

VOLUNTARY ASSISTED DYING BILL 2021

Legislative Assembly Second Reading Debate – copied from Hansard 14 November 2021

First Reading

Bill introduced on motion by Mr Alex Greenwich, read a first time and printed. Second Reading Speech

Mr ALEX GREENWICH (Sydney) (10:00): I move:

That this bill be now read a second time.

On behalf of 28 members across both Houses, I proudly introduce the Voluntary Assisted Dying Bill 2021. The bill will create a safe framework for people who are in the final stages of a terminal illness and who are experiencing cruel suffering that cannot be relieved by treatment or palliative care to be provided with the choice to die peacefully, with dignity and surrounded by loved ones. New South Wales is fortunate to have one of the best palliative care systems in the world. It has brought great comfort to thousands of people with a terminal illness. Palliative care funding in this State has grown, and that growth must continue with this bill. It is my hope that the bill will increase demand for palliative care as more people discuss their end-of-life options with doctors. However, the best palliative care cannot alleviate all end-of-life suffering for all people.

Palliative Care Australia estimates that 4 per cent of patients are beyond its help, and there is evidence that palliative care cannot effectively control 10 per cent to 20 per cent of end-of-life symptoms. The 2016 *Palliative Care Outcomes Collaboration* report found that 4 per cent of terminal patients had severe pain and 6.5 per cent had other severe physical symptoms. A majority of doctors surveyed by the Australian Medical Association in 2016 reported treating patients who palliative care could not help. The stories within those statistics are heartbreaking. I know all members have heard from the loved ones of someone who died a slow and agonising death—stories of people who died choking on their bodily fluids and slowly suffocated to death, whose tumours grew so large they broke bones, who were unable to swallow, whose bodies were covered in painful open sores, whose organs shut down causing symptoms like violently regurgitating faeces, and whose bodies slowly wasted away.

Without the option of voluntary assisted dying, people who receive bad news about their terminal prognosis live in fear, and sadly the rate of death by suicide among people who are terminally ill is high. Data from the National Coronial Information System shows that in this State at least 20 per cent of suicides in people over 40 are associated with a terminal illness. That accounts for over 10 per cent of all suicides. Those hardworking police, paramedics and health workers on the front line do not find those statistics surprising. They regularly attend call-outs where there have been suicides and suicide attempts by people who are terminally ill. That is why the Australian Paramedics Association, the Police Association, the Health Services Union [HSU] and the NSW Nurses and Midwives' Association strongly support the bill.

A modern, advanced healthcare system should not leave anyone to feel that their only options are either a slow, cruel, agonising death or a violent and lonely suicide. Some people choose to starve and dehydrate themselves and cease vital treatment like dialysis to speed up their death. However, this can take weeks and cause severe symptoms, discomfort and distress. People who have a terminal illness deserve better. The Voluntary Assisted Dying Bill 2021 will provide a safe framework for patients whose death is imminent and whose pain and suffering has become unbearable to get help to end that suffering at a time of their choosing. It follows the same eligibility, process and safeguards as bills passed in all other States.

I turn to the provisions of the bill. The bill meticulously sets out in detail the principles that underpin the legislation, including the eligibility criteria to access voluntary assisted dying; the steps that a person must take before they can get access; the protections for healthcare workers, including to ensure that they can conscientiously object; the rights and responsibilities of institutions and facilities that refuse to provide voluntary assisted dying services; the eligibility criteria of other persons involved in the process such as

doctors, nurses and witnesses; the make-up of a voluntary assisted dying board; the option to request a review through the Supreme Court; offences; and requirements to review the legislation.

To be eligible to receive voluntary assisted dying, a patient must be at least 18 years of age and an Australian citizen, permanent resident, or have been living in Australia for at least three continuous years and ordinarily reside in New South Wales. A patient must be diagnosed with at least one disease, illness or medical condition that is advanced, progressive and that, on the balance of probabilities, will cause death within six months or, in the case of a neurodegenerative disease, within 12 months. The disease, illness or medical condition must cause suffering to the patient in a way that cannot be tolerably relieved. Importantly, the patient must have decision-making capacity to make a voluntary assisted dying decision. In seeking assistance, the patient must be acting voluntarily and without any pressure or duress. Pressure or duress includes coercion, intimidation, threats and undue influence.

