LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),
Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

Submission Number: 051

Date Authorised for Publication: 011 December 2023

From:
To: LA Committee - VAD
Subject: Select committee response
Date: Friday, 8 December 2023 2:03:55 PM

Hi,

Please see below for my response. If you would like me to discuss or present information in person, I'm happy to.
—-

Attn: Select Committee for the Voluntary Assisted Dying Bill 2023.

As a resident of Canberra, and a young person who cared for their father who died from Parkinson's disease, I welcome this bill and it's rigorous approach to both enabling dignity in death and safeguarding those most vulnerable.

My experience of terminal illness and death as a Canberran resident.

My late father, Nebojsa Pavkovic, came to Australia as a young adult, with nothing but his hard work ethic and minimal English. He made his way by building houses, and even helped build the biggest house of all, Parliament House.

He was diagnosed with Parkinson's disease at the age of 50 and after a decade of suffering he was eventually unable to walk, talk or eat any solid food. He required 24/7 care, which we were unable to manage even with the support of the NDIA.

My father would try to grasp onto his last sense of independence and would attempt to go to the bathroom or kitchen by himself. Each day, it would be a gamble for if he would still be in bed or on the floor of the bathroom when we returned home. And more often than not, we would need to pick him up from the floor and walk him to a chair.

Imagine, being at your peak fitness. The provider of the family. And in the span of ten years, having your independence stripped away piece by piece. The things we take for granted, walking, talking, eating, swallowing, grasping, showering, going to the toilet, all taken away.

It was at this time we had a community nurse tell us that we were being negligent in not providing 24/7 care. As a family, and with support from social workers, we made the decision that dad would go to the emergency hospital whilst we worked with our support services to come up with a care plan.

One week into his hospital stay, my dad asked if he could make the choice to end his life. A choice he had often verbalised to my mother, but had now verbalised to me and his doctors.

Given the lack of a VAD service, his only choice was to stop eating food all together to put an end to his suffering. A choice he had to keep making every day for over a month, despite his hunger and pain, to finally receive peace.

He spent a total of 3 weeks in the hospital, and 2 weeks in palliative care. During this time, he lost so much weight, that in the end, he was skin and bones. Every day he would be given his pain medication, which made him more "numb" and less my dad. He eventually couldn't open his eyes, his breathing became laboured, and he often communicated he was in pain through squeezing peoples' hands.

When doctors say "be careful what you say around him, he looks asleep and can't respond, but he can definitely hear you", it makes you question if his pain was even being managed or if they were simply silencing him by drugs.

The aim for palliative care is to relieve pain in final moments. Spending my time near my fathers deathbed, I rarely saw these moments of "relief". I saw my father, breathless in pain, groaning in pain or curled up in pain. Relief for my father would have meant choosing how his life ended on his own terms, surrounded by people he loved, peacefully and painlessly.

23 of March. His birthday, and now the day that he passed away. This was the day, I played him his favourite songs. When night came, I asked him if he was in pain. He squeezed my hand. I asked him if he wanted pain medication. He squeezed my hand. I organised for the nurse to give him what would be his final dose. I squeezed his hand and said "happy birthday dad" and left.

One hour later, nurses called to let me know he had passed. Death - the relief he had asked for time and time again, and what would be his final birthday present.

In the moment, you have people tell you, "he waited for you to leave before he passed away".

But then over time, you reflect, and the doubts and regrets come to the surface.
I still have thoughts like:
"He was all alone in his last moments."
"I should have been there by his side."
"We should have been able to plan his goodbye."

At his time of death, voluntary assisted dying, was not available in Australia. Since then, many states have now passed legislation allowing people to have choice and control over how they die, and prevent people with terminal illness and their families experience traumatising final days together.

ACT on the other hand has lagged behind (not a usual circumstance in our Territory, where we are often the leaders in the country). This leaves many suffering Canberrans with another choice taken away who already have little self determination, and worse, taking their own lives.

As Australians we have come a long way to help people through their suffering. And hopefully soon as Canberrans, we might be able to share the same rights as our fellow citizens.

Over the years I have spent my time advocating for the rights of those who haven't been able to have the freedom to choose how they die. I've spoken on radio multiple times, discussed with politicians and presented to the ACT Legislative Assembly - all with resounding support that voluntary assisted dying is needed.

Death, and understanding what a good death might look like is often considered taboo or too confronting to discuss. But we have taken some massive steps forward to being able to debate this bill.

Through this, I hope that those reading this submission take the time to reflect on what a peaceful death may look like and perhaps discuss it with a friend or family member.

The Voluntary Assisted Dying Bill 2023 aims to promote the right to life in two key ways:

- By enabling an eligible individual to both 'enjoy a life with dignity' and 'die with dignity'. The right to enjoy a life with dignity is a core element of the right to life. Courts overseas have recognised that 'the rights to dignity and to life are entwined. The right to life is more than existence – it is a right to be treated as a human being with dignity: without dignity, human life is substantially diminished.' By providing a choice to not endure intolerable end of life suffering, the Bill promotes this aspect of the right to life.
- By putting in place safeguards so that an individual's life may not be ended arbitrarily, particularly involuntarily. Involuntary euthanasia represents an egregious, and criminal, breach of the right to life. In particular, failing to protect vulnerable individuals may threaten their autonomy to choose to continue to live. The Bill promotes the right to life by ensuring that VAD as an additional end of life choice cannot become available to an individual unless they are acting voluntarily, without coercion, and with decision-making capacity; and by providing dozens of other safeguards to ensure no life can be taken arbitrarily.

Like all legislation, the Bill may not be perfect. But it is a perfect next step to enabling our people the right to die with dignity and not suffer intolerably at the end of their lives. This is also extended to their family members who continue to suffer even after their loved ones have passed.

If my father has access to VAD, the last few weeks of his life would have been completely different. Instead of fear, anxiety, and apprehension for each day of his hospital visit, it would have been filled with love and appreciation, despite the sadness. Family would have had the opportunity to be present, and more importantly, my dad would have felt like he was in control and independent to the end.

Voluntary assisted dying is wanted. It's needed. And it's time for Canberra to catch up.

Kind regards,
Katarina Pavkovic