**Submission
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INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Dying with Dignity NSW

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Dying with Dignity
New South Wales

Submission to the Inquiry into the Provisions of the Voluntary Assisted Dying Bill 2021

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on behalf of Dying with Dignity NSW

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ABOUT US

Dying with Dignity NSW (**DWD NSW**) is a law reform organisation pursuing a change in the law that will enhance self-determination and dignity at the end of life. Our aim is legislation in NSW that entitles a mentally competent adult experiencing unrelievable suffering from a terminal or incurable illness to receive medical assistance to end their life peacefully, if that is what he or she wants. As well as our role in advocacy and lobbying to bring about a change in the law, we promote the use of Advance Care Directives to assist with patient control at the end of life (EOL) and we provide our members with information about changes in the legal climate for EOL, both in Australia and overseas. We are a not-for-profit charity and we rely on membership, donations and bequests in order to continue our work. We presently have over 100,000 supporters.

We also take phone calls from a substantial number of people each year who ring us to seek information about their end of life options. Of course, we have to explain to them that voluntary assisted dying (**VAD**) is illegal in NSW. In the course of these conversations we learn a lot about the background to our callers' desires to obtain relief from their suffering and believe that we have gained considerable knowledge over the years about the reasons why people seek VAD and about their circumstances.

In addition, we have closely monitored VAD debates in other states and around the world and have researched various schemes. As a result we've built up a degree of expertise on the subject.

SUMMARY

The NSW VAD Bill represents a conservative regime for voluntary assisted dying and contains rigorous safeguards against abuse which are consistent with those in the VAD laws now adopted in all other states. Those laws have been developed after extensive analysis of international evidence and consultation with the public and stakeholder groups.

We believe that the Bill should be adopted in its current form, without amendment, save for extending the timeframe in clause 16(I)(d)(ii) to 12 months in all instances.

To amend the substantive provisions of the Bill in any way which introduces more onerous criteria or processes, particularly in relation to medical assessments, would significantly reduce the ability of dying people to access the regime.

This would have the effect of increasing the suffering of people who are already struggling with significant burden of illness, without adding any meaningful protections against abuse. It would also disadvantage those in regional and remote areas who already have more difficulty accessing medical care.

As reported in the Sun Herald on 5 September 2021, the chair of the Australian Medical Association's ethics committee, Dr Andrew Miller has broadly endorsed the NSW Bill indicating that it is very similar to the laws in place in Victoria and WA and saying that "It has proven to be an effective compromise in my opinion in WA, and it has been introduced smoothly and without fuss…. Basically [the NSW bill] looks to be consistent with the evolving national model."

It is our strong view that the NSW VAD Bill is safe and effective, giving terminally ill people in NSW the same end-of-life rights as other Australians and should not be amended in any way that makes it more onerous or difficult to access.

BACKGROUND

Australia has conducted a greater number and more rigorous inquiries into the subject of voluntary assisted dying (**VAD**) than any other country in the world. Since 2016 we have had three extensive parliamentary inquiries into end of life choices in Victoria, Western Australia and Queensland along with a thorough review by the Queensland Law Reform Commission which have resulted in authoritative reports which have exhaustively canvassed the best models for a safe VAD regime. Between them, these inquiries examined overseas experience in detail and looked at many years of evidence about how VAD regimes in other countries have worked.

The drafting of the New South Wales VAD Bill has taken careful note of all this accumulated wisdom and looked at the best features of the bills that have been passed, not only in Victoria, Western Australia and Queensland, but also in Tasmania and South Australia. In addition to this, it has the advantage of being able to examine how the Victorian VAD regime has operated – a scheme that has been safely operating for more than two years without any sign of abuse occurring and its operation has been detailed thoroughly in the six monthly reports from the Victorian VAD Review Board.

A second thing that it is crucial to understand at the outset is that the Australian model of VAD is quite different from the regimes operating in the Netherlands and Belgium (**the Benelux model**) and also, the process of introducing medical assistance in dying (**MAiD**) that occurred in Canada. Opponents of VAD in NSW often cite cases from these countries as evidence of inherent dangers of VAD, but, such examples are not relevant, as those regimes are based on quite different principles.

