



# The Damage Done



**Go Gentle**  
Australia

# **The Damage Done**

The contents of *The Damage Done* are explicit and emotionally powerful. They may be challenging and disturbing, particularly to readers dealing with grief after the death of a loved one. We advise those readers to consider whether they should seek support or even delay reading the testimonies contained in this book.

*The Damage Done* is not about suicide. If you are interested in increasing your understanding of suicide and how to support someone experiencing suicidal ideation, visit the Conversations Matter website [www.conversationsmatter.com.au](http://www.conversationsmatter.com.au) or the beyondblue website [www.beyondblue.org.au](http://www.beyondblue.org.au)

If you or someone you know needs immediate assistance, contact one of the following 24/7 crisis support services: Lifeline (13 11 14), Suicide Call Back Service (1300 659 467), MensLine (1300 78 99 78), beyondblue (1300 22 4636), Kids Helpline (1800 55 1800) or eheadspace (1800 650 890).



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Go Gentle Australia has been established to help relieve the distress, helplessness and suffering experienced by Australians with untreatable or terminal illnesses and also their families and carers.

If you have a story to share, or would like to learn more about what we do, visit us at [gogentleaustralia.org.au](http://gogentleaustralia.org.au)

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# Acknowledgements

This book was pulled together in just under four weeks, an extraordinary effort fuelled by a determination to bring urgency to the debate about assisted dying in Australia.

In that time, we collected almost 150 testimonials. The tip of the iceberg.

My thanks to editor Glenda Downing for her expert advice and steady hand in overseeing the production schedule and calmly ensuring deadlines would be met.

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Across Australia, the state dying with dignity organisations threw their support behind the project and sought stories from their members on our behalf. In Adelaide, Professor Arnold Gillespie gathered testimonies from doctors who believe that to stay silent is to do harm.

Other testimonies came from the Victorian End of Life Choices Inquiry, as well as members of the Voluntary Euthanasia Party, and Christians Supporting Choice for Voluntary Euthanasia.



Some were written to me directly or are excerpted from interviews conducted in the podcast series *Better Off Dead*.

All of this was achieved under the watchful eye of Bronwen Reid, a warrior if ever there was one.

Finally, my abiding thanks to the families and individuals who entrusted us with the intimacies of their loved ones' deaths.

We promise you will be heard.

Andrew Denton

# Introduction

As she was dying of cancer in 2015, 90-year-old Eileen Dawe kept a diary. Despite her clearly stated wish to die she was forced to endure 17 painful weeks until the disease finally took her. Hoping to hasten nature's course, she began to starve herself to death. In her diary she wrote, *'My country's laws decree "Death by a thousand cuts for me".'*

Eileen's is one of 72 testimonies in this book that describe with horrifying clarity the damage being done across Australia in the absence of a law for assisted dying. Written by sons, daughters, husbands, wives, partners, and friends, as well as the dying themselves, they detail trauma and suffering on a staggering scale.

The testimonies have come from people of all ages and walks of life. They represent almost every Australian State and Territory. They are blue collar, white collar, devoutly religious, avowedly not. The diseases they have faced are mostly cancer, but also MS, motor neurone disease and other medical horrors. What brings them together is the cruel way in which they all suffered – or suffer still.

With descriptions such as 'akin to torture' and 'like a horror movie', what strikes you about these testimonies is the repeated expressions from those left behind of shock, anger, and helplessness, sometimes reaching back decades. Some describe keeping grandchildren and children away from a cherished parent, or aunt or grandfather, because the dying was so hideous, so scarring.

Talking about death is hard enough. Talking about bad deaths is even tougher. It takes courage. For many it means admitting to the terrible sense that they've failed their loved ones.

Perhaps bravest of all are the testimonies from doctors and nurses, some of whom have openly admitted to helping patients die. The trauma many of them have had to deal with in the face of their patients' suffering is palpable. May their example encourage others in the medical profession to come forward and speak openly about what they have seen – and even what they do.

Had the abuses, cruelty, and harm inflicted by our laws, and so vividly captured in this book, happened within one institution we would, long ago, have had a Royal Commission. But because they have happened in many places – palliative care wards, nursing homes, general hospitals, people's houses – and because each has been a private tragedy, they have been invisible. Deniable. Ignorable.

This book is not intended as a critique of Australia's palliative care services or the dedicated doctors and nurses who give of their best. Rather it reveals what happens despite their efforts.

In June 2016 a cross-party Victorian Parliamentary Inquiry into End of Life Choices reported on the evidence it had uncovered. The most extensive of its kind ever held in Australia, its findings mirror the anguished testimonies listed here: of inadequate pain relief being delivered to dying patients for fear of breaking the law; of the inability of palliative care, despite its many benefits, to relieve all suffering; of people being put on trial for helping those they love find a merciful end; of doctors being forced to break the law in order to help their patients die, but having to do so without support, regulation, or accountability; of the trauma experienced by families as they watch their loved ones die harrowing deaths.

The testimony of Victorian Coroner, John Olle, in particular, rocked the Committee. Coroner Olle told of the horrific ways in which desperately ill Victorians are taking their own lives in

order to end their suffering. This included a 90-year-old man with cancer who killed himself with a nail gun. Coroner Olle estimated these violent self-inflicted deaths are happening at the rate of one a week in Victoria.

Faced with evidence of such damage, the Committee found that maintaining the status quo was unacceptable. By a majority of 6–2, reflecting the 80 per cent support amongst the Australian public, they recommended a law for assisted dying be passed in Victoria. (A summary is at the back of this book.)

There is every reason to believe that the harm the Committee found in Victoria is happening across Australia, and that it's not going to go away or get less. As our population ages, it will only increase. And yet our politicians have refused to address it.

Over the last two decades 28 attempts have been made in different State parliaments to pass a law. Not one has got to a stage where the detail of such a law could be debated. The claim most commonly used to defeat it, that 'no safeguard can be devised to protect the vulnerable', has never been seriously examined, despite voluminous evidence from overseas that safeguards can, and do, work.

The testimonies written here stand as a rebuke to this dereliction of duty. They ask serious questions of us as a society. After all, who could be more vulnerable and in need of protection than a person who is dying?

Enough copies of this book have been printed to send to every State and Federal politician in Australia. Should they continue to stand in the way of a law for assisted dying, they will do so in full knowledge of the suffering taking place in our community because of that refusal. Suffering that will continue every week, of every month, of every year, until they act.

The damage done.

Who, amongst our politicians, has the courage to address it – and in so doing, reflect the wishes of the overwhelming majority of Australians?

Andrew Denton

August 2016



**Bearing  
witness**

## The law robbed us of a final farewell

**A**s a nurse and midwife, I've witnessed life's first and last breaths many times. It amazes me that something so simple as two breaths parenthesise individual lives that collectively tell the story of humankind. Usually the first breath is lusty; the final breath little more than a sigh – but not always.

I left nursing to have a family. We had a fulfilling life with its share of ups and downs. When our two sons were in secondary school I commenced a university degree while my husband worked long hours at the urology unit he'd developed with a colleague. Urology was not just a career for him. It was a passion.

Then our lives changed. My husband was diagnosed with lung cancer. Following a right pneumonectomy his aim was to return to work as soon as possible. I wasn't surprised. He'd always seemed invincible. But the postoperative pain was too severe, requiring strong analgesia, so he had to postpone this wish.

The cancer metastasised and he went through a program of radiotherapy followed by chemotherapy, which debilitated him. He had no option but retirement. Months of treatment were emotionally and physically exhausting but he tried not to let it overwhelm him. He loved a good debate with friends. When breathlessness stopped him midsentence he'd wave a white handkerchief – a signal indicating a comma, not a full stop.

It's impossible to describe what it's like to live with death by your side. You avoid looking at it. You try to live in the moment. But it's there, unmistakably, and silently you prepare for that final farewell. In a strange way you become detached from the

outside world and discover an inner world to sustain you. Even so, there were times when I was in anguish, taking my despair outside so I could weep unobserved. I knew I had to hold myself together for my family's sake.

Eventually all treatment failed and he required increasingly stronger analgesia. I vowed to make his final days as bearable as possible, letting him guide me so I could meet his needs without being intrusive or insensitive. Despite his condition I continued to sleep beside him, to provide a sense of comfort and security, because I've seen so many lonely deaths.

We were fortunate. A supportive palliative care team were called to manage my husband's end of life treatment at home.

“His eyes opened and in  
a strangled voice he cried,  
'No!' It shocked me”

Despite the cocktail of drugs, his mind was as sharp as ever. He understood exactly what was happening to his body. Given he only had two-fifths of diseased lung tissue left with which to breathe, his one fear was dying badly.

He tried to maintain his physical independence but frequently I had to call a son to help me carry him from the bathroom. Ultimately he became physically debilitated and bedridden. His body was wasting away, respiratory distress and pain became impossible to endure. When the nurse quietly asked if he wanted this to continue he said he didn't. He agreed to have a cannula inserted into his abdomen so drugs could be delivered steadily via a mechanical 'driver'.



This method of providing continuous pain relief is effective, but I knew the drugs would induce a coma that would inevitably lead to death. There's a fine line between the aim of such treatment and the consequences. Therefore no-one addressed them. Technically it could be deemed illegal and we'd all be complicit. So we sat silently holding hands while the procedure went ahead. The law had robbed us of a final farewell. The heartbreak was indescribable.

During that night I lay beside him, keeping vigil. He seemed deeply unconscious, his breathing unusually steady. In the early hours of the morning I was aware his condition had changed. His breathing had become more laboured. The sheet was damp. I realised his bladder had emptied and knew death was near.

I'd been taught that patients were unconscious during the agonal phase preceding death. Now I'm not sure. How can we know? The dead can't tell us what it's like. I was also taught hearing was the last of the senses to shut down so I whispered, 'It's all right. I'm here with you.'

His conscious state seemed to lighten. He kept trying to clear his throat as though struggling to communicate. I was sure he was aware of the situation and was going to wake up. Then his eyes opened and in a strangled voice he cried, 'No!' It shocked me. I was terrified I'd roused him from his coma. I had no way of knowing. Possibly his tolerance to the drugs had increased, or maybe they were having some sort of adverse effect. I didn't know what to do to help him. What followed were the most violent death throes I've witnessed.

He was trying to swallow, but he couldn't. His eyes glazed in terror and confusion. The fluids in his throat built up until he was gurgling. Then his body jerked in spasms. This went on and on. I felt his agony with every fibre of my body.

My distress was so overwhelming I saw sinister robed figures crouched in the corner. I knew they weren't real: it was a lucid nightmare. I had to end it for his sake. I did the only thing possible. I disconnected the syringe from the driver and injected the entire contents into his body.

Shaken, I realised there was no back-up – nothing left to give him if this failed. I didn't know if I could do the unthinkable. His agony seemed to last forever, but it was probably another fifteen to twenty minutes before he took his final shallow gasp. His ordeal was over.

