



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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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

**Submission Number: 077**

**Date Authorised for Publication: 14 December 2023**



## ACT INQUIRY INTO THE VOLUNTARY ASSISTED DYING BILL 2023

### Submission from Dying With Dignity NSW

December 2023

Written by Dr Elizabeth Jacka  
on behalf of Dying with Dignity NSW

Website – [dwdnsw.org.au](http://dwdnsw.org.au)

Dying With Dignity NSW  
PO Box 25  
Broadway NSW 2007

#### ABOUT US

Dying with Dignity NSW (DWDNSW) is the peak advocacy organisation which for many years campaigned for a change in the law to enable NSW residents to have greater control over their end of life primarily through the legalisation of Voluntary Assisted Dying (VAD). Now that VAD is a legal option in NSW, our work consists of monitoring the implementation of VAD in our state to ensure that is safe and equitable, and continuing to provide information and education to our large database of members and supporters and to the general public. We also see ourselves as having a role in and contributing to debates about VAD across Australia. With this in mind, we make this submission on the ACT's draft VAD legislation.

#### OUR SUBMISSION

We applaud the common sense and practical approach shown by the ACT government in framing the Voluntary Assisted Dying Bill 2023 (**ACT Bill**) and note with approval that it shows signs of having learnt from some of the problems and unforeseen consequences that exist in other Australian jurisdictions where VAD is legal.

Generally, we support the measures in the Bill and have only one quibble, which relates to the section on the obligations of entities (Section 99 ff.). We elaborate on this in what follows.

## *Eligibility Criteria*

A unique feature of the ACT Bill (in the Australian context) is that in Section 11 (1) it does not stipulate a time till death in its eligibility criteria. All other states specify that the person seeking VAD should have a life expectancy of either less than six months (or less than 12 months for neurodegenerative diseases) as in Victoria, WA, Tasmania, SA and NSW; or less than 12 months for all conditions as in Queensland. The absence of a numerical measure is a great improvement over the other arrangements as it caters for people who are suffering greatly from their disease and for whom there is no hope of recovery but who have the kinds of diseases (for example Parkinson's Disease, ALS, Multiple Sclerosis etc) for which medical practitioners cannot confidently predict when the individual has only 6 or 12 months to live.

We receive many calls from our members and from the public outlining cases of indescribable suffering, and loss of dignity and control. For example, the case of LM who had end stage Multiple Sclerosis (MS). LM had lost the ability to control nearly every part of her body after 40 years of living with MS. She had no movement below the neck but was in constant pain. She had no control of her bladder and bowels and was completely reliant on carers. LM was a courageous campaigner for VAD law reform but unfortunately she died before the VAD legislation passed in NSW. However, if she had lived to see VAD become legal, she may not have qualified for assistance to die because her doctors may have found it difficult to confirm when she had less than 12 months to live. There are many such cases so the ACT VAD legislation, if passed in its current form, will provide a peaceful and compassionate end of life for ACT residents in such situations. The requirement that people are suffering from a disease that is "advanced, progressive and likely to cause death, and that they are "suffering intolerably" is surely all that is needed to give people the relief they seek.

There are many other examples of people with unbearable, end-of-life suffering who desperately want to access VAD but who may not meet the very narrow eligibility criteria of having less than 6 months to live. The only other state that has provided an avenue for these people in their VAD legislation is Tasmania. In that state, a timeframe exemption is possible through an application to the VAD Commission. The first annual report from Tasmania shows that one person successfully achieved an exemption and died via VAD. DWDNSW applaud the ACT for providing the most effective and compassionate option for people such as LM.

### ***Suffering is both mental and physical***

The ACT Bill makes it explicit that suffering can be both physical and mental. The definition of suffering in Section 11 (3) is highly nuanced and allows that a person's suffering can be exacerbated by co-existing medical conditions that, by themselves would not qualify for VAD, but which taken together with the primary disease, can add to their terrible suffering and anguish. In Section 11 (3) (ii) it also recognises the notion of anticipatory suffering, that is, the dreadful recognition that it's only going to get worse, and the fear that is caused by that recognition, as well as the suffering caused by the treatment of the disease. This complex understanding of the dimensions of suffering is to be commended.

### ***Decision about administration of the prescribed substance***

We support the provision in the ACT Bill that the person seeking VAD may choose to self-administer or to have a health practitioner administer the substance, and that the decision can be made in consultation with the coordinating practitioner (Section 42(2)(b)). Very sick people who are frail and vulnerable do not need the extra anxiety of wondering whether if they self-administer, something might go wrong, and they would end up even worse off.