Under the Benelux model the criterion for requesting an assisted death is that 'the patient's suffering is unbearable with no prospect of improvement'; there is no requirement for a terminal illness and it has never been part of that model. No model of VAD in Australia is as broad as this. All, including this bill, require the patient to have a terminal illness likely to cause death within six months or a severe and incurable neurodegenerative illness likely to cause death within twelve months. Therefore, suggestions that the NSW VAD Bill will inevitably be extended to non-terminal illness or severe mental illness are not supportable..

The situation in Canada is also very different from Australia. As committee members will know, the Canadian MAiD scheme came about as a result of a Supreme Court of Canada judgement that refusing a person relief at the end of life violated their human rights, as set out on Canada's Bill of Rights. The first Canadian Bill was introduced in 2016 as a direct result of this court mandate. Following subsequent representations to the Quebec Supreme Court, the court ruled that discriminating against people whose suffering was psychological rather than physical was also a violation of the Charter, in that it discriminated against people with mental illness in the delivery of services. As a result, the Canadian parliament was instructed by the court to amend its MAiD law to correct this position and, in 2020, it resolved to add mental illness as an eligible condition and to conduct a two-year inquiry into how best to do that.

Because Australia does not have a bill of rights and because it is not possible to for the High Court to instruct any of our parliaments to pass certain laws, the fact that Canada's MAiD law has been expanded is irrelevant to the situation in Australia. The only way in which an Australian VAD law could be expanded is by Parliament passing new or amended legislation.

In other words, parliaments are in control of whether there is any "slippery slope".

Arguments about the risks of expansion of VAD laws in Australia, based on the existence of different regimes in the Netherlands, Belgium and Canada are not supported by evidence.

It is also worth pointing out to the Committee that Australia is being regarded as an exemplar in the legislation and delivery of VAD. The Irish MP, TD Gino Kenny, who is proposing a VAD bill in Ireland, has said that he intends to base his bill on the Queensland one, and Dr Cam McLaren, who has been the coordinating medical practitioner on a number of VAD deaths in Victoria, is assisting New Zealand with its training of VAD practitioners.

FEATURES OF THE VAD BILL 2021

Eligibility criteria

Timeframe until death

This draft bill proposes that a person can qualify for access to VAD if they have an eligible disease that will cause death within six months for a terminal illness or twelve months for a neurodegenerative disease. We submit that the parliament should consider making the timeframe 12 months for all eligible diseases.

This is the timeframe adopted in the recently passed Queensland VAD Bill. It is worth noting that original versions of VAD bills proposed in the other states, including Victoria, did have a single, 12 month timeframe until death. This timeframe came about as a result of expert evidence presented to parliamentary working groups or expert panels set up to draft the VAD legislation. The timeframe until death was reduced to 6 months for diseases other than neurodegenerative diseases, during the parliamentary debate to ensure those bills passed into law. So it was political pragmatism that led to a shorter timeframe, not evidence.

Data and anecdotal evidence from members of the VAD Community of Practice in Victoria and information in the Voluntary Assisted Dying Review Board (**VADRB**) Reports seem to indicate that many dying individuals leave it very late to apply for VAD. Many have died before being able to fully progress through the high-safeguarded assessment process. This is why we think it would be more compassionate to allow someone to navigate through this process, if that is their choice, before reaching the last few months, or sometimes weeks, of their life. Just because someone knows that they want VAD as an end-of-life option does not translate to them taking the medication early. There is clear evidence from overseas, and now also Victoria, that having control provides a palliative effect and sometimes that is all that is needed and the person dies without taking the medication.

In the period leading up to the Queensland Parliament dealing with their assisted dying bill, the Queensland Law Reform Commission undertook a very wide-ranging inquiry into the question of whether it was desirable to specify a timeframe till death in the eligibility conditions for access to

VAD, and if so, how long should it be. After considering reports from inquiries in Victoria and Western Australia, inspection of provisions in comparable jurisdictions and consulting widely with the community and with medical experts, it came to the conclusion that it was desirable to specify a timeframe and that it ought to be 12 months for all eligible diseases.

Its reasons were as follows. They noted that whether a disease, illness or medical condition will cause death within a particular timeframe 'is a clinical assessment based on an individual's own particular circumstances including their condition, their comorbidities, and the available treatments that they are prepared to accept, noting the right to refuse medical treatment'.