The bill also requires a patient's request for voluntary assisted dying to be enduring. It sets out in detail each step that a patient must take before they can access voluntary assisted dying, from the first request to disposing of any unused substance. Each step must be recorded in specific forms that are sent to the voluntary assisted dying board. The process is entirely voluntary. There is no obligation on a patient to continue and the patient is told multiple times throughout the process that they can withdraw at any time. The first step is for the patient to make a first request to a doctor. The doctor must either accept or refuse the request. A doctor can refuse because they have a conscientious objection to voluntary assisted dying, or are unwilling or unable to perform the duties of a coordinating practitioner.

To be eligible to act as a coordinating practitioner, a doctor must be highly experienced. They must either be a specialist, an overseas-trained specialist or a practitioner with general registration who has practised for at least 10 years. The doctor must also have completed training approved by the Secretary of NSW Health, which will cover eligibility criteria and how to identify risk factors for pressure or duress. If the doctor accepts the first request, they become the coordinating practitioner. The coordinating practitioner must then conduct a first assessment of a patient against each eligibility criteria. That covers residency, diagnosis, prognosis, decision-making capacity, whether the request is voluntary and without pressure or duress, and whether the request is enduring.

The bill makes it absolutely clear that if a coordinating practitioner is uncertain about whether a patient has a disease, illness or medical condition that complies with the requirements, they must refer the patient to a medical practitioner who is qualified to make that decision such as an oncologist or a neurologist. Similarly, if a coordinating practitioner is uncertain about whether a patient has decision-making capacity for a voluntary assisted dying decision, or whether the person could be subject to pressure or duress, they must refer the person to a psychiatrist or another registered health practitioner who is qualified to make that decision, such as a geriatrician.

In the case of pressure or duress, if appropriate a patient can be referred to a person who is not a registered health practitioner provided they have the skills to make an assessment—an example could be a social worker. If the coordinating practitioner determines after the first assessment that the patient meets the eligibility criteria, they must provide the patient with extensive information about their diagnosis, prognosis, treatment and palliative care options, and the process going forward if the patient chooses to continue. The coordinating practitioner must tell the patient that they may decide at any time not to continue further. If the coordinating practitioner is not satisfied that the patient meets any criteria then they must assess the patient as ineligible and the process ends. The coordinating practitioner must then refer the patient to another doctor for an independent assessment.

The doctor who receives the referral can accept or refuse it.

A doctor can refuse a referral because they have a conscientious objection to voluntary assisted dying, or because they are unwilling or unable to perform the duties of a consulting practitioner. They must refuse the referral if they are not eligible to act as a consulting practitioner. The eligibility criteria for a consulting practitioner is the same as the coordinating practitioner. If the doctor accepts the referral they become the consulting practitioner and must independently assess the patient against each eligibility criterion. The

mandatory obligations on the consulting practitioner to refer a patient, if they are uncertain about a particular eligibility criteria, reflect those of the consulting practitioner in the first assessment.

If the consulting practitioner is not satisfied that the patient meets any criterion then they must assess the patient as ineligible. If the consulting practitioner assesses the patient as eligible, they must provide the patient with the same information required of the consulting practitioner after the first assessment to ensure that the patient is kept informed about the medical situation and the outcomes of their decisions throughout the process. Importantly, the patient is told again that they are under no obligation to proceed with the process.

Patients assessed as eligible in this rigorous process who choose to proceed with their application, must then make a written declaration. The written declaration involves making a request for access to voluntary assisted dying in writing, which declares that the request is voluntary and without pressure or duress, and that the patient understands the nature and effect of voluntary assisted dying. The patient is required to sign their written declaration in front of two witnesses. Each witness must certify in the declaration that in their presence the patient appeared to freely and voluntarily sign the declaration.

After the patient has given the written declaration to their coordinating practitioner they must make a final request to the coordinating practitioner. The final request cannot be made earlier than five days after the first request was made. However, if both the coordinating practitioner and consulting practitioner agree that the patient is likely to die or lose decision-making capacity within that period, the final request can be made earlier. The coordinating practitioner must then conduct a final review of all assessment forms and certify that the assessment process has been complete and that the patient has decision-making capacity, is acting voluntarily and not because of pressure or duress and that their request for voluntary assisted dying is enduring.

The coordinating practitioner must then request an authorisation to prescribe a substance from the Voluntary Assisted Dying Board. The board can refuse the authorisation if it suspects that the eligibility requirements have not been met. Before issuing a prescription, the coordinating practitioner must provide the patient information on the substance, including how the substance is to be administered, stored and prepared; the expected effects and risks of taking the substance; and the period after taking the substance when the patient is expected to die. The patient must be told at this time that they are under no obligation to proceed. The coordinating practitioner can then prescribe a substance to assist the patient to die. The prescription is sent directly to an authorised supplier.

