Voluntary Assisted Dying Bill 2021

Your Questions Answered

Responses to frequently asked questions from Members of Parliament

1) Who is eligible to access voluntary assisted dying under the New South Wales bill?

Only adults diagnosed with a terminal illness that will cause death within six months, or 12 months for neurodegenerative conditions, and who are experiencing suffering as a result of the condition that cannot be tolerably relieved will be able to access voluntary assisted dying. There are strict provisions to ensure the person has the capacity to make and understand the consequences of a voluntary assisted dying decision and that they are acting voluntarily and without pressure or duress.

There are also residency requirements that limit access to Australian citizens, permanent residents or people who have lived in Australia for at least three continuous years, and who ordinarily reside in New South Wales.

2) What protections exist to stop a vulnerable person from being pressured into seeking voluntary assisted dying?

Multiple overseas and Australian inquiries have found that there is no evidence of pressure on people who have a terminal illness to end their lives sooner where voluntary assisted dying laws operate. Notwithstanding, the bill provides a number of robust safeguards.

Two experienced doctors will need to independently assess a person seeking assistance and independently come to the conclusion that they are acting voluntarily and without any form of pressure or duress. The bill gives a very comprehensive definition of pressure and duress covering coercion, intimidation, threats and undue influence and arguably provides the strongest definition in all Australian voluntary assisted dying laws. All doctors will be trained in recognising the signs of pressure or duress and if they are unsure whether a patient is acting voluntarily, or whether pressure or duress could be a factor, they must refer the patient to someone who has the skills and training to make a determination. This could be a psychiatrist, psychologist, social worker or the police for example, determined on a case-by-case basis depending on the circumstances.

The bill creates new offences for pressuring someone into making an application for assisted dying with strong penalties including seven years' imprisonment for inducing another person to request access to voluntary assisted dying. If there is concern that someone is not acting voluntarily or that pressure or duress is playing a role, an appeal can be made to the NSW Civil and Administrative Tribunal, during which there is a pause in the application process.

Voluntary assisted dying will only be available to someone who is at the end stage of a terminal illness, whose suffering is beyond any meaningful medical help. At this stage, people are already able to make a range of life or death decisions including on whether to withdraw treatment, assisted ventilation, renal dialysis, nutrition or hydration. These decisions occur every day without the safeguards included in this bill.

3) What about protections for people who are terminally ill who might feel that they are a burden to their family or carers?

The bill is designed to give people control over the timing of their death at a time when their death is imminent and they feel they have suffered enough.

Safeguards exist to ensure the person cannot make a decision based on fleeting feelings. The eligibility criteria include a need for the person's request to be enduring which will be assessed by two independent medical practitioners. The process itself is designed to give the person time to think about their decision. The person must repeat the request on three separate

occasions, including in a written declaration signed by two witnesses independent of the voluntary assisted dying doctors, and there is a mandatory five-day cooling off period between the first request and when assistance can be given.

4) What training will health professionals receive?

Before a medical or health practitioner can accept either a first request for assistance, a referral for a consulting assessment, or the role of the administering practitioner, they must have undergone mandatory training, along with having specific statutory qualifications and experience.

The training will cover practitioners' legal obligations, the strict eligibility criteria and how to assess whether someone meets those criteria. The bill expressly requires training to cover how to identify signs of pressure or duress. There is scope for the Health Secretary to approve mandatory training for other health practitioners administering voluntary assisted dying services.

A doctor will only be able to act as a coordinating or consulting practitioner if they are a specialist with at least one year's experience as a specialist, or are a general practitioner (GP) with at least 10 years' experience as a GP, consistent with Western Australia. There are also provisions for overseas-trained specialists. A health practitioner will only be able to act as an administering practitioner if they are eligible to act as a coordinating practitioner, are a GP with at least five years' experience, are a nurse practitioner, or are a registered nurse with at least five years' experience.

5) Will health professionals be able to conscientiously object?

Voluntary assisted dying is a voluntary process for all participants at all stages. There is no obligation on health practitioners to provide assistance and the bill includes express provisions to confirm that all health practitioners are able to refuse to provide assistance due to a conscientious objection or any other reason. They can refuse to participate in any part of the process including in the request and assessment process; prescribing, supplying or administering the substance; or being present at the administration of the substance.

