

**Submission  
No 104**

**INQUIRY INTO PROVISIONS OF THE VOLUNTARY  
ASSISTED DYING BILL 2021**

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To: Standing Committee on Law and Justice

## **Submission for the Inquiry into the provisions of the Voluntary Assisted Dying Bill 2021**

Thank you for the opportunity to make this submission and I would be happy to appear at a public hearing, if requested to do so. Although I am currently the Vice President of Dying with Dignity NSW, this is my personal submission.

I have been an advocate for voluntary assisted dying (VAD) law reform for nine years following the death of my beautiful mother Jan, from an aggressive brain cancer. When Mum died in late 2012, there was no law to provide her with a more compassionate, end-of-life option so she was forced to endure the terrible end stages of this dreadful disease and we, her loved ones, were forced to watch on powerless and traumatised.

My mother loved life and she had a loving family supporting her and caring for her through the entire seven month journey from diagnosis to death. We were also supported by a caring, community, palliative care team from one of Sydney's top hospices, Sacred Heart in Darlinghurst. Despite all that support, Mum did not die the way that she had wanted to and the last 15 days of her life were cruel and harrowing.

Just two weeks before her death, Mum started to ask for some form of medication that would just knock her out but nothing the doctors prescribed achieved a peaceful state. Each day it just got worst. Mum had had enough. She kept asking, "Why are they doing this to me?" "Why are they torturing me?"

I will include Mum's story at the end of this submission but I know that you will receive literally hundreds of similar testimonies so I would like to prioritise some key points about Mum's situation in order to support particular provisions of the NSW Voluntary Assisted Dying Bill 2021, or perhaps even recommend some improvements.

### **1. I recommend a twelve month prognosis instead of six months**

Mum was diagnosed with Multifocal Glioblastoma Multiforme (multiple brain tumours) on April 26<sup>th</sup> 2012. At the first appointment with the neurologist she was told that there was nothing that could be done to save her life and she had less than 12 months to live.

Mum died on 27 November 2012, just seven months later.

Mum knew within the first few weeks of her illness that she didn't want to suffer the final stages of brain cancer. She loved life and wanted to live for as long as possible but she made it very clear that she did not want to suffer at the very end of the illness. She even asked if the neurologist would help her. Of course, he could not answer that question.

If VAD had been legal in NSW in 2012, my Mum probably would have chosen to apply for access to VAD at the earliest possible opportunity, not because she wanted to end

her life at that stage but so she could be confident she would not have to endure unbearable suffering at the end. Being granted access would have given her peace of mind during the 7 months she had left providing a much-needed palliative effect.

Looking back on Mum's deterioration, if she had not been able to access VAD in the first few months after being given that 12 month prognosis by the time she reached the 6 month mark she may have been too unwell to make it through what is quite a gruelling process. According to the data from Victoria it takes an average of 36 days to get through the highly-safeguarded VAD application and assessment process.

I am very confident, and the evidence from Victoria and overseas shows, that Mum would have made the most of what time she had left and she would have only chosen to take the life-ending medication a few weeks earlier than her eventual death. However, just knowing that she could control her end would have provided an enormous palliative effect, as has been shown with VAD patients in Victoria. It would have been so much better than the constant fear and anguish she endured for 7 months.

## **2. Decision-making capacity and state of mind**

Some opponents of voluntary assisted dying believe dying individuals who request VAD should undergo mandatory psychiatric assessment. I believe this would be totally unnecessary and extremely burdensome for these people who are so desperately unwell. Nowhere in the world is a mandatory psychiatric assessment part of a VAD law. I feel confident that the coordinating medical practitioner and/or the consulting medical practitioner in a NSW VAD scheme would refer a dying individual for assessment, if they suspected that the request was due to clinical depression or if they were uncertain about the person's decision-making capacity.

When my Mum began asking to be "knocked out" her palliative care specialist actually suggested that she might have depression and he referred her to a psychiatrist. This was just two weeks before Mum died and she could hardly speak at that point. I acknowledge that Mum felt hopeless but that was because she was dying of brain cancer and her life was coming to an end, not because she had a mental illness. To even suggest that she was mentally ill just added to her suffering and made her despair even greater. She was already on medication to help relieve anxiety, what good could have come from a psychiatric assessment in the last two weeks of her life?

## **3. Conscientious objection and entity participation**

While I respect an individual health practitioner's right to conscientiously object to participating in the VAD process, I would recommend that the clauses in the NSW VAD Bill 2021 that relate to conscientious objection and entity participation be maintained.

