



**Submission to the NSW Legislative Council
Committee on Law and Justice**

Voluntary Assisted Dying Bill 2021

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Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

Our core function is to influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e. self-advocate).
- To educate and inform stakeholders (i.e.: about the needs of people with a physical disability) so that they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

Recommendations

Recommendation 1

That the Bill sets the anticipated life expectancy in 16(1)(d) at 12 months irrespective of disease, illness, or medical condition.

Recommendation 2

That the class of person permitted to discuss VAD with an individual in all cases, be restricted to a medical practitioner.

Recommendation 3

That the NSW Legislation extend the timeframe between first and final requests to include a minimum wait time of 9 days, with the option to decrease the wait time if circumstances necessitate this.

Recommendation 4

That the right of an individual with disability to communicate and receive information via the most appropriate means for them be expressly articulated in the legislation.

Recommendation 5

That a translator is expressly defined as a someone who is accredited and certified.

Recommendation 6

That the Bill expressly provides for the use of electronic signatures and the approved form for the written declaration permit the use of accessible formats for persons with disability.

Recommendation 7

That supporting regulation provides examples of the types of actions that would ordinarily be expected to be within the scope of reasonable efforts by residential facilities and health care establishments to facilitate access to VAD both on premises and offsite.

Recommendation 8

That the legislation prescribes penalties for residential facilities and health care establishments which do not facilitate an individual's choice to access VAD or act outside the interests of the individual when facilitating access to VAD.

Introduction

As the peak representative organisation for over a million people with physical disability in NSW¹, the Physical Disability Council of NSW (PDCN) appreciates the opportunity to comment on the Voluntary Assisted Dying Bill.

Euthanasia is a difficult subject for many with disabilities due to its inherent connection to quality-of-life judgements. Many in society, including legislators, project their own ableist biases when assessing quality of life and it is the role of organisations such as PDCN to challenge the assumption that disability, in and of itself, reduces the quality of a person's life.

These assumptions, particularly when reflected across public policy, entrench prejudices about the lives and capacities of people with physical disability in the community, which in turn can cause damage to individuals with disability, affecting how society relates to them and how they think and feel about themselves.

It is important to note that the last two years have been a time of increased vigilance for the disability community. Public policy decisions regarding issues such as vaccine allocations and lockdowns have placed the health and welfare of people with disabilities, many of whom have increased vulnerability to the virus, at increased risk. The situation in the UK has been much more dire, with reports that people with disabilities and their families have been coerced to sign “do not resuscitate” directives to conserve ICU resources.²

The Voluntary Assisted Dying Bill tackles the issue of when our society as a collective considers an individual's life quality is reduced sufficiently that they should be permitted the choice to die. PDCN does not have a moral position on euthanasia as a concept and expects, in any event that NSW will follow the other Australian States and Territories in introducing an Act allowing euthanasia at some stage. Our interest is in ensuring that any Act that is passed within NSW meets the following criteria:

- *That it does not display inherent biases which undermine the value of the lives of people with physical disability*
- *That it contains rigorous checks and balances sufficient to ensure that an individual who chooses to die using a voluntary assisted dying process makes a fully informed decision of their own free will*
- *That the process allows the individual an opportunity to reflect on their decision, and potentially revoke the decision if circumstances change,*
- *And lastly, that the mechanisms of the process are accessible for those who may want to access assisted dying, and may require accessible communication to follow the prescribed process*

The underlying principles of the Voluntary Assisted Dying Bill

PDCN considers that the principles that govern the Voluntary Assisted Dying Bill are sound.

¹ Australian Bureau of Statistics (ABS) *Disability, Ageing and Carers Australia: Summary of Findings*, 24 Oct 2019 (with reference to NSW Data Cubes) < [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](#) > accessed 26 November 2021.

² Tapper, James, *Fury at 'do not resuscitate' notices given to Covid patients with learning disabilities*, The Guardian (Australian Edition), 14 February 2021 < <https://www.theguardian.com/world/2021/feb/13/new-do-not-resuscitate-orders-imposed-on-covid-19-patients-with-learning-difficulties> > accessed 26 November 2021.

We strongly support the first principle (s. 4(1)(a)), which requires all persons exercising a power or administering a function under the Bill to have regard to the principle that every human life has equal value. It is significant, and appropriate that this is the first principle guiding those involved in the execution of this legislation.

