Dying with Dignity
New South Wales

NEWSLETTER | Spring 2025

Contents

Brothers Rowan and Julian with their mother Felicia who accessed voluntary assisted dying in August 2024.

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President's message

Time is flying and in just a few months it will be the second anniversary of voluntary assisted dying (VAD) being available to New South Wales residents.

We eagerly await the official data from the NSW VAD Board for the year ending 30 June 2025. Anecdotally, it appears there has been a surge in VAD applications over recent months.

We hope to see the Annual Report very soon but we're increasingly hearing VAD stories from our supporters and on social media, and have seen a steady flow of articles in the media.

We've also received a very significant increase in requests to our volunteer witnessing program. Since late May – August this year we've had three times the previous monthly average. We now have 174 trained volunteers and have handled over 200 requests for witnesses. We're very pleased to have been able to organise this support for people applying for VAD.

August was a busy time in the end-of-life space with Dying to Know Day activities taking place across the country, educating people about the importance of making plans and talking with loved ones about death and dying. See page 3.

Since our last newsletter we've held two very well attended sessions in our End-of-Life Webinar Series.

In April we heard about the VAD death of Professor Felicia Huppert in August 2024 from the perspectives of her son Rowan and the NSW Health VAD doctor and Care Navigator who supported her through the process. It was a very moving tribute to Felicia and a wonderful opportunity to see how VAD works at 'the coalface'. On pages 8-10 Rowan shares more about his mum's illness and death and the great sense of relief she experienced when she knew she was able to access VAD.

In September we were delighted to be joined by Palliative Care NSW to help us understand the support that palliative care can provide and how and when to access it. A number of myths were busted and practical information provided, particularly about the important support available for carers and loved ones, and the various ways in which palliative care can be delivered. Some key points are outlined on page 11, along with ways to access more information and volunteering opportunities.

Do you have a Will? If not, you should get one in place ASAP, even if you have limited assets. Having a valid Will will save your loved ones a lot of stress and expense. We are pleased to partner with Gathered Here which offers a free Will writing service. You can find out more on page 4.

For football enthusiasts we have a Q&A on page 6 with author Andrew Pettifer whose planned book about his beloved Tottenham Hotspur's successful 2024/25 season turned into something more intimate and meaningful as his week-by-week record of the team's journey coincided with the deterioration and ultimate VAD death of his friend and fellow Spurs superfan, Cameron Whyte.

We feature a very different book on page 12 – *The Power of Choice* – which captures the stories of VAD with stunning images by award winning photographer Julian Kingma. It really is something special.

In news from across the country and around the world (pages 14 and 15), the ACT's VAD law comes into force in November and there are increasing signs that the Northern Territory might (finally) be making progress towards a VAD law.

VAD laws in both Scotland and the UK have passed crucial stages in their parliaments but their success is by no means guaranteed. New York State has passed a VAD law which is awaiting the Governors signature (fingers crossed) and there is a chance that the VAD law in New Zealand may be expanded to remove the 6-month prognosis requirement.

As always, thank you for your support,

Penny Hackett
President

Dying to Know Day

Nobody knows: the secret I'm glad I shared

Hopefully you're already aware of Dying to Know Day (D2K Day) which is held on 8 August each year as part of a wider campaign to get the community more comfortable talking about death, dying and grief.

The more we talk about it, the easier it gets (yes, really). Making plans and discussing your end-of-life wishes with loved ones and healthcare professionals can save everyone a great deal of distress and anxiety when things get to the pointy end.

This year's Dying to Know theme is 'Nobody Knows: the Secret I'm Glad I Shared' with the campaign receiving national media coverage and unprecedented social media engagement - it seems that the 'secrets' are finally coming out. Let's hope that continues.

People across the country hosted D2K Day events in early August, from kitchen table conversations to public forums. We were very pleased to participate in events targeting two groups in our community which experience difficultly accessing culturally appropriate end-of-life care - culturally and linguistically diverse Australians and the LGBTQ+ community.

The Dying to Know Day Expo at Fairfield Youth Centre was organised by NSW Health with the support of Liverpool, Fairfield, Canterbury-Bankstown and Campbelltown councils which represent some of the most ethnically diverse suburbs in the country.

There were presentations on end-of-life issues and a wide range of support and advocacy services, providing resources in Vietnamese, Arabic and Chinese languages. With around 300 attendees it was a wonderfully vibrant event and a great opportunity for us to share information about VAD and end-of-life planning while also learning more about the ways in which different cultures approach ageing and death.

