

VOLUNTARY ASSISTED DYING BILL 2021

Legislative Assembly Second Reading Debate – copied from Hansard 25 November 2021

Mrs LESLIE WILLIAMS (Port Macquarie) (10:49): I am not here today to support the Voluntary Assisted Dying Bill 2021 because I have been through the torment of watching a loved one with a terminal illness take their last breath on this earth. Many have spoken about their own personal experiences and they have shared their sadness. Losing a loved one hurts, particularly if it is unexpected or you did not have time to say goodbye or share with them their favourite port just one more time. Yes, I miss my dad terribly and it still hurts. But I am very thankful that I did not see him suffer. I did not see him in the hospital during those last few days of his life. I am so thankful that I have only treasured memories that I can hold close and never let go—beautiful memories not tarnished by suffering or torment. Unfortunately, the experience for Emma of Port Macquarie was vastly different when her husband, Amahl, died at age 36 of motor neurone disease. She described it as:

A merciless disease that barges through a person's life at an unwavering pace, leaving a string of losses behind it.

Emma describes how Amahl would lose his work, his motorbike, his sport, his cuddles with his baby. He would lose his smile, his speech, his ability to swallow and to walk, his ability to hold up his head, to empty his bladder and bowels and, eventually, to breathe. During this debate I have heard the words of Gandhi reiterated:

The true measure of any society can be found in how it treats its most vulnerable members.

But Emma's story and those of so many others reflect just the opposite. Amahl was at the most vulnerable time of his life, as was Emma as she watched helplessly as the nightmare of motor neurone disease unfolded before her. But instead of giving Amahl the opportunity to conclude his time on this earth peacefully, with dignity and without the horrific suffering, we stood by and we let the hurt continue. How is that caring for the most vulnerable? Where is the compassion and the empathy for Amahl? Emma said Amahl generally received exceptional palliative care, but physicians could not legally accelerate his death. She said the response was simply, "We are palliative care." Emma tells how she felt so alone where no-one would help for fear of implicating themselves. She said:

We should have been working to make sure Amahl had the most gentle death possible. In fact, we were playing a stupid game of "who goes to jail". When he was so sick and death was so close, does it really matter how long it took him to die?

I have never met Emma or Amahl but I have seen with my own eyes this suffering in so many others—this cruel and undignified end that has a plaguing ripple effect on those that have to stand by helplessly and witness such cruelty. I am supporting the bill because I cannot unsee what I have seen, I cannot unhear what I have heard and I cannot ever erase the recall of the gagging stench from the necrotic wounds of a patient with stage four metastatic melanoma. As a nurse in the palliative care ward it was a privilege to work alongside what many would call heroes, whose commitment, compassion and care were beyond reproach. While they worked untiringly with patients, families and carers to curtail the pain and alleviate the suffering they could not curb the inevitable death. Palliative Care Australia describes its work as:

Person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

Palliative care does not save lives. But Emma knew Amahl's life could not be saved. She just wanted his life to end peacefully. She wanted assisted dying to be an option. Canadian Judge Lyn Smith's landmark ruling after hearing evidence for and against voluntary assisted dying from experts around the world paved the way for that country's medical assistance in dying law. Judge Smith summarised her position saying:

It is unethical to refuse to relieve the suffering of a patient who requests and requires such relief, simply in order to protect other hypothetical patients from hypothetical harm.

I also reject the assumption that this debate is about competing views on how to best manage the pain of terminally ill patients. Respectfully, pain is just not that simple. We should be guided by the writings of Dame Cicely Saunders, the founder of the modern hospice—or palliative care—movement, who introduced us to the concept of "total pain" of the dying, which can include psychological, spiritual, emotional and intellectual pain. Dr Roger Hunt, a palliative medicine specialist for over three decades said:

Dying people have varied and sometimes intense suffering, including physical, emotional and existential suffering. All surveys of palliative patients, including those in most renowned hospices, show they experience multiple concurrent symptoms. Severe refractory symptoms, including suffocation, pain, nausea and confusion, requiring palliation with deep sedation, have been reported in up to 50% of palliative care patients.

Further, the only person who can measure and communicate the extent and the complexities of the pain is the person experiencing the pain and so to suggest that simply increasing analgesia will eliminate or at least moderate that pain is misleading. For many who are terminally ill palliative care may be an option and New South Wales is well resourced, but no matter what one's views are on voluntary assisted dying one would, of course, welcome more funding because just like any portfolio we know we can always do more.

The New South Wales Government invests \$220 million every year into palliative care, reflecting its commitment to the sector through the End of Life and Palliative Care Framework, bolstered with extra funding of \$100 million in 2017; \$45 million in 2019; \$56 million in 2020; and an additional \$82.8 million in 2021. The June 2021 Australian Health Practitioner Regulation Agency medical board statistics reveal that New South Wales with a 147-strong body of palliative medicine specialists is 41 more than Victoria, and more than Queensland, Western Australia and South Australia put together. [*Extension of time*]

I refer again to Cicely Saunders, who it is often said transformed the way we look at death and dying and the care and treatment of the terminally ill. Saunders says:

You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

To suggest that investing more funding into palliative care would have allowed Amahl to die peacefully, or even live until he died, is an absolute fallacy. It is widely acknowledged that palliative care does not help everyone. The 2016 *Palliative Care Outcomes Collaboration Report* found 4 per cent of terminal patients had severe pain and 6.5 per cent had other severe physical symptoms. We must acknowledge that suffering in many cases will not change with palliation. Peta Quinliven from Busselton, Western Australia, whose husband died in 2016 of lung cancer, shared her frustration:

If people spent all this time with someone who was suffering, they might have some idea of "he died peacefully".

