COMPASSION DOES NOT KILL

The Right to Life NSW

Submission to the

Legislative Council's Standing Committee on Law and Justice Inquiry into

Voluntary Assisted Dying Bill 2021

November 2021

EXECUTIVE SUMMARY

The proposed Private Members Bill of Alex Greenwich is a bad bill at a bad time.

It is a bad bill because it confuses two very separate issues: suicide and assisted suicide. While we all agree that suicide, especially in the young, is tragic, advocates of the bill say that at the end of their lives people should have the capacity to choose suicide. Whether this is ethically right or not, the issue of assisted suicide is a very different question.

The Greenwich bill asks the state to get involved in the issue of life and death. It asks the state to regulate, approve and fund the act of suicide by an individual and requires public health professionals to be co-opted into participating in the process. The question that should be being debated is not whether people should have the right to suicide (which is now generally legalised) but whether the state should actively support the process. Right to Life NSW believes the state should never actively participate in the taking of the life of a citizen, except in the extreme case of defending imminent threats to lives of other citizens.

Of great concern with the bill is that the so called safeguards embodied in it exist in name only. There are no explicit measures to deal with the problems associated with informed consent for indigenous persons, persons with mental illness, protections of people with disability and the risk of elder abuse and wrongful death.

What has happened overseas is that schemes that were originally designed to be narrow in scope expand rapidly to become a form of opting out for people who find life too hard. This explains the massive acceleration of scheme participation in overseas jurisdictions. In Canada access to the scheme grew 34% in its second year. Right to Life NSW estimates based on data in Canada and other overseas jurisdictions that this bill will lead to 1,200-1,400 deaths of persons in NSW per year by 2030.

It also is a bad time for this bad bill. At the time this submission is lodged there are almost 2,700 active COVID-19 cases in NSW, 180 recorded new cases today. We face the threat of a new wave of the virus after the protection from the vaccines starts to wane. We are facing the worst public health crisis in the State for a century. So it defies belief that the Parliament should make assisted suicide the legislative priority at this time. Instead, health professionals rightly call for increased resourcing to the public health system.

It is also not possible to say that a person can have a real and effective choice to end their life through assisted suicide when palliative care is underfunded in regional and remote NSW. It is shameful that this bill could be contemplated in the absence of adequate palliative care funding. There are also significant concerns about the efficacy of the drugs chosen in other Australian jurisdictions. Right to Life NSW believes the Commonwealth agency, the Therapeutic Goods Administration, needs to test the efficacy of the drug.

RECOMMENDATIONS AND PROPOSED AMENDMENTS

Right to Life NSW makes the following recommendations in relation to the Voluntary Assisted Dying Bill 2021:

1. The bill should be opposed.

2. A Second Reading amendment be debated in the Legislative Assembly to note that there has been insufficient formal community consultation, especially with indigenous communities, for the bill to be adequately considered for a vote on Third Reading of the bill.

3. The Legislative Council Inquiry by the Legal and Justice Committee be granted an extension of time of 3-6 months to formally engage with indigenous communities in regional and remote areas of NSW including conducting public hearings in country.

4. If the bill passes the Second Reading in Legislative Assembly the eligibility criteria in Clause 15 be amended to include the requirement that free palliative care services be offered to all persons in NSW to a standard the Minister attests by regulations is adequate, specifically:

    a. In Clause 15. Insert after line 8— (ba) the person has been offered free palliative care and treatment under an authorised palliative care plan;
    b. In Clause 15. Insert after line 22— (2) In this section— authorised palliative care plan means a palliative care plan that provides for the delivery of a level of palliative care and treatment that at a minimum complies with the requirements prescribed by the regulations for this section.

5. If the bill passes the Second Reading stage in the Legislative Assembly the bill be amended to ensure that the Voluntary Assisted Dying Substance, the drugs to be prescribed, are subject to review by the Therapeutic Goods Administration like all other drugs prescribed in Australia, specifically:

    a. In Clause 7 add after “death”, “if the substance is listed on the Australian Register of Therapeutic Goods”.

6. All references to Voluntary Assisted Dying in the Bill be changed to reflect World Medical Association accepted referents.