Seventeen years later that night is still imprinted on my mind.

I have found this very difficult to write. I did not want to publically expose my husband's last moments: the most intimate, private moments anyone can share. It's even more difficult because they were so grotesque. I feel as though I'm dishonouring the memory of a dynamic, fascinating man. But sending a message to those empowered to make decisions on behalf of the terminally ill is more important and it's what he'd want.

It's not death you should fear – the real fear is painful, protracted, possibly lonely dying.

No-one is advocating 'killing' people. If that were the case medical assistance wouldn't be required. Nor do debilitated people want to use brutal methods to end their pain. But slitting your wrists is a better option than being dragged back to consciousness in an almost dead body to experience suffering so magnified it becomes a marathon of sheer torture. This state of affairs will continue until those empowered stop washing their hands of responsibility and legislate for change.

What if the change doesn't come before *your* time comes?

Adrienne Meagher

## Isn't torture a crime?

My dad died this year from a brain tumour. The minute he was diagnosed he wished for the 'green needle', as he referred to it, having seen what they offer dogs to put them out of their misery. From diagnosis to death there was not much time fortunately, and I say fortunately without a shudder as there was so much suffering in this short two months that in the end we were relieved that the suffering had ended. It's not exactly the way you want to feel when a loved one dies! To think some people suffer for years upon years in this living purgatory *does* make me shudder. As you would know there seems to be two socially accepted major grieving triggers: the diagnosis and the death. But they don't tell you how much the suffering in between takes the wind out of everyone. How it demoralises the terminally ill, shapes the memories of family and friends and adds extra agony to the end, and how being in this limbo in so many ways is the worst part of it all. I saw the toughest of men cry when they saw Dad in his state of dying. As my dad said many times as his health rapidly deteriorated and he lost the capability to do all things, plus at the same time, ache with cancer-driven pain, 'This is cruel.'

My dad was a bush larrikin, very active, a foodie and an artist. This illness took all of these things away from him in rapid succession. Add that to the pain and discomfort and the only way you can describe it is torture. Isn't torture a crime?

Meg Hall

“ I saw the toughest of men cry when they saw Dad in his state of dying ”

## She just had to suffer it out

**M**y sister Michelle was originally diagnosed with cervical cancer 12 years before she was re-diagnosed with a cancer called adenocarcinoma. She fought for 18 months, had chemo, which didn't work, and had to travel from her home to Rockhampton for treatment and follow-up visits. We watched her slow decline where pain was a constant.

She had had a stroke, which affected her ability to walk, and she was unable to talk. She could still write but that was hard to decipher sometimes. She got around using a walker and a mobility scooter.

Eventually the cancer was almost everywhere and she finally had to agree to be admitted to hospital, because her pain had become too hard to manage at home. She had been a nurse so she knew what was to come. She had signed the paperwork for no medical intervention except pain relief. She had prepared to die.

For five weeks she ate nothing, willing herself to pass away. Then she wanted pizza, which she had a nibble of. Other than that she had water, ice blocks and ice. I had promised her that she would not be on her own, so for 10 long weeks we were with her 24 hours a day. Her husband, her daughter, our brother and his wife and I did as I and my niece had promised her we would do. This was done in shifts, with more time falling to my brother and me as it became too much for her family. I include this to show that we were so aware of her pain and suffering because we were there constantly.

Her pain increased as the cancer advanced. She was allergic to morphine. The hardest part was watching her wake from fitful sleep and seeing the look of 'oh no I'm still here' on her face. Watching the nursing staff, the majority of whom did their

utmost to keep her comfortable, holding back the tears because they could do no more. Some of these wonderful people had worked with my sister. My sister-in-law, who is a nurse, pressed the buzzer for more and more pain relief when Michelle's daughter and husband became distraught with watching the pain she was in. I had what is called a Tontine moment, where I was very briefly tempted to put the pillow over her face and press down.

I cannot fully express the horror of watching a loved sister die so wracked by pain, and by law nothing else could be done. Her son, in the end, couldn't face being there. Her beloved grandchildren were kept away because it would have been too much for them. Her youngest daughter couldn't bear to come and is now dealing with the grief of losing her mother as well as a sense of guilt.

“ I cannot fully express the horror  
of watching a loved sister die so  
wracked by pain ”

Sometimes it is beyond comprehension that this is the way we treat our dying. Those who have no hope of cure and in my sister's case, no peaceful passing because of the pain.

She had lost the sight in her right eye and could barely see from her left eye so invasive was the cancer. She had tumours that could be felt on her arms, near her collarbone and on her thighs. She was so frail but she just had to suffer it out. How cruel is that?

Lyn Godier

## A sister's story

My sister was diagnosed with breast cancer at age 25. By 39 she had died of secondary cancer undetected but assumed to be numerous small tumours throughout her abdomen. She exhibited 'ascites', the build-up of fluid between the organs in her body that could only be drained at a rate of 2 litres per week to avoid her body going into shock. Needless to say the fluid built up faster than it could be drained. The ascites was literally crushing her organs. She blew up like a full-term pregnancy. She suffered vomiting and difficulty breathing, apart from the obvious discomfort of suddenly being in the later stages of pregnancy. Her doctor could find no chemotherapy that would make any creditable difference to her state. She was dying.

At first she refused drug treatment to ease her pain. I advised her that it would be impossible for her to be administered a lethal dose if she refused all drugs and suggested she just keep asking for more pain relief. Her new doctor, a good Catholic, believed that 'nature should take its course'. I challenged him as to why she was being administered saline via a drip if her issue was fluid retention. The next day the drip was gone.

She hung on for eight weeks. Every time she awoke from the drugs her eyes would cast around the room and she would breathe a heavy sigh, realising she was still alive. When nurses asked would she like anything, she replied, 'A lethal dose?' It was akin to torture, her being kept alive. She wanted to die. She was declared incurable. Her life was pointless. She had said all of her goodbyes. Nothing could be done but she was left to suffer in the name of good medicine. She and I have always been firm supporters of euthanasia.

Kerri Laidlaw

## **‘I just want to go, Rach’**

I lost my mum last month. She had pancreatic cancer. We told friends and extended family that Mum passed away peacefully. It's customary to do so and respecting convention, we fell into line. At the very end I guess it was peaceful. But in the months leading up to Mum's death, she was frustrated, upset and angry. Throughout her life Mum had been an independent, headstrong, fearless woman. She had also liked to be in control. Following her diagnosis of terminal cancer, my mother felt she had no control.

Mum was diagnosed with pancreatic cancer last November. The surgeon who delivered this terrible news told her that without treatment her life expectancy was three to six months. When my mother asked him what he would do if in her position, he told her quite emphatically that he would do nothing. At first Mum accepted this news with a pragmatic attitude and a calm head. She announced to us, her immediate family that her time was up and that she wanted no treatment. My father and my siblings all told Mum that we understood – that we loved her but this was her decision.

Then she received a call out of the blue from an oncologist who had reviewed her case and believed he had better news. This call was on the back of many conversations with well-meaning friends who told her she should ‘do something’ and not give up so easily. Believing that perhaps there was a treatment that might save her, or at the very least buy her a significant amount of extra time, Mum endured six weeks of chemo and radiotherapy. In hindsight this did nothing but diminish her quality of life and in her final months prolong her agony.

It was following the treatment that Mum often spoke of her wish to ‘just end it’. She hated the way her body swelled with fluid

from the disease. Her 'pregnant cancer belly', a terrible reminder the tumour was growing and taking hold of her emaciated body.

Then in August Mum fell badly on her kitchen floor at home, breaking her hip and right arm. She was rushed to hospital and spent several weeks in a ward alongside other elderly, sick people close to the end of life. The man in the bed opposite was suffering dementia and had a bulging hernia. His daughter told me she had been called to his nursing home to say goodbye but miraculously he had rallied and was now waiting for surgery. As we sat around Mum's hospital bed waiting for her number to come up I wondered, what were we doing? Somehow Mum survived a general anaesthetic and a plate was inserted into her broken hip.

The next day the registrar wanted her out of bed: 'You need to get moving, Judith.' Remember that, before the fall, Mum could not walk without a walking frame. And even then she fell. Now she had a broken hip, a broken arm and had just undergone surgery. Were the doctors crazy?

'I just want to go, Rach. I just want it to be over,' Mum would say to me and family. 'I would like it to end,' she would say directly to doctors and medical staff.

The only person I ever saw acknowledge Mum's pleas was a young nurse. My family and I were shocked when she used the 'E' word. 'Euthanasia as you know is not legal,' she said. We were shocked because this was a subject everyone else avoided. 'All we can do is manage your mum's pain. I can give her some more morphine but you need to ask for it.' She also admitted that if she pushed things too far other nurses would notice and she risked getting into trouble. She said: 'I wish I could do more but I can't.' These end of life conversations were very uncomfortable for the hospital doctors.



Unable to give her what she wanted, all they offered was surgery, more chemotherapy and physiotherapy. In fact in her final days, as she slept, a team of six oncologists (four of them students) barged into her room to talk about treatment. They had been sent by a surgeon Mum had seen two days earlier. Mum had told the surgeon she wanted to die. The surgeon thought it was a good idea to send a team of oncologists. The mind boggled.

In the last few months of her life Mum lost her sense of self. It wasn't just the indignity of needing help to visit the bathroom, it was the inability to tidy her home, to dress herself and to make a cup of tea.

I started to write this piece the day before Mum passed away. I was sitting alongside her bed. We were both waiting for her time to go. She was unconscious, her breaths shallow but steady. She was like this for three days before finally her tiny body gave up.

I can't say with any certainty that things would have been different had assisted dying been available to my mother. What I absolutely can say for certain is that having a choice about how and when she died would have provided her with a tremendous amount of comfort and peace.

Since Mum's funeral I have read many articles on assisted dying. It upsets me when I hear those against assisted dying prescribe how death should be. Like they know better. As if a long, drawn out death is worth more.

Of course they are entitled to their point of view just as I'm entitled to mine.

Rachel Friend

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## **Andrew Ross ‘Jim’ Carswell (1956–2016)**

Andrew Ross Carswell, a skilled musician, at times tedious intellectual, much loved friend of many, valued family member, and adored husband to Carolyne, died an unnecessarily protracted, distressing death on Sunday 13 March as a result of the continuing absence of legislation that could have otherwise allowed a man of his integrity experiencing the final stages of liver cancer peaceful, timely access to euthanasia. May he finally be able to enjoy the long sleep he had been anticipating and may the anti-euthanasia lobby collectively experience the tediously prolonged, objectionable demise they are so determined to impose on everyone else.