Meanwhile, at the Inner West Pride Centre, our Treasurer David Pieper participated in an LGBTQ+ Dying to Know Day Panel Discussion presented by ACON's LOVE Project. Experts from the end-of-life and death sector shared essential information about planning ahead, advocating for end-of-life wishes and caring for loved ones in the context of a community which is often subject to discrimination and stigma, especially in healthcare. We were very pleased to be asked to participate in this event as ACON and other LBGTQ+ groups have supported our cause over many years and were key members of the NSW VAD Alliance that ultimately led to the successful passage of the NSW VAD laws in May 2022.

While D2K Day and the rash of events during August might be over, the campaigning continues to make conversations about death and dying part of everyday life, because we never know what is around the corner.

Never forget that sharing your end-of-life wishes is a gift to your loved ones.

Organ donation – leaving a lifelong legacy

Donating organs and tissue after VAD

As we approach two years of voluntary assisted dying in NSW, there seems a long way to go before most NSW residents know how and when they can access VAD.

So it's hardly surprising that when it comes to topics such as organ donation after VAD, there is little community discussion, and only a few reported cases by media nationally of successful donations post-VAD.

According to NSW Health's VAD guidelines, organ and tissue donation may be possible for some patients who choose VAD, however it depends largely on their diagnosis.

The vast majority of people accessing VAD have terminal cancer, and their average age is around 75 years. In general, patients with metastatic or haematological cancers, or aged over 75 years are not suitable for solid organ donation. However tissue donation (eyes, musculoskeletal tissue, cardiovascular tissue, and skin) may still be possible.

Earlier this year, Central Coast woman Frances Flemming who had been living with multiple sclerosis (MS) for almost 50 years, decided to access VAD. She had primary progressive multiple sclerosis, a rare form of the disease that affects about 15 per cent of MS patients.

Frances donated her kidneys for people on the transplant waiting list, and her brain and spinal cord to MS Australia's Brain Bank, hoping it could lead to better insight into her form of the disease.

"Without [VAD] I don't think I would have ever had the opportunity to contribute to science like this," she said.

An article published in *The Australian Nursing and Midwifery Journal* entitled A Big Heart, shared another successful organ transplant story from a 45-year-old man who accessed VAD soon after commencement in NSW.

"Six weeks after VAD became available in NSW, our service received a request to simultaneously facilitate VAD and organ donation. Our patient was a 45-year-old man who was deteriorating from a non-metastasised cancer and who had chosen to access VAD.

He enquired about donating his organs as he wanted to be able to help others and leave a legacy for life. His wife was very supportive of this wish. The VAD Coordinator liaised with other health professionals to achieve this request," the article said.

For solid organ donation like kidneys and hearts, the administration of the VAD medication needs to be within a hospital setting. For tissue donation to proceed, death can occur in the home or hospital as tissue can be recovered up to 24 hours post death.

The first Australian to donate organs after VAD, nurse Marlene Bevern from Ballarat in Victoria, donated her lungs, liver and kidneys in 2023. Marlene had an aggressive form of motor neurone disease and wanted to avoid a bad death after watching her husband Robert die painfully eight years earlier from pancreatic cancer. She applied for VAD and requested organ donation information. At only 66 years of age and living with a non-cancerous terminal disease, Marlene was eligible to donate her organs.

She was in hospital for her final days so arrangements could be made for both VAD and organ retrieval. Marlene was told that her organs would go to four people, and according to her family it was an extremely proud moment.

Her son, Scott Bevern, said "We'd rather Mum still be here, but I can't really put into words how it makes you feel ... that Mum chose to do that and was given the opportunity for this to happen."

In NSW, the NSW Organ and Tissue Donation Service is the state-wide body which coordinates organ and tissue donation and is known as DonateLife NSW - www.donatelife.gov.au.

Do you have a valid Will?

Don't leave a mess for your loved ones

Leaving your affairs in order is a gift to your family.

Dying without a Will can create delays, conflict and expense for those left behind.

A valid Will ensures your wishes are followed and protects your loved ones.

Write or or update your Will for free

Dying with Dignity NSW has partnered with online Will provider Gathered Here to help you write or update your Will using their quick and easy online tool.

Wills written on Gathered Here are completely free of charge and include free updates for life. If you change your mind, you can change your Will too.

Why do you need a Will?

Your Will specifies how your assets are distributed after your death, ensuring that your loved ones are looked after. You can also provide for specific gifts to family, friends and the charities you support.

If you die 'intestate' (ie. without a Will) the government determines how your assets are distributed and there could be significant delays, extra costs and complex legal issues for your loved ones.

