Dying with Dignity
New South Wales

*Non-profit company
limited by
guarantee*

August 28 2205

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Subject: Parliamentary Inquiry Into Voluntary Assisted Dying

To : the Legal and Constitutional Affairs Committee

From: Dying With Dignity NSW

Please find attached a copy of the submission this organisation made in 2023 to the Expert Advisory Panel. We would like to tender this as a formal submission to the present inquiry.

Perhaps the most important part of our original submission was our advice about the problems caused by having a six-month prognosis for eligibility. We still believe that having such a restriction causes immense suffering to those who are at the end of life and whose quality of life, due to age, frailty and many concurrent hopeless medical conditions is poor.

We continue to support the other positions taken in that submission.

Yours Sincerely

Penny Hackett
President
Dying with Dignity NSW

Northern Territory Government: Inquiry into a framework for Voluntary Assisted Dying in the Northern Territory

Submission to the Expert Advisory Panel

From Dying with Dignity New South Wales

Who we are

Dying with Dignity NSW (DWD NSW) is a law reform not-for-profit organisation which for many years has campaigned for a change in the law, so NSW residents have control over their end of life. Now that this law has passed in NSW, our role is to support and monitor its roll-out and help to ensure that it is implemented effectively and safely and is accessible to all residents of NSW no matter where they live. In addition, we continue to keep abreast of developments and research into voluntary assisted dying (VAD) in Australia and around the world to make sure people are educated and informed about VAD based on evidence and facts.

As well as performing these key functions, we promote the use of Advance Care Directives to assist with patient control at the end of life and we provide our members and supporters with information about changes in the legal climate for end of life, both in Australia and overseas. We also take a significant number of queries and requests for information from our members and supporters and the public, and those extensive conversations mean we have developed our expertise in choice at end of life. We are a not-for-profit organisation limited by guarantee and we rely on membership, donations and bequests to continue our work.

DWD NSW supports the intention of the Northern Territory (NT) Government to pass a law to allow VAD in the territory. We believe that Australia already has some very good models of VAD particularly those of Queensland, Tasmania and New South Wales. In what follows, we address the most central questions canvassed in the Discussion Papers.

Who should be able to access VAD?

We agree that only those with decision-making capacity who are free from coercion should be able to access VAD. We recognise the tragic plight of those suffering from various forms of dementia, whose suffering may be acute, and who have no hope pf recovery. However, at this stage of development of VAD in Australia, we believe it would be premature to allow people to make advance requests for VAD. It is our view that in the medium-term future the issue of dementia and the right to access VAD will need to be addressed, and we suggest that the NT keeps it on its agenda for future reviews of the legislation.

To access VAD in the NT we believe that a person should have a serious and progressive disease which is causing them unbearable suffering and for which there are no remedies available that are acceptable to the person. On the question of the definition of suffering, we believe it is arbitrary to exclude psychological and existential suffering. The distinction between these kinds of suffering and so-called physical suffering is ill-defined, so it is the patient who decides if their suffering, of whatever kind, is intolerable or unbearable. If there are eligibility conditions that recognise physical suffering but do not recognise psychological and existential suffering, this will require doctors to decide the kind of suffering the patient has and whether the patient is suffering enough, a situation that may deter physicians from participating. We would urge that the Tasmanian approach is the most humane.

Time until death

Most jurisdictions in Australia (and many overseas) have 6 months until death as the timeframe for terminal illnesses and 12 months for neurodegenerative diseases. Queensland specifies 12 months for all conditions, including terminal illnesses such as cancer. The experience in many parts of Australia has taught us that often the requirement for 6 months until death has prevented eligible people from accessing VAD because they were unable to complete the sometimes-onerous application before their death. The delays in securing approvals, as we know, can be because the person lives in a regional area and has trouble accessing enough eligible doctors, or it can be because in the final stage of their illness, a person becomes too feeble to undertake the travel needed to access specialist medical practitioners. For this reason, we would urge the NT at a minimum to adopt the 12-month period.

We would also suggest consideration be given to having no specified time frame, following the lead of the proposed ACT bill. What is proposed in the ACT is the following.
A person is eligible for VAD if the person:

- has been diagnosed with at least one relevant condition that, either on its own or in combination with one or more other diagnosed conditions, is:
    - advanced: an individual's relevant condition(s) is advanced if the individual's functioning and quality of life is in decline, and any treatments that are available and acceptable to the individual lose any beneficial impact, and the individual is in the last stages of their life; and
    - progressive
    - expected to cause the person's death.

- Is suffering intolerably in relation to their conditions. An individual is suffering intolerably in relation to their relevant conditions if persistent suffering (whether physical, mental or both) that is, in the opinion of the person, intolerable is being caused to them by:
    - One or more of their conditions or combination of them, and/or the treatment they have received, or
    - The anticipation or expectation, based on medical advice of suffering that might be caused by any of the above, or
    - A medical complication that will or might result from any of the above.

Such a nuanced definition of suffering can include cases, for example, of extreme aged frailty, where a person is completely helpless and has multiple conditions, that by themselves, are not fatal, but when added together, result in an existence of utter misery and futility. It also includes those extremely debilitating neurodegenerative diseases where a person can be unable to move their limbs, unable to breathe unaided, have difficulty swallowing and talking and be totally dependent on 24-hour care. They may spend several years in what they consider intolerable suffering and from which there is no prospect of anything except a slow painful decline.