*The Age*, 16 March 2016

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## Those hours will haunt me forever

 On Friday 1 November 2013 I buried my husband of 61 years. Earlier that year he was diagnosed with aggressive lymphoma which was strangling his intestine. Sounds horrendous, doesn't it? His final three days were spent in hospital and on the third night he lapsed into semi-consciousness. He had been having litres of fluid drained from his abdomen at intervals during the treatment process, and in the early hours of the fourth day fluid in large quantities continued to rise into his throat and he was gurgling and drowning while he struggled dreadfully to get a breath. All the while he kept raising his hand to his head imploring someone to help him. This inhumane action continued without ceasing for seven hours!!! How I wished we lived in a compassionate, loving society that approved an injection that would save him from this hideous state.

A nurse entered the room towards the end, saying, 'I have been crying reading his advance health directive where he wrote that it was his wish to have some kind person euthanise him.' This document had been signed by him, a doctor and a Justice of the Peace some years ago, but of course that wish is entirely overlooked by Australian law at the present time. It was just his wish – as it was mine. Towards the end, one and a half litres of blood-soaked fluid gushed out of his mouth before he took his final breath. Those hours will haunt me forever. Why should anyone die that horribly?

As a practising Christian couple we viewed the present law as ungodly. We are God's hands and feet, he has no other, and while we do nothing this horrendous practice will continue.

Joan Smith

## Everything went wrong

**M**y strong, wonderful mother had a living will and was determined to avoid the fate of so many of her friends who had suffered painful deaths, subject to all manner of unhelpful intrusive medical interventions. At 87, she had seen many people die and dreaded spending her final days helpless and in misery. Yet that is just what happened. She had a fall, broke her hip and ended up in a surgical recovery ward. Then she had a pulmonary embolism, which should have delivered the fast, peaceful death she so wanted. She lingered for two horrible weeks. Everything went wrong. She screamed every time the nurses turned her over. She's just afraid of falling again, the nurses assured me. It tore me apart.

But one evening a palliative care nurse happened to be on night duty. She asked what was going on. It turned out my mother was in terrible pain, having grown tolerant of her morphine level and missing the medication for her crippling arthritis. That superb nurse tried to fix things. She had her moved to a ward which had proper palliative care, arranged for higher morphine levels, less regular turning. But then my mother got terrible diarrhoea, which led to more pain, intrusion, endless assaults on her dignity.

It was devastating struggling so ineffectually to provide that peaceful death my mother so deserved. Here I was, an educated, assertive person, thoroughly familiar with the medical system having for many years taught both doctors and medical students. Yet I failed dismally. Wandering the hospital corridors with me were other families totally crushed by their impotence to ease their parents' suffering.

It is a total nonsense to suggest that the solution to a peaceful, dignified death is now available through palliative care. Yes, this

care can make a huge difference. But many, perhaps most of the elderly, die in nursing homes and normal hospital wards, often cared for by people who lack the skills to provide that care. And palliative care experts acknowledge that even with state-of-the-art palliative care, terminally ill patients can still experience distressing symptoms that make their lives unbearable – weakness, breathlessness, nausea, suffocation, psychological distress, confusion.

“ She screamed every time the nurses turned her over. She’s just afraid of falling again, the nurses assured me ”

Our community knows this – most of us (over 70 per cent) want laws changed to allow doctors to provide assistance to terminally ill patients to commit suicide and to be able, where appropriate, to give lethal doses to such patients. Yet we continue to allow a noisy minority to lean on politicians and prevent Australia from providing the legal support for assisted suicide available in other parts of the world – Oregon, Switzerland, the Netherlands, for example, well-functioning legal systems which have not resulted in the dire consequences predicted by the doomsayers.

My friends often joke about shooting each other when the time comes. But we will face the same dismal end-of-life prospects as many of our parents unless we get moving now. The noisy, activist baby boomer generation should have what it takes to turn this issue around.

**Bettina Arndt**

## How can you watch her in such pain?

I'll give you an example of one night that was probably in the last 10 days of Deb's life when I was on night duty, so to speak, with her. The doctors can only administer, as you would know, a certain amount of morphine over certain hours otherwise that can put the patient to sleep permanently, and obviously that's not allowed. So as much as the patient may want that, the doctors are understandably – and nurses – scared stiff of overdosing their patients. The pain was getting so intense on this particular night that Deb sort of called out to me and said, 'Spencer, I need to walk. I must walk. I've just got to do something.'

We walked around the corridors of this hospital for six hours until she was allowed to have more morphine and during those six hours – I've probably still got the marks – her nails were clawed into my back through sheer hell. We walked past doors that led into utility rooms and she'd scratch at the door. She had to do something to alleviate the horrendous pain she was in. I've never seen pain like it. I've been a journalist for 49 years; I've seen people in pain all over the world in wars and whatever else. I have never seen anybody in such pain that she was in that night.

That little red buzzer that you press, my finger was on it almost all the time, and of course they are busy people, the nurses, especially on night duty, so I was forever walking out to the nurses' station looking for nurses, searching for them.

They said, 'We're not allowed to give any more for another two hours and 14 minutes,' or whatever. 'It's all written down on the chart.' 'Why not?' I'd say. 'Because that's the amount the doctor says. We're not allowed to give any more than that.' 'Why not?' 'Because it's the legal limit that we're allowed to give.'

Deb was only allowed a certain amount every hour or two hours or whatever. But because the pain just keeps growing and growing and growing, the amount of morphine grows too but not in accordance with the pain. It's very hard to measure that, but you can tell when someone's screaming in pain and they're just crying. 'Please can she have some more?' 'No.'

I said, 'How can you just tell me that? How can you sit and watch her in such pain and tell me she can't have more morphine?' 'Because the doctor says I can't.'

Spencer Ratcliffe

“ I've been a journalist for 49 years, I've seen people in pain...in wars...I have never seen anybody in such pain ”

## **I will never forget his agony**

**M**y father died of lung cancer in the mid-1980s. He was told it was inoperable and that chemotherapy would likely make him very sick and that it would only extend his life by a month or two. He declined chemotherapy, thinking that he didn't want his last months being sick that way. He died within six months of diagnosis.

At home he was on pain medication which became less effective towards the end, requiring higher and higher doses. The medication made him vague, tired, agitated and constipated.

In the last six weeks he was told that the cancer had metastasised to his brain. The kind of death he might face was described to him. Four weeks later he was in hospital and was so agitated – because of both the cancer and the medication, we were told – that the hospital said they needed to strap his wrists and ankles to the bed. Even though he was clearly heavily sedated and unable to focus or talk, he was moaning, yelling, writhing and trying to get out of the straps.

At that time the option was given to the family to withdraw feeding and liquids. It took a further six days for him to die. He was still agitated, and struggling and writhing against the bed straps, on his last day. He died an agonising death – physically, mentally, emotionally and existentially.

I will never forget his agony. I can still see and hear him in that hospital bed as if it were happening now. If I were to develop a condition which would likely result in an extremely painful death, I would want the choice of dying with dignity. And I wish the same choice for everyone.

**Michele Foster**



## Please turn the 'Jesus machines' off

Ever since having seen my late mother, Edna Fitzgerald, suffer so much when all she wanted was to slip away peacefully, I have been a strong public advocate, for others and for myself, of Dying with Dignity.

After a long struggle with a series of hospital physicians, my mother, Edna Fitzgerald, eventually died in her mid-80s. A few years before her death, due to a combination of glaucoma and cataracts, my mother went blind. She was then hospitalised in Melbourne with a series of complaints, which eventually involved both of her legs being amputated.

Despite her stated wish to be able to die with some peace and dignity, the hospital physicians continued to 'treat' Edna for a variety of illnesses and complaints. When I requested that all the 'Jesus machines' please be turned off, the lead surgeon told me that he was doing all of these procedures to help my mother. It was only when I responded, 'No you're not. You're doing all

“ All she wanted to do was  
slip away peacefully ”

this to help yourselves', and then *insisted*, again and again, that all Edna's life support machines be switched off, that the hospital physicians finally relented and let my mother die. But this was many weeks after she clearly wanted to die without having to suffer any more medical interventions.

Ever since observing Edna's very difficult and unnecessarily lengthy death, I have been a strong, public supporter of Dying

with Dignity, in the form of physician assisted dying or voluntary euthanasia.

My mother's unfortunate hospital experiences is one of a number of reasons why my wife, Lyndal, our daughter Emerald and myself decided to join Dying with Dignity NSW and also the Australian Sex Party. Indeed, strong support for Dying with Dignity is a central reason why, this year, I decided to stand for federal parliament as the Australian Sex Party's lead Senate candidate for NSW.

**Professor Ross Fitzgerald, AM**

## I'm so sorry I didn't kill you

Dear Mum,

I'm so sorry I didn't kill you. I came close, believe me. The pillow was millimetres from your mouth. But I just couldn't do it.

How could I take life from the one who gave it to me? My suckler and snuggler, role model and mentor, nurturer and nemesis: you were all those things.

To your daughters you were an impossible picture of perfection. Successful career woman, devoted wife, loving mother – a feminist before your time. You laid out your manifesto: 'I want you to be independent women. You don't have to have babies. The world is your oyster. Go out there and show them what you're made of! Who says you have to be sugar and spice and all things nice?'

Brave, bold and beautiful, you always called a spade a bloody shovel. Possessed of a wicked wit, you could cut to the quick.

That humour came in handy the day you were diagnosed.

The oncologist held up an X-ray dappled with snowflakes (unusual, on a sunny day in March). 'You can see the cancer here, here, here...and here,' he said. 'It has spread from the pancreas to the lungs. Any chemotherapy will be palliative.'

You turned to Dad with a wry smile: 'Might as well go outside for a smoke. No point giving up now!' I had to laugh.

At a family meeting you set KPIs for the coming months. There was to be no pity, no moping, and no wailing, but there must be mercy.

A conversation we'd had many times around the dinner table suddenly had currency. 'If I lose control of my faculties then put me down,' you said clearly. 'They do it to dogs. Why can't they do it with us, as well?'

We all agreed. Voluntary euthanasia was a given in our house.

The next six months were the worst – and best – of my life. We looked at old photos, decorated with 1970s flares, floppy sunhats and floral jumpsuits.

(Incidentally, why did you sew matching outfits for Suzie and me? We weren't twins! I should have taken you to The Hague for those purple and green smocks. They were a crime against humanity.)

You gazed at me lovingly as I stabbed needles into your stomach, kept down a modicum of meals, and patiently painted shadow boxes as keepsakes.

We laughed at the bandanas you made us wear to your chemo sessions, at my dreadful Manuel impressions in the kitchen, and at the stupid things people said when they dropped by.

'Oh, we know it's terminal. But it's a gift, isn't it? All this special time you'll be having together in these next few months,' they'd sigh.

Well, if that's a gift, I want a refund. It's clearly faulty.

One day it got too much. We could no longer care for you at home. We drew up a roster so there was always someone to hold your hand during those bright sunny days and dark desperate nights. Your screams of pain were blood-curdling.

It was a Tuesday, I think, when I pinned the oncologist to the wall.