You can ensure that your wishes are respected by having a Will in place - even a very simple Will.

Updating your Will

It is important to update your Will when your circumstances change - life changes such as marriage, divorce or the death of a loved one can impact your Will.

gatheredhere FREE WILLS

HOW TO WRITE YOUR FREE WILL

Fill out online Use the step-by-step guide to create your Will online: https://gatheredhere.com.au/c/dying-with-dignity

Print your new Will Download and print your Will.

Sign and witness to complete your legally valid Will.

Your Legacy - leaving a gift in your Will

We are very fortunate that past supporters have made generous bequests to Dying with Dignity NSW. Those funds were critical to the success of our campaign for voluntary assisted dying laws in NSW.

Gifts in Wills have a lasting impact. A legacy from you, no matter how large or small, would help us ensure that voluntary assisted dying is accessible to those who need it, and allow us to continue our fight to protect and expand your end-of-life rights. Even a small gift can make a big difference.

While writing a free Will you'll have the option of leaving a gift to Dying with Dignity NSW, but there is no obligation to do so. Your priority is making sure your loved ones are provided for after your death.

Don't leave it too late

If you don't already have a Will we encourage you to write one ASAP - either with the help of a solicitor or through the free online service provided by Gathered Here - https://gatheredhere.com.au/c/dying-with-dignity

When the Final Whistle Blows - Andrew Pettifer

Andrew Pettifer is the author of "*When the Final Whistle Blows, Glory, Grief and Tottenham Hotspur*" dedicated to his friend and fellow Spurs fan, Cameron 'Commander' Whyte who died using voluntary assisted dying (VAD) in Sydney's Chris O'Brien Lifehouse in May this year.

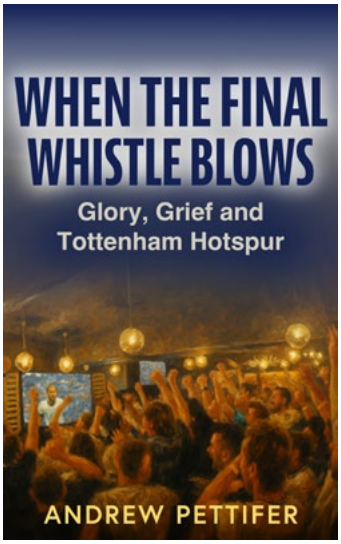
Born in the UK before moving to Australia aged 42, Andrew enjoyed a successful 30-year career in building engineering before he decided to leave the community he was proud to be part of, to write books and travel with his wife Tracy. He is a proud Dad and Grandad and whilst career success was initially important for him, he says more recently he's been fortunate to see the world and focus on having positive relationships and making a useful contribution to the world.

When asked what he learnt through writing his new book *When the Final Whistle Blows*, Andrew said "I've come to realise that human connection is the most important thing in life. I set out to track my personal emotional journey but in the end that was not important." Andrew was supportive of VAD before writing the book, but through his relationship with Cameron, a central character in the book, his attitude has changed from being supportive but not really engaged in the issue, to being a passionate supporter.

Tell us about your love for Tottenham Hotspur and why you initially embarked on the book about the last season and the Australian coach, Ange Postecoglou.

As I say in the book, "Being a Spurs supporter was never a conscious decision for me, it was a birthright. A life sentence, some might say. My dad bought me my first Spurs season ticket for my 10th birthday. It was the 1975-76 season."

I wanted to write a book but, being a novice author, the thought of planning out the whole thing felt quite daunting. So I hit upon the idea of writing it contemporaneously, week by week, as the season unfolded. I would write about the emotional



journey of following the club, intertwined with the stories from our travels and reminiscing about my 60 years of being a supporter.

My hope was that 2024/5 would be a successful season and fans would flock to buy it to relive the glory. It kind of turned out like that, but became something far more interesting and meaningful.

Has your opinion on VAD changed as a result of what you went through with Cameron?

Cameron himself didn't know about the availability of VAD until late in his illness. At one particularly difficult stage he said to his oncologist, "If I had a pill and could die now, I would take it." That is when she made him aware of VAD. By the time he told me about his decision it had all been agreed and a date set. It was very clear to me at that point that he drew great comfort from his ability to take control of his situation. He told me that it had been a difficult decision but he was clear that it was the right one. I of course had a great sense of sadness but also felt strangely uplifted by his resolve. The calmness and dignity with which he was dealing with the situation was remarkable.

