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: 070

Date Authorised for Publication: 27 February 2024

Corinne Vale

13 December 2023

Select Committee on the Voluntary Assisted Dying Bill 2023

Office of the Legislative Assembly

Via LACommitteeVAD@parliament.act.gov.au

Dear Select Committee on the Voluntary Assisted Dying Bill 2023

Submission to the Inquiry into the Voluntary Assisted Dying Bill 2023

Thank you for the opportunity to make a submission in relation to the Select Committee's Inquiry into the Voluntary Assisted Dying Bill 2023 (the 'Inquiry').

We make this submission on behalf of the late Rosslyn Williams AOM and her loved ones. Ros took her own life in April 2023 because she was dying of motor neurone disease, did not have access to voluntary assisted dying, and wanted to die with dignity at a time of her choosing. We make this submission in the hope that these important laws are passed without delay and other terminally ill Canberrans and their loved ones are spared the cruel and needless suffering that we have experienced.

We have included with our submission a statement from a senior palliative nurse who was involved in Ros's care, which provides insight into the moral injury experienced by ACT palliative staff in the absence of a voluntary assisted dying option for their terminally ill patients.

If you publish this submission and covering letter, please ensure Corinne's address, email address and phone number (italicised above) as not made public.

If it would be helpful to the Committee for us to elaborate on this submission, or respond to questions, we would be willing to appear at a hearing.

Your sincerely,

Corinne Vale and Jim Williams, daughter and husband of Ros Williams

SUBMISSION OF THE FAMILY OF THE LATE ROSSLYN WILLIAMS AOM TO THE PARLIAMENTARY COMMITTEE INQUIRY INTO THE ACT *VOLUNTARY ASSISTED DYING BILL 2023*

It is our submission that this Bill is critically important and should be enacted by the ACT Parliament without delay. We urge this Standing Committee to finalise this inquiry as quickly as possible so as not to delay its enactment and implementation.

These laws were too late for our dearly loved mum/wife Ros Williams, who took her own life in April 2023 because voluntary assisted dying was not accessible to her. She was dying of motor neurone disease (MND) and after rationally considering all the end of life options available to her in the ACT, she decided that suicide was her 'least-worst option'. No-one should have to make this terrible choice.

Voluntary Assisted Dying is an option available to the terminally ill in almost every other State and Territory in this country. This Bill adopts the important safeguards that have been shown to work effectively to prevent unintended consequences in other jurisdictions. These laws will be reviewed after three years, which will allow for any necessary fine tuning. What are we waiting for?

We share Ros's story so that others will understand why these laws are important to relieve human suffering, to honour human dignity and autonomy, and to prevent moral injury to our wonderful palliative nurses and doctors who tell us they have one to two patients a week asking them if they can access VAD. We include with our submission a statement from one of Ros's palliative nurses (at **Attachment A**), which outlines the moral injury caused to her by the circumstances of Ros's death. She wrote this statement in the week after Ros's death so that it could be included with our family's submission to the Coroner. She has provided her consent for it to be included in this submission.

Our family has made the decision to share Ros's intensively personal story in detail, despite how much it hurts to recount it, because it is incomprehensible to us that anyone could bear witness to her story and fail to understand why we need these laws. And why we cannot afford to delay them by even one more day.

Ros's end of life story

Ros was a dearly loved wife, mother, sister, mother-in-law, and grandmother. The pain of losing her slowly to MND, and eventually to suicide in the absence of voluntary assisted dying or a palliative option acceptable to her, defies words. She is also greatly missed by her many close friends and her broader family, as well as members of the two community groups that she convened prior to her diagnosis, and the broader community that benefited from the work of those groups – the Canberra Mental Health Forum and the Alliance for Coronial Reform. We know Ros would have wanted her story to be told to help speed the passage of these laws.

Our family is not seeking to blame any individual for Ros's decision to take her own life. As can be seen from the psychiatrist's report extracted below, Ros made that decision herself calmly, rationally and by carefully weighing the options available.

Ros's MND diagnosis and physical decline: March 2022 – March 2023

Ros was diagnosed with MND in March 2022. MND is a terminal illness with no known cure nor effective treatment. It gradually paralyses all the muscles in the body while leaving mental faculties intact. If the disease is left to run all the way, without intervention, the patient usually suffocates to death when the muscles required for breathing can no longer function. At the time of her diagnosis, Ros was told the average lifespan post diagnosis for those of her age is 14 months.