'Is there nothing else you can do for my mother's pain?' I pleaded. 'Can't you up the morphine to put her out of her misery?'

'If I do that, I'll lose my job. I'm sorry,' he answered kindly.

We asked the nurses. 'Please, someone, anyone, end this godforsaken suffering.' (Which was a big call for an atheist – I had been forsaken long before this.)

They, too, were kind, patting us on the back and saying, 'There, there. It won't be much longer now.'

It made me wonder, how long is too long? Is there a mathematical equation for this? 'I've heard three shrieks, five hollers, and one "Please, kill me now". Is that enough, nurse?'

So we decided to do it ourselves.

Suzie stood there all night pressing that bloody red button to flood your body with morphine. The next day she showed me the bruise on her thumb.

'I know I could go to jail but I don't care,' she declared.

But her bravery was for naught. You kept breathing. And writhing. And screaming.

And so, at 3am, I got up from the recliner chair, lifting the pillow I had wedged behind my back.

I told you I loved you. And I lowered the pillow over your face.

It hovered there for what seemed like an eternity.

“ I told you I loved you  
and I lowered the pillow  
over your face ”

But in the end, I couldn't do it.

I was weak. A coward. Not my mother's daughter.

I collapsed on the floor, sobbing. You must have known: you died hours later.

Finally, you were in peace.

Mum, I hope you forgive me.

Not for the clumsy way I've written this letter (you were

always a masterful wordsmith) but for not having the courage to help you when you needed it most.

If it's any comfort, Dad, Suzie and I are campaigning for voluntary euthanasia.

Let your suffering – and that of so many others – be a lesson to those short-sighted, selfish, puerile politicians who refuse to show compassion to their fellow man. And woman.

How many of them have seen someone they love die in agony, and live with feelings of grief, regret, and helplessness?

Like I do.

Love you, Mum.

Your daughter, Tracey

Tracey Spicer

## **A terrible, painful, frightening death**

John had suffered for five years with terminal bowel cancer. He had had more than 60 per cent of his liver and half his bowel removed in two separate operations. He was on chemotherapy for most of that time. He then got cancer in his femur and it broke, another operation and weeks of rehabilitation to walk again. Then John's acetabulum fractured and it was decided he would have a total hip replacement.

John was a brave man and I can truly say he hardly ever complained. He was close to a perfect patient. John loved living. In between all the above health problems he was able to smile and still woke up each morning and said, 'Another beautiful day,' irrespective of the weather.

We had heard positive things about palliative care at home and thought that would be for us. Unfortunately it has left me regretting our decision. While the people from palliative care who visited were wonderful, caring and pleasant, John had a terrible, painful and frightening death. After John died I had three police visit with heaps of questions and forms to complete. Then I had to wait for someone from the Coroner's Office to take John's body to Gosford Hospital.

John was dying in pain and could hardly breath. I contacted the after-hours palliative care number and obviously woke the person up. I explained what was happening to John and she told me to change his position. Try sitting him up and if that didn't work to lower the bed down further. Perhaps get him on his side. All of which I did, to no avail. I then tried to phone her again but the telephonist at the hospital told me, 'She isn't picking up, so I have left a message to phone you.' I had

given her my name and phone number. She never did get back to me. I didn't know what else to do. John was struggling to breath, arms flailing, trying to speak but all that came out for ages was terrible gurgling noises. In final desperation I called an ambulance and by the time they arrived John was still in that terrible state. They said that it was too late to take him to hospital as he would be dead on arrival.

My wonderful husband died a terrible death and left me with a terrible image.

John had suffered for five long years and to watch him suffer so much for hours at the end was terrible. I write this now in the sincere hope that you, or someone will do all that you can to see that no-one else suffers as much as my John did.

Jessie Edney

“ John was struggling to breath,  
arms flailing trying to speak but  
all that came out for ages was  
terrible gurgling noises ”



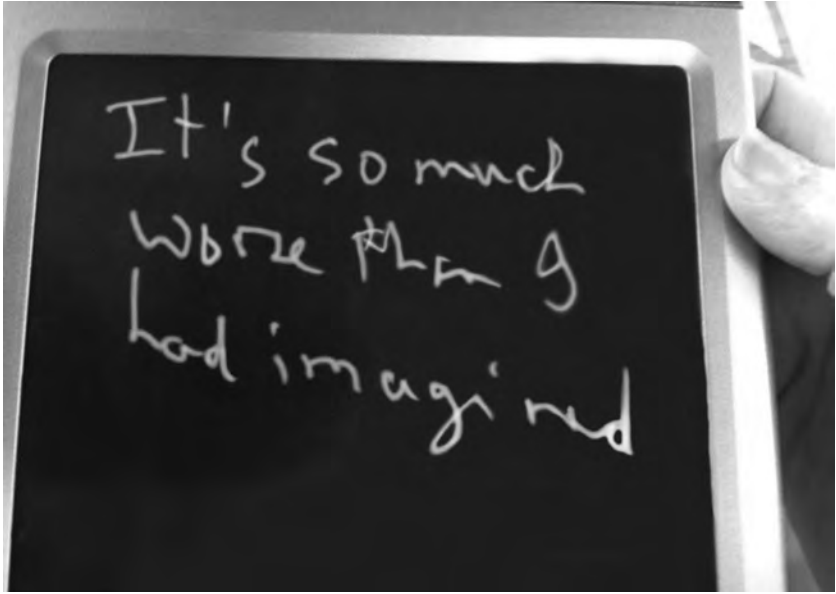
## **It's so much worse than I had imagined**

**A**fter much thought I am forwarding to you one of the last messages my dearest friend wrote, three weeks before she died from motor neurone disease (MND), surely one of the cruellest of deaths.

My hesitancy comes not because I do not wholly support your campaign, I do, and so did my friend, but from the sadness which is still raw, even after nearly two years. But perhaps two years is an indicator that the grief should be directed more constructively. It is about how long my dear friend lived after her diagnosis, a classic prognosis for MND.

Her wish was to die at home and with the best possible support from her husband, daughters and friends and an excellent palliative care team – that is what she did. During her illness she explored the Dignitas option for which she was accepted, and she wrote to me saying what comfort this gave her. But classically when she could go to Switzerland, she wasn't ready and when she was ready she was too ill to travel. Other options were explored too but finally she altruistically decided to leave her brain and spinal cord for research and in this interest to see the disease to its natural end. Her enormous courage and stoicism in the face of extraordinary mental anguish and physical discomfort at every level is, I think, underlined by the scrawled message in her barely recognisable hand. Highly intelligent and erudite, even in the extreme effort to write when she could no longer speak, she still got the grammar right...I treasure that apostrophe!

She wanted me to use the photo I took of her message to advance the case for dying with dignity and her family is happy for it to be so used.



I hope it will be a useful addition to your evidence so that one day compassionate legislation will be passed.

Elisabeth Inglis

In January 2016 Lady Stephen wrote Prime Minister Malcolm Turnbull an open letter discussing problems of national importance. In it she conveyed her thoughts on medically assisted dying.

## The right to die


**A**lmost all of my contemporaries have died. I visited friends who were in intensive care for a long time, connected to machines and being constantly prodded and poked, which no doubt cost large amounts of money. Many wanted assistance to die but instead were kept alive, many to face long, drawn out, painful and undignified deaths. How silly is that?

As a near centenarian, I know I will die soon, and I treat every day as a wonderful gift. However, I think terminally ill patients with their cognition in place have a right to be assisted to die a peaceful and dignified death.

Lady Stephen

“Almost all of my contemporaries have died”

## **‘I want this ordeal over’**

 On 27 December my friend Graham had no idea he'd spend the next 10 weeks on a rough road through hell. He'd become dizzy, blacked out and ended up in a large hospital where an MRI revealed seven lesions in his brain. Graham was a practical man, a highly intelligent engineer, with an excellent sense of humour. His illness was causing short-term memory loss but he was otherwise lucid, chatty and happy.

That day in the hospital he asked me to be his legal guardian, to watch over him if he reached a stage when he could no longer make decisions. He fixed me with his eyes and made me promise to stop anyone trying to railroad him into heavy chemotherapy, and to otherwise prevent 'it' from dragging on.

Four weeks and dozens of invasive tests later, the final diagnosis was delivered: primary central nervous system lymphoma. Graham chose to have only enough mild chemotherapy to get him home to sort out his affairs. He knew he was aiming for a good time, not a long one, but sadly only had one day. A series of seizures sent him straight back to a small regional hospital, unable to communicate effectively for another six weeks.

He talked constantly, but his words jumbled, leaving him frustrated and angry. His eyes said it all, but occasionally complete sentences sneaked out. He'd say, 'This is hell!' and 'I'm over this mate! I've had enough. I want this finished.' He clearly understood everything we said to him. At my request, the doctor withdrew the steroids that were 'calming' inflammation in his brain. Why prolong this palliative nightmare? Ten days before he died Graham stunned his doctor by saying, 'I want this ordeal over by 3pm, and if not then...by sundown.' I'd been relaying his scarce comments for weeks, but perhaps it was this

clear statement from him that confirmed Graham's desire to die. Drug regimes changed and things moved faster from there.

The next day Graham fell while trying to walk, and probably broke his hip. That hip remained a source of extreme pain until the morning he died, despite increasing doses of morphine. Palliative sedation and medication for seizures were his only treatments. It was all his doctor could legally do.

Eventually pneumonia carried Graham off before the brain lesions did. I will never again hear anyone call it the 'old man's friend'. There is *nothing* friendly about drowning in one's own phlegm. There is *nothing* good about listening to desperate, healthy lungs gasping and grasping at air for two days. Even though I'd witnessed his advance care directive I desperately wanted to call for antibiotics. Either that, or end his suffering by smothering him with a pillow. I did neither, but sat there, distressed and horrified, wiping away oozing phlegm for 15 hours. The only good thing was that it finally released Graham from his living hell. The doctor told me it was far worse for me than for Graham. I certainly hope so.

I was left shocked and traumatised by witnessing Graham's death from pneumonia. But I walked out of that hospital and didn't have to go back. What of the poor nurses who helped us? They were clearly shaken. They were the kindest, most compassionate people I've ever met. How often are they traumatised by bad deaths? Daily? Weekly? How can we, as a society expect them to carry such an appalling burden in their own lives? How can we expect them to just carry on? It's time to change the law to make inevitable deaths less distressing for all concerned. We intervene in almost every other aspect of life...why not the moment of death as well?

Sandra McEwen

## She was ready to go

**M**y mum, Betty, had a wonderfully full life. She had been very active mentally and physically but the aging process was causing her to give up most of what she loved doing: to go out almost every day, doing things for other people, browsing the shops, pokies, trying new things, crosswords, reading at least 12 books a week, watching *Coronation Street*, sewing, knitting. The only sour note was that she missed my dad terribly for the 16 years since he had passed.