It was clear at that point that Cameron was reaching the late stage of his cancer. VAD allowed him to go on his own terms, in the manner he wanted, with his loved ones around him. It meant

Q and A with Andrew Pettifer

that he avoided the indignity, pain and suffering of the last two or three weeks. I really don't understand why anyone would want to deny that right to anyone in a similar position.

What was your initial intention for the book?

The direction of the book was always going to be determined by my emotional journey through the season, but because it was being written week by week I just didn't know what that might end up looking like. The situation with Cam was central to my emotional state as the season came to an end, with him being such a key figure in our supporters' club in Sydney. So the decision I had was to either include Cam's story in the book or not finish the book at all. In the end I decided to ask Cam for his permission, which he gave, and it was at that point I told him I would dedicate the book to him and donate the proceeds in his honour. That conversation took place two days before he died, which was the last time I saw him.

How do you feel about this decision now?

It was the right thing to do. I am honoured that Cam gave me his permission to tell his story and that I am now able to take forward his legacy in such a meaningful way, both by raising money for cancer research and supporting the case for VAD to be adopted in the UK.

What did you learn about life through writing the book?

It really reinforced my belief in the good nature of most people and their ability to come together in times of both joy and grief. I set out to track my personal emotional journey but in the end that was not important. Spurs ended up winning their first trophy for 17 years just four days before the day that Cam had chosen to leave us. That brought a lot of joy to a lot of people, including Cam himself. But it was nothing compared to the outpouring of love, and the reinforcement of friendships, that resulted from Cam's passing.

Andrew Pettifer

What did you learn about the human spirit and the intersection between sport, fandom and life?

We all want to feel connected to others and to feel part of something bigger than ourselves. That is what supporting a particular team does. It's tribal. I can walk into a Spurs bar anywhere in the world wearing the shirt and I will be welcomed with open arms. We all go on a shared emotional journey every year, knowing that more likely than not it will end in disappointment. What matters more is the friendships that we build in the process.

Cam was in the Chris O'Brien Lifehouse in his last few weeks, so I am donating the proceeds from the book to them. He was so complimentary about the care he received.

The paperback can be ordered through Andrew's website. An e-book is available on Amazon and other online stores. Links on the website here www.andrewpettifer.com/whenthefinalwhistleblows.

Accessing VAD gave Felicia control, agency and relief

A son's tribute to his mother

Rowan Huppert is a father of two, Board Member of Dying with Dignity NSW and volunteers with our VAD witness program. He began his career in construction, has a love of adventure and the outdoors, and is currently studying his Masters in Psychotherapy and Counselling.

Rowan's Mum, Felicia, accessed voluntary assisted dying (VAD) in August 2024. Rowan shares her story here.

My mum, Felicia Huppert, led a full and vibrant life. At 79 she remained a world-renowned researcher in positive psychology, retired, as she said, "only from her salary". She was a loving friend, sister, mother and grandmother, and a generous supporter of the arts, indigenous culture, environmental responsibility and conservation. She was fit and strong, enjoying daily beachside walks and travel adventures.

Mum grew up in Sydney after being born in what is now Uzbekistan as a war refugee, but had a lovely early childhood. She studied psychology at Sydney University and became a Professor at Cambridge University, initially working in the fields of memory, dementia and ageing. About 25–30 years ago she became involved in this new field called positive psychology. She was one of the earliest practitioners. She was never a clinical psychologist and in her group she was the hard-core scientist. She was into the research, the data and making sure everything was evidence-based. She had an extremely sharp mind and she occasionally had a rather sharp tongue as well.

Her superpower

Her special power, or her superpower was buying gifts. She had this incredible, not just generosity, but ability to know what people would want and buy beautiful considered gifts. This is something she was famous for in the family and amongst her friends. She was very driven, self-driven and motivated. She was however reliant on others. She had an eye

Felicia Huppert and her two grandchildren.

condition, macular degeneration, from her teens. So increasingly she became reliant on research and personal assistants to help her but also relied on strangers. She would stand at a bank ATM and ask the other people in the queue to help take money out for her which was very trusting.

She was always very fit and active. She didn't let her eyesight stop her. She used to cycle to work well into her fifties. That came to an end when she didn't see a parked car and rode into the back of it! She hiked and did climbs including ice climbs up glaciers. Even into her seventies, she had a personal trainer and worked out. She was a determined, generous and loving person who made amazing connections.

Exploring treatments

In about 2012, Mum developed breast cancer. She had a mastectomy and chemotherapy and that seemingly did the trick and for essentially 10 years and she was well during her remission. The cancer came back in 2022 as metastases in her bones and organs. She underwent surgery to remove them from her leg and her brain, but further treatments soon stopped working. In about March 2024 she started having intestinal symptoms that were cancer-related and she went into hospital.

