

“I’m sorry I had to do this”

# Suicide by people with terminal illness in NSW

A background paper by Go Gentle Australia, March 2022

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# Executive Summary

In October 2021, a report from the National Coronial Information Service (NCIS) found 1 in 5 suicides in people over 40 in NSW is by someone with terminal or debilitating illness, or who had experienced a significant decline in physical health<sup>1</sup>.

Figures were tragically similar in Victoria, Western Australia and Queensland.

Fortunately, five Australian states have now passed voluntary assisted dying (VAD) laws. These laws provide people with terminal illness the legal option to end their suffering at a time of their choosing, on their own terms.

The only state not yet to have passed VAD laws is NSW.

Without a VAD law, the options available to people who are suffering unbearably with terminal illness are few; wait out a potentially prolonged and painful death, hope their doctor is willing to take a risk to help end their suffering, or take matters into their own hands.

The suicides that result from this impossible set of choices are often violent, lonely and premature – before the person loses their physical capacity to act.

While suicide prevention is a complex area, the traumatic circumstances under which terminally ill people feel they have no choice but to take matters into their own hands can, in part, be addressed by implementing strictly safeguarded VAD laws.

In our work we speak to families whose loved ones have suicided when faced with untreatable terminal suffering. We hear, too, from medical professionals and first responders who are traumatised by such deaths. But we also speak with families whose terminally ill loved ones avoided such desperate measures because they had the choice of a legal and safe VAD process. The difference could not be more stark. You can read more in the Testimonies section.

It is time for a voluntary assisted dying law in NSW. A bill, which passed the Lower House by a significant majority in December 2021, is currently before the Upper House. Yet, despite clear evidence that VAD law reduces end of life trauma and suffering, numbers remain tight as opponents continue to falsely argue that VAD is suicide.

The largest suicide prevention peak body in the world – the American Association of Suicidology – responded to the US assisted dying debate, publishing a position statement in 2017<sup>2</sup> that clearly sets out the difference between assisted dying and suicide, and warning against conflating the two.

In Australia there has been only a limited attempt to do the same, with a principled participation in the WA VAD debate (2019) from Lifeline WA<sup>3</sup>.

We are calling on Australian suicide prevention organisations to follow the lead of their US counterpart and support the advocacy of terminally ill people in NSW, their families and carers. We ask them to do so by writing to members of the NSW Parliament to reinforce the distinction between voluntary assisted dying and suicide, and to seek the passing of NSW's Voluntary Assisted Dying Bill, without delay, and in line with VAD laws already passed around Australia.

The people of NSW do not suffer any less at the end of life than people in other states. Tragically, we now know, they are equally vulnerable to suicide when faced with terminal illness for which there is no meaningful medical treatment.

We seek your help in holding NSW politicians to account to protect the terminally ill and their families from the generational trauma of suicide.

## VAD in Australia

NSW is the only Australian state yet to pass voluntary assisted dying (VAD) legislation. Every other state has passed VAD laws, and the laws are currently operational in two – Victoria, since June 2019 and Western Australia, since July 2021 – with the rest in implementation phases.

