LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

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

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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The Secretary

Select Committee on the Voluntary Assisted Dying Bill 2023

LACommitteeVAD@parliament.act.gov.au

Submission to the ACT Assembly Select Inquiry into the Voluntary Assisted Dying Bill 2023

Please accept this submission from the Knights of the Southern Cross in Australia which operates and controls many residential aged care facilities in Australia, and historically in the ACT.

While presenting the views of the Knights of the Southern Cross, the submission has been developed in consultation with the Catholic and Anglican Archdiocese of Canberra and Goulburn.

Yours faithfully

Mr Vince Granahan

Supreme Knight

Knights of the Southern Cross in Australia

Dr Brendan Long

National Executive Officer

Knights of the Southern Cross in Australia

COMPASSION DOES NOT KILL

The Knights of the Southern Cross in Australia

Submission to the
ACT Assembly Select Inquiry into

Voluntary Assisted Dying Bill 2023

December 2023

Executive Summary

This bill encapsulates a race to the bottom in terms of safeguards for vulnerable people at the end of their lives. It is the most dangerous euthanasia law proposed to be legislated in Australia.

Every state of this Commonwealth has legislated for euthanasia but all have chosen to specify a medically diagnosed time limit to expected death - normally of six months (12 months in Queensland) broadly following the model applied in the US State of Oregon. But, apparently, the ACT Assembly thinks it knows more than all the other legislatures and has gone its own way, and proposed a bill without time limits to expected death. This crucial safeguard has been thrown away, a safeguard medical professionals in Australia have supported when they support assisted suicide. And of course many medical professionals still oppose it and the AMA nationally has not changed its position against assisted suicide following the position of the World Health Organisation.

This is the slippery slope writ large. In this bill The ACT Government has proposed a regime akin to that which applies in Canada, which has no time to death limit. In this jurisdiction where the assisted suicide regime has expanded to so much to account for 4.1% of all deaths, 44,000 to date and 13,200 a year where the scheme is no longer about end of life care but simply a state sanctioned and funded option for suicide for those who think they lives are no longer worth living. We are better than this in Canberra, better than this in Australia, we must support people at the end of their lives through palliative care and reject the notion that accepts that for some people their lives are not worth living. We need to journey with compassion for people who are suffering and support them. To just take the lower cost option of a cheap poison bill or lethal injection effectively concedes that life is not sacred, does not need to be defended from its first moments to its natural end, and to give up on support for people at the end of their lives. This is not a moral or ethical choice for any government to make. It is an abrogation of the duty of end of life care.

This 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.

This 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. KSCA, which aligns itself with the positon of the Australian Catholic Bishops Conference and the Catholic community internationally 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.

It also is a bad time for this bad bill. The ACT health system is in crisis with some of the highest waiting times for elective surgery, some of the highest waiting times in Australia for treatment in emergency departments, and the lowest bulk-billing rates in Australia while a new wave of Covid-19 appears to be hitting the nation. The focus of health care in the ACT should be on supporting primary health care and the failing public hospital system. But the ACT Government prefers legislative experimentation over adequate health care service delivery and is more interested in prosecuting an ideological positon rather than caring for vulnerable Territorians. So the likely passage of this bill should be seen as a walk of legislative shame.

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 the ACT. 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. KSCA believes the Commonwealth agency, the Therapeutic Goods Administration, needs to test the efficacy of any proposed euthanasia drug.

Key recommendations and proposed amendments

KSCA makes the following recommendations in relation to the Voluntary Assisted Dying Bill 2023:

Recommendations:

1. **The bill should be opposed.**
2. **That notwithstanding the stated in principle concerns that the eligibility provisions under s11 include an expected time to death diagnosis of 6 months or 12 months for persons with a neurodegenerative disorder following the the Victorian legislation.**
3. **That provisions in relation to conscientious objection be amended to ensure that a corporation that runs a health service or a residential aged care facility can opt out of the regime if it can establish that it has an adequate process for obtaining consent from a client or patient to agree to not seek VAD as part of the application procedure for attendance at the health care facility or residential aged care facility and that obtaining this agreement removes the obligation for active referral of a client to a VAD Navigator under Division 7.2 of the bill.**
4. **that clause 10 be amended to add the requirement for a palliative care plan to be offered to the applicant.**

The Knights of the Southern Cross in Australia (KSCA)

The Order of the Knights of the Southern Cross is a national organisation of Catholic laymen who operate with the support of the Australian Bishops. Autonomous Branches of the Order operate in each Australian State. The Order is guided by the Catholic faith and the cardinal and chivalrous virtues of prudence, faith, justice, fortitude and temperance in all its charitable works. It strives to serve the wider community and support those in need.