Right to Life NSW

Right to Life NSW is the peak community based non-religious advocacy organisation on end-of-life issues in Australia. With many thousands of members and supporters in NSW we work with governments, politicians, business and civil society to enhance debate and reform public policy that best defends the dignity of all human life from its beginning to its natural death. Our aim is to inform public policy debate with sophisticated evidence-based argumentation and ethical analysis of proposed legislative changes.

When the civil rights movement of the 1970s began to consider what the key rights of human beings were, Article 3 of the UN Declaration on Human Rights outlined that the most inalienable right was that to life.

In 1973, the first Right to Life group began in Victoria. The movement quickly spread throughout Australia – providing an organisational structure for collective citizen action against abortion, embryonic stem cell research and assisted suicide. Since the 1970s and 1980s Right to Life NSW has run political campaigns and public demonstrations.

Terminology adopted in this submission

Of the great tragedies in the euthanasia debate in Australia is a lack of honesty about the terminology. In essence, the appropriate term to describe schemes that involve support by the state to act to end the life of a person is not a matter of controversy and had been agreed at international professional fora. The language adopted by the World Medical Association at the 70th WMA General Assembly, Tbilisi, Georgia, October 2019, and used consistently for many years, is [1] "Physician-assisted suicide".

Adhering to the terminology used by Australian Care Alliance [ACA] – an alliance of eminent Australian Medical doctors and Health Professionals - this submission will use euthanasia and assisted suicide to refer to the acts proposed to be legalised under the term "voluntary assisted dying", which ACA describes as 'vague, novel and euphemistic.' Use of expression VAD is an attempt to avoid the obvious truth that VAD involves the intentional ending of a human life.

The sanctity of life

Right to Life NSW has had a consistent position for many decades calling for government to respect the ultimate sanctity of all human life. We claim that governments must always make their first priority the defence of all human life and this means the state cannot allow euthanasia or assisted suicide. We are not alone in this view which is supported by many leading commentators in Australian political life. Here it is possible to point to the contribution of former Prime Minister Keating in his remarks on the Victorian legislation in 2017:

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[1] WMA Declaration on Euthanasia and Physician-Assisted Suicide – WMA – The World Medical Association, https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/.

> “There is probably no more important issue in contemporary bioethics or a more serious ethical decision for our parliaments than that raised by the Voluntary Assisted Dying Bill 2017 being debated this week in the Victorian Parliament. Under this bill, conditions and safeguards are outlined that will allow physicians to terminate the life of patients and to assist patients to take their own life. This 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.” Paul Keating: Voluntary euthanasia is a threshold moment for Australia, and one we should not cross (smh.com.au)

The wrong time for an assisted suicide bill

It also a bad time for this bad bill. At the time this submission is lodged there are almost 2,700 active COVID-19 cases in NSW, 180 new cases today. We are facing the worst public health crisis in the State for a century. So it defies belief that the Parliament should make assisted suicide the legislative priority at this time.

We face the threat of a new wave of the virus after the protection from the vaccines starts to wane. Overseas countries are experiencing new waves of virus and deaths approaching the level of the first wave. Fighting COVID-19 should still be the key focus of health policy in NSW.

In this context legislating for assisted suicide should not be considered as public health priority. It is simply the worst time possible to be focusing on this issue – it is an unwarranted distraction from the key public health priority. Health professionals call for caution and the Health Professionals Say No network has called for a focus on health service delivery to deal with the remaining threat posed by COVID-19 rather than prioritising assisted suicide measures.

Assisted suicide is a different issue than the ethics of suicide

The Greenwich bill is a bad bill because it confuses two very separate issues: suicide and assisted suicide. While we all agree that suicide, especially in the young, is tragic, advocates of the bill say that at the end of their lives people should have the capacity to choose suicide. Whether this is ethically right or not, the issue of assisted suicide is a very different question.

The Greenwich bill asks the state to get involved in the issue of life and death. It asks the state the regulate, approve and fund the act of suicide by an individual and requires public health professionals to be co-opted into participating in the process. The question that should be being debated is not whether people should have the right to suicide (which is now generally legalised) but whether the state should actively support the process. It should not because the state should never act to take the life of a citizen, except in the extreme case of defending imminent threats to lives of other citizens.

So the parliamentary debate to this point has largely been about the wrong issue: the right to choose suicide. The debate should rather be about whether the state should decline to become involved in that decision.