Over the year that followed she quickly lost the physical capacity to do most of the things she loved doing – cycling, going to the beach, playing the piano, playing with her grandchildren, gardening, and cooking. She lost her trademark energy. She lost her capacity to walk and to stand, and to shower and go to the toilet by herself. In her last weeks she was getting close to losing her capacity to communicate as her voice was getting croaky, her breathing was becoming affected, she was finding it difficult to hold her phone, and she could only type with one finger. It took two people to get her into bed, and her nights were long and uncomfortable - being stuck in one position without the capacity to roll over or even move one leg off the other without assistance.

Respite care in a palliative hospice – March 2023

In March 2023, Ros spent two weeks in respite care at a palliative hospice in the ACT. That stay gave her the opportunity to consider what type of care and end of life options would be available to her in that hospice, if she chose to die there. It had been hard for her to find clear and sufficiently detailed information about her end of life options in preceding months.

We have decided to include details about her experiences at the hospice as we believe this provides important context to her state of mind shortly before she died, and underscores how carefully she weighed all her available end of life options before deciding that suicide was her 'least-worst option'.

During her stay at the hospice, Ros spoke with family and friends about how nice individual staff were to her, and about how much she appreciated the beautiful location of the hospice. She also told us how difficult it was for her that there was no consistency in the staff that cared for her. She estimated that she met around 60 different carers during her stay, and said she never knew who would respond when she rang her buzzer for assistance. She found it particularly confronting, and a terrible loss of dignity, to have young male nurses she had never met before turn up to assist her with toileting and showering (despite the fact that they were all very nice to her). She was not given the opportunity to voice her preferences as to what gender of staff performed these very personal tasks, nor the security of meeting these people in advance.

She had expected that during her stay at the hospice she would be cared for by a relatively small number of carers (maybe a group of around 5 or 6 staff), who would quickly become familiar with her, and who she would become comfortable with as they attended to her personal care needs, such as taking her to the toilet, wiping her bottom and showering her. Ros was struggling with the indignity of having others perform those tasks for her. Prior to going into respite care, she had only allowed her husband, Jim, and three support workers (all female), help her with these tasks.

Ros also explained to us how exhausting it was for her to have to explain to every new staff member she encountered what her individual care needs were. For example, to have to tell every different person who brought her breakfast, that she needed them to remove the lid of the yogurt and cut her food into small pieces. Or about the mobility assistance she required in order to move safely to and from the toilet (a situation that was rapidly evolving).

Two very distressing incidents occurred during her stay that rocked her trust in the quality of care the hospice could provide:

1. One morning she rang her buzzer to ask for assistance to get to the toilet. After she was helped on to the toilet she asked for a few minutes of privacy. The staff member who was helping her never came back to help her back to her bed. She was forgotten. She was dressed only in her night gown and got very cold waiting on the toilet. She tried calling out for a long time but no one heard her calls for help. She could not reach the emergency buzzer in the bathroom as she could not turn around. After a long time – she believes around half an hour – she managed to reach the toilet brush and use that to extend her reach to activate the emergency help button. She risked a fall by doing this and hurt her arm in the process. She was very cold and crying when help eventually came. She tearfully recounted to loved ones how awful this experience had been for her, and how terrible it was to feel so vulnerable and have your trust violated.

2. Later in her stay, she rang for assistance to get to the toilet during the night and two staff members assisted her to the toilet. Her legs gave way as the staff members were helping her off the toilet and she fell hard onto the tiled floor of the bathroom. This experience was very painful and distressing to her. She was lucky not to break any bones nor sustain any lasting injury.

These events occurred at a time when Ros still had the capacity to speak for herself, and to operate an assistance button that she had with her in bed (when it hadn't fallen to the floor). The prospect of being in that facility at a later stage of MND, and a time she could no longer communicate her needs, was terrifying to her. If she was in pain or discomfort or distress then, how would anybody know? If she couldn't trust them to look after her when she could still advocate for herself, how could she possibly trust them to anticipate and meet her needs when she could longer communicate them?

In addition, she could not bear the prospect of languishing for weeks in a condition where she could no longer get to the toilet and had the indignity of carers she did not know

changing her nappies and looking after her personal care needs - especially in circumstances where her mind was active. She was absolutely adamant that this was not a future that was acceptable to her. During her stay in the hospice she observed a patient in a more advanced stage of MND being wheeled around the grounds. Ros told close friends and family, 'There's no way I'm letting myself get to that stage'. She wanted control over when to call it quits.

