

VOLUNTARY ASSISTED DYING BILL 2021

Legislative Assembly Second Reading Debate – copied from Hansard 12 November 2021

Ms JO HAYLEN (Summer Hill) (10:43): I am pleased to contribute to this incredibly important debate on the Voluntary Assisted Dying Bill 2021. I acknowledge the many people from the Summer Hill electorate who have written to me about this issue. I have received emails and calls from people in support of this legislation and from those who are opposed. No matter the view, all those emails and calls have been respectful, have spoken from the heart and have been rooted in firmly held beliefs and rich lived experience. I assure everyone who has contacted me opposing the bill that I have read their emails, listened to their views and considered them intently. I understand the reasoning behind their views and I appreciate the conviction with which they hold them.

Similarly, I thank and acknowledge my colleagues both in the Labor Party and across the Parliament for the respect and rigour brought to this debate. Matters of conscience allow us to interrogate long-held ideas and to gain a better and deeper understanding of the fundamental beliefs that bring us here. No matter which side of the debate we sit on, I have appreciated the long discussions, the spirited debate and the shared sense that we are working on something important—something that will make a real difference for people across New South Wales. This is not an easy conversation but one that is long overdue, and I thank the member for Sydney for his dedication to this issue and for bringing this bill forward. I thank the 28 colleagues who I am proud to join in co-sponsoring this bill in the New South Wales Parliament.

My views on this issue are formed by my deeply held belief that policy must be based on evidence and that all of us have a fundamental right to make choices about our lives and about our deaths. The Voluntary Assisted Dying Bill seeks to give options to people living with terminal illness. New South Wales is the only State in the country where people are not able to exercise choice around their death in the circumstances detailed in the bill. As the member for Sydney has outlined, the bill establishes a safe and cautious framework for people in the final stages of terminal illness. This is a compassionate bill. It is a considered bill. It offers choice without compromising the safeguards the community would expect. The member for Sydney has expertly detailed how the scheme is legislated by this bill and how it would work.

I touch on a few key facts to give my community certainty about the safeguards in the bill. Eligibility for voluntary assisted dying will be strictly limited to those aged 18 and over who have been diagnosed with a terminal illness that will cause death within six months or 12 months in the case of neurodegenerative conditions. A person must be suffering in a way that cannot be tolerably managed. There are clear and firm rules to ensure a person has the capacity to make a decision around voluntary assisted dying and is not making a decision under duress. Concerns that people may feel pressured to take their own life have been raised with me by a number of constituents and by those opposed to the bill. I note that the Council on the Ageing NSW has put the record straight in a recent letter to all members of Parliament. It said:

Unfortunately, much of the discourse on these issues has been highly emotive and unconstructive, including false claims that older people will be vulnerable to unscrupulous relatives encouraging the use of VAD for financial gain.

There is simply no merit to this argument.

The proposed Bill builds on work done in other jurisdictions and contains robust safeguards to ensure that people seeking voluntary assisted dying are protected from any coercion or malpractice.

Two highly experienced doctors will independently assess applicants and determine that they are making decisions free of duress, and the bill sets out offences for placing duress on or inducing a person to apply for assisted dying. They will also work to ensure the person applying to access support is eligible and has the capacity to do so. Having the capacity to make a decision on voluntary assisted dying is defined as having the ability to understand the consequences of the decision being made, comprehending and retaining information, processing advice and being able to weigh up the decision. In addition to consulting with two medical practitioners, the applicant must sign a declaration countersigned by two independent witnesses to confirm that they wish to proceed. Witnesses must certify that the applicant appeared to sign the declaration of their own free will and without coercion.

The process of consulting with two medical practitioners is also designed to provide further time for a person to contemplate and consider their decision, as is the five-day cooling-off period between the first and final request. Medical practitioners involved in the process of accepting requests, referring for consulting assessments or acting as the administering practitioner must have undergone extensive mandatory training and meet strict statutory qualifications. That training specifically includes how to identify the signs of pressure or duress. Coordinating and consulting practitioners must be specialists with at least one year of specialist training or have general registration with at least 10 years' service. Administering practitioners must be a doctor with specialist registration with at least five years' general registration, or be a nurse practitioner or a registered nurse with at least five years' experience. Medical professionals can refuse to participate in this process due to conscientious objection or for any other reason. The principle that this bill is voluntary extends to doctors and health professionals. No-one is compelled to participate in this voluntary scheme.