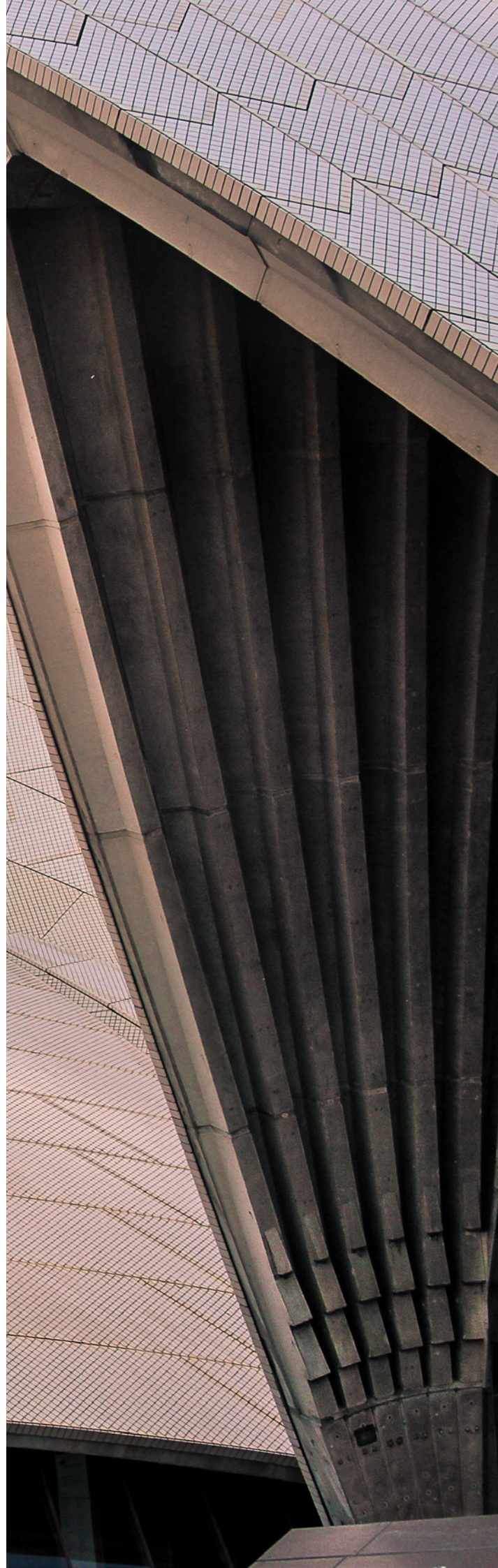
Among the five states to have passed laws, a broadly consistent and tightly safeguarded Australian model for VAD has been achieved. The laws allow terminally ill, mentally competent adults who are suffering unbearably the option to choose the timing of their death. Two doctors must agree the person meets strict eligibility criteria.

Victoria's law has been operating for more than two years, safely and as intended, as is WA's law. These laws are much needed, and have consistently attracted high public support between 70-80% across Australia.

The VAD bill before NSW Parliament is a private member's bill, put forward by Independent MP Alex Greenwich. It passed the Lower House 52-32 votes in November 2021 and is currently before the Upper House.

A positive resolution in the Upper House is not guaranteed.

We obviously want the law to pass. But we are equally concerned that it passes without harmful amendments that define VAD as suicide (including on death certificates), or that unfairly restrict people's access to VAD in NSW – amendments which have been tried, and which have failed to pass, in every other state. We also want our politicians to stop delaying passage of this law. Each week without VAD choice is another week where a terminally ill person is coerced to consider suicide.



# The distinction between VAD and suicide

Voluntary assisted dying is not a choice between life and death. It is the choice of a terminally ill person about the manner and timing of their death (which is imminent and unavoidable), and the suffering that must be endured.

The distinction between suicide and a rational decision to end inevitable suffering was also clearly understood by New York's chief medical examiner, Charles Hirsch, when investigating the deaths of office workers who jumped from the Twin Towers on 9/11.

Faced with a terrible choice – a slow, agonising death by fire, or a quick death by jumping – many New Yorkers chose to jump. Seeing this as a rational choice to avoid needless suffering, Hirsch refused to classify their deaths as suicides.

In 2017, the American Association of Suicidology published a position statement declaring that assisted dying and suicide were separate issues and should not be conflated. The Association stated:

In general, suicide and physician aid in dying are conceptually, medically, and legally different phenomena...The American Association of Suicidology is dedicated to preventing suicide, but this has no bearing on the elective, anticipated death a physician may legally help a dying patient facilitate.

A patient's choice of PAD (Physician Aid in Dying) that satisfies legal criteria is not an appropriate target for "suicide" prevention.

In Australia, there has been no similar intervention by suicide prevention organisations, apart from an acknowledgement of the dangers of conflating suicide and assisted dying issued by Lifeline WA during the campaign in that state to pass an assisted dying law in 2019.

Words can cause harm. Any linkage between euthanasia and suicide has the potential to cause harm.