Considering her end of life options

In March 2023 Ros had private conversations with her close family members and told us that she thought her 'least-worst' end of life option was suicide. She told us she had spent months thinking about this and researching options for taking her own life, and had procured a substance that she believed would do the job. It broke our hearts to learn that in the absence of VAD, planning her suicide had occupied so much of her energy and focus in the year since her diagnosis.

Ros spoke to us of her ongoing anxieties. What if she attempted suicide and it didn't work? What if she didn't have the courage to go through with it? What if she left it too long and lost the capacity to swallow the substance she had procured? What would it be like for loved ones to find her dead? Would we be angry at her for choosing suicide? Would the coronial inquest take a huge toll on us? Having lived through an inquest into her son's death, Ros was aware dying by suicide meant her death would be investigated by the Coroner, and our family knows better than most how difficult an inquest can be.

How tragic that so much of Ros's energy and focus in the precious time she had remaining was spent worrying about these things. She told us how much she wished she had access to VAD, and what a difference it would have made to the quality of her life since her diagnosis if VAD had been a clear option right from the beginning.

In those tearful conversations with Ros in March 2023, we struggled to accept her opinion that suicide was her least-worst option. We had already researched Australian VAD legislation in the early days of her diagnosis, but researched them again just in case there was a new rule that would allow an ACT resident to access to VAD in Victoria, Queensland or WA (where VAD schemes were already operating at that time). There wasn't. Had Ros been able to demonstrate a connection to Queensland she may have been able to access their scheme, but she didn't have any such connection.

Since Ros wasn't eligible for VAD in other parts of Australia, we considered whether we could get her to Switzerland to access their VAD scheme. Corinne called *Go Gentle Australia* for their advice on this option but was told the approval process would take too long for Ros, and the airlines probably wouldn't agree to carry her anyway given the advanced stage of her illness. Also, Ros was absolutely adamant she could not manage the long-haul flight.

Next, we researched palliative end of life options and, through our own research, came across the concept of 'palliative starvation'. After Ros's return home from respite care, she contacted her palliative care team and asked them what they could do to ease her passing if she decided to stop eating, noting her advanced care plan precluded artificial feeding and other life-prolonging intervention. It was clear that voluntary starvation in a terminally ill

patient is not considered suicide, which meant that if Ros died that way she could spare our family a coronial inquest. However, Ros made it clear that palliative starvation would only be acceptable to her if it wasn't too long and drawn out, it didn't involve the indignities associated with being bedridden for weeks, and if it didn't involve too much suffering.

Ros calmly and clearly explained to her palliative care team that suicide was her fall-back plan. When they asked for details about the substance she had procured and how she had procured it, she politely refused to tell them. She was well informed and compassionate to others, and she knew she could put others at risk of a criminal charge of assisting suicide if she shared too much. She made it clear to loved ones and her palliative care team that if she chose suicide as her least-worst option, she couldn't afford to wait very long or she would lose the physical capacity to do it without assistance.

The 'palliative sedation at home' plan

In late March/early April 2023 Ros had several long conversations with her palliative care team including a palliative nurse and two palliative doctors. One of those palliative doctors was an MND expert from NSW who was employed as a part-time locum palliative doctor in the ACT. They were very empathetic, listened carefully to Ros's needs and preferences, and worked hard to come up with a palliative sedation option that would be acceptable to Ros as an alternative to suicide.

The two doctors proposed an option where, if Ros indicated that she'd had enough suffering and stopped eating, within a couple of days of refusing food her palliative care team would administer palliative sedation to her at home. After pressing these doctors for details, Ros's understanding was that she would probably lose consciousness within a couple of days after starting palliative sedation, and would probably pass away 2-3 days after that. She understood the whole process would probably take about a week. It could happen at home and her loved ones could be with her.

Ros decided this 'palliative sedation at home' plan was acceptable to her. The family felt very relieved that Ros no longer felt she needed to take her own life. We hoped that, having settled on this plan, Ros would be able to make the most of the time she had left, and might even decide to stay with us for longer.