About one month into her stay, she had a setback. They had been encouraging her to eat, thinking that would get her intestines working but it then became clear that there was a blockage in the lower

half of her stomach due to the cancerous growths and doctors planned to take her into surgery. From a surgical perspective this was a relatively straightforward operation, but from an anaesthetic point of view this surgery came with complications. They were worried that she might aspirate some of this undigested food which could have been fatal.

We were warned she might not survive. We, her loved ones, experienced that as an intense grief or an intense preparation for grief. My brother and one of Mum's sisters were still in England, and I had to call them and ask them to speak to Mum before the surgery and say their goodbyes. This was an important day emotionally, thinking we might lose her then.

Qualifying for VAD

The second emotional day I want to highlight, was a day not long after the surgery when she was still in hospital. Medical options were increasingly extreme or unlikely to work. We were confronting her remaining life being an inevitable slide through discomfort, disablement and pain. I was visiting her and at one point we had a corridor consult with her treating doctor.

He was very generous - he was literally walking past us and we cornered him for about 45 minutes or an hour. During that conversation I asked if Mum might qualify for VAD. This thought had only come into my mind the previous day and I hadn't even raised yet with Mum (which I felt and still feel a bit guilty about). When he essentially said yes, my Mum could have floated to the ceiling. The instant that she was told that VAD was a possibility for her, gave her such a sense of control, of agency, of relief.

Her mood lightened immediately, and it was clear she felt empowered by this renewed control over her destiny and empowered to confront her new limitations and medical care needs.

We soon met with the VAD team from the South-East Sydney Local Health District who were compassionate, clear and generous with their time. The paperwork and the process were straightforward. The application made, reviewed and approved. Throughout the process Mum felt great calm, gratitude and acceptance. Someone asked me recently if she had felt fear or fearful on the day that she died, and she really never did.

There's this term 'radical acceptance' that I'd heard about previously but had never seen, and she absolutely embodied that when it came to her mortality. Even in the acute phase when she was in hospital, in ICU, and facing risky surgery, she was able to say, "I love you all, and this has been such a fantastic life, and if it ends on an operating table in the next few hours, that is ok". She really was alright with it.

Mum ended up being in hospital for about two months. The limited energy and capacity for movement and independence were deeply challenging to her strong sense of autonomy and capability. It was hard for her and her loved ones to see her diminished like this, overlaying memories of suffering and need upon memories of vitality and strength.

Fortunately, she did make it home. Discharged from hospital, Mum spent her last two months at home, doing a little more of what brought her joy – seeing loved ones, walking, and listening to music. She was being fed through a tube that went up through the nose and down into the intestine and that tube became blocked quite regularly. She used the time to share memories, last thoughts, pass on instructions and wishes for her death, her burial, her memorial, the words she wanted on a bench overlooking her beloved Coogee Beach.

My mum, Felicia Huppert

Felicia's story continued

Choosing the date

She wasn't really physically suffering much at home, what she struggled with was choosing the date. In NSW you have two options available to you. You can either drink something or have it injected. You can do either of these at home or in hospital with medical supervision. Mum chose to have it injected as doctors weren't sure if she swallowed that it would be ingested, so she was required to book in a date and time with the VAD team. She found this very hard.

She knew that this was the route she wanted to take but she wanted to do it before she was in too much discomfort or disability, or lost capacity, making VAD impossible. In NSW you need to be able to consent to VAD, right up to the final moment, and if you aren't able to do that, you aren't able to access it.

It was hard to choose a day, because it's such a novel thing to think about, but she also was considering others with commitments on that day! She had some psychotherapeutic support, which helped a lot. But in the end, she'd had such an immensely rich and full life, that she realised each additional day no longer really added to that. She was then finally able to choose the day to end her life.

I can't thank the NSW Health VAD team enough. Her VAD practitioner Dr Patrick Bolton and VAD Care Navigator, Warren Stewart, were generous with their time, their explanations, their compassion and their availability throughout the process.

Love lasts longer than life

Just two days before she died Mum told her grandchildren that 'love lasts longer than life'. I remember that and hold that dear. She's right, it does.

The third emotional day for me, was the day itself. When it came, it was calm and was our last chance to express our love and admiration for her. She read a few messages that she'd received. My brother had been here from the UK for that last two months, and we'd both received some good news overnight that we shared with her. Her sister came over too and we had a lovely morning together.