We recommend that any public debate surrounding euthanasia refrains from making the link to suicide, as this can provoke suicidal ideation.



# The cost of not acting

Multiple Australian parliamentary inquiries into end-of-life care in the last five years have revealed a disturbingly high incidence of suicides of the terminally and chronically ill.

National Coronial Information System (NCIS) data shows in NSW **in 2019 there were 101 suicides by people over the age of 40 with terminal or debilitating illnesses** – or who had experienced significant decline in physical health prior to their death. These account for more than 20% of intentional self-harm deaths in that age bracket in that year. (Please see the references section at the end of this document for the full report).

In Queensland, **seven people with terminal and debilitating illnesses took their own lives every month** in 2016 and 2017.

During WA's parliamentary inquiry ahead of their VAD law passing, the State Coroner presented evidence that **one in ten suicides in WA in any year are by people suffering with terminal or debilitating chronic diseases**.

Prior to the introduction of Victoria's VAD law, State Coroner John Olle estimated **a similar number of suicides each year – around 10% – were by people with chronic, debilitating or terminal illnesses**. When asked if palliative care and support services might have reduced these 240 suicides between 2009-13, he responded:

These people we are talking about... have made an absolute, clear decision. They are determined. The only assistance that could be offered is to meet their wishes, not to prolong their life.

Australia is not alone in facing this problem. The most recent analysis (April 2022) by the UK's Office of National Statistics<sup>4</sup> found that people with severe and terminal illnesses (low survival cancers, chronic obstructive pulmonary disease (COPD) and chronic ischemic heart conditions) were twice as likely to take their own lives in England. Other research estimated that up to 650 terminally ill people are taking their own lives every year in the UK in lieu of the safe, legal choice of assisted dying<sup>5</sup>.

The causes of suicide are too complex to draw direct inferences. However, as VAD laws come into effect around Australia the instances of suicide among the terminally ill are likely to reduce. This may or may not be visible in suicide statistics.

Victoria's experience since its law came into effect in June 2019 certainly refutes opponents' claims that VAD laws lead to an increase in suicides. (They reach this conclusion by disingenuously adding the number of VAD deaths to the suicide statistics). In reality, the state's suicide rates are stable and in 2020 there were actually 20 fewer suicides reported than in the previous year.

# Testimonies

## NSW Families

### THE CONNELL FAMILY

Greg Connell, from Gooloogong in central NSW, is one of the tens of thousands of advocates fighting for voluntary assisted dying reform in NSW.

Greg's father, Cletus, died in 2015 when he threw himself headfirst out a two-storey window after an intense, two-year battle with bone cancer.. He left a note behind for his family, saying it was "time to go".

Greg says his father should have had the option to end his suffering with dignity and peace.

We are not upset for what he did, he had to do it because he was suffering and it was the last stage of his long-fought battle. The sad part was that he had to end his life in such an undignified way, alone, in the dark, with no family with him.

He had seen his own father suffer enormously at the end of his life and didn't want to have to go through such a prolonged and unbearable death as well.

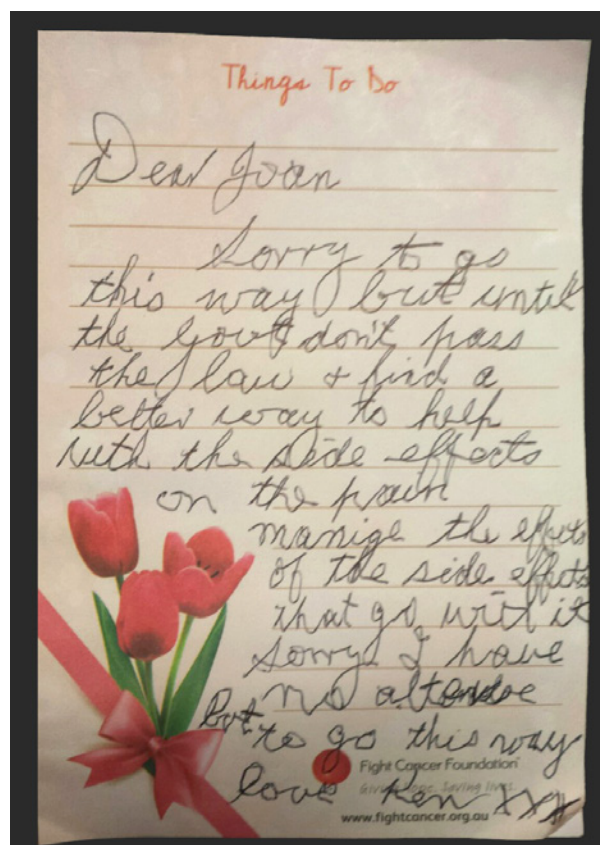
It's time for NSW to introduce these laws so that terminally ill people at the end of their life have a choice to die with dignity and not have to resort to lonely and traumatic suicides.

