

VOLUNTARY ASSISTED DYING BILL 2021

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

Ms JENNY AITCHISON (Maitland) (16:00): I speak in debate on the Voluntary Assisted Dying Bill 2021. Over the years I have been moved by the people who reached out to me about voluntary assisted dying. Their stories have detailed very personal narratives about the final and what can only be described as heroic moments, days, weeks, months and even years of their loved ones' lives. Others have exposed their own fears and anxieties about what their own end of life could be like. The grief, the sense of powerlessness and the suffering experienced by these people when watching the loss of a loved one or when facing their own mortality has made them determined not to let others endure similar experiences. They have been determined to share the insights that they have gained and to offer hope for a better way. These stories, the depth of emotion expressed and the raw honesty have been moving and compelling.

It has been hard to sit within the difficult and complex issues that those stories raise, but as a representative of my community I have been honoured to do so. I thank every person who has shared their story or their views with me, which is why I am honoured to be a co-sponsor of the bill. That is not to say that everyone who has shared their views or their story shares the same opinions on this legislation. However, the overwhelming majority of people who contacted me think that we can do better helping our fellow humans through their end of life and into death.

In 2017 I undertook a survey of my community that indicated over 90 per cent support for a change in legislation to allow voluntary assisted dying. Of the 8.5 per cent who did not support a change, the majority saw a vote for voluntary dying as a vote against more funding for palliative care. That is a false dichotomy. When I heard the words of the Premier earlier in this debate when he spoke about palliative care, it was clear to me how important it is that we have this debate. The Premier said:

... I failed in my former capacity as Treasurer to address this issue but as Premier I will fix it. We have made a start, but clearly there is more to do.

He went on to say:

I want every person in New South Wales, whoever they are and wherever they are, to be afforded the care and support they need to have a dignified end of life. Everyone in our State must have the right not just to die with dignity but to live with dignity to the very end.

We should not have to have a debate on voluntary assisted dying to get a commitment for adequate funding for palliative care, but we need to go far beyond that. We need to ensure that people have the appropriate supports however they face death. Wherever members are on this issue, we all share the common belief that people should live with dignity to the very end. I make a commitment to this House and my community that whatever the outcome of this debate, I will hold the Premier accountable for his promise to properly fund palliative care, and to ensure that everyone in this State has the right to live with dignity to the very end and that this is their reality. More than that, I want to ensure that everyone in this State lives with dignity.

Earlier today I spoke to Dr Peter Saul, an amazing intensive care specialist and medical ethicist. Dr Saul has been a long-time hero of mine. 10 years ago I listened to his TEDx talk calling on us to "occupy death", which has had a profound impact on me and my relationship with death. Dr Saul hit the nail on the head when he spoke of the need for a new approach to advanced care planning that respects the end of life and the dignity of life for people facing their own mortality. When I spoke to Dr Saul this morning, he spoke about the ethical statement of the Royal Commission into Aged Care Quality and Safety in its *Final Report - Volume 3A: The new system*. It states:

Self-determination is having autonomy, control and choice over your own life. It is closely connected with dignity. Choice and control, and involvement in decision-making, promotes dignity. It is hard to maintain dignity when there is an inability to be involved in decisions about your own life. However, being able to make decisions and choices has been shown to improve quality of life and health outcomes, and may help maintain cognitive function. Having a sense of control can make the transition to old age easier.

In essence, elderly people and those facing death should be able to make bad decisions about their own health. There is dignity in risk, and it is legitimate to make decisions such as choosing to refuse medical care or seeking assistance to end your life when the suffering becomes too great. Dr Saul said that when we unpack dignity, it is about respect for the individual and their choices and our universal wish to be treated as an individual and not as a number or a case. He added that there is no real freedom of choice if we can only make what others perceive to be good choices. Dr Saul told me that this legislation will work very well for about 0.5 per cent of people who will have access to voluntary assisted dying. Another small percentage will have access to palliative care which, if we are to believe the Premier, will be more easily available and better funded. However, many others will not have access to either voluntary assisted dying or palliative care because they will not know that they are in a terminal stage of their lives and will not be encouraged to make the choices that will make that end easier.

We need to ensure that this bill is not the end of the discussion and not just about providing more funding for palliative care, although that is very important. We should be committed to ensuring that more people are able to have dignity both in their lives and in their deaths. It should not be about empowering the 0.5 per cent; it should be about empowering all of us to manage our health choices. This conversation should not just be happening on a dementia ward or when frailty is coming; it also should be happening when people are young, vibrant and still engaged with life.

Many years ago I was diagnosed with the breast cancer gene. I am pleased I got that information because when I experienced cancer in 2017, my diagnosis was early, my treatment was less severe than many other cancer patients have to suffer and I was able to get back to normal life much more quickly. However, I remember going through a stage of grief and experiencing a sense of loss when I first found out I was a previvor. It was a watershed moment in my life that brought me face to face with my own mortality as a 38-year-old mother of two young children. I thought about never growing old with my husband, never seeing my children grow up and never being able to achieve my potential as a human. It was a sobering and exhausting "what if" moment that stretched to a couple of years. I have been so lucky because finding out that I had that gene, with all the pain and worry that it caused, and that I had an increased risk of dying earlier still gave me choices. It gave me control and dignity. My choice to have risk-reducing surgeries, medication after I had cancer and later more surgery to reduce the risks were choices that enabled me to have control over what was happening with my body and my life.