In mid-April 2023 Ros contacted her palliative care team to say she wanted to set a date within the next couple of weeks for activating the palliative sedation at home plan. One of the palliative doctors arranged for Ros to have a psychiatric assessment, which was undertaken by a psychiatrist from Canberra Health Services on 21 April 2023. The lengthy psychiatric report concluded:

> Today on review, Ros was not clinically delirious or depressed. She is not plagued by hopelessness, worthlessness or despair; she does not describe a pervasively depressed mood and her loss of enjoyment in life relates only to those things that she can no longer do as a consequence of her disease process. Ros does not have any psychotic symptoms. She is not delusional, nor does she have any experiences of thought interference, passivity phenomena or hallucinations. She lives in an environment which is filled with unconditional

> love and support. Ros has not previously experienced a depressive or manic illness, and there is no personal psychiatric history.
>
> Ros clearly has decision-making capacity; after careful consideration, reflection and extensive discussions over the last twelve months with those closest to her, she has no doubt about how she sees her future. She intends to ensure that her death can occur in the way that she has lived her life, with dignity, compassion and thought for others. Now, as her death nears, Ros is advocating for herself, just as she has done for countless others over the course of her life.

We would be happy to provide the Committee with a full copy of the psychiatric report if it would provide useful additional context.

Retraction of the 'palliative sedation at home' plan

Unfortunately, despite the psychiatric report, the end of life plan that was agreed with Ros was retracted after intervention by Calvary management. Our understanding is that a more senior doctor learned of the plan and took action to prevent it happening. Ros was later told that this senior doctor had taken the issue 'right to the top of Calvary' to prevent Ros's palliative care team from proceeding with it. At that time, Calvary was responsible for running palliative care services in Canberra, so there were no other choices.

The senior doctor came to the house to speak to Ros. Jim and Ros's sister were also present during this conversation. The senior doctor told Ros that if she decided to stop eating, she would have to go into the palliative hospice to have palliative sedation. It could not be administered at home. He said care would be taken to ensure the drugs administered at the hospice did not hasten Ros's death from starvation. At that time, the hospice was also run by Calvary. Ros understood this to mean that it would probably take her 2-3 weeks to die. When Ros asked that doctor whether she would be conscious during that time, he told her that drug administration would be at the discretion of whichever doctor happened to be on duty at the hospice. Ros told him this was 'cruel' and noted that in the same circumstances a dog would be put down so they could die quickly and without suffering. She told him that he was leaving her with no choice but to take her own life.

Visit by three armed police officers

A couple of days after the senior doctor's visit, at about 9pm at night, three armed and uniformed police officers knocked on the door. Jim and Ros's sister answered and were told the police had come to do a 'welfare check'. The police wanted to come into the house but Jim denied them entry on the grounds they may well precipitate the very event they were there to prevent if Ros knew they were there. She was having a good night, peacefully watching television, and he didn't want the visit to upset her. With some difficulty, and after allowing one officer to look through a glass door to see Ros watching television, he convinced them to leave. Despite the police officers being polite and professional in their manner, the police visit was very stressful for Jim, who felt it was a form of intimidation. He knew Ros would be angry and upset if she found out about it, and wanted to spare her any unnecessary negative emotion. When Ros asked who was at the door, Jim told her it was a neighbour.

Jim telephoned the senior doctor the following morning to ask who had arranged the 'welfare check' by police. The senior doctor told Jim he had contacted the 'Coroner's office' to ask for 'legal advice' because Ros had told him of her plan to take her own life. We are relieved that Ros never found out that the police officers had come to the house that night. We believe she would have been angered by the visit and may have become anxious that police would turn up again and take steps to try to prevent her from carrying out her plan.

Agonising decisions

Ros told her close family members of her decision to proceed with her suicide plan. She told us she did not want it to come as a shock to any of us. It was an extremely traumatic time. We respected her decision, and of course wanted to be with her while she died to support her and tell her we loved her. No terminally ill person should have to die alone. Yet she did not want any of us to be exposed to criminal liability for assisting her suicide. She told us this meant she could not afford to wait very long as she could lose the capacity to self-administer the substance she believed would end her life.