### THE DICKSON FAMILY

Kenneth Dickson, 81, took his own life on 9 October 2015 after many years living with cancer. His daughters tell his story below.

Our beautiful dad, Kenneth Stanley Dickson, took his own life on Friday 9 October 2015 at the home he shared with Mum and Down Syndrome son, Jason.

Dad was 81 and suffering terribly with his third bout of cancer. He had cancer of the oesophagus,



a tumour behind his eye and also non-hodgkin's lymphoma. Although Dad was on a lot of medication there were days when it just wasn't enough and the side effects of the medications were unbearable.

He got down to a weight of just 45kgs. Dad was a true gentleman, loved and respected by everyone who knew him. It hurt Dad's dignity and pride that his daughters and wife had to shower him and change his soiled pants, but we would do it all again for him tomorrow.

Dad was a devoted and dedicated Christian. A Baptist, he was very involved in the church and his dad had been a Baptist minister. Towards the end he became a strong supporter for euthanasia to be legalised in Australia.

What Dad went through, especially in the end, was horrific. He made the heartbreaking decision to take his own life, hanging himself in the backyard.

Jason, who has Down Syndrome, was the one to find Dad and that made the situation even worse, if that was possible. Jason is still saying that Dad is coming home soon. He just doesn't understand.

Dad left behind a note to our mother, expressing his desperation at the end. All he wanted was for someone to help end his suffering so that he could die in peace with dignity, which is what he deserved.



## THE DANIEL FAMILY

Lawrie Daniel, 51, took his own life in September 2016 after almost 10 years living with Multiple Sclerosis. He died alone, taking sleeping pills he had saved up over weeks.

Since then, his wife and children, now both young adults, have advocated for VAD law reform on his behalf.

Lawrie wrote a letter to the NSW Coroner ahead of his suicide (see next page).

His son Bertie, now aged 21, recently wrote the following in a letter to MPs in the NSW Parliament Upper House:

The pain and loss of function of his limbs was finally too much for him and on the 25th of September 2016, he ended his life all alone in the middle of the night. He had sent us off on a holiday and didn't tell us his plans so we wouldn't have been implicated. I was 15 at the time and my sister was only 13.

My dad's death was unexpected and abrupt, he had to die on his own, in a dark room, overdosing on painkillers – earlier than he wanted because his

hands were slowly being paralysed and he would not have been able to do it otherwise.

When he received his diagnosis in 2009 he was told that the only thing he could do was go home and wait until he died. It is not a dignified death. It is a death preceded by years of agony and suffering that not even palliative “care” could impact in any meaningful way. Nothing could eliminate or manage his pain, he could barely use his legs or hands and he had no quality of life and yet was forced to keep living.

NSW law states that suicide is legal. If you want to end your life you can, but no one else can know or they will be implicated in the act and receive jail time. This means that people with terminal illness who are miserable and suffering constantly have to end their lives alone and without support, often in truly horrific ways.



To the NSW Coroner:

Dear sir or madam, if you are reading this it is no doubt because I have made an attempt at voluntary euthanasia and I sincerely hope I have been successful.

I experienced my first physical MS symptom in 2007 and since then (nine years!) I have experienced progressive loss of function, with the accompanying loss of my social roles and my capacity to complete the activities of daily living. I have multiple, seriously disabling symptoms, and I am in chronic unrelieved pain, wheelchair bound and mostly housebound.

