

Jon Adams



Dear Sir / Madam,

Re: Proposed Legislation to Legalise VAD in the Northern Territory.

I write in support of proposed legislation being considered by the Legislative Assembly of the Northern Territory as part of their Parliamentary Inquiry concerning Voluntary Assisted Dying. As an emergency medical worker for many years, I'd witnessed my fair share of death and dying, but nothing could prepare me for the torment of watching my sister, Gay, suffer a slow and agonising death as her body was consumed by a cancer that ate her organs and stole her dignity.

Her final days were simply grotesque. Indeed, the pain was so severe that she lapsed into a hallucinatory state and despite being conscious, was unable to communicate with those around her and remained in this condition for several days before finally succumbing to the disease. In effect, Gay was tortured to death by her own body, and unfortunately, she is not the only one who has died a horrible, terrifying death.

Cancer of the brain and spine is notorious for being uncontrollable and is often unmanageable, even in a palliative care setting. Australia's most eminent pain specialist, Professor Michael Cousins, said in 2010 that 10 per cent of cancer pain was so difficult to treat at the end of life that patients were given drugs to sedate them to unconsciousness, culminating in death over several days to a week or more. This method has been described by some doctors as slow euthanasia.

Gay would have been an ideal candidate for voluntary assisted dying. She was rational and clearly understood she would die within a matter of weeks. She was in a supportive family environment, and her decision would not have been rushed or pressured. Gay was not afraid of death. Her greatest fear was dying in agony. Had Gay been allowed to end her life at a time of her choosing, she would have been spared the horrific death she was soon to experience, but also, those who knew and loved her would not have to live with the traumatising memory of that gruesome death.

Instead, she suffered the indignity of losing all control of her body as the cancer slowly ate away at her organs, but the worst was yet to come. Three days before she died, a tumour in her spine ruptured and with every heartbeat it filled with more blood until it finally exploded. Words cannot begin to describe the agony she was in. I was there. I saw it and it is simply unconscionable that anyone could be subjected to such needless suffering when a humane and compassionate solution was readily available.

After her passing, one of the palliative care nurses told me that Gay's death was one of the worst she had ever seen. She described it as unimaginably awful and that no-one deserved to die like that, but Gay did. Me and my brother, her husband and her friends have been haunted by her death for more than a decade and will continue to be for the rest of our lives.

Other Australian states have successfully introduced legislation to address issues associated with VAD. Indeed, the experience from around the world shows that VAD has, without exception, been used appropriately and effectively to alleviate suffering for the terminally ill.

However, that has not stopped opponents of VAD trying, albeit unsuccessfully, to describe VAD as 'legalised murder' and the 'convenient removal' of the elderly. Of course, when pressed for evidence, these fearmongers are unable to provide any data to back their claims. Instead, they resort to hearsay and unhelpful 'whataboutisms' as a justification for forcing their personal beliefs on to the wider community.

If we care about the doctrine of the separation of church and state, these arguments from religious conservatives should be ignored as they are driven by a personal belief system rather than by the prevailing community standards which overwhelmingly support the rights of the dying to exit this world on their own terms.

Of course, there are many questions that the community want answered, and the N.T. government is in the enviable position of being able to review other jurisdictions' existing VAD laws to create a fair, equitable and well tested legal code for the Territory.

Queensland successfully introduced their VAD legislation four years ago, with the passing of the Voluntary Assisted Dying Act in September 2021. It came into effect on January 1, 2023, and has been meeting the needs of the dying while providing safeguards for the community ever since.

In response to the many questions posed by the public I would suggest the following answers.

What eligibility criteria should a person need to meet before they can access VAD?

The N.T could do worse than adopt Queensland's well-structured legislation in terms of the eligibility criteria.

How could the NT make sure that an eligible person can access VAD in a safe and effective way, including people living in remote areas, and Aboriginal and Torres Strait Islander people?