I don't think so. Yes, he might have been looking like he was peaceful at the end, anyone on that amount of painkillers might look peaceful at the end, and anyone that is so exhausted from what they've been through might look peaceful at the end, but what about all the part leading up to it that wasn't peaceful?

During the debate we have heard members suggest that there is a real risk of coercion of the terminally ill and that we must take measures to protect those who are vulnerable. There is no evidence to support such assertions, and on the contrary, the bill has a plethora of safeguards including: if a person seeking voluntary assisted dying does not meet the criteria—over 18 with a terminal illness that will cause death within six months or 12 months for neurodegenerative conditions—they will be ruled ineligible; independent assessments by two doctors looking specifically for mental competency and signs of coercion; a person seeking voluntary assisted dying has to state throughout the process that they know what they are requesting; both doctors must inform patients about their treatment and palliative care options; a person seeking voluntary assisted dying can say no at any time; a person seeking voluntary assisted dying must make three requests—one written and witnessed; the doctors assessing patients are being reviewed in real time, with real-time consequences, including imprisonment, for failing to act according to the law.

In addition to the two assessing doctors, there are many others overseeing the process of application for voluntary assisted dying, including the care navigators, the witnesses to the written request, the nominated contact person, who must return any unused medication, the pharmacists, hospital staff and other members of a person's treatment team and the secretariat. Additionally, the Voluntary Assisted Dying Review Board also has eyes on each individual application. Compare those safeguards with what is happening now in New South Wales. As someone who has worked in palliative care, I can validate this, but it has already been verified during the debate by other members who shared their own personal stories. Melbourne GP Dr John Stanton also confirms it when he shared his experience. He said:

When I think back over the years when I've helped people at the end stage of life, there was actually no safeguards there for me. There was no peer review. There was no one looking over my shoulder saying yes you're doing the right thing or the wrong thing.

Right now in New South Wales, terminally ill patients are having their deaths medically expedited with no safeguards and no regulations, decided by the doctor and sometimes with family members but very rarely with the person who is dying. Endorsing the Voluntary Assisted Dying Bill 2021 is protecting the most vulnerable. The bill will protect them from a miserable, painful and undignified end of life by giving them a choice about the time of their inevitable death as they face the complex and cruel reality of a terminal illness. It is that simple.

Finally, it has been suggested that people will choose voluntary assisted dying simply because they feel they are a burden on the ones they love. Reflecting on the evidence, I assure the House that no-one in Oregon chose an assisted death because they feared "being a burden". It is true that in Oregon those choosing assisted dying are surveyed about their reasons for opting for this course. They are given a multi-choice list of end-of-life concerns they feel they are facing as they die, including loss of autonomy, loss of dignity, loss of enjoyment of life, loss of bodily functions, inadequate pain control and feeling like a burden. A quick glance at the Oregon Death with Dignity Act 2020 data summary reveals that this claim is misleading, and in fact "being a burden" is not cited as the only or even main factor influencing their choice. It is also reported that since the inception of the Act in 1997, not a single person in Oregon accessed voluntary assisted dying because they felt like a burden.

Before concluding, I foreshadow that I will be moving a number of amendments in relation to the signing of written declarations, interpreters' capacity to charge for their service and access to information and resources about palliative care for assessing doctors. A number of members both opposing and supporting the Voluntary Assisted Dying Bill have already tabled amendments for consideration, and I thank them for the advance notice of their intentions. However, I sincerely hope that when the House comes to consider the amendments, we do not see a flurry of activity with further amendments being tabled on the day, as we did with the Reproductive Health Care Reform Bill. The member for Sydney has provided ample opportunity for members to consider the detail of the bill—over four months, in fact. I commend him for his approach throughout the lengthy process of developing the bill to its final form. I know very well that he has invited all members, no matter what side of the debate, to discuss concerns in relation to the bill. Frankly, I think the tabling of amendments on the day of the final debate is disrespectful both to colleagues in this House and to the community, who, as we all know, overwhelmingly support the bill.

I absolutely respect the varied views of my colleagues and applaud the manner in which the debate has progressed thus far. However, as members of this House, it is incumbent on all of us to ensure that respect is ongoing and that the bill is finalised in this House before the week's end. I reiterate my thanks to all members who have carefully considered the Voluntary Assisted Dying Bill and who have weighed up the arguments for and against it. I acknowledge we have all come to our own conclusion, reflecting on our personal experiences of a loved one dying, on our faith, on our research and on evidence. Like many, I also reflect on the views of my community. The Port Macquarie electorate has given a resounding "yes" to voluntary assisted dying time and again. The most recent survey of over 2,800 respondents reflected that 91 per cent were in support of the bill. In closing, I want members to consider Janet Cohen's thoughts. Janet is from Camden Head in the Port Macquarie electorate, and six years ago she was diagnosed with lung cancer. Janet said:

I don't want people to say that I lost my battle with cancer. I want an empowered, meaningful death and to live my death as I live my life, with purpose and conviction. Being able to access an assisted death has been one of the greatest comforts on this journey, enabling me to stop worrying so much about the end of my life and to get on with living the rest of it well and with purpose.

I commend the bill to the House.