Limits on the power of the state in relation to matters of life and death

Of all the achievements of the free democratic peoples in the modern area, the greatest is perhaps the recognition that the most fundamental, alienable right of persons is the right to life. Recognising this, most modern democracies have come to the view that the state cannot take a life, except in the defence of other lives, in extremity. The great minds that helped form the philosophical foundations of modern liberal democracy; John Locke, Thomas Jefferson, John Sturt Mill, called for constraints on the role of the state. Locke and Jefferson stated that the right to life was the first and most fundamental right of a person and the greatest duty on the state is to protect that right. Building on this strong philosophical foundation, most modern democracies have come to the position that the strongest constraint we place on the state is that it cannot authorise or cooperate in the taking of a life except in the defence of other lives in extreme circumstances. We in Australia have acted on this principle by abolishing the death penalty. Like the United Kingdom, Canada, European Union countries and most States in USA, we have chosen to deny governments the power to legislate to take the life of a human being.

The capital punishment issue is the appropriate analogy to consider when assisted suicide laws are considered as indicated by Hon. Lindsay Tanner in his contribution to the debate in the Federal Parliament in 1996 – a position he still holds. Modern democracies place limits on the power of the state for sound reasons. The strongest constraint we place on a state is that it cannot authorise or cooperate in the taking of a life except in the defence of other lives in extreme circumstances.

Alex Greenwich’s bill seeks to erode this fundamental right and asks the people to allow the state to permit, positively aid and fully fund a medical professional assisting a person taking their own life. It involves abandoning the fundamental role of the state, as it’s first task, to defend the lives of its citizens. This would be a decisive turning point in the history of this State, a decision that effectively removes the state its primary philosophical duty to sustain the very lives of the people it exists to serve. Whatever view we take about whether a person should decide to end their life if they feel that they no longer which to continue, the state can never be part of that decision. It can never assist in a suicide. Not only does this breach the fundamental duty of the state to protect life it also presents a confused message to the country in that in the last Federal Budget enormous funding was given to prevent suicide. There is great policy dissonance when on one hand governments fund suicide prevention while on the other hand decide to aid and fund persons in a suicidal act.

Irreconcilable role conflict for medical professionals

Assisted suicide legislation would fundamentally change the relationship between a doctor and their patients. No longer would the doctor or medical professional be engaged to preserve or sustain the lives of their patients but under an assisted suicide regime would face a direct tension in their medical ethics: a need to manage the extension of a patient's life without pain and with strong care and the request to end that life through a lethal drug. These two goals are antithetical and unreconcilable. A medial professional cannot fully commit to sustaining life and also be to charged to end it. Assisted suicide mitigates against the necessary professional commitment to sustaining life. The medical professional must be the life saver, the life sustainer. To ask that person to also be the life taker is to place on them an impossible tension, to ask them to fulfill two opposite roles. If we want our medical professionals to be life sustainers, which we certainly want, we cannot ask them to be the agents of ending life. These two roles simply involve irreconcilable conflict. This is a key reason the international medical community opposes assisted suicide regimes.

Palliative care is effective where service delivery is adequately funded

The Australian and New Zealand Society of Palliative Medicine has recently stated that "ANZSPM does not support the legalisation of euthanasia and physician-assisted suicide…" ANZSPM's position statement also says:

> "ANZSPM acknowledges the significant deficits in the provision of palliative care in Australia and New Zealand, especially for patients with non-malignant life-limiting illnesses, those who live in rural and remote areas, residents of Residential Aged Care Facilities, the indigenous populations and those from culturally and linguistically diverse backgrounds."

Some key points need to be emphasised in the debate on palliative care in NSW:

- Palliative care practice is highly effective at 98.5% success rate in pain control.
- Persons only die in pain when effective palliative care services are either not funded nor delivered.
- Funding palliative care in the regions is more important than funding suicide for persons who are unwilling to receive palliative care.
- Palliative care is underfunded in NSW
    - NSW currently has approximately 91 FTE palliative care specialists for the state, or just 1.1 palliative medicine specialists per 100,000 population. To meet Palliative Care Australia's benchmark of 2 FTE specialist palliative medicine physicians per 100,000 population, NSW should have almost double the number of palliative care doctors it currently has. While this lack of available palliative care has significant effects in regional NSW, there is a lack of palliative care even in major hubs. For example, Westmead Hospital, which serves a population of 1.85 million and has almost 1000 beds has no dedicated palliative care beds.