With primary progressive MS, Medical science has nothing to offer me, not even effective palliation of pain or symptom relief. If I had some hope at all, perhaps I would be encouraged, but all I can expect is a continual decline over who knows how many years until death claims me. As one doctor expressed it, "MS is like dying in slow motion".

Where I am in the disease course now is unenviable, but the next stages of this disease are truly horrifying. However, in the absence of voluntary euthanasia laws in this country, I have no option but to experience whatever the disease imposes on me, or to turn to self-help.

Some time ago I downloaded the Peaceful Pill Handbook, and asked my doctor to let me try Endep, ostensibly for neuropathic pain and to help me sleep. Instead of taking the Endep after I had gotten into bed at night to 'help me sleep', I hoarded it.

Once I had enough Endep, I had to wait until my family went on respite, because the handbook said that I needed six to twelve hours undisturbed (closer to 24 hours if possible), and so I had to be sure that my wife and children would be out of the house for more than a day, because I could not risk anyone coming into my room after I had taken the Endep, and an ambulance being called.

I felt obliged to make this attempt perhaps sooner than I should have, because my arms and hands were getting worse, and I had to be sure that I had sufficient fine motor skills left to me so I could take this action myself. MS is unpredictable and in my circumstances, opportunities for getting close to 24 hours undisturbed are rare. I felt I had to act now, before the opportunity was lost.

If we had a compassionate voluntary euthanasia process in this country I would not have had to approach my doctor with a hidden agenda, make preparations secretly, or to do this alone and without medical supervision. I have had to do this dreadful thing without the formal approval of society, without the ability to prepare my family, and my very limited options for finding the time and place to do this means that a carer is likely to be the one to find me, and no doubt involve emergency services, and I would have spared everyone from experiencing things this way if I could have. I am truly sorry.

I know that some 2500 people take their lives in Australia every year, in lonely and often violent circumstances. Many are the chronically or terminally ill, or the very aged. I hope your position and conscience allows you to speak for these voiceless, and for compassionate voluntary euthanasia laws to be enacted soon. I also hope that you will permit my death certificate to state my death was by heart failure as I believe Endep will have that effect, or from 'the complications of MS', not suicide.

Sincerely,

SB Daniel

24-09-16

I CERTIFY THIS TO BE A TRUE COPY OF THE ORIGINAL

SB Daniel 24-09-16

## Victorian State Coroner John Olle

In 2015, John Olle appeared before the cross-party Parliamentary Inquiry into End-of-Life Choices to explain why he supported the passing of a voluntary assisted dying law in Victoria. He shared with the panel five stories he had referred to the Coroners Prevention Unit for further investigation.

He spoke of a very particular group of people: older Victorians with no history of mental illness and with loving family relationships, who were taking their own lives in what he described as “desperate and violent ways”.

What these people had in common, he said, was that each was suffering an “irreversible decline”, either from a terminal disease, or multiple chronic illnesses, or permanent physical pain. All were people of rational mind, he stressed.

The first individual is a 59-year-old man. He had a wife of 38 years, survived by his children and his wife, with whom he shared close and loving relationships. He had no mental health documented, a medical history of metastatic colorectal carcinoma, multiple confirmed colorectal and liver metastases... He was admitted to hospital with a fever, dry cough, ultimately he wished to go home. He would inform his son and family members he would rather take his life than live a life dying in a bed. He was well aware of his suffering and what was ahead of him. So he would rather die than stay in a ward. Ultimately he was observed by a motorist on a major freeway in Victoria hanging from a bridge. A note indicated his intention to take his own life.

Another case I have seen was an 82-year-old lady. She lived on her own and was survived by her children, again with whom she shared a loving lifelong relationship. Her documented medical history: hypertension, insomnia, arthritis, gastro-oesophageal reflux disease, gout and on and on and on it goes. She was feeling very poorly about it and depressed about her lot. Her vision was nearly gone. Her love of reading books, her quality of life was greatly diminished. She was described by her doctor as lonely, isolated, frustrated, impatient. Her daughter was informed by a neighbour who had told her she could not read anymore. It was the most important part of her life. She also informed her on a number of occasions she wanted to die.