It is of great concern to me that opponents of VAD, including some MPs, think that the feelings of health practitioners should be prioritised over the feelings of the dying individual. To argue that an "aged care facility" or "retirement village" should be able to ban VAD completely on their premises is, in my opinion, outrageous. To suggest that staff, or other residents, could be disturbed or traumatised if a dying individual, behind closed doors, died peacefully via VAD, is unbelievable. People die all the time in these places and although other residents and staff may be sad and grieve, I am sure hearing a dying person crying out in pain or distress (which does happen now) would be far more upsetting for fellow residents and staff.

The NSW Nurses and Midwives Association recently surveyed their members and found 86% supported VAD legislation. I strongly recommend that the provisions in the NSW VAD Bill related to this aspect of the scheme are upheld.

## **Key points in support of VAD legislation**

I am confident that other submissions from organisations, such as Dying With Dignity NSW and Go Gentle Australia, will provide the Committee with detailed arguments as to why NSW should pass the VAD legislation that is under consideration, including the fact that every other Australian state has already passed similar laws.

However, the strongest point that I would like to make in support of VAD laws is that, despite the best efforts of palliative care professionals, there are some diseases that create symptoms that cannot be adequately relieved at the end stage. I know my experience was not unique and I know that MPs have been receiving thousands of emails from families who have witnessed the 'bad' death of a loved one.

Some opponents of voluntary assisted dying argue that we should simply maintain the 'status quo' but I totally disagree. At present we have a situation in which a very small number of medical practitioners are willing to break the law and risk prosecution by providing medication that will allow their patients to die peacefully at a time of their choosing. In other situations, some palliative care specialists may be willing to provide terminal sedation, knowing that it will hasten death. They too are working in a grey area of the law. But I believe the majority of medical practitioners involved in palliative, or end-of-life care, while trying to abide by our current laws, will only provide terminal sedation as a last resort and only after a patient has endured horrendous suffering and often it is without the patient's consent.

This should no longer be tolerated. It should not be a lottery as to which type of doctor a dying patient gets. It makes no sense to turn a blind eye to compassionate doctors who are breaking the law and at the same time leave some patients at the mercy of other doctors who are unwilling, for legal or religious reasons, to grant the wish of a dying patient to die peacefully. The law needs to be changed.

Some opponents, including some MPs, argue that there is no need to change the current law because people can already choose to stop all treatment and "allow the natural process of dying to continue". What this suggestion fails to mention is that this "natural process" usually includes the refusal of all food and water and basically starving and dehydrating yourself to death.

In NSW, in the absence of an assisted dying law, family members, carers, doctors and nurses have to accept a person's decision to begin this long and psychologically cruel process. It is legal but it can be devastating for all involved based on the testimonies sent to MPs. A VAD law in contrast would give the dying individual the option to die quickly and peacefully at a time and place of their choosing.

I trust that after hearing real stories such as my mother's (see below), the committee will be able to recommend a bill that will include all the necessary safeguards but which will also make a voluntary assisted dying law workable, so that unnecessary and prolonged suffering can be avoided.

I sincerely hope that NSW will soon join every other state and pass the VAD legislation.

As mentioned, the cruel death of my mother from brain cancer in 2012 highlights the failings of current medical practices and has motivated me to become an advocate for the voluntary assisted dying.

## Here is Jan's Story:

*My mother, Jan Scott Ryder, was a beautiful woman who adored her partner, her three daughters and her five wonderful grandchildren. She loved her life.*

*In May 2012, aged 77, Mum was diagnosed with terminal brain cancer. Initially she spent 3 weeks in hospital and, with each visit from her doctors, the news got progressively worse. Mum had a very aggressive form of glioblastoma multiforme and with multiple tumours they did not want to operate, or do radiation therapy, for fear of causing severe brain damage. Before leaving hospital Mum asked her neurologist, if he would 'look after her in the end' and give her something 'before it gets ugly'. He, of course, could not make that promise and, in fact, she never saw him again as she was then referred to a Palliative Care Team.*

*Mum did not want to enter a hospice and we were happy and able, to care for her at home. However, Mum always had the expectation that the doctors would not let her suffer in the end and that she would have a peaceful death. This is not what happened.*

*In the beginning Mum still managed to get some pleasure in life, even though she rarely left home. However, like many people with a terminal illness, Mum's quality of life deteriorated quickly.*

*Mum underwent a number of courses of chemotherapy hoping to extend her life a little but she always understood that there was no cure. As the months passed her physical condition and quality of life continued to deteriorate.*