A 12-month timeframe was considered to be consistent with current health care practice and the end-of-life and palliative care framework in Australia. They noted that health practitioners commonly use the 'surprise question' (that is: 'would I be surprised if my patient died in the next 12 months?') when planning and discussing the treatment and care of people who are at the end of life, as well as other prognostication assessment tools. They report that the Western Australian Expert Panel considered that such tools have been shown to provide 'an accurate, yet conservative predictor of the risk of death within 12 months' and did not consider that there should be more than one timeframe—for example, six months for some conditions and 12 months for others. In its view it is difficult and potentially discriminatory to weight the suffering of one terminal diagnosis above other terminal diagnoses. (QLRC: *A Legal Framework for Assisted Dying May* 2021, pp. 100 ff.)

There is other legislative precedent for making such a prognosis about a terminal illness. Under federal superannuation legislation, benefits can be released to super fund members if they have a terminal medical condition which is likely to result in the member's death within 24 months, as certified by two medical practitioners. In addition, life insurance benefits are usually payable while the beneficiary is still alive, but expected to die within 12-24 months.

Qualifications of the practitioners

Opponents of the NSW VAD Bill are expected to seek amendments to require that one of the VAD practitioners must be a specialist in the patient's disease. We do not believe this is necessary.

Section 26 explicitly states that, if the coordinating practitioner is unable to decide whether the person has the disease that meets the criteria in Section 16, he/she 'must refer the patient to a medical practitioner who has appropriate skills and training'. The same applies to the coordinating practitioner (section 37).

Evidence included in the reports from the Victorian VADRB indicates that the requirement in the Victorian law that either the coordinating or the consulting medical practitioner needs to be a specialist in the person's disease has resulted in significant barriers to access, particularly for those in regional and remote areas of Victoria, where specialist care is difficult to access. These barriers would clearly be more significant in geographically larger states.

This problem was identified during the development of the WA VAD law and the "specialist" requirement was not adopted. Other states have followed suit. It is the approach adopted in the NSW VAD Bill and we believe it to be appropriate.

Decision-making capacity and freedom from duress and coercion

A person cannot be assessed as eligible to access VAD unless they have decision-making capacity (which is rigorously defined in Section 6) and is acting voluntarily and without duress (defined in Schedule 1). Opponents of the bill assert that there is no way of being absolutely sure about these matters and that the regime will constitute a risk to vulnerable people such as the elderly and those with mental illnesses.

It is likely that amendments will be proposed to require an additional assessment of capacity by a psychiatrist or other specialist such as a geriatrician.

There is no such requirement in any VAD law in Australia or internationally and we submit that the existing provisions in the Bill give adequate protection.

Section 27 clearly states that if a VAD practitioner is unable to decide whether a patient has decision-making capacity, or whether they are acting under duress, he/she 'must refer the patient to a psychiatrist, another registered health practitioner or another person who has appropriate skills and training to make a decision about the matter'. This is consistent with VAD laws in all other jurisdictions.

Doctors are required to obtain patient consent for all medical treatments and are constantly assessing patients' capacity to make decisions about their care, for routine matters and those with life threatening consequences. Doctors are routinely involved in determining whether patients are, or may be, suffering from a mental illness which impairs their decision-making capacity. Indeed, before a person can be referred to a psychiatrist or any other specialist, a GPs assessment and referral is required.

It is worth pointing out that under the current law, a dying individual with unbearable suffering at the end stage of a terminal illness already has the legal right to hasten their own death. They can refuse all treatment including food and water and basically starve and dehydrate themselves to death to end their own suffering. This long process takes many days or sometimes weeks. It is cruel and can be physically painful and psychologically distressing for both the patient and their loved ones and/or carers.

This legal option is undertaken every day in palliative care settings, in aged care facilities, hospitals and in people's homes. There is no requirement for a mandatory psychiatric assessment before a person is allowed to make this decision that will cause death. There is no need for a doctor to be involved in these decisions at all. In some cases, the decision to withhold treatment, as well as food and water, is made without the patient's consent either by a doctor or by family members acting as the patient's substitute decision maker.

No other VAD law, here or overseas, includes a mandatory psychiatric assessment. Terminally ill people in NSW have no special or unique vulnerabilities which would require this additional and unnecessary process to be added to the VAD Bill.