Follow Queensland Legislation while considering ATSI cultural norms

How could the NT monitor the process to ensure VAD is delivered safely and effectively?

Adopt Queensland's legislation.

In closing, I implore you to be sympathetic to those facing imminent death. Numerous polls show people of the Northern Territory overwhelmingly support the introduction of voluntary assisted dying laws. Please listen to your constituents and bring appropriate legislation to the House without delay.

Thank you for allowing me the opportunity to provide testimony to the hearing.

Yours sincerely,
Jon Adams

Parliamentary Inquiry into VAD

This is my story - Jon Adams

In late November 2006 my sister Gay was diagnosed with advanced Stage 4 cancer. Her body was riddled with the disease which had spread to her lungs, breasts, spine, lymphatic system, bowel, and stomach. An X-Ray revealed one of the tumours had broken the vertebrae in her neck. She was admitted to Royal Brisbane Hospital where the surgeon told me he feared that even the slightest movement could snap her spinal cord leaving her paralysed. They inserted a titanium scaffold in her neck to prevent this occurring. She was given 2 – 6 months to live.

The cancer advanced swiftly and brutally and her condition deteriorated day by day. Faced with a terminal illness Gay decided to decline any further treatment, and we prepared an Advance Health Directive stating she wanted no further interventions, save those that would make her final days as comfortable as possible. Within weeks she was in constant, excruciating pain and it was clear her death would not be pleasant. While she faced her looming mortality with resigned courage, she was terrified at the prospect of dying in insufferable pain.

In late December I arranged a meeting with her medical team including her surgeon, the palliative care team, the unit's senior pharmacist, the pain management team and others. Gay attended the meeting with me, slumped in a wheelchair. Despite the pain, she was of clear mind and in her exhausted voice pleaded with them to allow her to die in peace. "I just want this to be over," she said. Then she asked the doctor, "How will I die?" He replied gently, "Most likely you'll suffocate, your breathing will slow down until it stops, but you won't know anything and by then you'll feel nothing at all."

The next day we discussed the meeting, and I reassured her that the palliative care and pain management teams were on top of it and that she would die peacefully, and without pain. I promised her I would be at her side.

In late January I arrived at the hospital and from the visitors waiting room I could hear a voice, ripped with such fear and terror, it sent shivers down my spine. Nurses were scurrying down the corridors and a team of doctors were darting here and there. It was then that I realised the screams I could hear were from my darling sister's room. I entered to find a team of doctors draining a tumour that had ruptured in her spine. A large glass bottle was filled with more than a pint of her blood. Her body was arched off the bed and her limbs were rigid - paralysed by pain. Her mouth was parched and in between her blood curdling screams she started speaking in a deep gravelly voice I'd never heard before. A nurse said, "Oh my God, the poor woman, she's hallucinating from the pain."

Finally, after watching her suffer like this for almost an hour I broke down and went running from the ward sobbing hysterically – my hands cupped over my ears, desperately trying to block out her screams of anguish. Even on the other side of the building – 50 metres away – I could hear her screams. I will never, ever forget it. It was simply grotesque. I was so traumatised I did not have the courage to venture back into the hospital for two days when I was advised Gay had been moved to the palliative care unit.

When I arrived the ward sister said, "She's more comfortable now. She missed you yesterday, she kept asking where you were." My stomach turned and I could feel tears running down my face. I had failed her so miserably when she needed me the most. I went into her room and sat down beside her. She was still conscious, although heavily sedated, and when I took her hand, I detected a tiny response. She knew I was there. I moistened her parched lips with water and

wiped the tears from her face and told her I loved her. In her faint and dying voice she uttered her last words to me. "Jon, you promised me it wouldn't be like this." But it was. I'd let her down so badly - and so had our health system which denied Gay the right to die peacefully and with dignity.

Gay passed away on Australia Day 2007 having suffered the most awful, unimaginable and intolerable pain. It was all so unnecessary.

Jon Adams