

Mum left us on her terms

With NSW the last Australian state to legalise Voluntary Assisted Dying, **Andrea Dixon** writes it gave her mother a dignified, pain-free end but is a far from perfect process.

On February 23, an anaesthetist at Nepean Hospital ended the life of my 86-year-old mother with three injections. When her wish was granted, Evelyn was surrounded by four of her five children and her two favourite grandchildren, while another two grandchildren waited outside. They had said goodbye to Nan at her bedside, but were not ready to witness death first hand.

As the anaesthetist prepared the first injection, I stepped forward and took my mother's hand. It seemed wrong that she should exit the world without human contact. She then called for her most beloved granddaughter to approach her bedside and hold her other hand. The rest of the family, all marked with different stages of anguish etched on their beautifully familiar faces, fanned out against the clinical white walls and watched death arrive. Only one was seated. As the second injection was administered, I felt my mother's quiet departure through her cool hand. It became strangely still – empty – and her blue eyes fluttered then closed.



Andrea Dixon with her mother Evelyn, who died this year aged 86 under the NSW Voluntary Assisted Dying Act, 2022, at Nepean Hospital.

Before the third injection was delivered, mum's troubled life met a peaceful end. It took no more than a few minutes to complete.

Throughout 2023, as her spinal cancer progressed, Evelyn had keenly followed the progression of the NSW Voluntary Assisted Dying Act, 2022. The legislation needed to be passed while she was still deemed competent to make and could communicate the necessary decisions associated with ending her life. The act passed into law on November 28, 2023, and Mum became energised. She wasted no time in opting in.

NSW was the last Australian state to legalise Voluntary Assisted Dying (VAD). The process has 11 steps, and robust safeguards. It entails three independent in-person assessments by different doctors, a written declaration and a final review. Then logistics regarding the medication and methods of administration are addressed. Legislation makes clear that VAD is only available to residents of NSW who are over 18 and who have an illness that will cause

death within 12 months or is causing suffering that cannot be relieved. It also establishes that the patient is acting of their own volition. Mum was terrified that her illness would claim her ability to communicate before she had the chance to complete the process.

VAD is not for people who are depressed, have dementia, are exhausted by illness or simply tired of life. Evelyn was not tired of life. Months before her death she had cataract surgery and bought new glasses so she could read – her favourite pastime. She loved gardens, sunshine and the ocean. She detested daytime TV and preferred to stare out of the window of her care home room at a jacaranda tree and its birdlife. She ate ice cream daily and enjoyed fresh oysters when family brought them to her.

Late last week the NSW Voluntary Assisted Dying Board released its annual report. The board's chair, Jenni Millbank, wrote in her message that the program was both accessible and strongly safeguarded. And in my

family's experience that is broadly true. However, while we are thankful for VAD – it saved Evelyn from months of pain and misery – the process did not account for the fact that many families are not in perfect harmony.

Like the birth of a child, nothing prepares a person for the carefully orchestrated death of a parent. It is uncharted territory. Now, 10

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months later, the delicate bonds that kept my family together have been destroyed. The stressors of VAD killed my family.

As part of the process, Evelyn nominated one of my sisters as her supporter and to help navigate the system. My sister would be the Key Person (KP), with Evelyn, for NSW Health to communicate with. She would take Evelyn to assessments

and be there at every stage of the process. From the start it was an emotional burden for my sister.

To facilitate the protocols and safeguards, a VAD co-ordinator was appointed to Evelyn and my KP sister. NSW Health requires medical staff to meet professional qualifications to act as co-ordinators. They must have successfully completed mandatory VAD training provided by the department.

The co-ordinator's purpose is to guide and support the family and to lend an empathetic ear. However, my KP sister had no relationship with my other siblings. She did not speak to them. With this division in mind, I was willingly recruited as news broadcaster from my KP sister to half of the family.