She was found on the couch in her lounge room. This 82-year-old lady had a stained towel wrapped around her left hand. There was a knife on the floor in front of her, an open wound on her left wrist. There was a white-handled knife that measured 14 centimetres on the floor beside her. In the bathroom was found two pairs of scissors, and another white-handled serrated knife, about 30 to 40 centimetres in length, was located on a table. There were traces of dried blood on all of these items. She died of exsanguination — she bled to death.

Another, 89-year-old. Again, a man. He lived with his wife of 61 years and enjoyed a long and loving relationship with his family. He had a very lengthy medical history — no hint of mental illness. His son stated his dad’s lucidity, memory and eyesight were failing. He could not listen to music, watch TV

or read, which he was known to enjoy. He ended up alone, grinding various tablets with either a mortar and pestle or food processor and died of drug toxicity.

Another, 75-year-old — the second last. He lived with his wife, with whom he maintained a good relationship despite their divorce. He is survived by his daughters, with whom he shared close, loving relationships. He had no documented mental health history, and again a very long, complex mental history. Not long before his death, some years, he was diagnosed with prostate cancer, treated — radical treatments — sadly without improvement and increasing pain with poor prognosis. He expressed to others his belief that his life would be so much easier if someone could help him die. He could not face his lot. He ultimately obtained a firearm which he discharged by holding the tip of the barrel against his chest and reaching for the trigger. He was found by family.

Finally, a 90-year-old man, survived by his family, again with whom he shared close, loving relationships. He was described as a delightful gentleman. He was extremely fit for his age and a proficient iPad user... The family explained that when he learnt of his cancer he went downhill emotionally. He was depressed and angry that there was no cure. He often told his family he would rather do something to end it straightaway and that if he could no longer drive, he might as well be dead. He mentioned a nail gun. He was subsequently found dying with nail gun wounds to his head and to his

chest. He died ultimately from the injuries sustained from the nail gun.

I have other cases still before us. The tally is not ending: a lovely lady who had the ability to step off the platform in front of a train; a man with the ability to tie a hessian bag full of sand around his waist and step off a pier. It goes on and on.

## Effects on health care workers

In all Australian states, support for voluntary assisted dying among first responders and nurses is high. Emergency workers are often first on the scene and nurses and healthcare workers are exposed to the consequences of suicide attempts.

The NSW Nurses and Midwives' Association (NSWNMA) is a member of the [NSW VAD Alliance](#) and has written to state MPs several times in support of this legislation. In their most recent letter to members of the Upper House, they wrote:

The NSWNMA is also strongly concerned about the ongoing social impacts of lack of access to VAD, specifically suicide and attempted suicide by people with a terminal illness. One of our members told us:

“My brother-in-law [suicided] by hanging after a short battle with terminal lung cancer and was wanting the option of voluntary dying. My sister has long effects from finding his body and my brother-in-law was denied a peaceful death with loving relatives by his side. Please help to change the law.”

This Bill provides for a clear and robust process that enables access to VAD in appropriate circumstances, whilst maintaining the rights of people to conscientiously object to participation in the process. The NSWNMA is comfortably satisfied with the range of legislative protections that are provided for nurses and other health care workers who may participate in the process or engage in discussions with patients regarding VAD.

The Australian Paramedics Association NSW is also a member of the NSW VAD Alliance. Gary Wilson, Secretary, made the following statement:

Every day, Paramedics see patients who are suffering intolerable and untreatable pain through a terminal illness. The Australian Paramedics Association (NSW) believes these people deserve a choice.

Voluntary assisted dying is not a replacement for palliative care, rather it is a safety net for those who wish to access it when palliative care can no longer meet their needs.

Australian data indicates that a significant number of suicide attempts are by people with terminal illnesses. These are unnecessarily traumatic for family, friends and emergency services personnel. Instead, these people should be able to access the option of safe and dignified voluntary assisted dying.