Under the provisions of the bill the Secretary of NSW Health will determine a list of substances for the purpose of assisted dying. A person who is eligible may choose to administer the substance themselves or by a medical practitioner who meets the statutory eligibility to administer the substance, including having undertaken specific training, and must have relevant experience. There are strict safeguards and rules around the storage and transportation of substances, which must be in a stored and sturdy locked box. The substance will only be available to select health facilities that are authorised by the Secretary of NSW Health. It must be provided directly to the patient, the contact person or the agent of the patient by the authorised supplier only after the coordinating practitioner provides the prescription directly to the supplier, and any unused substance must be provided to an authorised disposer by an appointed contact person. This ensures that the substance remains strictly controlled. These are some of the safeguards to ensure that the bill offers choice to those who wish to have access to voluntary assisted dying without causing harm to any vulnerable persons.

The bill seeks to create a framework for the small number of people for whom palliative care is no longer an option. There are some who would like to pit palliative care and voluntary dying against one another, as if one cannot operate without reference to another. Both operate with the same goal: to afford people with a terminal illness compassion and dignity. Professor Ian Maddocks, who is often described as the father of palliative care in our country, has said:

If compassion and loving care towards patients and families is what palliative care is all about then assisted dying is a part of that. It is time the profession dealt with it.

Voluntary assisted dying is a further end-of-life option. It does not seek to replace or take priority over palliative care. It is unsurprising that the uptake of palliative care in jurisdictions where voluntary assisted dying is in effect is high. In Victoria 84 per cent of patients requesting voluntary assisted dying were assessed in palliative care. In Oregon the figure stands at 95 per cent. Perhaps the reason is because voluntary assisted dying requires patients to discuss end-of-life options with their doctor. They are also able to access additional information about palliative care. It is critical that we continue to grow funding for palliative care in New South Wales to meet increasing demand. The Premier has reported that the New South Wales Government spends \$22 million on palliative care and support each year, with an additional \$82.8 million committed over the next four years in the current State budget. I note and welcome the Premier's commitment for more money because more money for palliative care is a good thing. It is clear that the system is underfunded and requires additional support.

One issue that has been raised in the course of the debate is that patients in regional areas do not have access to palliative care. While increased funding for palliative care should absolutely seek to increase palliative care in all communities across the State, GPs and nurses currently provide end-of-life palliative care across New South Wales and specialists provide palliative care when it is required due to the complexity of a case. Medical practitioners providing palliative care in regional settings link up to services in the city via telehealth. Whether in the city or the bush, I acknowledge and thank the extraordinary work palliative care workers across New South Wales undertake. They have a difficult and sometimes heartbreaking job, but their care, diligence and empathy has eased the pain and suffering of so many.

It is simply wrong, however, to suggest that palliative care and voluntary assisted dying are at opposite ends of the spectrum. Palliative care is focused squarely on quality of life and treats stress and symptoms of terminal illness. What it cannot do is address an underlying illness. As the member for Sydney has noted, Palliative Care Australia reports that palliative care may not be able to address between 10 per cent and 20 per cent of end-of-life symptoms. It is critically important that we remember that these are not statistics, they are people. Over the past few months and years we have heard residents' stories of what can only be described as

horrific and cruel deaths in cases where palliative care is no longer an option. I will put some of those stories on the public record. Kathleen from Marrickville said:

My 90 yr old mother has this year been diagnosed with metastatic melanoma. She survived surgery and is now on immunotherapy and we all hope that this be successful. We have talked about end of life issues as a whole family She is not afraid of dying but she is extremely concerned about how she might die, whether from this or some other illness. She wants the option of voluntary assisted dying as do I for her if this was the only way to relieve her suffering. I am a social worker with over 30 years experience and have worked in palliative care since 2012. I have enormous respect for the effectiveness of palliative management with terminally ill patients, both for the patient and their families and friends. In my experience it is relatively uncommon for patients to express that they would wish for an assisted death due to unrelievable suffering. But when I do see that degree of suffering and be unable to offer no hope of easing it is absolutely heartbreaking for all concerned. Research tells us having the option of voluntary assisted dying brings peace of mind to those facing death. We also know the take up rate of this option is very low. Us workers in palliative care (and especially social workers) are acutely aware of the need to protect the rights of vulnerable people and to ensure they are making decisions free of pressure or influence. We welcome the work that has gone into this bill to ensure individual rights are maintained.

