 the Minister is candid that she relies on the decision of the Canadian Supreme Court, which she states:

... has held that a prohibition on voluntary assisted dying contravened the right to life, liberty and security of the person, which were all taken to relate to autonomy and quality of life.

Judgements of the Canadian Supreme Court on this issue are extraneous to the interpretation of s21 of the Charter in Victoria and cannot be taken to fundamentally redirect the purpose of s21 of the Charter to encompass a principle (the right to medically assisted suicide) that is clearly outside its clear statutory intent (unlawful detention).

It is argued that the Minister’s interpretation of s13 and s21(1) is essentially speculative. Such speculation is not in the public interest as it distorts the meaning plainly intended under these sections of the Charter.

Conclusion

It is argued that there are deficiencies in the Minister's Statement of Compliance for the VAD with the Charter in relation to the efficacy of safeguards proposed in the Bill. It is argued that the VAD should not proceed for consideration of the Parliament until fundamental human rights concerns listed above are addressed or alternatively should be addressed in the Parliament's consideration of the VAD.

Dr Brendan Long

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October 2017