Ros's death

Ros was found dead by family members on the morning of 27 April 2023 with a suicide note beside her. We will not go into detail about this, but those details will be etched in our minds forever. Jim called Ros's palliative nurse to let her know and to seek her advice as to what we should do. She called Jim back to say that because it was clearly a death by suicide it was not possible for a doctor to sign a death certificate. As we knew, this meant that Ros's death would need to be referred to the Coroner and investigated by police. The palliative nurse offered to notify the ambulance/police on behalf of our family, and offered to come to the house with Ros's MND social worker (both of whom were known to our family) to support us while we waited for police. It was an offer we gratefully accepted. Their presence and trauma-informed support while we waited for police to arrive, and for hours during the police visit, was invaluable.

The aftermath of Ros's death – the police investigation

Whilst it is important for police to investigate unexplained or suspicious deaths, the police response to Ros's death seemed disproportionate and added to the distress experienced by our family. Ros's death was the death by suicide of a terminally ill person who had informed her palliative care team and close family members of her intention to take her own life and who'd had a recent psychiatric report testifying to having made this decision without undue influence and with a sound mind. The police welfare check shows police were aware of Ros's circumstances before her death. Upon their arrival at the house around midday, police saw the suicide note which was signed by Ros, they were provided with a copy of the psychiatric report, and were introduced to the palliative nurse and social worker who offered to provide background from a health care perspective on Ros's circumstances.

In that context, the following police response seems disproportionate in that it was likely to cause more harm/distress to the bereaved family than was necessary:

- Approximately ten police officers came to the house.
- Police were at the house continuously for over six hours (the first officer arrived around midday and the last left after 6:30pm that evening).
- Family members were separated and interviewed for hours by police officers who identified themselves as members of ‘the crime squad’.
- A large team of forensic police officers spent hours forensically examining the kitchen/family room area where Ros’s body lay, taking fingerprints, and seizing devices and other items from all areas of the house in sealed plastic bags.
- When the Coroner’s undertakers arrived to take Ros’s body away, the family requested some private moments with Ros but were denied access to her until the forensic examination had been completed.

Photograph taken at 6:25pm on the evening of Ros’s death showing the pile of seized items shortly before they were taken away. A total of 21 items were seized, including Jim’s laptop, Jim’s printer, Ros’s phone and Ros’s ipad.

The seizure of devices by police caused considerable distress to the family over the following days and weeks. The following day, without Ros’s phone, the family were unable to access Ros’s contacts to notify her friends of her death. Without his laptop, Jim struggled to find the names and contact details of the support workers who were due to come to the house to support Ros, and who needed to be informed. He was also unable to access the partly written report that he needed to complete for the Academy of Science (as part of his personal commitments as an emeritus professor).

Corinne therefore spent a considerable portion of the day following her mother's death making a series of phone calls to police to try to negotiate the prompt return of those devices. The initial response from the investigating officer was that it was not possible to say when the items would be returned. Corinne requested that the family at least be able to access the devices to obtain the needed information and documents from them. In the end, a relatively prompt return was able to be negotiated after Jim provided the relevant passwords to police, who were then able to examine (and presumably download) the contents of the devices. Whilst we are relieved that those devices were able to be returned relatively quickly, we are aware that many other bereaved families are not so lucky.

The seizure of Jim's printer was also the cause of considerable stress. The aftermath of the death of a life partner of fifty years is a time not only of intense grief, but of administrative burden. It is a time when many documents and forms need to be downloaded and printed and signed. After requesting the prompt return of Jim's printer, our family was informed that it was awaiting 'forensic analysis' and no timeframe could be given for its return. After complaining about this, we were informed there would be a 'significant delay' and 'it may be sensible to explore access to another printer in the meantime'. The cost of buying another printer was not a major issue for our family, but the time cost in purchasing it, and then setting it up so that it worked from Jim's laptop, was non-trivial.

Jim's printer was eventually returned on 7 July, ten weeks after it had been seized. Jim spent an hour trying to get it to work and called another family member around to help, who also spent an hour of their time without success. Jim called police to report the difficulty and was later given instructions for getting the printer working again, which required a complete reset procedure. We are left feeling that we have been treated poorly and unfairly, and not in a trauma-informed way. We find it hard to be believe that the ends justified the means.

Summary of suffering caused to Ros and our family in absence of VAD

Access to VAD would have immeasurably improved the quality of Ros's life in the year between her diagnosis and her death. It may also have extended her life, perhaps by some weeks or months. From the early days of her diagnosis, Ros was adamant that she was going to choose the timing of her death to ensure she could die with dignity. The absence of VAD left her with agonising decisions to make, and a suicide to plan, which sapped far too much of her time and energy.