The VAD team arrived and Mum was liberated from her feeding tube. She wanted some reflection time alone, so sat on the sofa in the kitchen facing the garden and fell asleep for about half an hour before we moved into the room she'd chosen. The VAD team talked thorough the process and they confirmed consent. Before the first injection she stopped the doctor to thank him for being so attentive and communicative.

We put on some Bach music that she'd chosen, played by a specific performer, as the VAD team started the medical process. We were there - my brother, Mum's sister and I.

One detail that I appreciated, is that the tube connected to the canula to administer the medication was about two metres in length, which meant that the three of us were in the inner ring, close to Mum in the bed. This made it feel less medical and more personal. We held her hands as she took her last breaths. She died with dignity, surrounded with love.

Grief is always hard. Death of a loved one will always be sad and painful. But being able to prepare, to plan, to know the exact moment, and to not see her suffer a drawn-out death was truly fortunate for her and us. It made our grief far gentler.

She and we, as a family, are immensely grateful to Dying with Dignity and other organisations who pushed to make VAD legal here in New South Wales. We know they have more work to do and are proud to support them with Felicia's story and our gratitude.

Rowan spoke about Felicia's VAD Journey in a webinar in April which also featured the VAD doctor and Care Navigator who were involved in her care. Read more and watch the video here: www.dwdnsw.org.au/eol_webinar_huppert_april25

All about palliative care

What it is and how to get it.

Do you know what palliative care is and how to access it in NSW? Do you wonder if it's available for everyone, and how it works alongside voluntary assisted dying? If you've found yourself asking these questions then our recent online webinar is available to help you find out more.

Our webinar, *All about Palliative Care, How it helps and how to access it*, with guest speakers from Palliative Care NSW, sheds light on what palliative care really means, when it is available, and how it can support both patients and families. With a live audience of more than 350 attendees our supporters are clearly interested in understanding more about the help that palliative care can provide.

You can watch the recording of the webinar on our YouTube Channel (details below) but here are some of the key points discussed in the session.

What is palliative care?

Palliative care is specialised medical and supportive care focussed on improving quality of life for people with a terminal or life-limiting illness.

It is not restricted to the final days of life. It may be available for months or even years, supporting people to manage symptoms during the course of their illness, and can even be provided in conjunction with active treatment.

Care is provided in many settings — at home, in aged care facilities, hospitals, or hospices — and is tailored to each person's needs. Often, a GP will work alongside palliative care specialists and community nurses. Where symptoms are complex or distressing, a referral to specialist palliative care may be necessary and a stay in hospital or a hospice could be beneficial.

Palliative care is distinct from voluntary assisted dying — its purpose is neither to prolong life nor to hasten death. However, people considering VAD can and should also access palliative care if they need that support at any time.

Beyond medical care

Palliative care is not just about medication. It also provides practical, emotional and spiritual support. Families and carers may receive guidance to help loved ones remain at home, as well as counseling, pastoral care and bereavement support.

If specialist palliative care is required it is necessary to get a medical referral from a GP or specialist. You should not hesitate to request this when there are complex or distressing symptoms or to ask about options for extra support for carers.

Access and resources

The type and availability of palliative care services can vary depending on your location. Palliative Care NSW has a searchable directory on its website to help you locate services in your area.

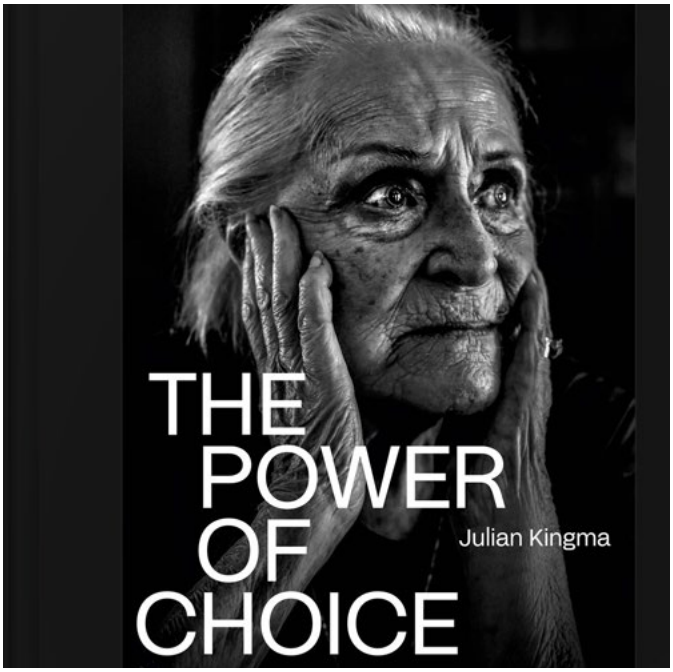
Their website has excellent resources and information for families and carers to help them better understand how to support a dying loved one. You can also contact their Guidance Manager for advice and support by phone or email.