# How it could be

We know from experience in Victoria that VAD legislation transforms many people's experiences of terminal illness, not just in providing reassurance and a peaceful death, but also comfort to their loved ones and healthcare teams who do not have to helplessly watch relatives and patients needlessly suffer.

## MARGARET HOGG'S EXPERIENCE

Lisa Hogg's mother Margaret worked as an aged care nurse for many years. When she developed the neurological condition corticobasal syndrome, she was clear she didn't want to go into a nursing home. However, as her body began to seize up, limb by limb, Margaret had to do just that – 18 months before Victoria's VAD law came into effect. In desperation, she told her daughters she would attempt suicide by throwing herself off the toilet with force or by using scissors.

However, Margaret did not have to resort to such violence. She became one of the first people to use Victoria's VAD law, taking the medication in her son's home surrounded by her family. Her daughter Lisa described it to Andrew Denton in the Better Off Dead podcast:

There were about 15 of us, and we took mum out for the day to his home and put her in a big recliner chair, and before we went there, we said, 'Do you want people to feel free to talk to you about it, or do you want them not to say anything?' And she just said she's happy for it to be an open thing, not this big secret. So, she spent the afternoon surrounded by her children, her grandchildren, her great grandchildren. And we all sat around and we

chatted, we laughed and everyone in their own time went up mum and just had a quiet moment. And we played music, we watched back over old videos of different family events that we'd had from, you know, 20 years ago. It was kind of like her life in a microcosm just there in that, that one afternoon.

We kept saying to Mum, 'Look at you, you created this, you know. If you and Dad hadn't met, this... none of us would be here. This is, this is your legacy.' It was just such a lovely thing to be able to have the opportunity to know that, yes, I'm going to die, and I want to have everybody I've loved to be with me just for one more time, all together, and it was perfect.

... She took the substance in three sips and closed her eyes, and she had my brother on one side holding her hand and my sister on the other, and they were just telling her they loved her. And just, very quickly, she went into a deep sleep. But she was still breathing, and she had chosen Rod Stewart's 'Sailing' as the music she wanted to be playing. And then I got a message from my brother 12 minutes after [Lisa was in Switzerland at the time, due to COVID restrictions] I spoke to her to say that she'd gone.

## ALLAN CORNELL'S EXPERIENCE

Four months after his diagnosis with aggressive motor neurone disease, Allan Cornell told his daughter Kristin, a medical doctor, that the inevitable march of his illness had made him realise how few options he had. His body would shut down completely, including his ability to breathe. He admitted he had considered suicide.

Kristin recorded their conversation which was included in the Better Off Dead podcast.

This is as melancholy as I've been, because now I'm not capable. I have to ask for someone to help me, and I can't 'cause there is no one who will. And, y'know, I'm talking about in illegal ways. I went through the dilemma of blowing my brains out, but I don't own a shotgun or a rifle. Okay, the ute's still there. 120k into a very sturdy tree. It's very common. That's messy. It's messy on the people who find you. It's a very badly thought-out plan. It's desperation at its worst. It's got to be soon, otherwise you won't be physically capable of doing anything.

It's ...not often I sook, but you end up in tears, you know? You sorta shouldn't be thinking this, and then you start thinking about your wife and your kids and it's very fucking uncomfortable. Fucking horrible place to be.

When Allan asked Kristin if she'd help him through the VAD process, which had only recently been made legal in Victoria, she said, 'Of course.'

Kristin is adamant that simply knowing VAD was an option had prevented her father violently taking his life. The VAD law had transformed her father's thinking. In another recorded conversation he said:

"Oh look, I'm just a different person since the VAD decision. It's just been so much better. And I'm sure there's a lot of people out there who go all the way with this horrible thing, to a horrible end. Now I don't have to do it. I can pick the day. I can talk to

you, I can talk to Pam, I can talk to anyone if I need to. And so, I'm now having a whole lot better period of pre-mortality now than I could ever possibly hope to live with this shit hanging on you, because all these lovely people have said, 'We can solve that.' And they do it lovingly, you know?"

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