The last few years saw her having to stop or reduce most of her favourite pastimes. Her eyes would tire, her hands would cramp, her back kept playing up, she would get tired long before she wanted to stop doing what she was doing. She found it very annoying. Then at 84, she got stomach cancer, which blocked the exit of food from her stomach. She felt fine as long as she didn't eat; she was simply not hungry. She asked them to help her die. But no, she had to remain in hospital while her body starved to death. By law, she had to have intravenous fluids, which only served to prolong the starvation process.

In the last four weeks, her veins began to collapse so she was put through daily agony having someone constantly trying to find another vein. Being bedridden meant she was plagued by discomfort and bedsores. I spent up to 10 hours a day with her. Each evening, I would say goodbye and tell her I hoped she would not wake the next day.

She was of sound mind, knew there was no solution to fix her body. She was ready to go, she wanted to go. She should not have been subjected to all that pain and indignity of the last four weeks – hurting her to keep her alive until she died.

Robyn Taubert

## We both said, ‘Well do it’

My mother, Catherine (Kit) Sanotti, was a fit, healthy, vibrant 73-year-old woman. She lived alone at Davistown and tended her garden almost daily. Her reward was its beauty. Her widowhood from four years earlier had been a great release for her and she threw herself into activities. She attended exercise classes, was in a craft group, volunteered at the hospital as a Pink Lady. And she walked, and walked and walked all around Davistown.

And then she was literally walloped with a very virulent form of lung cancer. It was six weeks from diagnosis to death and it was as though she had been shoved off the cliff of wellness and was plummeting into a chasm where there was no safety net.

My mother had always suggested to me and my sister and nearly anyone else who would listen that she expected us to shoot her if she ever went round the bend (with dementia). During those last few days she was frequently incoherent with pain and pleaded with us to ‘make it stop’, or to ‘get something’ for her.

By day 40 after her diagnosis she was seriously hallucinating with monster memories determined to get her. She was restless and unable to remain still, tossing and turning and groaning and moaning.

My sister and I cornered this poor young doctor and demanded to know, ‘Why is she suffering so much?’ And he said, ‘If I give her any more it will hasten her death.’ My sister and I didn’t even look at one another. We both said, ‘Well do it.’ He didn’t react to those words but suggested we should go and have a coffee.

Given all our previous conversations with Mum I had no compunction in saying this. She really did expect us to ensure

she didn't suffer. We all knew her condition was incurable and her pain was clearly intolerable.

When we returned, Mum gave every appearance of being at peace. She was no longer thrashing around and moaning but was serene and apparently in a deep coma.

Kay and I stayed with her for the next nearly 20 hours until she died. She remained tranquil and calm until the end. We each had private time with her and said our goodbyes to her and told her how much we loved her. She never woke to tell us she loved us but we knew. We knew.

Her suffering could have gone on for days or weeks but for the kindness of that young doctor. We are eternally grateful to him.

Judith Daley

“ My sister and I cornered  
this poor young doctor and  
demanded to know: why  
is she suffering so much? ”



## **RIP Dad. Love you always**

When Channel 7's *Sunrise* Facebook page asked viewers if medically assisted dying should be legalised, Denise's response was emphatic:

YES. YES. YES.

Anybody who disagrees and considers this murder has obviously not sat there and watched a loved one die a slow, painful and cruel death. They have not seen them cry in pain when the morphine isn't enough. They have not seen them gasp for air as they drown in phlegm. They have not sat and watched as their limbs swell with fluid from being bedridden and even cutting their fingernails bringing them to tears. They have not watched as their loved one is reliant on others to spoon-feed them, wipe their noses, roll them over to attend to the bedsores, to clean their faeces, to wipe their tears away.

They have not watched a once-proud and self-reliant man lose all his dignity and control and become bedridden as his body has failed him.

It is not murder to give a terminally ill person the option of ending the pain earlier.

RIP Dad. Love you always. 19 Nov 1939–24 June 2014

She later wrote in detail of her father's agonising death.

I think it is important that people know Dad's story, as although he supported the euthanasia choice, it was only in the final weeks of his life that he would have chosen this option, if it was available. Prior to this he fought hard to survive despite many health issues.

It all started in 2009 when he underwent a double knee replacement where he unfortunately contracted a serious staph infection. This resulted in many lengthy hospital admissions and several operations to clean out and replace the parts in his right knee in an attempt to clear the infection. On one occasion we were prepared by the hospital as they did not think he was going to survive the night, but he proved them wrong and nine weeks later he again returned home, although he had to take an assortment of pills each day to keep the infection at bay, as well as regular blood tests to monitor the levels.

It was during one of these admissions that he was also diagnosed with Parkinson's disease, which also added to the number of tablets he was swallowing each day (Dad thought that he 'rattled' due to the number of tablets he had to take).

Then in December 2013 I finally convinced him to go see his GP as he had not been feeling well for several weeks. He was immediately admitted back to hospital and an endoscopy showed that his 'upset tummy' was in fact an advanced oesophageal cancer at the base of his oesophagus and extending into his stomach.

Due to the staph, he was not a suitable candidate for chemotherapy and the idea of operating was also eliminated as it was a major operation that would involve cracking his chest open and removing a considerable amount of the oesophagus and stomach, which would have been too much for his already unfit condition. All his doctors and specialists (as well as his three daughters) supported this decision, as did Dad, as he knew he

was not strong enough to recover from an operation of this size. It was decided that he would instead undergo a course of radium to try to shrink the tumour enough so he could swallow (and keep) his food down, which he was now unable to do.

Unfortunately this treatment did not reduce the tumour, so he continued to lose weight and strength until he eventually was unable to even swallow his own spit.

At this stage Dad knew his time was limited so, in an attempt to hasten his death, he stopped taking his staph medication in the hope the infection would return and end his time on earth quickly and painlessly. Murphy's law was obviously in play, as this never happened.

“ He did not pass away peacefully  
like the movies portray ”

His doctors decided to insert a stent to open up the throat enough to allow his spit to get through. This operation was a success, and that night he even managed to eat 'real food', albeit mashed.

This 'success' was only short lived though, as at 2am the next morning he suffered a catastrophic stroke, paralysing him completely down his left side, weakening his right side and leaving him totally bedridden. His speech was slurred and at times he was delusional and would not believe that he was unable to get out of bed, which upset him just as much as it upset us.

He was unable to do anything for himself and was reliant on the nursing staff, my sister and me to feed him, wipe his face, clean him, roll him over, massage his legs and wipe away his

tears. As the weeks passed, his pain increased as the fluid built in his limbs and the morphine was not enough. The Parkinson's was also a factor for his pain as his muscles seized and spasmed.

The doctors tried fentanyl patches, increased his morphine doses and eventually commenced a morphine drip but his pain was still unbearable. He stopped asking the nurses to hoist him into a chair so he could be wheeled outside as the slightest movement would bring him to tears, even when we tried to trim his fingernails. As a tough, rough, old truck driver who was once the strongest man I've ever known, this was devastating.

He put up an incredible fight against the staph, Parkinson's and the cancer, but the stroke robbed him of any quality of life and it was only at this time that he had no fight left and no desire to 'live' another day.

Dad lived seven weeks and three days after the stroke and this whole time he suffered, both mentally and physically.

He took his last breath with my sister and myself at his side. He did not pass away peacefully like the movies portray though. He drowned in his own phlegm and the noise of this is something I can never describe. His eyes were rolled back in their sockets and he was groaning and gurgling and his breaths were laboured, shallow and frantic. My sister and I cried at his side, hoping that each breath was his last, but as the hours passed he continued his struggle for air until his body finally gave up and went silent.

I hope that Dad's story can assist to get a law. I just wish it was already a choice so my dad never had to suffer like he did.

Denise Kapernick

## I felt so utterly useless

**M**y brother Paul had been diagnosed with advanced pancreatic cancer that had spread to his liver. Wednesday, he was told by his GP that he would benefit from palliative support. On Thursday morning the oncologist told him that chemotherapy was not an option and had palliative care been in contact? Thursday afternoon palliative care arrived and told him that he did not need palliative care. Thursday was a 'good' day and he presented well.

On Saturday morning I found him asleep sitting in his chair, in the same position that he had been in the night before when I left him. I had read that cancer patients sleep a great deal and thought that he was doing just that. I had been concerned about his breathing, which was six breaths a minute and quite erratic. He was restless.

By late afternoon I tentatively called a number for palliative support and was told to call 000. An ambulance arrived. Paul was aroused and cried when he saw three paramedics in his lounge room. He could not answer questions easily as his speech was very slurred. After an assessment it was decided that Paul be taken to hospital as it was not clear what was going on. Could he have had a stroke? ...not sure.

In the emergency room he was very stressed and frightened. A blood test confirmed an infection in his liver. His kidneys were failing, as well as a thought that the cancer had gone to his brain.

Paul was put on fluids and antibiotics, which were both stopped the following day when I had spoken with the doctor stating that I wanted Paul to be made comfortable and allowed to pass with dignity.

I made the same request for my father when he was diagnosed with lung cancer a few years earlier. He was given two doses of morphine and simply went to sleep, never to wake.

Paul deteriorated over six days. He initially had periods of long sleeps, waking for a short while and recognising me and my cousin. Then the sleep periods became shorter. He would wake up suddenly with the most terrified look in his eyes. He did not indicate recognition of anyone but groaned as he reached out with his arms in pain. He was having difficulty with congestion, coughing, and was weak.

“ His eyes, a sight I will  
never be able to get from my  
mind, showed sheer terror as  
pain wracked his body ”

A pump providing regular bursts of morphine was provided and sedatives given but they did not have any desired effect and, in my mind, were not given quickly enough. Medication was administered only when Paul was in agony rather than topping it up before it got too severe. Once given it took a good 30 minutes to kick in.

The morphine pump was again increased, as it was clear that nothing was keeping the pain at bay. More shots of sedatives were given every hour but nothing seemed to work. Paul was moaning and his arms were reaching out in agony, his hands clutching in fists. His eyes, a sight I will never be able to get from my mind, showed sheer terror as pain wracked his body.

I felt so guilty that I had stopped the hydration and antibiotics, knowing that the effect of this was contributing to his pain. He was sweating but felt cool to touch. A tear welled in one eye.

He began breathing so hard that I couldn't understand how his heart could take the strain. My cousin questioned the fact that he must be hyperventilating which in turn would have added to his distress.

I was sobbing and pleading for help...to do something...let me sign something...I wouldn't let an animal suffer so! I have never been more frantic and felt so utterly useless. I could not help my brother and I just wanted to run away. I couldn't even pump a fatal dose of morphine into him as the pump was locked up solid within a casing, the keys locked away in a cupboard somewhere.

For six hours this went on. Even the darling young nurse looked desperate as she explained hospital policy.

Suddenly the frantic breathing just relaxed and he was gone... just like that!