Volunteering in palliative care

The webinar also highlighted the vital role of volunteers. Whether in hospices, hospitals or the community, volunteers provide invaluable support to patients and families. Palliative Care NSW offers training, workshops and networking opportunities for volunteers, along with guidance for organisations wishing to strengthen their programs.

To watch the recording of the webinar and access more information about palliative care (including links to the resources mentioned above and their volunteer hub) see our blog post https://www.dwdnsw.org.au/eol_webinar_palliative_care_jul25

The Power of Choice



Sharing the stories and images of voluntary assisted dying in Australia

From the arresting image on the cover through to the acknowledgements at the end, the recently published book, *The Power of Choice*, personifies the impact of choice and control at end-of-life across Australia.

Produced by national charity for voluntary assisted dying, Go Gentle Australia, with award-winning photographer Julian Kigma, *The Power of Choice* captures the personal and emotional value and challenges faced by people, their families and their network, including health professionals, to access VAD. It features large black and white photos of people facing death and those supporting them. It brings to the fore the question of what constitutes a good death.

According to Director of Communications at Go Gentle, Steve Offner, who wrote the words to accompany the photos, the book started with a phone call from Julian after he'd listened to the second season of Andrew Denton's podcast *Better Off Dead* which tells the stories of some of the first people to use Victoria's VAD law. "Julian was incredibly moved by what people were saying but as photographer he knew seeing their faces would have even more impact. So, he sent us a proposal for a project that became *The Power of Choice*.

"Originally, we thought it might be a series of photo essays and perhaps an exhibition (if we were lucky). But as soon as we saw the first images, we knew it was much more than that. Julian is such an extraordinary empath and artist. As we began collecting the stories behind the images, the idea of the book and a national travelling exhibition started to take shape."

Death's lasting impact

The book doesn't shy away from grief and the lasting impact dying has for the person facing imminent death and their loved ones, sharing intimate family and personal photos to illustrate the strength of human connections and compassion.

For almost two years Steve worked with Julian to identify stories of everyday Australians, sharing the privilege he felt at being able to be part of the process of compiling these and sharing them more broadly.

"It was always about the images, but we knew we couldn't do justice to people's experiences with just captions. People really wanted to tell their stories. As a storyteller, it's hard to focus on both. So, Julian did a short, initial interview to get people's immediate responses. These were often the most

The Power of Choice

powerful, reflecting the trust Julian created with people. Afterwards, I would follow up with a longer phone interview. It was balancing act between capturing the essence of the story and not bogging it down with unnecessary words."

Our community wants choice

In the six years Steve has been at Go Gentle, he has worked on all the state and territory-based VAD legislations since Victoria, and in his role has heard and shared many people's stories. In this time, he says he's learnt that Australians are passionate about having a choice. "We won't stand for anyone presuming to tell us how we should live or die. I've also learnt that we all deal with extreme situations differently - there is no right way.

"Another thing I've taken away from this project, and my work at Go Gentle in general, is that most people have an extraordinary capacity for generosity, whether it's leaving behind a legacy that helps others or making sure the people around them are taken care of."

One example of this, he says, is the story of Nigel Taimanu. "Even though Nigel is facing an imminent death and admits to being 'scared shitless', he never stops caring about the people around him. He even schedules his VAD the day after his birthday and one last party, so his partner Kath and his mum won't be alone. He's the one dying but he ends up comforting others.

"In the photo shown above, Nigel is comforting Julian. He says, 'I'm going to be OK, I've chosen this. Please don't feel sorry for me.' It's incredible generosity and compassion."

Now in its second print run, the book has received much media interest and sales have been strong.

"It was a real moment to see and hold the book for the first time. It felt more substantial and looked more beautiful than I'd expected. We've all been overwhelmed by how enthusiastically it's been embraced and are looking forward to taking the exhibition around the country."

To purchase *The Power of Choice*, visit the Go Gentle website www.gogentleaustralia.org.au or your local bookstore. An exhibition of the images is planned in Sydney in the first half of 2026.

News from Australia

We now have assisted dying schemes in all states of Australia and they seem to be working well, with no reported breaches of the law.