Natasha from Ashfield wrote to me to say:

Two weeks ago my mother passed away from a terminal brain tumour. Prior to my mother's rapid deterioration, she had expressed her fears and concerns that she would experience unnecessary pain and suffering as her terminal condition declined. As my mother's condition rapidly declined, she lost her ability to move, swallow and speak. She was put onto a continuous morphine pump, however as with many people on morphine, she developed tolerance and the morphine dosage provided limited pain relief. My mother's last 5 days involved extreme suffering, the morphine dosage was not high enough to completely relieve pain, and as she was unable to communicate her suffering, we had to urge doctors to increase her morphine to attempt to alleviate her pain. We did our best to manage my mother's pain, through breakthrough morphine administration, however she still continued to experience extreme pain. My mother's suffering was both traumatic for my family, but also for my beautiful mother who did not deserve to spend the last few days on this earth in such extreme pain. Everyday, my family and I watched my mother suffer unnecessarily because she did not have the choice to have assisted dying. The memory of my mother's last days alive will always ignite feelings of anger, desperation, and trauma that my mother could not pass away in peace. I strongly believe that no other terminally ill people or their families should experience what we endured, it is inhumane.

Emma from Lewisham wrote to me to say:

A few decades ago, my aunty Barbara had a terminal illness. She got to the point where she was as thin as a rail, couldn't keep down any food, and was essentially slowly starving to death. She was in so much pain. She decided to book into a motel room and take her own life. She was forced to do this to escape her extreme suffering, and she was forced to do this in secrecy. I feel so sorry for the poor person who must have found her body, who will carry the memory of this moment with them forever. This all could have been avoided, and she could have died with her family by her side. She could have died safely ("safely" may seem a counter-intuitive way of phrasing it, but suicide attempts are very dangerous, as one can instead incur permanent neurological and physical damage and disability, if one survives their attempt). She could have died with dignity.

Barbara's family notes that she was a talented artist and jewel maker, and she will be dearly missed. I am grateful to each of those women for writing to me and giving me permission to share their stories with the Parliament today. They are just three of many. As I noted earlier, the momentum for this reform is undeniable; it is propelled by a wave of popular will and evidence. New South Wales is the only State not to have legislated the reform. In other States where voluntary assisted dying is law, the sky has not fallen in. In fact, in Victoria between 19 June 2019 and 31 December 2020, 697 people were assessed as eligible at first assessment; 583 were assessed as eligible at consulting assessment; 486 permits were issued; and 276 people were administered medication.

Polls consistently show that 80 per cent of New South Wales residents support reform. The Council on the Ageing [COTA] notes that research conducted earlier this year as part of the COTA Federation State of the (Older) Nation report found that 72 per cent of people aged 50 and over in New South Wales support the legislation. The research also shows that more than half of older people in New South Wales consider voluntary assisted dying for themselves. Voluntary assisted dying is supported by the Older Persons Advocacy Network, COTA NSW, the Older Women's Network, the Health Services Union [HSU], the NSW Nurses and Midwives' Association, the Australian Paramedics Association and the Police Association.

It is commonsense reform with strong, broad-based support across the community. It is a considered, cautious and balanced bill. I acknowledge the important work of Go Gentle, Dying with Dignity and all those advocates who have brought personal experience, professional expertise and passion to the issue. For many, advocating on this issue can bring up trauma, pain and profound sadness. Please know that every email, every letter and every retelling of a story makes a difference. Those stories do not fall on deaf ears and are part of the change that is long overdue in New South Wales.

I strongly believe that in dying each of us should be afforded the same dignity, respect and compassion with which we live. Legislating voluntary assisted dying is about providing end-of-life options and agency for people who are suffering, often unspeakably. I can only speak for myself when I say that this is a choice I would like available to me if I were terminally ill. When it is my time to go and if I am suffering and unable to benefit from further care, I want to say goodbye on my own terms, surrounded by my family, with the same respect and dignity that I try to live my life. Frankly, those who do not wish to take up the option for voluntary assisted dying need not do it.

The bill treads a challenging path deftly, and with the level of consideration and care our community expects on an issue this important. Its principles are sound, offering choice to those dying, whilst protecting the rights and beliefs of those who oppose it. Its safeguards are robust, ensuring that agency is afforded to vulnerable people in death, whilst remaining resolute against abuse and coercion. It acknowledges the difficult complexities at end of life and remains simple enough for those who will benefit from it to understand and access it. I am proud to co-sponsor the bill, and commend it to the House.