It was two whole days later that I suddenly asked myself why I just didn't smother my brother with a pillow. To be honest I didn't think of it and was disgusted with myself. I would have... it would have been far more humane.

My brother was such a sweet man and should never have had to suffer such a dreadful death. He was so petrified that I can only believe that he must have had a premonition of what was to come.

I too am a coward who cannot stand pain and will help fight hard for voluntary euthanasia. I don't want my children to witness my suffering in agony, choosing rather a more dignified and pleasant end to life.

Sue Hayward

## **‘John, please kill me’**

**E**leven years ago, my mother had a stroke and took seven months to die. As her principal carer I divided my days into good days and bad days. A good day for me was when she said, ‘John, I want to die.’ A bad day was when she said, ‘John, please kill me.’ That was the only thing in her whole life that she had ever asked of me, and I didn’t love her enough to do it because of the legal consequences. Eventually she starved herself to death.

Now I live with the guilt: callous, cruel and selfish before God and my mother, but innocent before the law.

**John Acton**



## **‘Are you asking me to kill her?’**

**I** promise you, you will not suffer at the end.’ These words will resonate in my ears forever. After delivering a death sentence of motor neurone disease, these few supposedly comforting words, delivered by a neurologist, would become the only ray of light that we could focus on amidst a bleak, dark and devastating diagnosis. In hindsight we should have asked to have the word ‘suffering’ defined. There were a multitude of questions we could have asked and perhaps should have asked, but amidst the grief, shock and numbness, cognitive thought too is severely impacted.

As my mother’s MND progressed we were, on several other occasions, assured that her death would be comfortable and pain free. We placed our trust, and in fact our mother’s life, in a system which only now I can say failed her dismally.

As a retired nurse and having been passionate about end of life care issues for many years, I was only too aware of the contentious issues associated with this highly emotive topic. I can now only berate myself for not having objectively assessed Mum’s situation and asked, what I now reflect upon to be crucial questions. As it was my dear beautiful mum went to palliative care to die. Her and our intention and understanding was that she would be cared for right up until the moment of death. And up until a few days before her death I cannot emphasise how exemplary her care was. I will remember every nurse that so gently and respectfully tended to Mum.

Not for one moment did we envisage that her death would be peaceful and calm. MND is a hideous disease, but not for a second did we envisage the horrific, inhumane and tortuous death to which she would succumb.

As Mum became weaker and we were forced to acknowledge that she was actually dying we met with the palliative care team. An important issue I do wish to emphasise here is that upon admission to palliative care, Mum was no longer under the care of her two neurologists but the palliative care specialist. Yet again we were assured that Mum would not suffer in the end and that terminal sedation would provide her with the least amount of pain and discomfort. She would supposedly be given adequate sedation to prevent any pain or associated anxiety. She would not, we were told, experience any thirst or hunger as a result of the withdrawal of fluids and nutritional supplements. *I promise you, you will not suffer at the end.*

I cannot precisely remember every moment of Mum's last few days. Most probably this is a survival mechanism as what I can remember will be seared in my memory forever. Mum did suffer. She had pain, breakthrough pain, because her prescribed dose was unable to adequately palliate her pain at all times. She managed to express to us her fear and in one of her conscious moments was able to convey to us that she wanted to be fed through her PEG tube. This was so very traumatic for all of us, many staff included. However, orders were relayed to us by equally distressed staff that we should inform Mum that she was not to be fed. Why should we have been expected to inform our dying mother that we could not fulfil a dying wish? We were overwrought with distress and after a period of great torment a very upset staff member allowed us to give her a meagre amount of Milo-stained water. I found and still do find this abhorrent. We had been assured that Mum would be devoid of hunger and thirst, but no, the dying process is not a templated one and whilst her case may have been unusual it was nevertheless real and it was happening to my mother. All that could be done was to deceive

her in an attempt to pacify her. I felt like a traitor, a failure to my dear mother, having to deceive this person who had never uttered a dishonest word in her life and had spent her whole life looking after and caring for others.

Mum suffered what I deem to be unnecessarily for days. Family members requested that her analgesia be increased. A request I made pleading for her analgesia to be substantially increased even if it meant hastening her obviously imminent death was directly replied to by the question, 'Are you asking me to kill her?' No, I was not trying to have my mother murdered I simply wanted her tortuous pain and existential suffering to end.

“Mum’s death taught all who knew her that death can be something to be afraid of”

Her last few days will be etched in our minds forever. Falling victim to MND was the cruellest twist of nature but helplessly watching Mum suffer unnecessarily was unforgiveable. We are told that death can be peaceful and that we should not fear it but no-one, even staff members, could leave her bedside unscathed. We chose not to allow young grandchildren and close friends to see Mum in her final hours. Such a scene would have been too traumatic for them and we did not want them to see this beautiful, gentle and forever nurturing mother dying devoid of the dignity she should have been provided. This hideously prolonged death was visually ugly and this once beautiful, vibrant and radiant individual should not have been subjected to the haunting and unforgettable images that we were privy to. Images that I cannot

and do not want to share. Mum's death taught all who knew her that death can be something to fear and in fact be very much afraid of. Our last memories of her will be seared in our minds and etched into our memories forever. I do not think they will ever fade but hopefully we will learn to live alongside them and allow the wonderful memories of our beautiful mum to shine.

I am angry – extremely angry. We live in a city, in a country which we consider to be progressive, a world leader in many fields of science, technology and communication. Yet we are unable to provide for our terminally ill a compassionate, caring and humane way to die. Faced with imminent death, it should be a basic human right for a competent individual to decide the manner and timing of their death.

To end suffering when palliative care cannot is not an act of killing, it is an act of compassion and love and one that we should all aspire to. My beautiful mum did not deserve to die the way she did.

*I promise you, she did suffer at the end.*

Jane M

## **That last week was like a horror movie**

**A**t the age of 73, my mother, Dulcie May Turton, was told she had a neuroendocrine tumour in her abdomen and a life expectancy of two months if she elected not to have chemotherapy. She had suffered a lifetime of major illnesses, but given her history and the prognosis even with treatment, she decided the fight would be too hard, and she chose to die.

Not in my wildest dreams could I have imagined what lay ahead when she made that brave decision.

She was transferred to hospital two weeks prior to her death where she was given a blood transfusion, which was in contradiction to her express wishes that nothing be done to prolong her life. By this stage, the pain was becoming unbearable and she was drugged to the eyeballs all the time. I clearly remember walking into her room with her sitting up in bed pretending to be Tweety bird, saying ‘tweet tweet, tweet tweet’ and laughing hysterically. Her dignity was rapidly disappearing.

My beautiful mother lay in that bed, rotting in front of my eyes for an entire week. Once they stopped taking her obs and said she was nil by mouth, it meant that medications that she had been so heavily dependent on (and was addicted to) were no longer being administered. In my opinion, that sent her into a violent withdrawal and she spent a lot of time thrashing about the bed, crying out, doubling over in pain, showing nothing but horror and agony on her face like an addict withdrawing. She was starving to death and by this stage was skeletal, and her dehydration was obvious. Her mouth was caked with thrush and because she had suffered very severe respiratory illnesses in her

lifetime, the infected mucus was pooling on her chest, further preventing her from breathing.

I spent that whole entire week (day and night) by my mother's side, speaking on her behalf to try and get her more pain relief or a sip of water (until nil by mouth).

In the last couple of days as the infection on her chest took hold and her organs progressively shut down, she was gasping for breath the entire time. She continued to rot in that bed and I continued to sleep in the room with her and to sit beside her and listen to her every breath in...and every breath out...praying that

“My beautiful mother lay in that bed, rotting in front of my eyes”

it would be her last one. Finally, she sat bolt upright in bed and her eyes flashed wide open with a look of terror on her face, then she fell back on the pillow and took her last breath. The mucus that had been pooling on her chest began to ooze out of her mouth, putrid, green sludge that just kept coming and coming.

That last week of her life was like a horror movie. It was entirely obvious that death was unavoidable, yet nothing was done to move it along so she could be spared the futile pain, suffering and indignity that she went through. Her final days served absolutely no purpose to her or anyone else, and left me with a type of post-traumatic stress from having gone through it with her.

**Sandie Wands**

## A fate far worse than death

I am a 90-year-old EDA veteran affairs pensioner. I have recently arrived home from Prince of Wales Hospital in Sydney where I had open-heart surgery. I have several other failing parts and I am scared stiff that I may be confined indefinitely in a nursing home suffering from Alzheimer's, dementia, incontinence and the like.

I have just had a check-up from the cardiologist and he said to me, 'You know Bill, you were born in 1925, you are past your use-by date. Your heart has suffered a lot of damage so you must accept the fact that your end is nigh.'

It is my firm opinion that enforced prolonged life when quality of life is lost is a fate far worse than death. I fear degeneration far more than I fear death. It is inhumane to leave those who have lost quality of life, whether it be degeneration or terminal illness, confined in a nursing home indefinitely.

Times have changed. In my grandparents' day there were no nursing homes. My parents cared for them at home, the family doctor came every other week to check on them and issue scripts, and when they lost quality of life he asked for a family conference and was given permission to ease them out with analgesics. It was not called euthanasia but rather compassion.

My strong belief in the right for everyone to make a choice for euthanasia should they lose quality of life has been influenced by two family occurrences. The first was a heavy smoker with cancer of the throat who deteriorated quickly. I could hear him gasping for breath as I entered the main hospital entrance. He could not communicate, did not recognise anyone and was being fed intravenously. Fortunately I was able to persuade a sympathetic doctor to ease him out in a dignified manner.

The second was a mate who served with me in the Second World War. He had always expressed the wish not to be confined in a nursing home. The doctor put his arm around him one day in my presence and said to him, 'Don't you worry Tom, when the time comes I will ease you out.' This gave Tom great peace of mind, however the time came when he had to go into a nursing home and was given medication to stop him wandering at night, crying out and disturbing the other patients. He deteriorated quickly, became incontinent in bowels and bladder, was bedridden, unable to communicate and did not recognise anyone.

“ I could hear him gasping  
for breath as I entered the  
main hospital entrance ”

When I approached the doctor for help he said, 'Sorry, I cannot do anything for him now as all medication in a nursing home has to be documented.' Tom was allowed to lie in his bed in this state for 15 months. Surely you must agree that this is an extremely cruel fate to impose upon someone who had served his country with distinction.

Bill Alcock



## I am still haunted

I lost my mum three years ago at the age of 87. She was doing so well for her age but deteriorated fairly quickly. She went from living on her own, doing her own shopping and cooking her own meals to being unable to stand on her own in a short period of time. We had no choice but to put her in a nursing home. It turned out she was only in the nursing home for about six weeks but most days she rang and begged me to get her out of there and would tell anyone who would listen that she wanted to die.