While the prevalence of abuse of the elderly and disabled by family members and in residential care is a significant problem in our society, we submit that the rigorous processes required to confirm eligibility for VAD are more likely to expose this kind of abuse, than to facilitate it. Furthermore, peak organisations representing the elderly such as COTA NSW have endorsed the NSW Bill and consider the safeguards to be sufficient.

Certain persons not eligible

Further to the question of the ‘slippery slope’, note Section 16 (2) of the bill which says: ‘A person is not eligible for access to voluntary assisted dying only because the person has a disability or a mental health impairment’. Of course, if such patients fulfilled the other eligibility requirements, they would not be excluded by reason of their disability or mental illness.

Assessment process

There are strict requirements that must be met by a coordinating practitioner or a consulting practitioner (Section 18). The opponents have suggested that doctors may collude with each other and even encourage or coerce patients to use VAD. We would argue that the criteria that such practitioners must meet and the oversight of the VADRB precludes the possibility that this will happen. Note the provision (Section 18 (d) and (e)) that the practitioner must not be a family member or stand to benefit financially.

The assessment process itself is rigorous and potentially lengthy (see Sections 25 – 42). There are strict reporting requirements and a large number of hoops to be jumped through. We would caution against making the process so complex and the safeguards so rigid that the patient’s ability to access VAD is made impossibly difficult. There must be a proper balance struck between being safe and actually blocking access or creating delays which prolong suffering

Opponents of the bill have criticised the fact that the Bill mandates that the time between the first and last request is only 5 days. They argue that this doesn’t allow a sufficient ‘cooling off period’. We would respond that if the Committee examines the flow-chart produced in association with the Bill, they will see that after the final request there is still a number of steps to go through, including the Board’s assessment of the paperwork, and it is likely that with even the most efficient system in the world, the whole process will take weeks rather than days. And as the Bill states (Section 54), the patient can at any time decide not to proceed.

Other provisions of the bill

As we have indicated, the NSW VAD Bill has been drafted with the examples of the other states’ bills in mind and in a number of respects this bill clarifies matters left uncertain in some of the other bills.

VAD not suicide

In Section 12 the bill states that ‘for the purposes of the law of the State, a person who dies as the result of and administration of a prescribed substance in accordance with this Act does not die by suicide’.

This provision will be of immense comfort to the family and friends of the deceased person, and reflects the important distinction between assisted dying and suicide; in the first instance the person is dying already; in the second, a death occurs which would otherwise not occur. It will also avoid unnecessary stigma and the risk of voiding life insurance policies.

Tele-health

In Victoria the experience has been that, because of Commonwealth law which prohibits using a "carriage service" to aid and abet or encourage suicide, some patients, who live in regional and rural areas, are having trouble accessing the assessment process for VAD. The Act mandates the kind of medical practitioner who may do an assessment and if such a practitioner is not available nearby, the patients may have to travel a long distance to access assessment. If the person is too frail or ill to be moved, this effectively blocks them from access to VAD simply as a function of where they live.

The NSW Bill recognises the inequity of this situation and attempts to address it by the inclusion of Section 12 and Section 183 which provides that: 'If it is not practicable for a patient to make a first request, final request or administration decision in person, the patient may make the request or decision using audio-visual communication' and the same applies to the medical practitioners involved. It is however, subject to the provisions of any overriding Commonwealth law, and the application of the "carriage service" offence to the NSW Bill remains unclear.

Who can initiate discussion about VAD

Section 10 (1) makes it clear that a health care worker cannot initiate a discussion about VAD with a patient. Severe penalties follow if this section is breached. However, under strict conditions a medical practitioner or a registered nurse can initiate a discussion about VAD or suggest VAD to a patient provided he/she also at the same time outlines all the treatment options available, the likely outcomes of the treatments, the palliative care options available and their likely outcomes. Contravention of this counts as unsatisfactory medical conduct.

If a patient requests information about VAD, a health care worker is allowed to provide that information.

We submit that this strikes the right balance between safety for the patient and their rights to have all information relevant to their healthcare.

The Victorian experience has shown the need for this balance to be struck. Under the Victorian VAD Law medical practitioners and health care workers are absolutely barred from offering suggestions about the availability of VAD, even in a situation where all medical and palliative care options have been exhausted and the patient is begging the doctor for help. In such a situation the inability of a doctor to raise the option of VAD is absurd and cruel, particularly when they are free to suggest other legal options to hasten death such as ceasing treatment, starving or dehydrating to death or even suicide.