In the absence of VAD, Ros explored with her palliative care team the limits they were able to go to in order to help her die with dignity. She struggled valiantly to find a palliative end of life option that was, in her mind, better than suicide. The 'palliative sedation at home' plan that her palliative doctors offered her – and which was ultimately retracted by Calvary management – was, in her assessment, better than suicide, although it was a tough call. Under the palliative sedation at home plan she had agreed to (before it was retracted), it would still have taken her about a week to die, and during that time she would have been bed ridden and reliant on others to look after her personal care needs. In her mind, whilst this was better than suicide, VAD would still have been her preference by a country mile.

The retraction of the 'palliative sedation at home' plan by Calvary management was cruel. 'Cruel' was Ros's word. It was cruel to her. It was cruel to us - her loved ones. It was cruel to the two palliative doctors that had tried valiantly to come up with a plan that met Ros's needs. It was cruel to the palliative nurses and social workers that had to bear witness to the terrible consequences of the retraction of that plan for Ros and our family, and who struggled to support us as best they could.

The retraction of the only acceptable palliative option meant Ros suffered the immense stress of executing her suicide, and of doing so in a way that would minimise distress for her loved ones and avoid exposing us to criminal liability. This situation was a minefield, and one that Ros handled with foresight, love, grace and phenomenal courage. We are deeply grateful to Ros for sharing with us in advance her decision to take her own life. It spared us the shock, guilt, confusion and anger we may otherwise have felt had she had died by suicide without having had these important conversations with us. Yet, knowing what she was going to do, and being unable to help her find a better end of life option, was also an intensely traumatic situation for us.

That feeling only intensified in the aftermath of Ros's death, after police were notified. As outlined above, the house filled with police officers and was turned into a crime scene, we were separated and interviewed by members of the crime squad for hours, and had important personal devices seized and retained for an indeterminant period of time. The coronial inquest into Ros's death is ongoing. Apart from intensifying the trauma of the situation for us, the coronial investigation has diverted limited public resources from other police investigations and coronial cases where they were desperately needed.

Moral injury caused to health workers from lack of VAD

In the week following Ros's death, a senior palliative care nurse prepared the following statement for our family to include with our submission to the Coroner. She has consented to its inclusion in this submission, although at her request, her name and other potentially identifying details have been removed.

Issue for consideration following passage of these laws – cross border application

The lack of cross border VAD arrangements with NSW, and other Australian jurisdictions, concerns us for the following reasons:

- It reduces autonomy for terminally ill people in deciding where they want to die, and where they want to spend time during their illness. This is particularly limiting for Canberrans given the small size of the ACT. Many Canberrans have relatives or holiday homes across the ACT border and may want to spend time there during their illness, with the option to die there, through self administered or medically administered VAD, if that is their wish when the time comes. Why should they be denied this flexibility and autonomy?
- If a terminally ill ACT resident starts the VAD process in the ACT and then decides to move interstate (for example, to live with a relative interstate that will care for them), they should not have to start the entire VAD process again. There needs to

be flexibility to transfer to an interstate VAD scheme part way through the process. The schemes are similar enough that there should not be too much practical difficulty in this.

- Lack of capacity to use an interstate medical professional may limit access for Canberrans to the scheme if there is slow uptake amongst ACT health professionals in getting requisite training etc to participate in the scheme. Allowing access to interstate practitioners broadens the pool, and also the choice of practitioners for the patient.
- ACT should be less restrictive about who can access the ACT scheme. The definition of 'substantial connection to ACT' could be broadened and we could ask for reciprocal broadening from NSW, Victoria and other Australian jurisdictions. Concerns regarding the offensively termed 'VAD tourism' are misplaced. Statistics from interstate show very low numbers of people in each jurisdiction using VAD each year. The benefits of reducing restrictions to the ACT scheme, in terms of encouraging reciprocity of other jurisdictions and increasing autonomy/flexibility for ACT residents, outweighs the costs.

In our view, these important issues should be resolved as soon as possible. However, the passage and implementation of VAD laws should not be delayed to allow time for this to occur. These laws are too important for there to be any more delay.

ATTACHMENT A – Comments of Ros's palliative care nurse

NOTE - These comments were prepared prior to ACT palliative services being transitioned from Calvary to Canberra Health Services.