Palliative Care Australia states that there is large unmet need in palliative care:

> "Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed. There is significant unmet need for high quality palliative

> care in Australia and forecasts indicate significant increases in need in the years ahead" 2019-VAD-position-statement-Final.pdf (palliativecare.org.au).

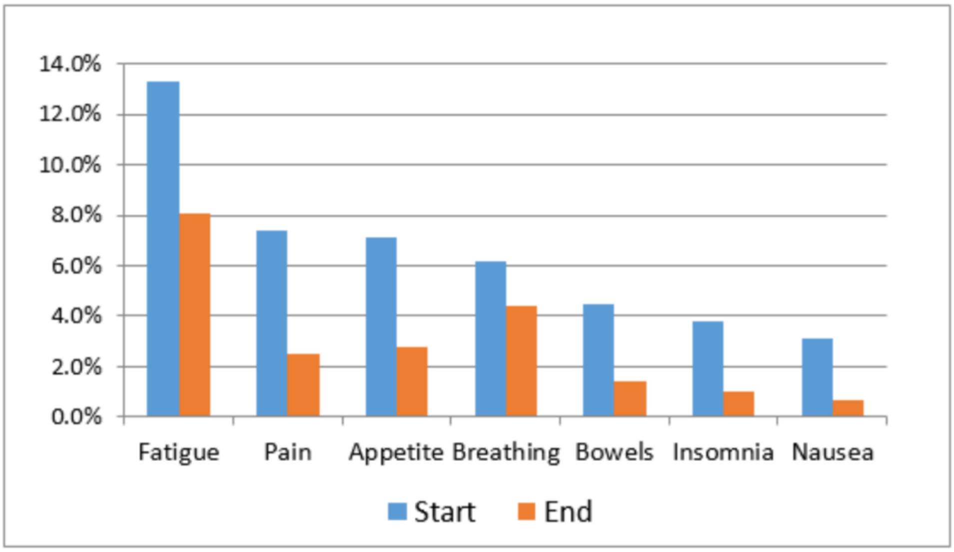
The truth on palliative care pain control

Mr Greenwich in his speech to introduce his bill stated

> "The 2016 'Palliative Care Outcomes Collaboration Report' found four percent of terminal patients had severe pain and 6.5 percent had other severe physical symptoms"

This is manifestly false.
As the graph below shows the 6.5% figure relates to pain before the palliative care begins. The figure just before death of 2% also includes people who go home to die and cannot get the best drug treatment or choose to decline treatment for religious or cultural reasons.

Fig. 1 Percentage of patients reporting severe distress at the beginning of palliative care and just before death



https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow264949.pdf
https://www.uow.edu.au/ahsri/pcoc/patients-families-friends/

Professor Stephen Duckett at the Grattan Institute says:

> "But palliative care services throughout Australia are woefully underprovided. People are dying in hospitals when they want to die at home. In addition to being a personal tragedy, under-provision of palliative makes no economic sense." How to improve palliative care - Grattan Institute.

It is inconceivable that assisted suicide legislation should even be contemplated when access to adequate palliative care is not available to all NSW citizens. The legislative priority in end of life care should rather be ensuring access to adequate palliative care is a guaranteed legal right.

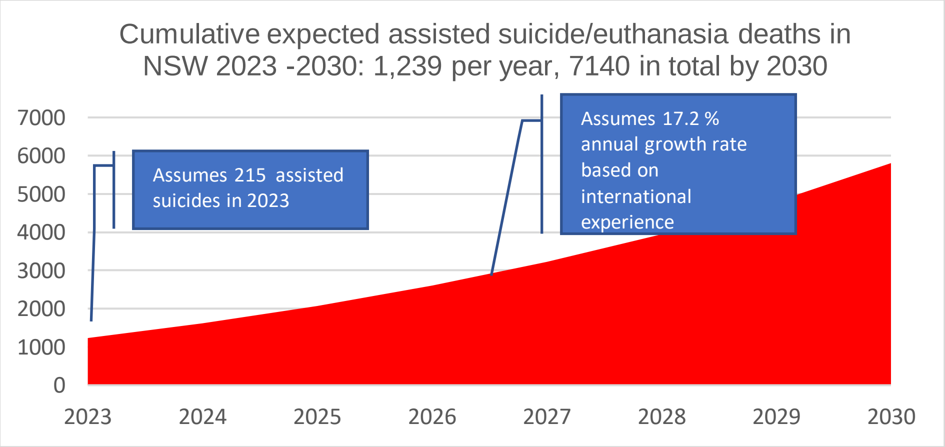
While Right to Life NSW opposes this bill and calls for it be voted down, we do believe that legislating an effective right to palliative care in NSW would be likely to reduce the worst impacts of the bill. When palliative care plans are in place and services are well funded people tend not to see the need for assisted suicide. They have hope and confidence to proceed in the last days knowing that they will be well looked after.