My mum had heart failure and pulmonary fibrosis. She was admitted to hospital in a very distressed state and with breathing difficulties. She was probably about 4'9" and 38 kilos by this stage. Anyone who came into her hospital room – nurse, doctor, pink lady, dinner person – she would gently grab their wrist and say, 'Please let me die'. I turned up to the hospital one day and she was so distressed. I crawled into bed next to her and held her while she chanted forever, 'I'm so sick. What day is it today? I want to die today. Why can't I die today?'

She made it clear to everyone that she had had enough. I turned up later and she was in the bathroom with a nurse, sobbing. I could hear her saying, 'I'm sorry. You shouldn't have to clean me up. I should be allowed to die.' It broke my heart. My mum had always been beautifully groomed, always wore make-up, hair dyed and with her nails painted. You would take her shopping and people would come up to her and tell her how lovely she looked. To see her like this was soul destroying.

The only way I could honour her wishes was to sign a 'nil by mouth' form, which I did. Can anyone explain to me what the difference is between me signing a form consenting to my mum being given a needle that would peacefully end her life

surrounded by family who could say their final farewells and me signing a 'nil by mouth' form, which meant my mum had a very slow, seven-day death? They are both a death sentence, except one is humane and the other is cruel.

After a couple of days she lost her voice, which was so frustrating for her. She couldn't even lift her arms so she could only communicate by frowning and opening and closing her eyes. I had to watch her fingers and toes turn black. She died alone in the middle of the night.

I am still haunted by the memories of her chanting her wish to die.

Ann-Louise Kitto

“ I had to watch her fingers and toes turn black. She died alone in the middle of the night ”

## Her suffering defied belief

**M**y bestie, Rhoda, was the outgoing one of our group. She loved socialising. A fit, outgoing divorcee who had a wicked sense of humour and still had ‘an eye for the blokes’ at the local RSL dances and the seniors table tennis group.

When first diagnosed with motor neurone disease, her life expectancy was one year to 18 months. She did not realise the disease would become so debilitating in such a short space of time. She stoically dealt with her disease just as she had done throughout her life’s journey. At the time of diagnosis she was a classy, good-looking redhead, 72 years of age...In saying that she could have passed herself off as being many years junior to that age and often did!!!

“ The last week of  
her life was a horror  
I will never forget ”

The disease was aggressive and gathered speed at a great pace. First bodily function to shut down was her swallowing. She could only eat puréed food and then thickened drink, progressing to not being able to swallow at all. A PEG tube was then inserted directly into her stomach to give her sustenance and keep her alive. Her speech was badly affected, her frustration intense. She said she felt sorry for people trying to understand her! A computerised keyboard, voice synthesiser was a blessing to her, to be able to communicate rather than painstakingly writing everything down.

The last month of her life she spent in a very nice, very expensive nursing home, surrounded by the very elderly. The care was excellent. She was grateful she had some savings which could allow her to have this care. Many do not. She was being kept alive by the PEG feeding directly into her stomach. Her quality of life was *nil*. She was fully alert and conscious but trapped in the prison of a non-functioning body. The last week of her life was a horror I will never forget.

My dear friend's eyes were full of fear and terror. We requested more morphine for her, and the nursing staff agreed she needed it but by the time permission was given by the palliative care doctor hours would pass. *She did not seem to get enough to calm her.* The fact she was fully conscious and aware was the worst. Her suffering defied belief.

As her friend, I felt so very inadequate that I could not do something, anything, to take away the terror in her blue eyes that still sparkled, beseechingly begging for help. She was a spiritual and quite religious being, who believed in the hereafter. She deserved a peaceful passing. The horror in her eyes in those last days will always be with me.

Annie Sobey

## Like a Stephen King novel

Let me begin my partner's story by stressing that the nursing staff were dedicated and kind. They do all that they can within the confines of their delegations.

My partner had stage 4 cancer and had many medical issues including a broken hip that was causing her much pain. She was rushed to the hospital on Easter Sunday with a high temperature. From then until Wednesday several specialist teams were working on a plan to improve her quality of life for whatever time she had left. This involved a series of CT scans, which were very painful for her. From Tuesday, 29 March to Thursday, 31 March we told the doctors that she was acting very strange, forgetting things and sleeping with her eyes open. They put it down to the pain medication and her various infections. On the last scan where she was making sense a clerical error meant that she did not receive her pain medication before the scan. The last thing she said to me with tearful wide blue eyes was, 'I'm scared'. I will never be able to get over that.

It turned out that all the scans and all the pain were in vain since a later brain scan revealed that she had suffered a massive stroke (probably starting Easter Sunday) and on the morning of Friday, 1 April I was told that it was too late to do anything about the stroke and that 'she is dying'. I and other family members were told that there was little chance of saving her and that surgery would likely be fatal. I begged them to perform the surgery since if she died on the operating table under general anaesthetic it would be a peaceful death. But they refused stating that they could 'do no harm'. They said they would keep her comfortable and she would probably be gone in 12 to 24 hours.

I had no idea what palliative care involved. They remove

anything that would help her stay alive, including saline drips and antibiotics. One staff member told me that she will virtually die of thirst and that it can take several days or even weeks. She was given a steady infusion of morphine, a sedative a few times a day and a drug to help dry out her throat.

### **Days One to Four**

For the first few days she was constantly gurgling and coughing in an attempt to clear her throat. She appeared terrified. After much complaining on my part they finally included the sedative in her continuous feed and allowed 'breakthrough' sedation and pain medication once per hour instead of a longer period earlier. It was horrible to watch her with her face scrunched up in pain and trying to breathe through liquid and desperately trying to cough – but she was just too weak. I begged too much for her to be euthanised to the point where the palliative 'care' nurse suggested that other family members should request breakthrough medication since the nurses did not trust my judgement and thought that I might 'do her harm' with a morphine overdose. The complete lack of any logic is in itself unbelievable.

### **Day Five**

Still groaning and trying to cough, sometimes almost screaming. I asked the palliative 'care' nurse who was very sympathetic and doing what she could to stay and watch my partner. After a few minutes she went and spoke with the palliative 'care' senior doctor. They tripled her dosage of sedation and pain medication – too little too late. I was told by the nursing staff in an attempt to be kind but in actual fact was horrific that 'hearing is the last thing to go' and 'she will recognise your voice'. At the same time being urged to go home and get some sleep. I told my family and

the nursing staff that I would not leave her side. ‘I’m not leaving my wingman,’ I said.

She seemed to recognise me when I came in after a breakfast break. She started moaning and I stroked her head and spoke to her trying not to cry. I started reading to her from her beloved Kindle and she seemed to sleep.

“ At last the poor thing  
had some peace – after  
seven days of unnecessary  
and unbelievable cruelty ”

### **Day Six**

She was getting weaker and sometimes just couldn’t get a breath. Fighting for life not knowing she had no chance – so incredibly cruel. She fought the whole day. At about midnight when I asked for more relief to stop her needing to cough up the liquid, I was told ‘we can only give that three times a day and she had some an hour ago’. My god! Were they afraid it might make her sick? I felt I was living in a Stephen King horror novel.

### **Day Seven**

She finally got so weak that she stopped trying to cough and just breathed more and more shallowly. I was alone with her with my head on her pillow holding her hand when I noticed the breathing had stopped. At last the poor thing had some peace – after seven days of unnecessary and unbelievable cruelty.

John Paynter

## As I write this I'm crying

**M**y mum, Gloria Mable Ohma, was diagnosed with multiple sclerosis (MS) in her late 30s. Mum went through a gradual decline coupled with acute episodes for 50 years as she lived with this disease.

Mum maintained a great attitude despite ongoing hardship and gained simple pleasures such as sitting in her wheelchair on our back verandah with the sun shining down on her as she watched a rabbit hopping around in our paddocks. I saw Mum beam when our bougainvillea was covered in a flush of purple flowers and at many other simple things. Mum was intelligent, accepting of her situation and never bitter.

Mum got to the stage of accepting the 'indignities' as she called them. She was unable to toilet herself adequately and got uncomfortable when her pad/pants and her bedding or seat became urine soaked. It became part of her life but it was a life she wanted to terminate as further decline was inevitable.

Mum lost control of her life at 80 when she fractured her spine and needed hospitalisation. At 83 Mum was broken and mental torment now kicked in big-time. The physical decline of MS, severe depression and the hopelessness of her own situation changed her and crushed her soul. Mum would ring me (with the help of the nursing home staff) or sometimes the staff would ring me directly. Mum would be terrified and in a tortured mental state. She was suffering horrendous delusions such as being locked in a concrete-floored shed and left there to starve, she was cold and frightened. This may have been a delusion but her mental state was very real; Mum was absolutely terrified and in severe mental distress. She would tell me to come and get her and told me that she would bang really hard on the corrugated-iron



walls so that I could find her. She was mentally tortured by these delusions and in absolute distress.

What made my mum lose her mind? This might be conjecture but I think Mum's situation sent her mad. She was in constant physical pain and mental anguish, on heavy medication and had no control over her predicament.

Mum was mentally and physically tortured by this time. In constant pain and discomfort, control over any part of her life had eroded and was almost non-existent. As I write this I'm crying, my feelings of inadequacy are still overwhelming. It's 18 months since Mum passed away and I wonder if this feeling will ever leave me. I looked after Mum all my adult life, I was 50 when she died and we were very close. My mental torture at seeing Mum's decline, knowing she wanted to pass peacefully and my inability to help will never stop tormenting me.

Jo Sorensen

“My mental torture at seeing Mum's decline, knowing she wanted to pass peacefully... will never stop tormenting me”

## My father asked me whether he could end his life

My father was 59 years old when he first experienced symptoms of what would later be diagnosed as motor neurone disease, a disease that cripples the body and leaves intelligence and understanding untouched. Over a space of six years he gradually lost the use of his fingers, hands, arms and legs. He lost his power to speak and to swallow food. He had to be toileted, usually by his wife who nursed him for the full duration of his illness. He dribbled and so, as an intelligent civil engineer he spent his long, long days in one chair by a window with a large bib on.

As his speech became difficult to understand and then non-existent he would communicate using an E-Tran board. This is a transparent plastic frame printed with colour-coded letters of the alphabet. He communicated with us by indicating a colour and then a segment of the board. We could then write down the letter he was referring to and gradually piece together words and short sentences. When my father could no longer eat food he elected to have a feeding tube inserted into his stomach. This enabled PEG feeding and it is how he consumed his food and drink.

Approximately five years into his disease, my father asked me, via the E-Tran board, whether he could end his life. I researched the law and was able to tell him about the 2003 Victorian Supreme Court case of *Gardner: re BWV*. The Court proceedings were initiated to obtain a ruling on whether artificial nutrition and hydration delivered through a PEG tube was regarded as ‘medical treatment’ or ‘palliative care’.