ACT VAD Law almost implemented

In June 2024 the Australian Capital Territory passed an assisted dying law – the ACT Voluntary Assisted Dying Law. It will come into effect in November 2025.

It will be watched with great interest because, unlike all the other laws in Australia (and most overseas ones) it will not include a requirement for a six or twelve month prognosis. Instead, it provides that a person is eligible for voluntary assisted dying if they have been diagnosed with at least one relevant condition that, either on its own or in combination with one or more other diagnosed conditions, is advanced, progressive and expected to cause the person's death, and they are suffering intolerably.

This means people with multiple medical issues who are frail and have lost all quality of life could access VAD even though doctors could not say for sure that they would die within six or twelve months. We have heard from frail, elderly people and those with long term conditions, whose quality of life has diminished intolerably but who don't qualify in NSW. We can hear their suffering and despair. We wait to see whether the broader ACT law will provide relief for such people.

What hope for the Northern Territory?

The Northern Territory is now the only jurisdiction without a VAD law, despite being the first to introduce one in the nineties. This was almost immediately invalidated by a Commonwealth prohibition.

Campaigners have been toiling for years but the journey towards assisted dying in the NT has been painfully slow.

The previous Labor government did kick the process off in 2024 when it commissioned an "expert panel" to study the issue and make recommendations. This panel consulted widely and published its report in June 2024. The report was encouraging. It recommended that the NT introduce a law with provisions along the lines of the Queensland VAD Act, with a 12 month prognosis, relaxed residency requirements and a specification that residential aged care facilities could not block clients from accessing VAD.

Unfortunately, the momentum was lost at their next election when a new government was voted in. The new CLP government, headed by Lia Finocchiaro, seemed reluctant to pick up where Labor had left off. However, when a Greens MP threatened to propose a private members bill, the government established a second inquiry and consultation process. This is currently holding meetings and taking submissions and is due to report in September 2025.

It is likely that the NT government will at last legislate for assisted dying because of the pressure of being the only place in Australia without VAD. However the implementation period is likely to be lengthy, so NT residents may have some time to wait before they have the same end-of-life rights as other Australians.

News from around the world

Getting closer in the UK and Scotland

Assisted dying bills have passed key votes in both the United Kingdom and Scotland.

In the UK the Assisted Dying Bill for Terminally Ill Adults passed the crucial vote in the House of Commons on 20 June 2025, with 314 MPs in favour and 291 against. The bill will now progress to the House of Lords for further scrutiny and potential amendments before it can become law. There has been a fierce and bitter debate about the issue, with vociferous opposition coming from both religious quarters and the disability sector.

In May 2025 the Scottish assisted dying bill passed its first stage at the Scottish Parliament with a vote of 70 to 56. This bill, proposed by Liberal Democrat MSP, Liam Gallagher, aims to allow terminally ill, mentally competent adults to request medical assistance to end their lives under strict safeguards. The bill must now clear two further stages of parliamentary scrutiny to become law. It will include debates on amendments and a final vote and is expected to take several months.

Progress in the USA

There are two notable developments in the US, one in New York and the other in California.

In July 2025 New York State passed a bill in both Houses of the legislature and the Governor is now considering whether to sign it into law. The provisions of the Medical Aid in Dying Act are very similar to those in most US states and in Australia. It requires patients to be adults with a terminal illness and a prognosis of six months or less to live. The person must be mentally competent and make both oral and written requests for the medication which they must self-administer.

The Act emphasises that the process is entirely voluntary for both the patient and the healthcare providers.

When California passed its assisted dying law in 2015, it contained a sunset clause which specified that the law would cease to operate in 2031. Having now operated for eight years without mishap, there is a proposal to repeal the sunset clause. Predictably, opponents are campaigning against it.

Moves to expand NZ law

In New Zealand the ACT party (which sponsored the End of Life Choice Act) intends to introduce amendments to remove the "prognosis" clause.

The requirement for a terminal illness with life expectancy of six months would be replaced with a requirement that the person has a condition that is "advanced, progressive and expected to cause death". This is consistent with the broader criteria which applies in the Australian Capital Territory and would be a very welcome development if the amendments are passed.

Making a donation

DWD NSW

We are totally reliant on membership fees, donations and bequests to operate. We are a registered charity so all donations over $2 are tax deductible.

Donations can be made via our website: www.dwdnsw.org.au

Alternatively, you can make a donation via our other payment options.

Please post your completed form to:

DWD NSW

PO BOX 25

BROADWAY NSW 2007

Or scan the completed form and email it to us at dwd@dwdnsw.org.au

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