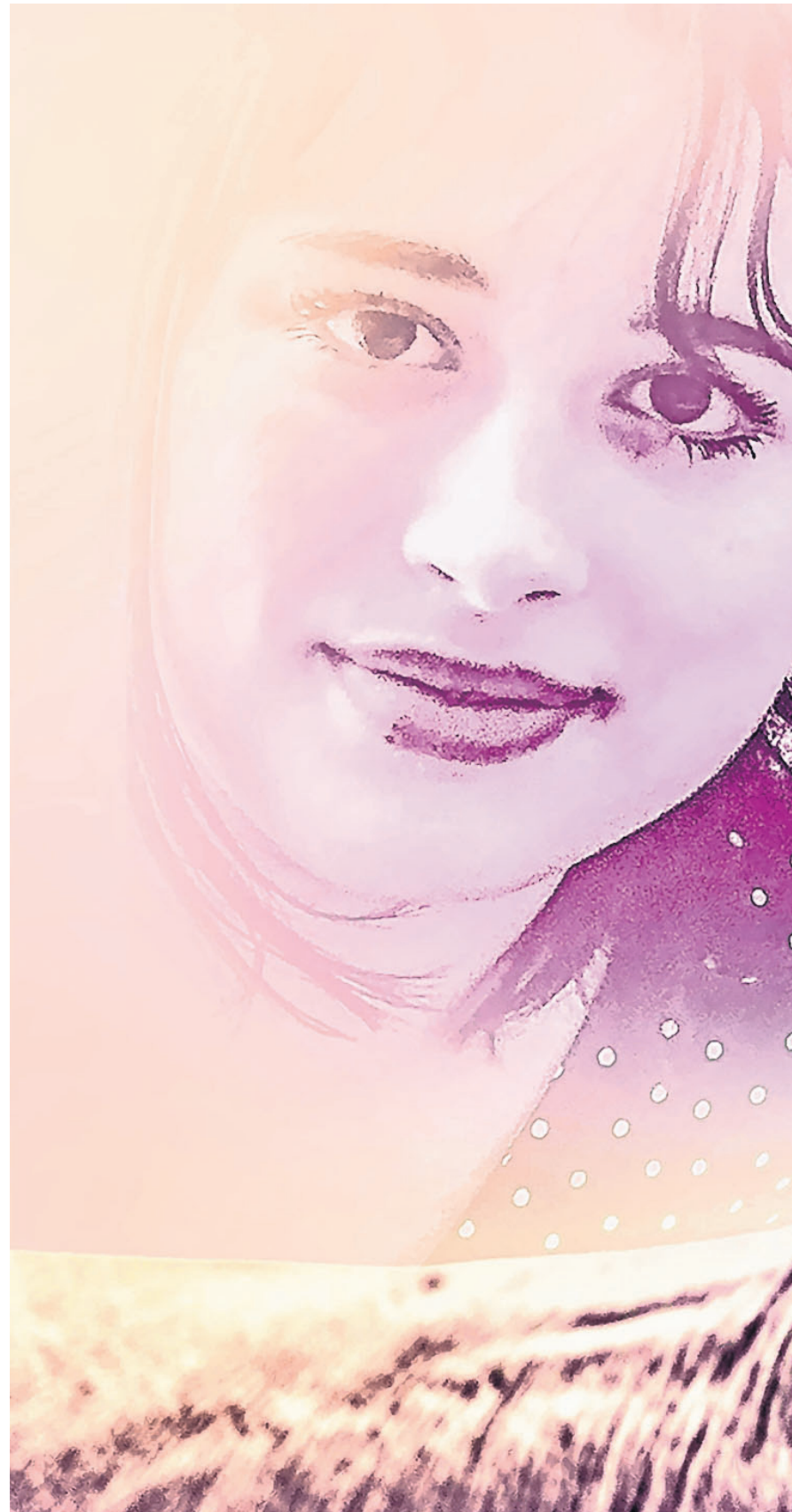
After attending a couple of assessments, the KP sister was struggling to cope emotionally. It was a brutal experience for even the most resilient adult child to accompany a parent who is arranging their own death. Evelyn's dark humour – once funny – was now hurtful when she referred to VAD as "being put down". After months of supporting Evelyn at these confronting meetings, my KP sister struggled with feelings of irrational responsibility. She felt implicated in Evelyn's death and a blanket of guilt descended on her. The co-ordinator offered a counselling service for support but when my sister rang the counselling service desperate for professional support, the call went through to a recorded message of the charity Griefline. She hung up and ended her pursuit of outside support.

In January, the third and final assessment was passed, and Evelyn was granted permission to undergo VAD. She was elated. "I feel like a huge weight has been taken off my shoulders. Having a choice has improved my health no end. I haven't felt this free in years," Mum told me during a call.

She sounded so relieved and happy that I wondered whether she would go ahead with it. Until the lethal drugs are administered, VAD participants can opt out at any time. Mum set the date of February 22, 2024.

In January, I boarded a flight from London to Chicago for a research assignment. While on this trip, with many flights and an appalling time zone difference with Sydney, my role as the family news bearer crumbled. Important information was not being shared by the KP sister to half the family, and those siblings were desperate to know what was going on. One phone call I received pushed me to the edge of sanity. I implored my KP sister to contact our siblings and keep them up to date with the process. It was crucial. Sitting alone on a hotel bed in Mexico City, I wept with white rage as my sister would not co-operate.

My eldest sister and my brother



had to ask Evelyn for daily updates, which she found distressing and irritating. It was too confronting.

To relieve the pressure, my eldest sister approached the co-ordinator directly for information about the process on the appointed day. She also asked for counselling for the family. It was refused. NSW Health Policy was quoted: only one key person was allowed. An exception could be made if Evelyn gave permission for the co-ordinator to speak to an additional family member. Evelyn agreed and was ready to confirm it. The co-ordinator said she would ring Evelyn that day to verify the request and call the family back. Five hours later my sibling rang Mum. The co-ordinator had not called her, and in fact never sought verification from Mum, and never called my sibling. The wider family never heard from the co-ordinator again, though they were seen later by my mother's bedside.