*As the cancer progressed Mum lost her ability to walk, even with her frame. She lost her words and struggled to communicate. She was unable to write, unable to read, unable to talk on the phone and, towards the end, even listening to the radio or watching TV caused great discomfort. She was sleeping more and more each day and she had headaches and constant nausea. But even when Mum was bedridden and it took two people to carry her to the toilet, and she couldn't even wipe herself, she still wanted to live.*

*In early November the doctors decided to stop the chemotherapy, as it was doing nothing to improve Mum's quality of life. Each day Mum's condition worsened. We did everything we could to try to keep her comfortable. Every day I would rub her legs and feet because she said it felt like they were dying. The nausea medication did little to help her discomfort, apparently because it is the brain that creates the nausea, not the stomach. As Mum's right side became more and more affected she could not even lie in bed peacefully. It is hard to know what was so disturbing, but we constantly had to reassure her that she was lying in the centre of the bed. She was very agitated and distressed.*

*Mum started to ask for some form of medication that would just knock her out but nothing the doctors prescribed achieved a peaceful state. Each day it got worst. Mum had had enough. She kept asking, "Why are they doing this to me?" "Why are they torturing me?" When the Palliative Care Team visited on November 12<sup>th</sup> 2012 her ability to communicate was nearly gone and she struggled to get the words out but she did manage to get her message across. Tragically there was nothing they could do.*

*By 14<sup>th</sup> November Mum no longer wanted to eat and she had difficulty swallowing her medication. On the following day she asked me whether it would be over soon. Each day she asked, "When will it end?" "Just give me something to end it", but I couldn't. I was so afraid. No one tells you what to say or what to do in these situations. I knew the end was near but it*

*was so hard to see my beautiful mother suffer like this. The doctors had been so dishonest. They had told her that in the end she would just sleep more and more and then just not wake up one day. I know, in the end, if Mum had been able to end her own life she would have but by that stage she was like a rag doll. I felt like I had failed my Mum. I had promised her that I would be with her to the end and that I would not let her suffer. But that was just not possible.*

*By Tuesday 20<sup>th</sup> November Mum no longer smiled. On Wednesday morning she struggled to say, "Not another night," then later that day her final word - "Finish". At that point Mum's G.P. suggested it was time for Mum to go to a hospice. That was something our Mum and the whole family had never wanted but we felt we had no choice. The palliative care team had not been willing to provide 'terminal sedation' at home or certainly not at that point, despite Mum's pleas over the previous few weeks.*

*The next day Mum was taken to a top quality, private hospital and she was under the care of one of Sydney's top palliative care physicians (Professor Richard Chye). I am not sure if she even knew what was happening by then. She couldn't speak, she just stared. Fortunately the hospital allowed us to stay with Mum and we were so grateful for that but we still couldn't prevent a traumatic end.*

*Right at the beginning of Mum's illness she had suffered two seizures. The first was what led to her diagnosis and the second happened just days after she was originally discharged from hospital in early May. Mum's greatest fear throughout her illness was that she would suffer another seizure. She had described it as like having a giant slamming back and forth inside your body but fortunately changes to her medication prevented this. That is, until the end.*

*By the time she was admitted to the private hospital Mum could no longer swallow, so she was unable to take the anti-seizure medication. On that first night my worst nightmare came true and Mum suffered another seizure. It took nearly an hour and a half to get the seizure under control because the nursing staff were only authorised to administer a certain amount of Midazolam every 15 minutes. It was so traumatic to watch Mum suffer and I couldn't understand, and I still can't, why she wasn't given the chance to pass away peacefully in those final days.*

*I now realise that unless you can find a compassionate doctor and supportive nurses who are willing to effectively break the current law, a dying patient will be forced to endure horrendous suffering before the medical staff are willing to hasten death using terminal sedation. In other words, you cannot request a peaceful death to avoid that suffering.*

*Mum suffered a seizure, pain and other distress over three days before she was eventually sedated to a level that at least masked those symptoms. She died 48 hours later but I will never forget the tortured expression on her face once she had taken her final breath.*

*How can we say we live in a humane society? Nothing could have stopped my mother's death from brain cancer but it would have been possible to provide a peaceful end, if only voluntary assisted dying was legal. Despite all that Mum had been through it was only in the last few weeks that she pleaded for someone to end her suffering. We all let her down and that is a burden I will carry for the rest of my life.*

Yours sincerely

Ms Shayne Higson