Conscientious objection (CO)

All VAD Acts in Australia allow individual CO for health practitioners, as does the NSW Bill. In Section 9 it says that a 'registered health practitioner who has a CO to VAD has the right to refuse to do any of the following: participate in the request and assessment process, prescribe, supply or administer a VAD substance, be present at the time of administration of the substance.

However, such a practitioner is not allowed to leave the patient high and dry. Under Section 21 (4) (5) practitioners must 'give the patient the information approved by the Health Secretary, by

Gazette notice, for the purposes of this section' – presumably information that VAD is legal in NSW and referral to a VAD navigator service.

It is expected that amendments will be proposed which remove this minimal requirement, which would be deeply unfair and amount to abandonment of the patient.

In the first VAD laws passed in Australia (Victoria, Western Australia and Tasmania), the question of a possible institutional CO was not specifically addressed. However, a number of hospitals and aged care facilities have declared that they would not participate in any part of the VAD process and would not allow it to be carried out on their premises. They, in effect, demanded that their institutional CO be recognised.

This means that patients may be denied access to a legal medical procedure by virtue of the ethos of the facility they happen to be treated or residing in. A significant proportion of Australia's heath and aged care is provided in faith based facilities, and in parts of the country those are the only facilities accessible to some patients

In subsequent Acts (South Australia and Queensland) the question of an institutional CO was expressly addressed, as it is in the NSW Bill. There was heated debate about this aspect of the Queensland VAD Bill with religiously affiliated entities, seeking a blanket right to refuse to allow any part of the VAD process on their premises.

The problem with this approach is that the rights of the patient are made subordinate to the rights of the health care institution. In the Queensland Bill and in the NSW Bill, there is an attempt to balance those competing rights. It could be argued that if a patient intends to access VAD they should not become a patient in an institution which has a CO to VAD. But this is completely unrealistic. A person is unlikely to know whether they would want to request VAD months or years before they have begun to suffer from a life-limiting illness. Furthermore, because religious entities are so prominent in the aged care and health care fields, a patient might have no choice about where to go at the end of their life. So, it imperative on moral and compassionate grounds that the patients' rights and needs are in balance with those of the entity.

In Sections 88 - 107 this draft bill goes out of its way to achieve this balance. It spells out in careful detail the obligations of the entity with the CO at every stage of the process. It distinguishes between aged care facilities, which are regarded as a person's 'home', and health care establishments, such as hospices and hospitals, which cannot be considered the patient's 'home'.

In the case of patients in a residential facility, the entity must allow access for health practitioners and VAD navigator service personnel to enter the facility in order to provide information, receive request for VAD, carry out assessments for VAD, receive administration decisions and to self-administer or be administered the VAD substance. If the patient is not a permanent resident of the facility it must facilitate the transport of the patient to another location where the patient can receive the VAD substance.

In the case of patients in a health care facility, if the facility has a CO, it is nevertheless obliged to give the patient information about VAD and to allow access to the VAD Navigation service. For the other stages of the VAD process it is obliged by the bill to facilitate the transfer of the patient to another location where their needs can be met.

Some might argue that this last rather cumbersome process is tilting the balance too far in the direction of the institution. The practical and logistical challenges of transferring a terminally ill, and presumably very frail person from a care facility, hospice or hospital on multiple occasions for each stage of the process are significant and likely to add to the distress and suffering of the patient whose needs should be paramount.

We would submit that the provisions in the NSW Bill are already skewed too heavily in favour of objecting institutions and believe any amendments to strengthen the CO rights of institutions would be unfair and add to the suffering of people who are already extremely vulnerable.

Other issues

Based on our knowledge of the VAD debates elsewhere, opponents of the NSW Bill, both inside and outside the parliament, will seek amendments to the Bill to address alleged dangers and risks, the existence of which is not supported by evidence. We will deal with them in turn.

Dying people's reasons for requesting VAD

Opponents of the NSW Bill quote the annual data reports from Oregon (where assisted dying has been legal for 24 years) which shows that the most common reasons people offered for requesting assisted dying were not uncontrollable pain. Most often they cited loss of autonomy, loss of the ability to engage in activities that make life enjoyable, loss of dignity, loss of control over bodily functions and being a burden on others.