Operating now for 100 years in Australia the Order continues to govern, in some jurisdictions, aged care residential facilities. The Order has historically operated residential aged care facilities in the ACT, those operations are now conducted by other Catholic agencies.

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.

[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-assistedsuicide/.

Specifics concerns with this bill

The ACT is too small to manage an assisted suicide regime

The ACT is a small jurisdiction. If the ACT Government were to implement a radically different legislative regime to other jurisdictions, particularly NSW, this would place a very high burden on the regulatory regime in the Territory. This carries risks of unintended consequences. The ACT has a unique problem of being a jurisdiction located geographically within NSW. It is typical for legislation to require a period of residency within a jurisdiction for 12 months. This is very difficult to enforce, especially as applicants apply for VAD at the end of their lives. There is very limited opportunity for regulators to assess residency before a person dies and the test required in the bill is a very loose one. It is a time consuming process for a regulator to obtain and verify residency criteria in time for effective access to the scheme. In fact, questions have been raised as to whether a residency requirement is effectively enforceable. Given the highly porous border between NSW and the ACT, with many persons living in one jurisdiction and working in the other, having a different regulatory regime in the ACT to NSW would create immense regulatory challenges. In essence, the bill appears to accept the NSW residents will access the proposed ACT regime. This is not just a shifting of costs to the Territory but also encourages 'suicide tourism' where applicants seek the most amenable jurisdiction to apply for a claim to end their lives. This is not good public policy.

Management of an assisted suicide regime with a statutory governing board and regular reporting is an expensive and administratively challenging task. The question can be asked if the jurisdiction of the ACT is simply too small to operate a complex legislative regime with a very different set of rules to other regimes. This complexity, especially relative to the size of the administering jurisdiction, naturally raises the question as if the ACT is large enough to run such a complex scheme, and if attempting to do would increase the risk of government failure, regulatory failure, which would effectively amount to the incidence of wrongful deaths.

Recommendation: The bill should be opposed.

The six month to death rule

The model for assisted suicide, essentially adopted in Victoria and across the nation is the model in force in the US State of Oregon. This model, in place for decades now, places great weight in maintaining strict safeguards to target that cohort of the population. To that end, it has continually applied a 6-month limit to expected death required for eligibility to the scheme. While the efficacy of the safeguards in the Oregon model can be questioned, the requirement for stringent safeguards has been a key element of the parliamentary consideration of legislation in the 5 jurisdictions in Australia where it has been legislated

The requirement for a six-month diagnosis is an important part of the safeguards under Australian and US legislated schemes. The time limit to death requirement acts as a safeguard to ensure that persons applying for access to the scheme are genuinely seeking to relieve suffering at the end of life rather than seeking a premature end to their life as a result of their perception they are a burden to others or that their life is not worth living. This guards against the risk of wrongful death, coercion and inheritance impatience where tacit pressure is placed on a dying person to end their life so the family can access the estate. This is an uncomfortable truth but a real one as data from Oregon over many years shows that the perception of being a burden to family members is a consistently stated

reason for assessing the scheme. Only a system with stringent safeguards can protect vulnerable Territorians from potential abuse of the statutory intent motivating the legislation.

The most significant element of this bill, which differentiated it from all other jurisdictions in Australia, is that it does not apply a specific time limit to death. The wording chosen of being close to death is extremely loose and effectively not an enforceable safeguard. By going for this model the ACT is seeking to implement the most liberal model in the nation and the system with the weakest safeguards. If the ACT Government decides to 'go it alone' and introduce a different model it has to be confident that there will be the capacity to support a wholly new safeguard and compliance regime. This is likely to be an expensive strategy with a high element of regulatory risk.

The jurisdictions most compatible with Australia in which there is no specified time to death limit is Canada. The Canadian experience of legislating assisted suicide without a time limit has been salutary. In Canada all that is requires is that the person has a serious and incurable illness, disease or disability, is in an advanced state of irreversible decline in capability, and have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable. In its current form the ACT bill seeks to introduce a regime which is broadly similar in scope to the Canadian regime, breaking with the Oregon model adopted by the other states in Australia.

What has occurred in Canada is massive expansion of applicants to the scheme. The data speaks for itself.