Consequently, Right to Life NSW proposes that if the bill passes Second Reading in the Legislative Assembly the eligibility criteria in clause 15 be amended to include the requirement that free palliative care services is offered to all persons in NSW to a standard the Minister attests by regulations is adequate, specifically:

a. In Clause 15. Insert after line 8— (ba) the person has been offered free palliative care and treatment under an authorised palliative care plan
b. In Clause 15. Insert after line 22— (2) In this section— authorised palliative care plan means a palliative care plan that provides for the delivery of a level of palliative care and treatment that at a minimum complies with the requirements prescribed by the regulations for this section.

This would effectively mean that assisted suicide was only available after palliative care services are offered throughout the State free of charge at a standard the Minister specifies as adequate in regulations. Any Government in which the Health Minister proscribes an inadequate standard of care is likely to suffer significant political repercussions. This measure is also likely to lead to greater attention to provision of adequate palliative care services in NSW for all citizens even outside of context of access to assisted suicide.

1200-1400 deaths per year



Dr Long, from Charles Sturt University, now CEO of Right to Life NSW, estimated in 2017 that the average annual growth rate in people accessing these schemes was 17 per cent a year in 2017 (Australian 21 September 2017 https://www.theaustralian.com.au/nation/nation/its-projected-1000-people-a-year-will-access-assisted-dying-by-2030/news-story/1a39ed0cb57f6e2787bd2b1fe1c8f496).

Using this same analysis Dr Long estimates that in 2030 the annual level of deaths from assisted suicide in NSW will be approximately 1,230 persons per year.

The massive expansion of the scope of the Canadian assisted suicide scheme highlights the problem of radical expansion in access to the schemes: the slippery slope. Canada only passed its legislation in 2018 but the recent report showed that there 7,595 assisted suicides in 2019, accounting for 2.5% of all deaths in Canada, rising at an annual rate of 34%. If this rate of assisted suicide applied in NSW there would be 1,400 assisted suicides per year. There we only 359 road fatalities in NSW in 2019 (Crash and casualty statistics - NSW general view - Interactive crash statistics - Statistics - NSW Centre for Road Safety

Risks to the vulnerable

One of the key policy arguments against assisted suicide regimes is that they have the unintended consequence of increasing risks to vulnerable persons. Considered arguments have been made by politicians in Victoria (Dr Daniel Mulino), Western Australia (Nick Goiran) and Queensland (Dr Mark Robinson) in minority reports indicating these risks.

The extreme risks for some of the most vulnerable people were also highlighted by former Prime Minister Keating in contribution to the debate in Victoria:

> “An alarming aspect of the debate is the claim that safeguards can be provided at every step to protect the vulnerable. This claim exposes the bald utopianism of the project – the advocates support a bill to authorise termination of life in the name of compassion, while at the same time claiming they can guarantee protection of the vulnerable, the depressed and the poor. No law and no process can achieve that objective.”

These risks are outlined in the areas of concern for indigenous persons, people with mental illness and disabilities, the risk of elder abuse and wrongful death.

Lack of indigenous consultation

Paul Keating’s concerns are also supported by Senator Patrick Dodson who stated that in relation to Western Australian Bill:

> “I have serious concerns about this bill and believe if passed into law it will be the source of confusion and potentially contain unintended consequences. Because of communication and medical protocols that are not clear, and concerns over the principle “free prior and informed consent”, Aboriginal people will yet again be at the mercy of the professionals who are authorised to prescribe and administer the lethal drugs if you indicate a willingness to end your misery in this life.”

In an article in October 2020 ” Aboriginal Deacon Ralph Madigan who makes pastoral visits to remote communities in far north Queensland said:

> "Euthanasia is wrong. In my family circle we wouldn't think of it. We believe in dying naturally. We've had family that have died from sicknesses, and much in pain, but we wouldn't dream of having euthanasia. Life is important, life is precious."