However these reasons are not part of the eligibility criteria for VAD in Oregon, where the overriding requirement is a terminal illness with less than six months to live. They are certainly reasons which contribute to the suffering of a terminally ill person but do not, by themselves qualify a person to access VAD.

It is also important to acknowledge that "suffering" is more than just pain and physical symptoms, it also encompasses psychological and existential suffering which can often be more difficult to alleviate.

Palliative care

All advocates for VAD, including DWD NSW, support all patients having access to quality palliative care wherever they live and see palliative care and VAD as complementary practices, with VAD accessed by a small number of patients who cannot be helped by palliative care. The detailed reports from the Victorian VAD Review Board indicate that the vast majority of people who use VAD in Victoria are also in palliative care and this is consistent with data from other jurisdictions.

Some opponents of the Bill have argued against it on the grounds that the 'palliative care sector' is against it. This is not the case. While some individual palliative care doctors and nurses oppose VAD, many others support it. And it is important to note that the palliative care profession's official body, Palliative Care Australia, is neutral on the subject. Here is an extract from their current position statement on VAD:

"A decision about whether or not to legalise voluntary assisted dying is one for governments. PCA neither advocates for, nor argues against the legalisation of voluntary assisted dying."

The position statement goes on to say that it considers palliative care and VAD to be entirely different things, but acknowledges that some palliative care professionals and institutions may choose to be involved in VAD.

Opponents of VAD claim that if everybody had access to top quality palliative care, there would be no need to for VAD. But even Palliative Care Australia acknowledges that not everyone can have all their pain and suffering alleviated by palliative care saying that: *"It cannot relieve all pain and suffering, even with optimal care."*

Pain and suffering can include psychological and existential suffering, as well as physical pain and symptoms. The Australian 'Palliative Care Outcomes Collaboration (**PCOC**) Report 2016' showed that of patients in the terminal phase of their illness, 4% had severe pain, 3% had severe psychological distress and 6.5% had other severe physical symptoms. Some patients at the end of life suffer unbearable physical symptoms such as inability to swallow, inability to talk, severe breathlessness, choking, weakness, incontinence, severe constipation, uncontrollable vomiting, seizures, delirium, agitation, insomnia, ulceration, discharge and odour. Suffering encompasses much more than just pain; loss of autonomy, being less able to engage in enjoyable activities and loss of dignity can deeply affect those at the end of their lives, but cannot necessarily be relieved by palliative care.

The annual reports from PCOC and numerous other sources, confirm that there is a small but significant number of dying individuals who experience severe end-of-life suffering that is unrelievable even with the best of palliative care.

For those patients with these "refractory symptoms" all that palliative care can offer them is "terminal" or "palliative" sedation which involves the patient being rendered unconscious. Clinical guidelines indicate that this should only be used when the patient is days from death and its use is at the discretion of the treating doctors.

VAD Advocates argue that the only difference between palliative sedation (which is lawful) and assisted dying is the time it takes the patient to die. Picture a person suffering from terminal prostate cancer who has ceased to eat and drink. They will eventually die of hunger and thirst as well as of the underlying condition and they may be given sufficient morphine and other drugs to keep them unconscious and free of agitation and fitting until they die. This may take a few days, a week, or more. Why is it not more merciful, once death is an inevitable end point, to give them access to an assisted death at the point where unconsciousness is induced, in which case the death will take only a few minutes instead of a week or more.

Opponents of VAD voice a fear that legalising VAD will have an adverse impact on delivery and access to, and funding for, palliative care. The evidence, both overseas and in Australia, shows that this is not the case.

In 2018, Palliative Care Australia commissioned an independent review by Aspex Consulting "Experience internationally of the legalisation of assisted dying on the palliative care sector Final Report 28 October 2018". It concluded that:

"An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced"

“Learnings from the implementation of assisted dying legislation in international jurisdictions reveal an increased focus on, and public policy attention towards, end-of-life care. It is noted that the implementation of legislation may drive a stronger focus on upholding patient choice and autonomy, and there may be opportunities to introduce system improvements in palliative care, either as a direct or indirect consequence of the planned implementation of assisted dying.”

First Nations People and VAD

Some opponents of VAD have suggested that legalising VAD will put Indigenous Australians at risk. They often cite the warnings issued by respected Indigenous leaders, Senator Pat Dodson and Noel Pearson.