- In July 2022 the Third Annual Report on Medical Assistance in Dying in Canada was published. It stated that there had been 10,064 reported cases of euthanasia and assisted suicide in 2021, bringing the total of such deaths since legalisation to 31,664. However, There were 13,241 reported cases of euthanasia in 2022, bringing the total of such deaths since legalisation to 44,958.
- The number of cases each year has more than quadrupled (466%) in 6 years from 2,838 in 2017, the first full year of legalisation, to 13,241 in 2022 with annual increases of 57.8% (2018); 26.4% (2019) 34.2% (2020); 32.4% (2021) and 31.2% (2022). In 2022 euthanasia and assisted suicide accounted for 4.1% of all deaths in Canada. Provincial rates of euthanasia are highest in Quebec - 6.6% in 2022 and British Columbia - 5.5% in 2022. The benchmark set by the Victorian legislation following the Oregon model was set at 0.4% of deaths from VAD.
- There is further concerning data from Canada. In 90.6 % of cases of euthanasia where cancer was the underlying condition, Canadians were euthanased without a discussion with an oncologist about this course of action.
- In Canada in 2022, for 8.3% of cases of euthanasia the "main condition" is reported as "multiple comorbidities" and a further 14.9% as "other conditions" - that is other than cancer, cardiovascular, respiratory, neurological or organ failure. For these two categories combined, 25% of cases involved "frailty" and 11.9% involved diabetes. Other conditions cited included vision or hearing loss; tendency to falls; and difficulty swallowing. For women these two categories now account for nearly one out of three (29.1%) deaths by euthanasia.
- In Canada 463 cases of euthanasia where "death was not reasonably foreseeable" were reported for 2022. Notably 273 (59%) of these cases involved women, so for those whose death is not reasonably foreseeable, women are being euthanased at a rate 44.4% higher than men.
- In 2022 there were 328 cases where palliative care was not accessible if needed – an increase of 63% from 2021 when cases had already increased by 60% from the 126 cases in 2020. The

2021 report notes even where palliative care was being accessed or was available "this result does not offer insight into the adequacy or quality of the palliative care services that were available or provided".

- In 2022 there were 568 cases where disability support services were needed but not received (up from 332 in 2020 – an increase of 71%). In 2021 this included 12 of the 219 people whose deaths were "not reasonably foreseeable".
- In 2022 some 2,294 Canadians were given a lethal injection because they were lonely: Why didn't the doctor or nurse practitioner just have a cup of tea and a chat with them instead of giving them a lethal injection?
- Of the 1746 physicians and 91 nurse practitioners who euthanased people in 2022, some 336 of them did so 10 times or more – up 29.2% from 260 in 2021. The 91 nurse practitioners killed an average of nearly 14 people each – twice the average for medical practitioners of 7 people each. These statistics should alarm policy professionals concerned about safeguards from coercion and wrongful deaths.

This hard data is evidence of the risks of operation of a regime without a medically estimated estimated time limit to death. Essentially, such a scheme is simply a state sponsored form of suicide for people who have given up on living rather than a form of assisting people cope with suffering towards the ends of their lives. This bill so mimics the structure of the Canadian law that it also risks the grave acceleration of assisted suicide along the line of the Canadian legislation. For the the sake of an abundance of caution, that must always apply in matters of life and death, the legislation should be amended to include a 6-month limit to expected time to death following the Oregon model.

Recommendation: That notwithstanding the above stated in principle concerns that the eligibility provisions under s11 include an expected time to death diagnosis of 6 months or 12 months for persons with a neurodegenerative disorder following the the Victorian legislation.

Conscientious objection

One of the key questions in assisted suicide regimes legislated in Australia is the issue of how a health care institution or a residential aged care institution founded on religious perspectives can opt out of the assisted suicide regime. It is generally clear in legislated regimes, and clear in this bill, that medical professionals can decide not to personally participate in administration of the lethal drug orally or by prescribing a lethal drug. This is welcome and is a fundamental recognition of rights of medical professionals to adhere to the principles of their consciences, be those principles informed by religious or other ethical perspectives.

What remains unclear, and yet to be seriously tested in law, is whether institutions can themselves opt out of the regime. There are difficult questions here as a suffering person close to death in the care of an institution that opposes assisted suicide might choose to opt for assisted suicide. In this case where do the obligations of the objecting institutions begin and end? Can the institution simply decline to participate in the process and in that case what processes need to be taken to ensure legislated rights to access to assisted suicide for the suffering individual at the end of their lives? Legislation passed in jurisdictions has not provided clear pathways to solve this difficult dilemma.