Residency requirements

On this question, we would argue that now that every state in Australia has passed a VAD law, the residency requirements make little sense. In the NT with its high proportion of Indigenous residents, it is possible that an Indigenous person born in the NT but living in another state might wish to return to the NT at the end of their life and access VAD on country. This should be possible. Furthermore, experience in Australia shows that there are cases where a patient lives, for example in Queensland, but their family lives in the NT. If this patient moves to spend their last days with their NT family they might not qualify for access to VAD in the NT, even though they would have qualified in Queensland, a situation which is an absurdity. In this case the person ought to be able to apply for VAD in the NT.

On the question of whether a person must be an Australian citizen or permanent resident to qualify, we would argue that anyone who has been residing in Australia for a considerable amount of time (two years) and who has been receiving medical treatment within the Australian health system should have the right to apply for VAD. It makes no sense to treat them up to their very last hours and then to suddenly say: “Sorry VAD is one health service you can’t have; you just have to suffer”.

Minimum age

On the question of the age, we support the minimum age for access to VAD being 18 years. We do understand that mature minors could have the capacity to make an informed decision about VAD however we believe that it is a very complex matter on which there is as yet, not a large body of evidence, and that it would be premature to allow access to minors at this time. We strongly believe allowing VAD for minors could become a focus for opponents to derail the legislation.

The process

The process as set out in Discussion Paper 3 is a suitable way of proceeding. We commend giving people choice on whether to self-administer or have a health practitioner administer. We support the suggestion that the reporting requirements during the actual process of assessment through to the final declaration are practical and simple to follow. The alternative, to submit paperwork at each stage, could delay the process for people and add to their distress and suffering.

We don't have to tell the Panel that the NT is a vast and sparsely populated place, and outside of Darwin and perhaps one or two other centres, finding enough qualified and trained VAD practitioners is vital. We recommend that Nurse Practitioners be involved in the process, certainly for the administration of the substance if the person chooses practitioner administration, but also perhaps for earlier stages. This could be especially relevant in remote Indigenous communities. Victoria is the only state that mandates that one of the assessing doctors be a specialist in the disease. Evidence suggests this is a roadblock for people especially in regional, rural and remote areas. We recommend Nurse Practitioners with a minimum 5 years' practice.

Tele-health consultations

A ban on tele-health consultations for VAD will constitute a huge barrier for patients in the NT. The large distances and shortage of medical practitioners may mean that if tele-health is not permitted, some people who may qualify for VAD, will just miss out. This is inequitable when people in the major cities can access VAD much more easily. Some states have taken the approach of putting a clause in their VAD Acts that say that a VAD death is not suicide, thus attempting to circumvent the problem of the carriage laws. This appears to have been thwarted by a recent Federal Court ruling which said that for the purposes of the carriage laws, VAD is suicide. This isa most disappointing result. We recommend following all the states except Victoria and include a clause on this in the NT bill. At the same time the Attorney General, along with counterparts in the states, must campaign for Federal legislation to repeal the carriage laws.

Medical practitioner initiated discussions

DWD NSW believes strongly that a health practitioner (not just doctors) ought to be able to initiate discussion of VAD with a patient, who is nearing the end of their life and evidently suffering. It is very common, as we know, for patients who are in extremis to ask their treating practitioners for a way out. They will say things such as “I can’t go on, can’t you help me.” How artificial, not to mention heartless, would it be to refuse to inform the patient that VAD is a legal option in their state or territory. Doctors in Victoria, the state with the longest experience of VAD, have reported that it goes against their values as doctors and prevents them from acting in their patient’s best interests. This will be discussed in Victoria as part of the current review of VAD. Obviously when VAD is mentioned, all the other options for treatment and palliative care should be discussed.

Role of the health services

DWD NSW believes that a health service, such as a hospital or hospice should be able to declare a conscientious objection to participating in VAD however it should also mean the following is adopted: (i) so patients have choice it should make it clear in all its marketing material and on its website that it does not permit VAD on its premises;

(ii) if a patient enquires about VAD the institution should provide information material about it and make them aware of the existence of the Navigator Service;

(iii) it should permit medical practitioners on to its site for the purposes of assessment of patients who are seeking VAD,

(iv) on the understanding that it will not permit an assisted death on its premises, it should facilitate the transfer of the patient to another site.

However, we do not support nursing homes or retirement villages, where people have been residents for sometimes years, and which has effectively become their true home, having the right to refuse to permit VAD on their premises. In this case we believe that such an institution that has become a person’s home (they have paid a lot of money to make this the case) should allow the full process of VAD on their premises in the privacy of a single room or designated area away from other residents and with provision for family to be present. We recommend the NT legislation includes this so people wanting to access VAD at home in nursing homes and retirement villages can do so. If this isn’t possible then we propose nursing homes and retirement villages fall under the same obligations as outlined above for hospitals and hospices.

Death certificates

We can't see a sensible objection to the approach in Victoria and New South Wales of having both a cause of death (eg cancer) and a manner of death (VAD) listed on the death certificate. Whilst we appreciate that some family members may consider this description as placing stigma on their loved one, and by extension, themselves, we believe it to be a very dishonest approach.

Oversight, reporting and compliance

DWD NSW believes that the procedures, frameworks and compliance already instituted in the states provides adequate oversight, reporting and compliance. DWD NSW does question whether this compliance reporting should be prospective or retrospective. The experience in Victoria suggests that having to refer the paperwork, once completed, to a government body for further checking is complete overkill. No good purpose is served by this additional step, and it just helps to delay an already lengthy process and cause further unnecessary suffering for the patient.