Augustine Father Robert Greenup, who visits remote communities with Deacon Madigan said:

> "When the first euthanasia laws were enacted in the Northern Territory in 1997 one of the starkest elements of the debate was indigenous people from remote communities saying, 'they would be terrified of going to hospital'. 'To paraphrase they would say 'Why would we get on a plane to go into Darwin knowing that doctors can kill you?"

Indigenous people do not support assisted suicide. It goes against their spirituality and they feel threatened by it. This was a key reason why euthanasia legislation in the Northern Territory was overturned. The key advocate here again is Senator Patrick Dodson: here are his views on the WA legislation on assisted suicide:

> "As representatives and legislators, surely, we must be focusing our attention to enacting laws that help prolong life and restore the right to enjoy a healthy life. Our endeavours should be directed to enabling all citizens to access the highest quality of health care. It's about priorities, values and care. The duty of care we saddle those administering and prescribing this system is an onerous one and morally cannot be conveniently shoved off to Government legal drafters.
>
> The Northern Territory experience in the 1990s suggests that the mere presence of this legislation may be a barrier to First Nations peoples receiving healthcare. Fears and suspicions of 'whitefella' medicine will only increase, and the capacity to ascertain informed consent will be difficult.
>
> I admire the dignity with which many have cared for their loved ones to their end. I do not condemn anyone for the choices they make. However, I also believe in the dignity and sanctity of the individual and the importance of not allowing a state to make such a conclusive decision on our common humanity – the power to assist someone in taking their own life."
> Voluntary Assisted Dying - a First Nations perspective - Senator Patrick Dodson

What indigenous persons have a right to expect is in relation to policies with such a dramatic impact on their lives is that NSW legislators would at least hold public hearings in country to hear what indigenous persons have to say. It is simply not good policy formulation process nor sound parliamentary practice to allow a member representing a small inner city seat to seek to impose a view on a vast state like NSW. The remedy here is to allow the Legislative Council Committee for Law and Justice the opportunity to travel to regional and remote NSW to hold public hearings in country.

In order for this to occur the reporting date of the Committee will need to be extended for 3-6 months.

Protecting vulnerable people with mental illness

The proposed safeguards in Australian assisted suicide legislation exist in name only. Persons with mental illness are particularly vulnerable. The leading psychologists like Professor David Kissane, Professor of Psychiatry, Monash University, Professor of Palliative Care Research, University of Notre Dame Australia, has indicated the risks to persons with mental illness of assisted suicide. In his submission to the WA Parliamentary Inquiry he stated:

> “Depression and demoralization in the medically ill are common reasons that bring about a desire to die. This is confirmed by Australian studies. Depression and demoralization often pass underdiagnosed and undertreated in oncology and palliative care. Depression and demoralization have a significant impact on decision-making capacity, and if unrecognised, the vulnerable are put at grave risk by VAD legislation.
>
> Treatment of depression restores interest in life-sustaining treatments or living until natural death intervenes. An additional factor is that doctors do make errors in diagnosis and treatment. Furthermore, prognosis is not an exact science. Protection of the vulnerable, the frail elderly, the disabled and the mentally ill is a crucial responsibility of society and its legislators. Legislators ultimately must make a choice between autonomy sought by a few vocal advocates and the safety of the wider community, whose lives may be put at risk through the difficult regulation of state sanctioned death.” Commentary_on_The_Report_of_the_JSC_on_End_of_Life_Choices.pdf (d3n8a8pro7vhmx.cloudfront.net)

In a recent briefing to NSW politicians Professor Kissane stated that persons with mental illness and depression have increasingly sought to access assisted suicide in European jurisdictions.

The last attempt to legislate euthanasia in NSW excluded people with mental illness. The Greenwich bill does not. It is instead modelled on the Victorian and Western Australian legislative approach to dealing with the issue of informed consent for persons with mental illness. Here the approach is to allow the 2 assessing doctors the capacity to call for a psychological review if they have any concerns in relation to the capacity of the person to make an informed choice.

We now know from the Victorian Voluntary Assisted Dying Board in its last report that only in 17 of 562 cases since the creation of the scheme was a specialist opinion of the applicant’s decision-making capacity requested: 3% of cases. We don’t know how many of these were then rejected. We simply do not yet have enough data to assess whether these safeguard mechanisms work. More time is needed to conduct research into the efficacy of these safeguards before the bill is legislated in NSW.

The evidence from the overseas jurisdiction is that demand for access to assisted suicide for those with mental illness has increased dramatically.

As stated in the Victorian Parliament 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 Belgium[79]

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 Netherlands[82]

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 is a quote 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 [assisted suicide] 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://bmcmedethics.biomedcentral.com/articles/10.1186/1472-6939-15-32)."

Ultimately, the safeguards for people with mental illness in this bill appear very weak in light of the international and current Australian evidence.

Protecting vulnerable people with disabilities

Disability activists like Liz Carr and Sam Connor have opposed assisted suicide legislation stating that it threatens to devalue the lives of persons with disability. These strong voices call for caution in relation to assisted suicide legislation indicating the strong risks it imposes on the most vulnerable of our citizens.

Persons with severe disability 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 acerbate 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 assisted suicide instead of sound medical treatment.

Here is a link which highlights the view of key disability advocates on this legislation. http://www.noeuthanasia.org.au/disability_advocates_tell_victorian_mps_why_they_oppose_assisted_suicide_and_euthanasia

Liz Carr, a disabled BBC Actor, made a presentation to the Victorian Parliament on this issue stating:

> “Maybe lots of us would feel happier, because people are not having good deaths now. People do not have choice in how they live, and the support that they might need in life. Ill and disabled and older people are not getting what they need now resource wise, health wise, pain wise, pain management, palliative care, housing, NDIS - that's in a mess.

> Until those things are sorted, can we really trust that the reasons that people give for wanting to end their lives are the real reasons, or that really it is about pain and suffering, or is it because we're not doing what we should be doing to support those people in life. It's too easy to go: do you know what, if I couldn't do that A, B, and C, maybe I'd want to end my life. I can't imagine. I'm rubbish with pain. I wouldn't want that. It's too easy to therefore assume that that's why those people might want to die. Maybe they just need decent pain control and support, and we need to make sure first, all of that's dealt with. Absolutely." Liz Carr: address to Victorian Parliament on assisted suicide - Hope Australia (noeuthanasia.org.au)

The risk of Wrongful deaths

Assisted suicide can never be made safe – there is always the risk that people will access the scheme without meeting the tests.

The Australian Care Alliance, the peak community group against euthanasia after Right to Life NSW, shows that overseas there have been many examples of wrongful deaths from assisted suicide. (see TWELVE CATEGORIES OF WRONGFUL DEATHS - Australian Care Alliance)

New data from Canada shows a shocking number of wrongful deaths:

- 4,120 Canadians were euthanised because they had cancer but with no discussion with an oncologist about this course of action;
- 2,650 people were euthanised who perceived they were a burden on their family, friends or caregivers;
- 1,373 people were euthanised who requested that their lives be ended because they felt isolated and lonely;
- 1,253 were euthanised with non-terminal conditions;
- 227 people were euthanised because they were frail;
- 322 people were euthanised who needed disability support services but did not receive them;
- 126 people who needed, but could not access, palliative care were given access to euthanasia;

59 people who the practitioner assessed as requesting a lethal injection "voluntarily" determined 'informed consent' without directly consulting with the person. The bill does nothing to prevent these wrongful death occurring in NSW.

The risk of 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 the ALRC suggests 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. It recommended a detailed study into the prevalence of elder abuse in this country, and a national plan to combat elder abuse to be agreed between federal, state and territory governments. This has not yet happened.

In recent years, it has become apparent that elder abuse and the risk of elder abuse are increasing threats in Australia. If an individual is unable to take care of themselves, has reduced decision-making capabilities and/or financial management issues, their vulnerability to be pressured into euthanasia by family members or others responsible for their care increases. A 2015 NSW Parliamentary inquiry revealed shocking accounts of elder abuse. The Committee Chair, Hon. Greg Donnelly MLC, wrote:

> “Within the context of the many priorities that governments juggle, abuse of older people can be overlooked, perhaps because elder abuse tends to be hidden away. Perhaps it is because of the ageism that exists in our culture, that allows us to disrespect our elders and tacitly accept disempowerment as an inevitable outcome of frailty. Perhaps it is too threatening for many of us – because we ourselves will one day be old and frail – to see this abuse for what it is: exploitation of and in some cases violence towards people who are vulnerable, people who in many cases are the least able to protect and defend themselves.”

Elder abuse can take many forms through subtle emotional pressure, to direct coercion. 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. As the ALRC report indicates (p.18) one third of all persons over the age of 75 have ‘severe or profound’ core activity limitations. The report continues:

- 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. However, no effective direct safeguards have been legislated in Australia to combat elder abuse in assisted suicide regimes.

It would be recklessly negligent of the NSW parliament to legalise euthanasia and assisted suicide in the state before putting in place a system to effectively address the scourge of elder abuse. If we cannot tackle elder abuse, there is no reason to believe that we can adequately safeguard against abuse when it comes to euthanasia and assisted suicide for our vulnerable elderly.

TGA approval of assisted suicide drugs

Normally drugs for use on humans need to be approved by the Therapeutic Goods Administration (TGA). If non-lethal drugs need to be tested for efficacy why should lethal drugs not similarly be tested to ensure suffering is not increased for a dying person by adverse consequences of the drug?

In Victoria the assisted suicide drug is pentobarbital. Pentobarbital is sometimes sold under the brand name of Nembutal, the drug for many years advocated by Dr Philip Nitschke. It was previously used in the United States to execute convicted criminals but is not longer used for this purpose in this country due to concerns that consciousness might remain in some form for a short time after the body functions are ended following medical research.

The dose to be prescribed in Victoria is different to any other jurisdiction that permits assisted suicide. There is therefore no available data on its effectiveness. Oregon data indicates that after ingesting the prescribed dose of pentobarbital (10g of pentobarbital liquid[2]) the time from ingestion to death was more than 60 minutes in 17.5 per cent of cases and more than six hours in 3.9 per cent of cases with the longest recorded time being 104 hours (four days, eight hours).[3] Other jurisdictions have also recorded adverse consequences.

The Victorian Act does not require a physician or other health care provider to be present when the lethal substance is ingested, so many Victorians may have uncomfortably prolonged deaths after ingesting pentobarbital.

In Western Australian, Queensland, Tasmania and South Australia we don't even know what the proposed drug is. Why don't we know what the dose will be. We don't know if there will be side effects. There is a lot we don't know about this drug and should concern all people in NSW as this is a critical part of this Bill.

The failure to indicate the drug to be chosen or any detail about how it is to be approved is a big failure with this bill. Parliamentarians can consider an approach that was taken by Dr Daniel Mulino, MLC when he moved an amendment in the Legislative Council to require the Voluntary Assisted Dying Substance to be reviewed by the Therapeutics Goods Administration like any other drug.

Then the drug would need to be registered as a therapeutic good in order to be prescribed. This is what the TGA does, it ensures drugs have their intended effects.

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[2] Jennifer Fess and Andrea Fass, "Physician-assisted Suicide, Ongoing Challenges for Pharmacists", *American Journal of Health-System Pharmacy*, 68 (9): 846–849, https://academic.oup.com/ajhp/article/68/9/846/5129756

[3] Oregon Public Health Division, *Oregon Death With Dignity Act: 2018 Data Summary*, See Table 4 *on* p.15 www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

Without TGA review we expect to have a range of problems with the drug that are likely to increase suffering. In Oregon the drug failure rate is high (over 10%) and in 17% of cases takes more than an hour to die with one case taking 104 hours!

Drugs that operate without TGA review are usually for a very specific purpose and tailored to the individual. If a person has a rare topical skin infection and it is not economical for a major pharmaceutical company to produce the very specific agent, then a pharmacist can mix it up after a doctor prescribes it off–label. Here there is no formal TGA review of the final product. However, this exception is not intended to be used to produce a drug for a group of patients as proposed with the Voluntary Assisted Dying Substance. Government policy is that drugs have to be TGA reviewed and there seems no reason this drug should be reviewed like any other drug.

TGA review of this drug helps ensure that the drug works as intended and does not increase suffering. If the bill passes the Second Reading stage in the Legislative Assembly it is recommended that the bill be amended to ensure that the Voluntary Assisted Dying Substance, the drugs to be prescribed, are subject to review by the Therapeutic Goods Administration like all other drugs prescribed in Australia, specifically:

a. In Clause 7 add after “death”, “if the substance is listed on the Australian Register of Therapeutic Goods”.

Essentially the amendment proposes to require the drug to be reviewed by the TGA as an additional safeguard.