However, no matter how eminent Senator Dodson and Noel Pearson are, they cannot claim to speak for all Indigenous Australians. Many Indigenous Australian support VAD and want the same rights as non-indigenous Australians if they become terminally ill.

In 2019, during the Western Australian debate on assisted dying, the Aboriginal Health Council of Western Australia (AHCWA) (which is the peak body for 23 Aboriginal-controlled health services across WA) made a submission to the Ministerial Expert Panel on VAD. AHCWA supported Aboriginal people having the same access to services, including VAD, as their non-Aboriginal counterparts. However, they insisted VAD must be delivered in a culturally appropriate way and, in a long submission, laid out how that could be done.

In July 2021 Wongatha-Yamatji woman, Mary-Ellen Parsons, who had suffered from motor neurone disease for six years, was the second person in Western Australia to access VAD. She was in palliative care, surrounded by her family, and at the end said, “I feel at peace within myself. I have the love of my children and they are saying ‘yes Mum, you’ve had enough.’”

During the Queensland VAD debate in September 2021, two Indigenous MPs in the Queensland parliament spoke in support of and voted for the VAD bill. Cynthia Lui, MP for Cook and Torres Strait Islander woman, spoke of the cultural practices around death in her community and how she saw no conflict between them and an assisted death. Leanne Enoch, MP for Algester, spoke of her family’s experiences of unbearable suffering at the end of life and said she though everybody should have the choice to ask for assistance to die when the suffering became intolerable.

Suicide contagion

It has been alleged by opponents that legalising VAD will send a message that society approves of or even encourages taking one’s own life. They claim that that suicide rates go up in jurisdictions where VAD has been legalised. This claim has been forensically examined by social researcher, Neil Francis, and has been shown to be false. For example, it has been , alleged that after VAD was implemented in Victoria in 2019 the suicide rate increased, but Francis has shown how that conclusion was based on a very selective use of the available data - Neil Francis Victorian suicide rate.

Another analysis by Francis on research conducted by three US academics on suicide contagion also contained selective and manipulated data and does not demonstrate that suicides increase in jurisdictions with VAD - Suicide contagion exposed.

CONCLUSION

Dying With Dignity NSW is of the view that there have been enough inquiries into VAD in Australia and that now is the time for New South Wales - the last state in the Commonwealth - to make it legal. It is clear that an overwhelming majority of the community wants the parliament to act, and this includes a majority of people with a religious faith.

Our organisation gets hundreds of phone calls a year from desperate patients or their loved ones who ring us up to share their predicament.

Dying with Dignity NSW has seen copies of the nearly over 27,000 emails sent to NSW MPs since 2017 - many have included testimonies of pain, suffering and desperation. These testimonies show us that, in spite of excellent palliative care, many people suffer intolerably and just wish for their lives to be over. They are not depressed, they are not suffering from a mental illness, they are not lonely or isolated. They are highly rational and have a very clear sense of their predicament, they just want to end it.

The evening before debate on the NSW VAD Bill commenced in the Legislative Assembly we received a copy of a message, sent to an MP, from a son who was at his dying mother's bedside as he wrote. Dated November 11, this is what he said:

> *My mother is currently struggling for her every breath in a palliative hospital ward on a mix of increasingly strong morphine and sedative doses to keep her pain free, calm and mostly unconscious.*
>
> *A week ago she chose against further invasive procedures, nutrition through PEG line feeding, and even saline drip hydration as it would all just prolong the physical, mental, emotional and social ravaging and absolute indignity that late-stage motor neurone disease has inflicted upon her.*
>
> *If voluntary assisted dying laws were available to her she would have chosen a few months ago to die with her dignity intact, on her own terms, with family members at her side.*
>
> *It was only 5 months ago, at 77 years of age, that a diagnosis of MND confirmed her absolute death sentence and turned a vibrant, social lady to something other than herself.*
>
> *The legislators should reflect on the possibility that this could happen to themselves or one of their loved ones and realise the complete humanity behind these laws.*
>
> *There is no such thing as suicide when you have no life left to live.*
>
> *Palliative care cannot help some dying people. You can give those people the right to control how their lives end? Do not abandon them to futile suffering.*

This submission was written by Dr Liz Jacka with contributions by Shayne Higson and Penny Hackett. All are directors of Dying With Dignity New South Wales.

If invited to attend a public hearing, Dying with Dignity NSW can be represented by:

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