6) What role do specialists play?

Requiring the coordinating practitioner or the consulting practitioner to be a specialist would present significant barriers to access in the scheme, especially in regional and remote areas. Most specialists are unlikely to have time to do the training, do not do home visits and are difficult to get timely appointments with.

In Victoria where either the coordinating or consulting practitioner must be a specialist, very few specialists have done the training and only a tiny number of those are in regional areas. The remoteness of New South Wales extends much greater than in Victoria.

Where a coordinating or consulting practitioner is not sure if a person meets an eligibility criterion, there is a requirement for the practitioner to refer the person to a suitable specialist, which is consistent with good medical practice. Most people with a terminal illness will have their treatment and care managed by a general practitioner who will refer them to specialists for advice.

7) What role do psychiatrists and psychologists play?

All doctors must assess decision-making capacity for their patients' healthcare choices as a part of the everyday care they provide. They must ensure a person understands the consequences and can provide informed consent in all treatment whether it is to start medication or undergo life-changing surgery. If they fail to do so, they face disciplinary action.

Under the bill, if a coordinating practitioner or a consulting practitioner has any concern that a person does not have decision-making capacity to make a voluntary assisted dying decision, they must refer the person to someone who has the skills and training to make an assessment. The appropriate person may be a psychiatrist or a psychologist if the doctor suspects the person is suffering from a mental illness, however it may be a geriatrician if the doctor suspects the person is suffering from early onset dementia, or a neurologist in the case of a neurological impairment.

8) What provisions are there for telehealth?

The bill provides for telehealth but this is limited to circumstances that do not conflict with Commonwealth laws, which currently prohibit the use of a carriage service, including telephone and internet, to counsel, promote or provide instruction on suicide. While the bill specifically states that voluntary assisted dying is not suicide, it can only legislate within New South Wales and it is unclear whether the federal courts and authorities will interpret voluntary assisted dying as suicide. Until clarification is provided, doctors need to take a cautious approach, using telehealth only to determine medical and administrative aspects of eligibility without detailed discussions on voluntary assisted dying and its consequences. Determining whether a person has decision-making capacity with regard to voluntary assisted dying through telehealth will be limited given the need to ask questions and specifically refer to the outcomes of a voluntary assisted dying decision.

9) How is decision-making capacity determined?

To access assistance, the bill requires a person to have decision-making capacity in relation to voluntary assisted dying. This means the person must understand and remember the information, advice and matters involved in a voluntary assisted dying decision and its effect, and weigh up the factors to make a decision. They will also need to be able to communicate that decision in some way. Essentially the person needs to understand the consequences of making a voluntary assisted dying decision.

People exercise decision-making capacity on various matters every day, from what to eat at breakfast to commencing life changing treatment. If a doctor suspects that there are factors that could interfere with a person's ability to make a decision on voluntary assisted dying, such as because the person is depressed, or is showing symptoms of dementia, they must refer the person to someone who has the skills and experience to assess the person and make a determination. The relevant professional will be different depending on specific circumstances and could for example be a clinical psychologist, a neurologist or a geriatrician.

People who lack decision-making capacity, such as people suffering from dementia, or who lose decision-making capacity during the process are not eligible for voluntary assisted dying.

10) Who can administer the substance?

After going through the extensive request process, a person assessed as meeting the eligibility criteria will be able to choose between administering the substance themselves or having a medical practitioner administer it for them. In most cases, the administering practitioner will be the coordinating practitioner, however the role can be transferred to another person who meets the eligibility criteria to be a coordinating practitioner, or who is a GP with five years' experience, a nurse practitioner, or a registered nurse with five years' experience. A person must have completed the mandatory voluntary assisted dying training to act as an administering practitioner.

11) How does the bill stop the substance from getting into the wrong hands?

A number of safeguards are set out in the bill. Firstly, any person in possession of the prescribed substance must keep it securely stored in a locked box as set out in the regulations. The provisions follow the Victorian legislation where a petty cash box is required.