On February 15, 2024, NSW Health postponed the procedure. It required two VAD-trained staff members, which staffing shortages precluded. Mum was tough and not given to weeping; however, this change brought her to her knees. She could not stop crying. She was terrified of dying and had psychologically prepared herself for it, only to be brought undone by a bureaucratic bungle. Again, I asked her why she was going ahead with it when she was clearly scared. "I'm more terrified of living," she said. VAD was rescheduled for February 23.

With my daughter Ava, I booked the first available flight to Sydney and visited Mum the day before she would die. She was fascinated to learn all about the forensic psychology course that Ava was studying. They had not seen each other for four years, thanks to the pandemic.

With my mother sitting in her lounge chair by the window

– but the system is flawed



While Evelyn (pictured here with granddaughter Ava) was able to make the decision to end her own life, the process of family communication can be stressful.

the most cohesive families can fracture under such an immense stress.

Such failings are easily remedied, but the trauma for our family will not be; the communications breakdown in my family is now permanent.

When asked to respond to our experience of the process and its shortfalls, the Nepean Blue Mountains Local Health District did not directly answer my questions. It said its staff valued and respected a patient's right to privacy and that it was patients who determined "who to inform that they were going through" the process. Patients were encouraged to "speak with their families and loved ones... so that everyone is aware of their wishes".

In the end, nothing in Evelyn's life became her like the leaving of it.

"Family and loved ones may be provided resources or referred to other services that can provide them with emotional and wellbeing support," it said in a statement. I hope that Professor Millbank reads my story and considers whether this is an adequate response to the issues I have raised, and what more could be done.

VAD is available in every state in Australia, though not in the Northern Territory and the ACT. In the seven months since it became legal, 1141 people applied for VAD in NSW, according to the NSW VAD Board annual report. In the same period, VAD was completed by 398 people, my mother among them.

Australia is streets ahead of Britain. In 2018, my father-in-law died a merciless death in England. The former country GP had Parkinson's disease and had been in residential care for several years. When he could still make decisions, he made clear that he did not want to live if he could not eat or drink. Specifically, he refused a feeding tube.

When John was no longer able to swallow, his death began. It took five days for him to die of thirst. I remain haunted by the harrowing nature of his departure.

Yet Britain is still debating euthanasia, which is legally considered manslaughter or murder. In London on Friday, the assisted dying bill for England and Wales was supported. Parliament voted 330 for, with 275 MPs voting against the proposal. But the legislative process still has a long way to go and no changes to the law are likely until late next year.

Yes, despite our flawed experience, our family is grateful to the NSW parliament for passing the VAD Act.

overlooking the jacaranda tree, she peppered Ava with questions about her course, her apartment, and her life in London. Between grandmother and grandchild the conversation bounced from law courts, mock crime scenes and

good value recipes for students. I sat on the bed watching the interaction, mesmerised as they laughed and exchanged ideas. The high level of interest Mum showed in Ava's life made it difficult for me to reconcile her decision to be

injected with a lethal dose of barbiturates the following day. I wanted to shake my head in case it was all an appalling jet lag-induced hallucination. It seemed unreal.

On February 23, we all arrived at Nepean Hospital at the appointed time of 10:30am. A hospital social worker was assigned to us in a private family room. After a whispered conversation with the KP sister, the social worker was introduced, promptly left the room and did not reappear.

Evelyn arrived at the hospital at midday dosed up with painkillers. She was awake and chatting to us before the medics arrived. When we all entered her room, the VAD co-ordinator was there. There was no acknowledgment of the failure to connect family with life-and-death information. The co-ordinator spoke only to the KP sister and Evelyn and offered a nod of acknowledgment to the rest of us.

Mum, calmer than she had been

in months, talked about the negative consequences of the family division. She then went on to whisper a private message to each person in the room.

Just after 1pm, she died. In the end, nothing in Evelyn's life became her like the leaving of it, such was the courage and grace she displayed.

NSW has opened a much-needed and civilised exit service for terminally ill people and must be applauded. In late 2023 and early 2024, the process was so new that documentation and leaflets were branded Queensland Department of Health. The process, however, has some way to go to properly smooth the model for the participants and the families who remain.

The system needs to have the flexibility to respond to family dysfunction and the staffing to ensure commitments are followed up, meaningful support available and postponements avoided. Even



Evelyn (centre) with her children and grandchildren (left to right) in 2018: John Weller, Adam Dixon, Kimberly Dixon, Ally Dixon (rear), a family member who does not want to be identified, Michelle Dixon and Alana Dixon.