I am a palliative care Nurse Practitioner. I am writing to give a healthcare professionals perspective on what occurred with Rosslyn Williams. In particular, the impact I saw on Ros and her family, the impact on healthcare professionals such as myself, and the potential impact of Calvary on future VAD access should it be legislated in the ACT.

Ros presented as a very high functioning woman for whom control over her situation was paramount. She had lost the ability to do many of her favourite activities such as cycling, cooking, gardening and playing the piano. Her MND was fast approaching a time when she would be fully dependent on others.

Ros had explored and experienced all services available to help her and her family, including the Motor Neurone Disease (MND) clinic, MND association, and the ACT palliative hospice. These services provided a variety of assessments, information, equipment and personal care assistance. Whilst Ros appreciated these services, she found the supports for end stage MND inadequate. For example, at the hospice, every shift bought a different nurse or carer to whom she needed to re-explain her particular needs. Ros saw the healthcare professional approach shifting from working to help her maintain independence, dignity and control, to her being viewed as a series of physical tasks for strangers to complete.

From my initial meeting with Ros, she was very open and honest about her intention to end her life. She asked how long it would take and what it would look and feel like if she stopped eating and drinking, and could this be done at home. We discussed palliative sedation as an alternative to being awake during voluntary starvation, but she was concerned about the impact of this on her family. She asked what would happen if she took her own life via a more immediate means. She understood it would be a coroners case.

Overall, Ros's main concerns if she ended her life by means other than voluntary starvation were around avoiding attempted resuscitation, life prolonging measures and transfer to hospital, and professional support for her family to navigate the situation if they found her deceased or debilitated after an unsuccessful attempt.

In my experience, if Ros was not depressed or psychotic and had the capacity to understand her decision (which I assessed she did), then it would be assault for health practitioners to act against her EPOAs instructions and her documented wishes about foregoing resuscitation and life prolonging measures.

I also thought the first point of contact for Ros's family, upon finding her dead, should be our palliative service's 24 hour phone line. Upon receiving the family's call, our service would ring, or advise the family to ring, the ambulance or police as appropriate, and provide

support as needed. Alternatively, in the case of a failed suicide attempt, our palliative service could inform the coroner and provide palliative care to Ros at home. I said this was my assumption, but I would need to confirm with the hospice and let her know.

Two consultant palliative doctors responded by trying to find Ros an alternative to taking her own life, such as palliative sedation at home. This required multiple medical interviews/assessments, a psychiatric assessments, and extensive in-house medical discussions. The final offer was palliative sedation of Ros at the hospice, likely lasting a few weeks, whilst her family watched her body starve to death. Ros found this unacceptable.

Ros then rang our palliative service again, again asking for information on how to avoid resuscitation, life prolonging treatments and hospital transfer, and arrange support for her family to navigate the system when they find her dead or debilitated.

As a nurse practitioner, my level of training is commensurate to that of doctors, so I feel sufficiently educated and trained to respond to such a situation and guide Ros's family. However, when discussed with our nursing staff, they felt they were not appropriately trained to respond in this situation, and said family should call an ambulance after any suicide attempt, regardless of Ros's condition.

I therefore sought further guidance from the acting medical director, who told me to ask the hospice manager, who directed the issue back to the medical director.

The acting medical director eventually said the family would have to call an ambulance, and if alive, Ros would need to go to the emergency department to receive palliative care in hospital. He said this was the legal advice from his indemnity insurer, who recommended he must avoid being seen as assisting Ros to take her own life. He said in an emergency department, there would be more doctors involved, all of whom would be new to the case, provide independent assessments and therefore not be subject to suspicion of aiding Ros's death.

A second hospice doctor later said that the acting medical director had no choice but to do this, because to do anything else could put the hospice under intense coronial and media scrutiny for potentially assisting people die.

I found this approach distressing. It seemed like our palliative service had made Ros jump through hoops so Calvary and its staff could tick boxes to prove they were not involved, and then walked away from providing any support to Ros or her family when they needed it the most. Ros was not asking for us to assist her to suicide. She was asking us for guidance and support for her and her family, whatever transpired. This seemed both reasonable and sensible. In response, our palliative service denied assistance because it was the 'safest' option. Ros was left to die with her concerns unaddressed.