None of those choices, to have or to avoid certain treatments, were without risk. I chose not to have radiation therapy because I did not want the side effects and I chose not to take tamoxifen because I would have experienced blood clots. As I said, I am lucky I was able to make choices for and against specific treatments. I have made choices along my health journey, and my journey in life, which have allowed me to live my life with dignity. Knowing that there is legislation that may one day enable me to make choices to help me face my own death with dignity helps to affirm the choices that help me to live a life every day that is full and rich.

People on the other side of this debate talk about hope as if they have a monopoly on it—as if there is no hope on this side. They talk about killing, attacks on doctors and missed diagnoses.

But for those of us who wish for dignity in death, we cherish each moment of this life. We also live in hope. Every moment of my life since I had that real engagement with my own mortality has been sweeter, more cherished and more valued because I had the choice. I chose life. By facing my own mortality—and by making the choices I have made on the continuity of care on the continuum of my life—I have been given the gifts of hope, agency and peace. It makes me grateful for every single day I have lived since then. It empowers me. I ask for a brief extension of time. [*Extension of time*]

According to Dr Saul, not one of our local hospitals has a mandated plan or policy for asking people their wishes about their death—what their plans are, who can make decisions about their care and what they want when they lose capacity to do so. It seems that members are talking about a very small percentage of people who will be able to access voluntary assisted dying as a result of this bill, but we are not talking about the tens of thousands of people who die every year without the opportunity to make full decisions about how they pass—or even those decisions that could extend their life. When I had both my children, I had a birth plan. Far beyond music or lighting, this was about options I would prefer for medical intervention if things went wrong:

drugs that I might need to take for pain relief and the impact they might have on my child, and what my preferences were about care for me and our baby after he was born.

Did my first birth go to plan? No, but at least going into it I felt a sense of safety and security. I knew that my partner and my medical practitioners were on the same page as me. I knew they were supporting me and our baby, and that whatever happened we would deal with it. The second time, when the same thing happened, we had a plan. We had reviewed the old one in light of what happened the first time and we were much more in control. It made me feel safer to have that plan. It helped me to know that my partner and my medical care team were with me all the way. It took what could have been the most traumatic medical experience in my life and made it just another part of my life journey.

Why, then, at the other end of life's journey do we not insist, or even recommend, that people have a plan in place? To even access palliative care you have to opt in for it. You have to know you need it. You have to talk to your doctor—and, most importantly, they have to talk to you. Too many times we hear that a specialist has not given their patient the hard information they need to make informed decisions. Even worse, sometimes they do not have the resources or access to services that will make that part of their plan go easier. There is no point to having more funding for palliative care if we do not remove the stigma, the shame and the fear of talking about death so that people can actually plan for it. That is why I wanted to talk about this today as not just a moment at the end of our lives but as part of our lives, and affirming of our lives.

I thank some very special people who have worked to help all of us have this conversation. I thank Go Gentle and Andrew Denton, and Dying with Dignity, particularly Penny Hackett. However, I further thank all of those people who participated in such respectful and life-affirming actions to bring us all to this place. I have enjoyed our conversations, however brief, for the real and lived experience they have shared that has turned them into reluctant but effective advocates. Many of them have been through such terrible times of intense and personal grief but have turned that into action, into purpose and now, hopefully, into change. That is important. It honours both those who have passed and those who have sat with them in their suffering—and who have tried to stop it happening to others. As I have said, those people have also started a conversation we had to have, a difficult conversation that many of us are too afraid to start about what happens at the end—and what makes us value this precious gift of life.

Today I have listened to other members in this debate speak of not having enough time to talk about amendments, of not understanding the bill or of unintended consequences. I pay special tribute to the member for Sydney. Given the generosity around the briefings and the many experts he has brought to this place or had speak with us on Zoom, there should be no questions from any member about the intent of this legislation or, more importantly, its effect. I thank Maitland's local palliative care senior staff specialist, Dr Gareth Watts, and all my local doctors for all they do to make those final periods of life the best they can be. I thank the volunteers for Palliative Care NSW in Maitland. I am a patron of the group, which has been operating since 1990. I know how hard those volunteers work, particularly coordinator Judith Robinson.

I also thank Friends of Palliative Care in Maitland, Singleton, Cessnock and Dungog, which raise much-needed funds for local people facing their end of life. I thank "Spud" Murphy and his family, along with the Hunter-Central Coast Cancer Council, for their work in bringing this issue to a head a few years ago. Finally, I thank Dr Saul for his long-term advocacy on these issues and his wise counsel, not just to me but to all of those who face these darkest days. I thank him for the care and comfort I know he brings.

We must continue to have these conversations about death and ensure that we can all face it without regret and without fear, but instead with true dignity, true joy and respect for the lives people live. I thank all the medical and aged-care practitioners and ancillary staff who spend each and every day at work facing the people many of us are too scared to face. They help the rest of us through that final time we must all face in the end. Their compassion, their care and their consideration make those days brighter and safer, and take away our fears. I thank them all for the work they do each and every day. I commend the bill to the House.