The patient will need to make an administrative decision on whether they would like to self-administer the voluntary assisted dying substance or have a health practitioner administer the substance for them. A patient who chooses to self-administer must appoint a contact person to be responsible for returning any unused substance to an authorised disposer and informing the coordinating practitioner if the patient dies. Where a patient has chosen to self-administer the substance, the substance can be supplied to the patient, their agent or the contact person and it must be stored in a locked box at all times. Where a patient has chosen to have the substance administered by a health practitioner the substance is supplied directly to the administering practitioner.

The administering practitioner is likely to be the coordinating practitioner; however they can also be a specialist, an overseas trained specialist, a general practitioner who has practised for at least five years, a nurse practitioner or a registered nurse who has practised for at least five years. They must have also completed the health secretary's training. The administering practitioner must administer the substance in front of an independent witness. The witness will need to certify to the board that the patient's request for access appeared to be free, voluntary and enduring.

The bill enshrines the power for facilities, which are referred to as entities in the bill, not to provide voluntary assisted dying services, while setting out responsibilities towards patients and residents, depending on whether the entity is a residential facility or a hospital. Residential facilities will have greater responsibilities towards residents because they are people's homes and nobody should be denied a legal medical option in their home because of the views held by management, especially given choice in residential care is often

limited. Residential facilities that do not provide voluntary assisted dying services will be required to let doctors and other participants attend the premises to provide voluntary assisted dying services. Those in residential facilities seeking voluntary assisted dying will be told to inform their residential facility. I thank Uniting and Catholic Healthcare Australia for this recommendation. Hospitals that are referred to as "health care establishments" in the bill, will only be required to help transfer patients to and from the hospital to access voluntary assisted dying services elsewhere. There is no obligation on a hospital to allow external doctors on site.

The Voluntary Assisted Dying Board will play an important oversight role. The board will collect and publish data; provide advice, information and reports to the Minister and the health secretary; and refer matters, for example to the police, the Coroner or the Health Care Complaints Commission. The board will be responsible for determining applications to prescribe a voluntary assisted dying substance and for sending information to the patient's contact person to ensure that they know how to comply with obligations. The board will be made up of five members jointly appointed by the Minister for Health and the Attorney General. The chairperson and the deputy chairperson will be required to have minimum specified practical legal experience.

The bill creates a comprehensive set of offences to protect against any misuse of voluntary assisted dying. These will act in addition to the safeguards that are built into the very robust statutory process. A new offence for administering a prescribed substance to another person outside of the provisions of the bill will incur a maximum penalty of life imprisonment, as does the new offence for inducing someone to take a prescribed substance. Inducing someone to apply for voluntary assisted dying attracts a maximum of seven years imprisonment. Advertising of schedule 4 or schedule 8 poison as a voluntary assisted dying substance, attracts a maximum penalty of three years' imprisonment. A contact person who fails to return any unused substance that remains after a person dies will be subject to a maximum penalty of 12 months' imprisonment. There are also offences to protect people's privacy.

The bill provides for the introduction of a care navigator service. Both Victoria and Western Australia have established care navigator services, which provide a point of contact for patients, the community, health practitioners, health services and residential facilities. Care navigators can provide general information, connect people with medical practitioners who provide services, and provide holistic advice on appropriate end-of-life services. The feedback on the care navigator service in Victoria is very positive. The legislation will be subject to regular review every five years after an initial review that must commence two years after the provisions come into force. Reviews will look at the operations and effectiveness of the laws, as well as access issues in regional areas or issues that are associated with language and culture.

Poll after poll, story after story, and years of compassionate campaigning across New South Wales have shown that the vast majority of this State's citizens support voluntary assisted dying legislation. I thank the Premier and the Leader of the Opposition for agreeing to a conscience vote on this bill. I ask all members to respect and listen to each other's views. I ask all members to not play procedural games that will only prolong people's cruel pain and suffering. I ask members to engage with me on genuine amendments and not filibuster with ones that will only create unfair barriers to access. Most importantly, I call on all members of the Legislative Assembly and the Legislative Council to listen to the genuine call of those who are dying cruelly and give them the choice, comfort, dignity and respect that they deserve. I commend the bill to the House.