A model is proposed in this submission to solve this problem. The model chosen is that the institution – the health care facility can opt out of participating in the assisted suicide process but with, and only with, a clear stated prior consent of clients in that facility, What is proposed is that

the health care or residential aged care facility can request that when entering the facility the clients is informed that the facility does not offer assisted suicide, the clients agrees to this upon application to enter the facility and that this decision is recorded. This imposes a high regulatory burden on the health care facility or residential aged care facility. It is proposed that when such a declaration is made, with information provided clearly, and agreed to by the client in writing, then the institution can decline participation in the assisted suicide regime. A clear choice of the client on application must be made, and recorded for the institution to claim an exemption from the regime. Here both the client and the facility have made clear choices without duress and such choices can and should be respected. In this occurrence, it is proposed that the requirement for active referral of the client by the objecting institution to a VAD Navigator is not to apply, but only when this administrative burden is met and proved to be met in clear documented evidence.

To that end the following amendments to the bill are recommended:

SUBSECTION 94 (3)

ADD AFTER CURRENT 94(3)(a)

b) is a corporation which provides health services or residential aged care services in the ACT where the corporation has included in the terms and conditions of acceptance of any patient into the establishment an acknowledgment by the patient that the patient—

(i) understands and accepts that the relevant service provider will not permit the

establishment to be used for the purposes of, or incidental to, voluntary

assisted dying; and

(ii) agrees, as a condition of entry, that they will not seek or demand access to

voluntary assisted dying at the establishment.

PROPOSED AMENDMENT ON ACTIVE REFERRAL

Division 7.2 NEW SECTION

This section does not apply If a corporation or health service provider or residential aged care facility is eligible to claim conscientious objection under s94 of the ACT.

Recommendation: That provisions in relation to conscientious objection be amended to ensure that a corporation that runs a health service or a residential aged care facility can opt out of the regime if it can establish that it has an adequate process for obtaining consent from a client or patient to agree to not seek VAD as part of the application procedure for attendance at the health care facility or residential aged care facility and that obtaining this agreement removes the obligation for active referral of a client to a VAD Navigator under Division 7.2 of the bill.

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 Australia:

- 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 Australia. The Australian Institute of Health and Welfare indicate that in Australia on average there are 0.9 clinical palliative care specialist staff per 100,000 persons where the World Health Organisation sets a standard of 2 FTE specialist palliative medicine physicians per 100,000 population.

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).

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 ACT citizens. The legislative priority in end of life care should rather be ensuring access to adequate palliative care is a guaranteed legal right.

While KSCA opposes this bill and calls for it be voted down, we do believe that legislating an effective right to palliative care in ACT 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, KSCA proposes that the eligibility criteria in clause 10 be amended to include the requirement that free palliative care services are offered to all persons in ACT to a standard the Minister attests by regulations is adequate, specifically:

a. In Clause 10 "the person has been offered free palliative care and treatment under an authorised palliative care plan"
b. In Clause 10 add the requirement "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 in the Territory free of charge at a standard the Minister specifies as adequate in regulations. This measure is likely to lead to greater attention to provision of adequate palliative care services in the ACT even outside of context of access to assisted suicide.

Recommendation: that clause 10 be amended to add the requirement for a palliative care plan to be offered to the applicant.

Initiating a discussion about assisted suicide

One of the key safeguards in the Victorian Act on assisted suicide is the prevention of a health care professional initiating a discussion about assisted suicide. This has been seen as a key defence against the risk of coercion by a health care professional who seeks to persuade a person, for whatever reason, to end their lives. While this safeguard has been modified across jurisdictions the approach taken in the ACT Bill in s152 is singular. This section states that a 'relevant health care worker' can initiate a discussion and this includes a social worker. Effectively the provision guarantees that an evangelist for assisted suicide can walk into a health care or residential aged care facility walk up to a dying person and advise them it is time for them end their lives. The provision is a very dangerous one. It almost seems to invite the 'relevant health care worker' to initiate the discussion completely turning the Victorian approach on its head.

This clause must be deleted or amended. If s152 is to remain the approach adopted in the West Australian legislation is a better model, where assisted suicide can be discussed along with other options.

Recommendation: delete clause 152 or amend to reflect the WA legislative approach.

7 days to 2 days to respond to First Request

In s14(1) of the bill it states that:

> Within 2 working days after the day an individual makes a first 17 request, the health practitioner must—
>
> (a) decide to accept or refuse to accept the request; and
>
> (b) tell the individual about the decision

In the Victorian legislation the equivalent time period is 7 days (clause 13).

The two-day rule is excessively tight and may not provide time for the individual to express conscientious objection. In addition, the inability to use a carriage service (fax or email) to convey the response to the request would make such a short timeframe unworkable.

Specialist medical officers

The Victorian legislation indicates that generally either the coordinating or consulting doctor assessing the application should be a medical specialist or another specialist should be consulted if there assessing doctors do not have expertise in the relevant condition.