### ***The categories of health practitioners envisaged by the ACT Bill***

DWDNSW applauds the fact that, no doubt having analysed what is happening in some other states where VAD is legal, the ACT government decided to broaden the category of health practitioners who can participate in the VAD process. Unlike in Victoria, there is no requirement that one of the assessing doctors be a specialist in the person's disease. This requirement has made the Victorian system very cumbersome and has limited people's access to VAD, especially in regional and rural areas. Combined with the assumed ban on telehealth, this requirement results in inequities between capital cities and the "bush".

In addition, the ACT Bill envisages that one of the assessing health practitioners can be a Nurse Practitioner (Section 92) and in its use of the term "health practitioner" in Sections 13 and 14 and Sections 83ff does not appear to require that such a person needs to be a "medical practitioner".

### ***Health practitioners able to initiate discussions***

Section 152 of the ACT Bill sets out the conditions under which health practitioners may initiate discussions about VAD with patients. Medical practitioners in Victoria have expressed their frustration with the ban that exists in that state which rather artificially prevents them from explaining to patients that VAD is one of the options they can choose at the end of their life. The proposed ACT legislation would allow medical practitioners, nurse practitioners and other health professionals to raise VAD with the patient on the condition that the patient is suffering from a severe condition likely to cause death and that they explain all the options, including palliative care, or (in the case of health professionals who are not doctors or nurse practitioners) make the patient aware that palliative care and other options are available (Section 152 (2)). This is surely a compassionate and common sense approach.

### ***Conscientious objection***

The proposed ACT legislation very properly allows that individual health practitioners who have a conscientious objection (CO) to VAD can elect not to participate in any stage of the process. It also envisages that some entities may be unwilling to allow VAD within their precinct but places clear obligations on them not to impede and individual's access to VAD if that is what they want. Sections 99 - 101 set out these obligations. If a patient asks about or requests VAD a facility must provide that patient with details of the Navigator Service (Section 99). It must also (Section

100) allow access to their premises for a “relevant person” who will provide information about or access to VAD if that is “reasonably practical”.

DWDNSW has some reservations about the term “reasonably practical” which is far from precise and would seem to allow a facility to invent any reason at all why it would not be “reasonably practical” to allow a VAD practitioner to enter their premises. For example, a facility could say that they cannot allow such access because it would upset the other residents. Is this a sufficient reason to assert that the access would not be “reasonably practical”? Even if it were the case that some residents might be upset, surely the rights of the person wishing to access VAD must be respected. Who will arbitrate the concept of “reasonably practical”?

Section 102 of the proposed ACT Bill does place an obligation on an entity that does not want to allow VAD on its premises that, if the patients cannot be transferred to another institution without severe harm to the patient, the entity then must allow access for relevant persons to their premises. But there is a considerable amount of delay and paperwork involved in this which would appear to be to the detriment of the person seeking VAD.

### ***Residency requirements***

As with much of the ACT Bill, the section on residency requirements exhibits a good deal of common sense. It allows people who do not live in the ACT to have access to the ACT VAD scheme if they have some sort of legitimate connection to the ACT, such as working or having medical treatment in the ACT, having relatives and carers in the ACT or is a First nations person with connections to country within the ACT. These are sensible and compassionate measures.

### ***Review of the legislation***

The ACT Bill proposes a review of operations three years after commencement (Section 159) and obliges the review to include examination of three issues, (i) residency requirements, (ii) access for minors and (iii) the use of advance care directives for dementia patients. We applaud the boldness and vision shown by the ACT government in being prepared to tackle these difficult issues, in particular, the one about dementia.

DWDNSW has so many communications with supporters and the public about dementia. Many cannot understand why such a grievous disease, which is a leading cause of death in Australia, cannot be captured with a VAD scheme. People watch their loved ones suffer much pain and indignity from dementia and cannot understand why we cannot help them. Dementia sufferers themselves voice their desire to be helped as those with purely physical illnesses can be helped. DWDNSW understands the critical importance of capacity and consent for VAD, and of voluntariness and freedom from coercion. But we all know that dementia is going to become a bigger and bigger problem over the next few years; the numbers are growing, ironically, because we are better at keeping people alive for longer. We are increasing quantity of life, but not necessarily quality of life. This must be faced up to and the ACT government has bravely declared it will be looking at this issue, even if other governments hide from it.