We also appreciate the inclusion of s. 4(1)(c), which recognises that it is essential to communicate information to an individual about their medical treatment in a way that they can understand. This is critical in ensuring equitable provision of information and support, particularly for people who have physical disabilities, including sensory disabilities, and may require alternative communication methods, such as braille, AUSLAN or the use of a communication device.

Equally we appreciate s. 4(1)(k) which provides all persons the right to be shown respect for their culture, religion, beliefs, values, and personal characteristics. We can see this general principle as a mechanism for protecting the rights of our members.

The eligibility criteria to access voluntary assisted dying

In general we support the eligibility criteria prescribed in the Bill. The legislators appear to have carefully considered the necessary requirements an individual would be expected to meet and appear to have taken significant effort to ensure that the right to life of people with disability is explicitly referenced, above and beyond s. 4(1)(a).

We note that there is no discretionary power for the Supreme Court to waive one or more of these pre-conditions based on an individual's specific circumstances, so it is important that the pre-conditions promote the inherent value of life, but do not unreasonably restrict an individual's right to access voluntary assisted dying (VAD) without a defensible rationale for doing so.

Express exclusion of disability as grounds to access voluntary assisted dying

One of the most positive aspects of the Bill is that it expressly provides that disability is not in and of itself a condition that enables a person to access VAD.

We strongly support that this has been made explicit in body of the legislation as the most effective way to ensure that this remains the case, both now and in the future.

At the same time, we consider that the Bill has carefully navigated a complication that can arise when an individual presents with a disease, illness or medical condition which causes a progressive decline in physical capacity, which on the balance of probabilities, will result in the individual's death.

Timeframes for anticipated life expectancy

The NSW Bill makes a distinction between neurodegenerative decline and other diseases, extending the timeframe of anticipated life expectancy to 12 months in the case of the latter.

We would seek to understand why such a distinction was made and question whether it is equitable to make distinctions between types of degenerative disorders. We also note that there could be a potential subtext that could be implied that that the life of an individual with neuro-degenerative decline is less valuable than the life of someone with full neurological capacity, or that neurodegenerative decline causes greater suffering than other forms of degeneration.

The other precursors set out in s. 16 – that the illness, disease, or condition is terminal and degenerative, that the individual can exercise free will and that they are experiencing suffering that cannot be relieved in a way that is tolerable to them, should be sufficient, without the need to refer to separate classes of degenerative conditions.

We prefer the QLD approach, which sets the anticipated life expectancy in all instances to 12 months.

Recommendation 1:

That the Bill sets the anticipated life expectancy in 16(1)(d) at 12 months irrespective of disease, illness, or medical condition.

The process to access voluntary assisted dying

We support a rigorous framework to ensure that:

- *The individual has access to all information they need to make an informed decision*
- *That the individual has the time to reflect on their decision and potentially withdraw consent if their decision changes*
- *Checks and balances are in place to ensure that the individual is making the decision of their own free will and*
- *That the individual has access to multiple health professionals to ensure that they are not unduly influenced by the biases of the health professionals they engage throughout the process*

In general, we broadly support the process of VAD as prescribed in the draft. The process serves the dual interests of the individual, applying checks and balances while at the same time creating a process that is clear, and not unduly onerous for the individual to access.

Medical practitioners should be the only persons authorised to discuss VAD with a patient

We agree with provisions which prohibit health care workers from initiating a discussion about VAD or suggesting VAD to a patient. We are uncomfortable that the NSW Bill permits health care workers to otherwise discuss VAD with patients, even if they inform the patients that palliative and treatment options available and should be discussed with their doctor.

We note the broad definition of health care worker in the Bill as being either (a) a registered health practitioner, or (b) another person who provides health services or professional care services in the Schedule, which includes a person who provides any of the following to another person under a contract for services:

- (a) *assistance or support, including the following—*
 - (i) *assistance with bathing, showering, personal hygiene, toileting, dressing, undressing or meals,*
 - (ii) *assistance for persons with mobility problems,*
 - (iii) *assistance for persons who are mobile but require some form of assistance or supervision,*
 - (iv) *assistance or supervision in administering medicine,*
 - (v) *the provision of substantial emotional support,*
- (b) *providing support or services to persons with a disability*

We are concerned that well intentioned health care workers who lack sufficient training or expertise may discuss VAD with a patient in a way that could influence a patient’s decision making and undermine the principles of the legislation.

It is vitally important that any professionals who do discuss VAD with a patient have the necessary experience, skills, and training to do this in a balanced and unbiased way. We would argue that this is recognised in the fact that coordinating and consulting practitioners for the purposes of legislation will be required to have practiced for at least 10 years, received specific training, and comply with any other requirements of the regulations.

We would recommend that discussing VAD in any capacity should sit with trained medical practitioners, or as an alternative, that health care workers only be permitted to provide specific approved (and accessible) resources on VAD on request.

Recommendation 2:

That the class of person permitted to discuss VAD with an individual in all cases, be restricted to a medical practitioner.

Timeframes between requests

We are hesitant to endorse the short timeframe in which an individual could complete the process of applying for, and accessing VAD.

While the process does provide checks and balances through using a coordinating medical practitioner, a separate consulting practitioner and final release of the VAD substance by the Voluntary Assisted Dying Board, an individual could make an initial request and then make their final request 5 days afterwards, or even sooner if the individual is likely to die or lose their decision-making capacity beforehand. We understand that the individual can revoke their decision at any time.

We are concerned that 5 days does not necessarily allow an individual sufficient time to reflect on their decision or to fully process the information they are required to be provided with to make an informed decision. We note that other States and Territories have adopted a slightly longer timeframe of 9 days between initial request and final request.

We would like to see a more generous minimum timeframe required between first and final requests, retaining the option to reduce this timeframe if it is reasonable to do so on account of the individual's specific circumstances – our preference is that the NSW Legislation aligns with other states and territories in requiring a minimum wait period of 9 days.

Recommendation 3:

That the NSW Legislation extend the timeframe between first and final requests to include a minimum wait time of 9 days, with the option to decrease the wait time if circumstances necessitate this.

The accessibility of the process

We appreciate that the Bill takes efforts to ensure that information about VAD is communicated to an individual in a way that they can understand (see for instance, s. 4(1)(c)).

We also appreciate that there are a variety of ways in which an individual seeking to access VAD can make their intentions known, for instance the use of gestures³ or via an interpreter⁴.

³ See s.19 (3)(b).

⁴ Section 19(4).

An express right for people with disability to communicate via their preferred method should be provided in the legislation

Notwithstanding this, PDCN would like to see an express requirement that all persons involved in the administration of VAD must consider the need for accessible communication methods for people with disability, and facilitate the right of any individual with disability to use their preferred communication method/s.

This request aligns with existing Australian international and domestic commitments towards people with disability and is informed by PDCN's practical experience that communication needs are usually interpreted in the context of CALD persons, not those with communication requirements relating expressly to disability.

In the context of our membership, people may have limited, or no capacity to speak, to hear, read or write, and may present with limited capacity to do one or more of these at any one time – for example, people who are deaf/blind. They may require the use of assistive technology to communicate such as story boards or text readers.

It is consistently reported to us that the communication needs of people with physical disability in a health care context are often ignored, or are unable to be resourced. In our experience it is standard practice for many health professionals to defer to using family members or carers to effectively “translate” or “speak for” an individual with disability related communication needs in lieu of securing assistive technology or using an interpreter.

We want to ensure that any individual with disability who seeks to access VAD has full participation, choice, and control across the entire process and that family members or other support persons do not become ad hoc mouthpieces as a matter of convenience. The first option should always be that the individual seeking to use VAD communicates their own wishes via the most appropriate means for them.

Recommendation 4:

That the right of an individual with disability to communicate and receive information via the most appropriate means for them be expressly articulated in the legislation.

Translator needs to be expressly defined as a certified professional

We appreciate that for some people, translators will be a critical aspect to this. We note that the legislation expressly permits communication with the assistance of a translator, which we support, however PDCN considers that there needs to be stronger caveats around this.

Currently, the name, contact details and accreditation details of translators are required when an individual uses an interpreter, which implies that the intention is that a professional accredited interpreter is always used, however this is not made explicit and we think that it should be, to avoid any confusion on the issue and prevent the scenario we have presented above.

Recommendation 5:

That a translator is expressly defined as a someone who is accredited and certified.

The written declaration

We understand that the written declaration will be in an approved form and will be required to be signed by the person seeking to access VAD.

It is important that the written declaration is accessible for people who have diverse communication needs, for instance that it can be read by an auto-reader, that it is provided in alternative formats, such as braille, or that the person seeking to complete the written declaration has access to a qualified interpreter. In some instances this may require the written declaration to be provided in an electronic format such as a PDF or a .docx.

We note that there is capacity for the individual to sign the form themselves, or have someone else sign on their behalf, in the presence of witnesses. We understand that in most instances an individual would provide their written signature, however, our members would benefit from the capacity to provide their electronic signature, in the presence of a witness, in the case that they cannot physically sign as an alternative to having someone sign on their behalf.

We are satisfied with the checks and balances in place to ensure that the individual's signature is their own, or that anyone else signing on behalf of the individual does so with the individual's consent.

Recommendation 6:

That the Bill expressly provides for the use of electronic signatures and the approved form for the written declaration permit the use of accessible formats for persons with disability.

Access to Voluntary Assisted Dying for those in residential facilities and health care establishments

A proportion of our members currently live in, or will transition to residential care or health care establishments at some point in their lives. Many of these facilities are privately operated and may not have the resources to administer VAD onsite. In other instances, there may be philosophical or religious barriers to certain facilities carrying out these processes. It is important that individuals who live in such facilities, either as permanent residents, or on a temporary basis, have the same right to access VAD as any other individual.

We believe that the NSW Bill has navigated this issue as well as can be expected, by requiring residential care facilities and health care establishments that do not administer VAD to facilitate an individual accessing those services either completely offsite or completely via outside personnel onsite.

Whilst the bill explicitly states that these facilities are expected to facilitate access to VAD, either onsite or inhouse, it will be necessary to specify what would be considered 'reasonable' in terms of arranging onsite access or transferring an individual offsite. For instance, in the context of facilitating onsite access to VAD, we would expect that the facility would provide a private consulting space, a private and comfortable place for the administration of the dying substance, and ensure that the individual has the usual supports and services they need to be able to effectively participate in any of these processes.

We are somewhat concerned that there will be a strong incentive for some facilities which do not provide VAD services on-site due to philosophical or religious objections to VAD to want to have VAD processes occur off-site and it is very important that this does not undermine the welfare of the individual who may be too frail to be transferred. It may be appropriate to set penalties for residential facilities and health care establishments that do not facilitate an individual's choice to access VAD or act outside the interests of the individual when facilitating access to VAD.

A further consideration should be whether it may also be appropriate for individuals to be able to participate in some aspects of the VAD process, for example making an initial request, via web consultation, noting that this may be an option for individuals who cannot be easily transferred, or are residing in remote or regional areas where a face-to-face visit with a suitably qualified medical practitioner may otherwise be difficult.

Recommendation 7:

That supporting regulation provides examples of the types of actions that would ordinarily be expected to be within the scope of reasonable efforts by residential facilities and health care establishments to facilitate access to VAD both on premises and offsite.

Recommendation 8:

That the legislation prescribes penalties for residential facilities and health care establishments which do not facilitate an individual's choice to access VAD or act outside the interests of the individual when facilitating access to VAD.

Concluding comments

We do not envy the responsibility of legislators in drafting this Bill, given the significant public interest it has generated and the polarised responses the Bill has already garnered across society. The contemplation of when it is appropriate – and legal – to end one's life, is both inherently a subjective decision, but also an objective one, since the line that is drawn in terms of eligibility must be determined with consideration of the fundamental principle that life is inherently valuable life, and society consensus on when the quality of life is sufficiently compromised to the point that an individual should have the choice to die.

Legislation which examines quality of life, has the potential to undermine the value of the lives of many groups of people – including people with physical disabilities, whose lives do not conform with mainstream norms Without sufficient checks and balances legislation that is supposed to give people the choice to end intolerable suffering could be used as a vehicle to inflict the exact opposite, with the worst possible consequences.

PDCN considers that the NSW Voluntary Assisted Dying Bill carefully navigates these issues and most importantly to us, contains strong safeguards to protect the rights of people with disability, via sound, rights-based principles that we can support.

Having said this, we do think that there are opportunities to further safeguard the interests of those seeking to access VAD and several ways of ways in which the Bill's principles might be realised more effectively.

PDCN would welcome the opportunity to engage further with the Committee regarding any aspect of this submission.