There are no safeguards of this nature in the ACT bill and in fact nurses can be consulting medical practitioners. This further reduces the safeguards present in the ACT Bill.

Publication of the reasons for the assessing assisted suicide.

For many years the Oregon Health Authority has published reasons for why an applicant seeks assisted suicide. The bill should involve a requirement for the proposed VAD Board to publish the stated reasons for seeking assisted dying when this is obtained from applicants.

Why this bill should not be supported

The sanctity of life

KSCA has had a consistent position throughout its 100-year history of calling for governments to respect the ultimate sanctity of all human life. KSCA claims 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:

> "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 the ACT Health system remains one of the poorest performing health systems in the nation with waiting lists for elective surgery and emergency room waiting times among the worst in the nation. And the compulsory acquisition of the Catholic public hospital has just disrupted an already struggling health system, essentially for ideological reasons opposed the idea of a Catholic hospital.

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 public health priorities. Health professionals call for caution and the Health Professionals Say No network has called for a focus on health service delivery rather than prioritising assisted suicide measures.

Assisted suicide is a different issue than the ethics of suicide

The 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.

This 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. 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 on this issue across the nation 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.

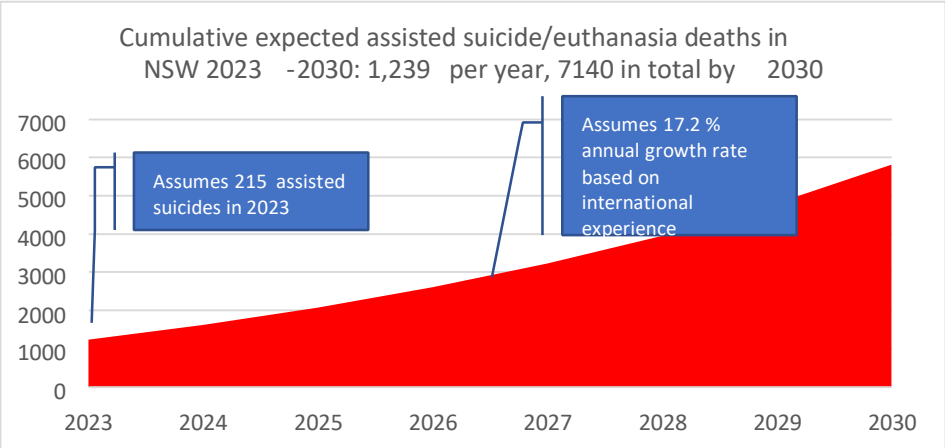
The capital punishment issue is the appropriate analogy to consider when assisted suicide laws are considered as indicated by Hon. Lindsay Tanner in his contribution to the debate in the Federal Parliament in 1996 – a position he still holds. Modern democracies place limits on the power of the state 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.

This bill seeks to erode this fundamental right and asks the people to allow the government, in the ACT, 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 its first task, to defend the lives of its citizens. This would be a decisive turning point in the history of the Territory, a decision that effectively removes from the ACT Government 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 striving to work towards suicide prevention. 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 fundamentally changes the relationship between a doctor and their patients. No longer is the doctor or medical professional engaged to preserve or sustain the lives of their patients but under an assisted suicide regime 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 irreconcilable. 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 fulfil 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.

1200-1400 deaths per year



Dr Long, from Charles Sturt University, National Executive Officer of KSCA, 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-willaccess-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 ACT will be approximately 65 persons per year after ten years.

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. No evidence has been provided by the ACT Government about a specific indigenous consultation strategy in the ACT on this bill.

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

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.

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

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%

> 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."

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/10.1186/1472-6939-1532)."

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)

In Canada shocking increase in the assisted dying case load hides a large number of deaths which can be called wrongful deaths in that are not supported by the legislation.

- In Canada in 2022, for 8.3% of cases of euthanasia the "main condition" is reported as "multiple comorbidities" and a further 14.9% as "other conditions" - that is other than cancer, cardiovascular, respiratory, neurological or organ failure. For these two categories combined, 25% of cases involved "frailty" and 11.9% involved diabetes. Other conditions cited included vision or hearing loss; tendency to falls; and difficulty swallowing. For women

these two categories now account for nearly one out of three (29.1%) deaths by euthanasia. Such deaths do not really meet the intended target of the legislation.

- 463 cases of euthanasia where "death was not reasonably foreseeable" were reported for 2022. Notably 273 (59%) of these cases involved women, so for those whose death is not reasonably foreseeable, women are being euthanased at a rate 44.4% higher than men.

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 no 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.

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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

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.

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

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. 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 56(1) 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.

www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf