

## VOLUNTARY ASSISTED DYING BILL 2021

*Legislative Assembly Second Reading Debate – copied from Hansard 19 November 2021*

**Ms LIESL TESCH (Gosford) (17:05):** I contribute to debate on the Voluntary Assisted Dying Bill 2021. The bill is about choice. We need to make it clear that at no point under this legislation is anybody in New South Wales being forced into voluntary assisted dying. I support the right of a person with an advanced progressive medical condition that will cause death and who is already suffering to have an additional compassionate choice about the way they choose to die. That person should be, and always will be, at the centre of this discussion. I sincerely thank every one of the many thousands who live in my electorate and beyond who have contacted me, spoken with me and met with me, or have followed up with letters in local newspapers to express their views or concerns about the bill. They are carers, doctors, nurses, family members, people of faith and people with no religious beliefs.

The gravity of this change in New South Wales is reflected in the volume of correspondence I have received. I am honoured to be in this place to see this important legislation debated in the New South Wales Parliament. The introduction of voluntary assisted dying is a major social policy shift, with significant implications for the health system, health and medical professionals, and the wider community. Let us also hope that, like in other States, discussing this legislation highlights and directs more funding towards palliative care, especially in regional and rural communities. I particularly thank the Central Coast group called Dying with Dignity NSW for its dedication and hard work over 25 years in raising community awareness about end-of-life issues, including the need for voluntary assisted dying laws. Through persistent lobbying and educational and social activities undertaken by a committed group of volunteers, Central Coast communities convinced politicians and aspiring politicians from all major parties that to represent them on the Central Coast they must support the rights of the terminally ill and support voluntary assisted dying law reform. All five of us in this place support the bill.

In a survey of over 155,000 people in New South Wales, 81 per cent agreed that "terminally ill patients should be able to end their own lives with medical assistance". On the Central Coast, that includes 73 per cent of Catholic people and 83 per cent of Anglican people who believe, as a demonstration of love and compassion, those with terminal illnesses should have the option of a pain-free and dignified death through legal voluntary assisted dying. It is about saying goodbye to your loved ones with dignity and in a timely manner that you can control, with thorough professional oversight and clear professional boundaries. It is about saying goodbye before you are struggling for breath, before you have bedsores down to the bone, before you starve to death because you cannot swallow, before you drown in your own saliva, or before you become incontinent. It is about choosing to die in a manner that allows you to deal with the pain and agony of a terminal illness or neurological degenerative disease before it turns into something that you cannot control and can no longer live with.

Many members have spoken about the increased risk to people with disabilities. In his speech, the Premier implied that people with disabilities are more vulnerable than able-bodied people in regard to assisted dying. Like his comments on palliative care and inequitable access to quality health care and community-based care across New South Wales, especially in our regions, this is not about killing people with disabilities. It is about our work as a government to improve lives and social structures to support people living with diverse abilities in our State.

If the Premier wants to improve the lives of people with disabilities today, bring it on! Let us improve the quality of compassionate care in New South Wales rather than make scaremongering comments in this place.

People with disabilities also have a choice. The bill is not about killing us; it is about quality health service while we live. Like able-bodied people, if we choose voluntary assisted dying, we choose it. We are a diverse population and our abilities differ between individuals, as do the supports we require in our everyday lives. If communication is difficult we use experts and techniques during our life to improve communication. Tonight I share the story of my friend Peter Beard, who lived with multiple system atrophy, a neurological disorder for which there is no cure.

Peter taught me a lot about living life to the max, as he took on the challenge of competing in the world championships in Halifax, Canada, just months before his death in 2014. It was Peter's dream, and the spinnaker at the front of his boat had "Reason to live" written across it. Whilst he could not talk, Peter had great decision-making capacity, which is a challenge. Peter could not talk but we knew what he was feeling through communication. He could only cry when he was thrilled or when he beat us in that eighth race—he was a beautiful human being. People around Peter also communicated with him effectively despite his non-verbal capacity. He could steer a boat with a joystick with his chin. We cannot take pity on people and determine that they cannot make a choice. I can tell members now that they would not have wanted to be in Peter's way. Peter died not long after Halifax. As we can only imagine, life was far from easy in those final months. This legislation would have given Peter, in the sunset of his life, time to make a choice before losing all control.

Safeguards are in place in this legislation. There are experts in language and physical disability care and other diverse supports for people with disabilities that enable us to live our best lives. Since the introduction of the National Disability Insurance Scheme our choices are increasing and our support is strengthening, as is our right to choose to die with dignity. The bill will enable people, with or without disability, to act voluntarily and without any pressure or duress. Pressure or duress includes coercion, intimidation, threats and undue influence. I commend the member for Sydney for including penalties to make it an offence to attempt to coerce others to go through with assisted dying, including possible imprisonment. Whilst people in this Parliament may make judgements about people with disabilities, I assure members that no-one will kill us and many people with disabilities will appreciate assisted dying within the framework of this legislation.

The bill is designed to provide choice to those who communicate that they would like to end their life due to a neurological or terminal illness. People with disabilities can also have a terminal illness and should have the choice to end their lives within this dignified framework. In Belgium renowned Paralympian Marieke Vervoort was diagnosed at age 14 with an incurable degenerative disease of the muscles and spine which caused severe pain, paralysis in her legs and made it difficult for her to sleep. She signed her euthanasia papers in 2008, made her wishes public in the lead-up to the Rio Paralympics and died by euthanasia in October 2019—11 years later.

It is interesting that in drafting this legislation New South Wales has selected six months for those with terminal illnesses and 12 months for those with neurological-related disorders as opposed to the Netherlands, Belgium and Canada, which have much longer time lines or no time line at all. End of life has no time line. The non-terminally ill in those countries can also apply. A number of doctors and professors to whom I have spoken in the lead-up to this legislation have emphasised the difficulty of associating terminal illness with a time line. A terminal illness is a sensitive period with an unknown timeline of potential illness, pain and possibly rapid deterioration. People with disabilities are often born with a terminal illness.

This is not a slippery slope that some of my parliamentary colleagues have spoken about; this is a logical sequential progression that may occur if our society demands it. Just like updating other forms of legislation, we as legislators need to move with the times—in society and for the people around us. That is what is occurring today. I am honoured to have an opportunity to vote according to my conscience. I agree that we have much more work to do to support palliative care across our State. I thank the team at Elsie's Retreat for the work that they do. I also thank all the staff at Gosford Hospital for their work in delivering and supporting palliative care beds on the coast. Palliative care can never alleviate all the suffering of all of the people. Clive Deverall, the founder of Palliative Care WA states, "Even in good time, if perfect modern palliative care was available for each and every patient, we would still have the nightmares." [*Extension of time*]

The introduction of assisted dying will offer a process of support for those who have previously chosen suicide due to their terminal illness or neurological condition. Lawrie Daniel, aged 50, took his own life after 10 years of living with multiple sclerosis-related savagely fast degeneration and neuropathic pain that never let up. Having that choice is much better than coming home to a letter from your husband, who was living with MS, saying:

Dear Rebecca [and the kids], If you are reading this it is probably because I've made an attempt at voluntary euthanasia and I sincerely hope I have been successful.

It is not the best choice to live with a debilitating disability or degenerative disease until the very end. Given the evidence and information from other locations, it will take approximately three to four weeks to implement the bureaucratic process to enable people to participate in this choice. It is about choice up to the very end. Quite a few people who make the decision to opt for assisted death will die without consuming prescribed medication. Since the Act came into force in Victoria in 2019, 581 people were assessed, 405 received permits, and only 224 people died from prescribed medication. People make the choice according to their own personal time lines. The majority of people receive and consume their medication within three to four weeks and others wait for more than 12 weeks for their chosen time, with or without their families beside them.

In May this year it was standing room only at the Central Coast Leagues Club when the member for Sydney and Shayne Higson visited to talk to supporters about voluntary assisted dying law reform—the twenty-fifth anniversary of our group—and to recognise the contribution of long-time coordinator Dr Beverly Symons. She was presented with a certificate and a celebration. I am pleased to say that I was part of the fantastic group that supports this legislation. I acknowledge also Joy Shannon's family. Joy was the former secretary of the Central Coast group who died last month. What a disappointment that she did not see this legislation through, but she made an effort to push us to get here. There was a tangible feeling of optimism in the room that day.

We all bring our own unique personal experiences and perspectives on this issue which is what makes our Parliament effective. In recent years I experienced the passing of both my mum and dad which further emphasises the importance of voluntary assisted dying legislation, with all the appropriate safety precautions, as an important choice for people at the end of their lives. My mum, who died of breast cancer and associated bone cancer, would be proud that I am in this place today. Before she passed we spoke about this on a number of occasions. She would be happy to see this legislation go through the New South Wales Parliament, as would all those who shared their stories with us. I thank all those families who shared their stories and personal experiences with their loved ones.

Voluntary assisted dying is about choice and about exerting control over one's circumstances, which is why legislation was enacted in all other Australian States and it is why we must strive for it in New South Wales. I thank everyone in this Parliament who has been involved in spirited, and at times entertaining, debate and those involved in drafting the amendments to increase the rigour of the bill. We are grateful for the dedication of all those across New South Wales and Australia who have been working to make this bill the most robust and safe framework possible for the people of our State, given the national and global experiences. I particularly thank the member for Sydney for his collaborative leadership on what Parliament should and can be.

I thank Shayne Higson and Penny Hackett from Dying with Dignity NSW for their passionate commitment to seeing this come to fruition in the New South Wales Parliament. I thank Andrew Denton for the journey he has travelled, for enabling so many of us to share that journey, and for the voice he has given to families who have seen their loved ones suffer. It is unbearable to watch loved ones suffering pain in the sunset days of their lives. I thank Christians Supporting Choice for Voluntary Assisted Dying, Go Gentle Australia and the 29 Voluntary Assisted Dying Alliance member organisations, which include key national healthcare and professional bodies. In particular, I thank the NSW Nurses and Midwives' Association, the Council on the Ageing, Doctors for Assisted Dying Choice, ACON, Cancer Voices NSW and all those who have lobbied for this change.

This is not mandatory. It is a voluntary choice about the precious last moments alive in this body in this lifetime, allowing control, comfort, solitude and peace. This legislation will not see any more people die. It will give those who choose this path a more dignified death. I am pleased to co-sponsor the NSW Voluntary Assisted Dying Bill 2021 tabled by the member for Sydney. It has my unqualified support.