I continued to struggle with how I could support Ros and her family given our palliative service refusing to do so. After discussion with one of Ros's palliative doctors and her social worker, I eventually gave Ros's husband my personal phone number, suggesting they ring me instead of the 24 hour palliative care phone number. I briefly contemplated offering support through my private registration, but was concerned Calvary would not approve.

When Jim rang to report Ros's death, her Canberra-based palliative doctor, her social worker, and myself wanted to support Ros's family, but given previous discussions, we were unsure what would be allowed. We approached the hospice manager and gained approval to offer in person support to Jim and the family. Ultimately the palliative doctor was too distressed to attend herself, and the psychiatrist involved specifically recommended that she not attend.

I was further concerned and saddened by what I witnessed at Ros's house after her death.

The house filled with police officers and their equipment, and family members were separated and interviewed for hours. All whilst Ros lay dead in her chair and family were unable to touch her for fear of 'disturbing a potential crime scene'.

After several hours of this, undertakers arrived and there was a sudden rush for police and equipment to be removed so family could have a private moment with Ros (while the undertakers stood by waiting) before Ros was taken away.

I contrasted this in my mind, with what it would have been like if Ros could have accessed VAD in the ACT as she had wished.

Ros would not have been treated like a criminal needing endless hours of interview/interrogation. Doctors would not have been seeking legal advice, and police would not have made a 'welfare check' visit to Ros's house. That would all have vastly reduced the distress for Ros, her family, and palliative staff.

Furthermore, Ros would not have been fearful that first responder healthcare professionals would attempt resuscitation and life prolongation. Ros would have had peace of mind that the medication would work, and in the unlikely event it failed, she would have known the health professionals would keep her comfortable.

Family could have been with Ros when she died, telling her they loved her and holding her hand. After her death, family could have sat with Ros, touched and hugged her, and generally spent relaxed time together with her. Instead, they had to wait with heightened emotions for authorities to arrive, unable to touch Ros or the surroundings. Having seen many hundreds or thousands of deaths in my career, I think forcing a physical and psychological distance between family members and their loved one during death and grieving, is particularly cruel.

Family could have called our palliative care service to provide a verification of death certificate, and Ros could have gone with undertakers at a time that suited the family, with a death certificate provided later, as pre-arranged with the appropriate doctor.

Ros's house would not have been literally full of strangers and their equipment at a time meant for grieving, police would not have spent hours interviewing and investigating family, family would not have had to consider what level of physical investigation should be allowed (pathology, toxicology, autopsy), and there would have been no rushed minimal touch goodbyes.

The contrast of what was, and what could have been, stunned me and still brings tears to my eyes.

With VAD becoming more widely available across Australia, requests to our palliative service for VAD are increasing. I am receiving one or two a week.

In researching why I found this experience so distressing, I came across the website of the Victorian branch of the Australian Medical Association which describes something called a moral injury as:

'the psychological, social and spiritual impact of events on a person who holds strong values (such as caring for patients) and operates in high-stakes situations, but has to act in a way inconsistent with those values. Symptoms can include strong feelings of guilt or shame (about not being able to uphold values, for example) as well as high levels of anger and contempt towards the system that prevents proper care. High levels of self-criticism, loss of trust in people and organisations and a weakening of personal relationships are further symptoms of moral injury.'

I identify strongly with this description. Ros was forced to endure unnecessary intrusion and continual uncertainty through her interaction with our palliative care service and in the end we were prevented from providing the reassurance and support Ros and her family needed. This has left me feeling angry with Calvary and the hospice, and impacted the trust and faith I had in the senior doctors involved and their patient care.

I am questioning if I want to remain in healthcare if this is how we treat our vulnerable, terminally ill patients. I am left asking; if this is the best we can do for Ros and her family; if patients and families must change to fit the system rather than the system working to meet their needs; if doctors and organisations are more concerned about their reputations than the experiences of patients and their families; then why am I doing this job? Why do I go to work and give of myself, from my heart, to help people every day? Why do I repeatedly expose myself to their suffering if I can so easily be rendered powerless to reduce that suffering?

I feel flattened. My previously endless passion for my job has eroded. I have taken time off work (which has not helped), sought counselling, and am filled with an urgent desire to leave Calvary, if not healthcare altogether. This would be a huge loss at a time when VAD laws may potentially be introduced in the ACT, and clinicians with my skills, knowledge, experience and supportive approach to palliative care and end of life decision making will be vital to assist people navigate the changing landscape.