Not all pharmacies will provide voluntary assisted dying substances with the bill requiring suppliers and disposers to be authorised by the Health Secretary. Victoria has centralised voluntary assisted dying pharmacy services in a tertiary hospital (The Alfred) and operates state-funded outreach services across the state to ensure a small team of pharmacists who are trained and experienced provide services. Western Australia is implementing a similar approach.

The coordinating practitioner must provide the prescription directly to the authorised supplier, ensuring that the prescription cannot be copied and that substances used to induce death do not become public. The authorised supplier must supply the substance directly to the patient or their contact person or agent and provide the Voluntary Assisted Dying Board with that person's details.

If a person makes a self-administration decision, they cannot get a prescription unless they appoint a contact person. The contact person must return any unused substance to an authorised disposer and there are substantial penalties for failing to do so.

The bill sets up a robust framework of paperwork that is lodged with the Voluntary Assisted Dying Board which enables the board to trace the substance from prescription, dispensing, use and disposal.

12) What is the substance?

The bill authorises the coordinating practitioner to prescribe the voluntary assisted dying substance from a list approved by the Health Secretary. The type of substance will depend on the person's illness, disease or medical condition and whether the person self-administers or gets assistance from an authorised health practitioner.

13) Will voluntary assisted dying compete with palliative care?

Palliative care and voluntary assisted dying are two distinct processes. Most people access palliative care before they seek voluntary assisted dying, aiming to maximise their quality of life and reduce pain and suffering. Voluntary assisted dying is available when palliative care and treatment can no longer relieve suffering in a way that is tolerable to the person.

Australia has one of the best palliative care systems in the world but even the best palliative care cannot help everyone or alleviate all suffering. Palliative Care Australia estimates that four percent of patients are beyond its help and there is evidence that palliative care cannot effectively control 10 to 20 percent of end-of-life symptoms.

14) Why is there a longer prognosis for neurodegenerative conditions?

The six-month end-of-life trajectory does not reflect the suffering experienced in non-malignant neurodegenerative conditions, which can for many be intolerable closer to the 12-month trajectory. The average life expectancy for people with motor neuron disease for example is two and a half years. People with motor neurone disease lose their fine motor skills relatively early in the disease and commence tube feeding and ventilation before they reach a six-month life expectancy. They can lose the physical ability to self-administer and need time to consider their options.

15) How does the bill treat people living in border communities?

The bill restricts voluntary assisted dying services to people who ordinarily reside in New South Wales, based on having lived in the state for at least 12 months. This provision will ensure that New South Wales healthcare services are used by New South Wales residents.

However the bill also recognises that there will be people who do not meet these requirements and would suffer unfairly if denied access to voluntary assisted dying services in this state. As such, the bill gives the Voluntary Assisted Dying Board the power to grant an exemption where a person has a substantial connection to the state such as someone who lives close to the border or has moved to New South Wales to be closer to family for care and support for their terminal illness.

16) If people can reapply after being assessed as ineligible, won't they just doctor-shop?

The bill allows a person who has been assessed as ineligible to reapply for assistance because their circumstances may have changed. It is not uncommon for someone to cease medication that previously interfered with their decision-making capacity or for their prognosis to deteriorate rapidly such as after they develop an infection. It would be unfair to exclude someone from seeking assistance on the basis that they have previously been assessed as ineligible.

The bill includes safeguards against genuine doctor shopping. Two doctors must independently assess a person as eligible for each application request the person makes. The extensive reporting regime in which doctors must submit forms to the Voluntary Assisted Dying Board at every step of the process, ensures that there is oversight when a person makes multiple applications and the board cannot authorise a doctor to issue a prescription until all forms have been received. The board can refuse to issue a prescription authorisation if it is concerned the person is ineligible.

17) Why is the scope of the bill so narrow?

The bill intentionally has a narrow scope. Its aim is to help the minority of people who are at the end of their life and for whom palliative care can no longer provide relief from suffering. It cannot help people who do not have a terminal illness or who are unable to make an informed decision. The bill's scope is consistent with legislation in other states.