Under the *Medical Treatment Act 1988*, ‘medical treatment’ may be refused but ‘palliative care’ may not. The definition of

‘palliative care’ in the Act includes ‘the reasonable provision of food and water’. The Court decided that PEG tube feeding was a ‘medical treatment’ and so can be refused by a guardian or an agent authorised to make medical treatment decisions on behalf of a person unable to make their own decision. Because my father was PEG fed he had the option to cease that treatment. However, this meant he would die of starvation and dehydration.

My father delayed further steps for the time being. However, approximately six months later he asked me to contact his palliative care doctor to discuss his options. My father had had intermittent contact with the palliative care doctor for approximately two years. This was usually when my father went into the palliative care hospice for occasional two-week stays to give my mother respite from the demands of 24/7 care. This pre-existing relationship with the palliative care doctor meant that they had met when my dad could still communicate verbally to some extent and they got to know and trust one another.

I spoke by telephone to the palliative care doctor and organised for Dad and he to meet and discuss his feelings. The doctor called at our home and spoke to my father. I understand my father indicated to the doctor that he wanted to cease PEG feeding.

The palliative care doctor then organised a family conference at our family home. My father, mother, brother, the doctor and myself attended. During this meeting, my father and the rest of the family talked about what he wanted to do. This discussion was facilitated by the doctor. Everyone was able to talk openly – Dad via his E-Tran board.

Needless to say it was a harrowing discussion but it was respectful and ordered, and allowed the views of everyone to be heard and considered. The decision-making remained my

father's. He knew that the muscles in his eyes were weakening and once he could no longer keep his eyes open and indicate letters on the E-Tran board, he would have no effective way to communicate his wishes.

The discussion ended with the views of all family members being known – albeit not necessarily accepted. My mother desperately wanted my father to reconsider his decision to cease PEG feeding. The palliative care doctor suggested that if and when my father was ready to act on his plans to contact him.

I believe the decision-making process available to my father was very good. I was able to get him information about the law when he sought it. He had a pre-existing relationship with a doctor who knew him and his disease. He had access to this doctor when he needed further information about his end of life choices.

Discussion of those choices took place in an open and transparent way. The discussion was facilitated so that the views of all the family were heard in a calm albeit emotional atmosphere. It was always very clear that the decision was my father's to make. There was no hurry to resolve the issue – it was up to my father to take each step, if and when he wanted to.

Sadly, the compassionate and considered decision-making about my father's end of life choices was followed with the cruel reality of his death. Because my father had PEG feeding (medical treatment), he had options to end his life that would not be available to other people who were still feeding via mouth (palliative care). However, while the law respected his right to decide to end his life, it gave him no help to do it and insisted that he must die slowly of starvation and dehydration.

Dying this way can take days or even a fortnight, so my father needed access to reliable palliative care to relieve his suffering.

Accordingly he asked to be admitted to the local palliative care hospice where he knew he would have quick access to pain relief if he needed it. He did not want to risk being without necessary pain relief at home. I suspected he also felt that his family would also need the support of the hospital staff rather than watching him die slowly at home.

A day in the following week, the family conference was set for his admission and he (and we) counted down his days left at home. His final morning at home was heartbreaking. My mother dressed him and he thanked her (using the E-Tran board to dictate the message to me) for their happy marriage and for caring for him.

He then asked to see, for the last time, the garden that he had planted. He sat for a long time in his wheelchair on the front veranda, with my mum, and just looked at the garden until the disabled taxi arrived and he left his home forever.

While the staff at the hospice were kind and considerate, there was no escaping the necessary steps of dying in this way. Mucus solidified in the back of his throat and needed to be regularly prised out with cotton buds, causing him to gag. His mouth was dry and could only be swabbed with water. Nurses, unfamiliar with his routines, tried to turn and bathe him and struggled to get him comfortable. He was eventually sedated when muscle cramps were so overwhelming and painful for him. I hope the sedation was effective in managing that pain. He died after 12 days.

I cannot help thinking how much better my father's death could have been. A thoughtful and respectful decision-making process allowed him to choose to die. Sadly, he was not then offered a humane option to implement his decision, such as a lethal injection or medication.

“ It would also have spared him the grief of leaving his home and neighbourhood to die slowly in a hospital a few kilometres away with strangers ”

Such an option would have spared him the physical distress of dying over 12 days from lack of food and water, his only choice under current law. It would also have spared him the grief of saying goodbye and leaving his home, garden and neighbourhood to die slowly in a hospital a few kilometres away with strangers tending him and his family watching his slow demise.

Those who argue against euthanasia rightly highlight the importance of each person being truly free to make their own decision about their end of life. I feel that my dad's decision-making process had good checks and balances and that his decision was sound and based on a process with integrity. It demonstrated to me that such decision-making can be made carefully and ethically to protect the rights of the terminally ill.

Anne Woodger

## We all let her down

**M**y mother, Jan Scott Ryder, was a beautiful woman who adored her family and loved her life.

In May 2012, aged 77, Mum was diagnosed with terminal brain cancer. Initially she spent three weeks in hospital and, with each visit from her doctors, the news got progressively worse. Mum had an aggressive form of glioblastoma multiforme, and with multiple tumours they could not operate or do radiation therapy for fear of causing severe brain damage. Before leaving hospital Mum asked her neurologist, if he would 'look after her in the end' and give her something 'before it gets ugly'. Of course, he could not make that promise and, in fact, she never saw him again as she was then referred to a community palliative care team.

Mum did not want to enter a hospice and we were happy, and able, to care for her at home, but Mum always had the expectation that her doctors would not let her suffer in the end and that she would have a peaceful death. This is not what happened.

Like many people with a terminal illness, Mum's quality of life deteriorated quickly; however, in the beginning she still managed to get some pleasure in life, even though she rarely left home.

As the months passed Mum lost her ability to walk, she lost words and struggled to communicate, she was unable to write, unable to read, unable to talk on the phone and, towards the end, even listening to the radio or watching TV caused great discomfort. She was sleeping more and more each day and she had headaches and constant nausea. But even when Mum was bedridden and it took two people to carry her to the toilet, and she couldn't even wipe herself, she still wanted to live.

Each day her condition worsened. We did everything we could to try to keep her comfortable. Every day I would rub her legs and feet because she said it felt like they were already dead. The anti-nausea medication did little to ease her discomfort and as Mum's right side became more and more affected she could not even lie in bed peacefully. She was agitated and distressed.

Mum started to ask for some form of medication that would just knock her out but nothing the doctors prescribed achieved a peaceful state. She had had enough. She kept asking, 'Why are they doing this to me?' 'Why are they torturing me?'

“ She kept asking, 'Why  
are they doing this to me?  
Why are they torturing me?' ”

By 14 November Mum no longer wanted to eat and each day she asked, 'When will it end?' 'Just give me something to end it', but I couldn't. I was so afraid. I knew the end was near but it was so hard to see my beautiful mum suffer like this. I know if Mum had been able to end her own life at that point she would have but by that stage she was like a rag doll. I felt like I had failed my mum because I had promised her I would be with her to the end and that I would not let her suffer. But that was not possible.

The next day Mum was taken to a private hospital. I am not sure if she even knew what was happening, she couldn't speak, she just stared. Fortunately the hospital staff allowed us to stay with Mum and we were so grateful for that but we still couldn't stop a traumatic end.



Right at the beginning of Mum's illness she had suffered two seizures. The first had led to her diagnosis and the second happened just days after she was originally discharged from hospital. Mum's greatest fear throughout her illness was that she would suffer another seizure. She had described it as like having a giant slamming back and forth inside your body but fortunately changes to her medication prevented this. That is, until the end.

By the time she was admitted to hospital Mum could no longer swallow, so she was unable to take the anti-seizure medication. On that first night my worst nightmare came true and Mum suffered another seizure. It took nearly an hour and a half to get the seizure under control because the nurses were only authorised to give small doses of medication, 15 minutes apart. Why weren't we given the chance to make Mum's passing a peaceful end?

I won't describe all the other things that Mum had to endure over the next four days but I want to point out that under the current law, medical practitioners can only treat symptoms as they occur. That means a terminally ill patient, like Mum, has to suffer, whether it be nausea, pain, or other symptoms. Nothing is given in doses high enough to prevent suffering, all for the fear of giving too much and perhaps hastening the death.


How can we say we live in a humane society? Nothing could have prevented my mother's death but doctors could have given her a peaceful end, if only it was legal. Through all that Mum had been through it was only in the last few weeks that she pleaded for someone to end her suffering. We all let her down and that is a burden I will carry for the rest of my life.

Shayne Higson



# **Desperate measures**

## Dad's note

ur father/husband, Kenneth Stanley Dickson, aged 81, was suffering terribly with his third bout of cancer. Fifteen months ago Dad was diagnosed with terminal oesophageal cancer and wasn't expected to live three months, but instead he suffered another 12 months. This cancer is a slow and painful death sentence. Although Dad was on a lot of medication there were days when it just wasn't enough and the side effects of the medications were unbearable. Dad got down to a weight of just 45 kilos. Dad was a true gentleman, loved and respected by everyone who knew him. It hurt Dad's dignity and pride that his daughters and wife had to shower him and change his soiled pants, but we would do it all again for him tomorrow.

Our beautiful Dad took his own life on Friday, 9 October 2015 at the home he shared with Mum and Down syndrome son, Jason. Dad left behind a note expressing his desperation to the end. All he wanted was for someone to help end his suffering so that he could die in peace with dignity which is what he deserved. If an animal is suffering to this extent you would 'put them down'. Surely we can do this for our terminally ill loved ones. Dad would want us to follow up on his note and keep the euthanasia debate going until hopefully one day it will be legalised so that people who have suffered, and will continue to suffer with a terminal illness in the future, can leave this life with the dignity that they also deserve.

“ Sorry, I have no alternative  
but to go this way ”

Things To Do

Dear Joan

Sorry to go  
this way but until  
the Govt don't pass  
the law + find a  
better way to help  
with the side effects  
on the front

manage the effects  
of the side effects  
that go with it  
Sorry I have

no alternative  
but to go this way  
Love

Ken

Fight Cancer Foundation

Give Love. Saving Lives.

www.fightcancer.org.au



Dad was a devoted and dedicated Christian. Towards the end he became a strong supporter for euthanasia to be legalised in Australia. It was tearing Dad apart to watch his family trying to keep him as comfortable as possible. He didn't want to be a burden. That was the kind of man he was.

What Dad went through, especially in the end, was horrific. He made the heartbreaking decision to take his own life, hanging himself in the backyard. Jason, who has Down syndrome, was the one to find Dad and that made the situation even worse, if that was possible. Jason is still saying that Dad is coming home soon, he just doesn't understand.

We all realise that there would need to be very strict guidelines if euthanasia was to be legalised in Australia, but surely people who have a terminal illness with no chance of a cure and suffering like our dad did would fit into this category. Euthanasia is legal in Belgium, Netherlands and parts of the USA – why not in Australia!!

Joan, Julie, Mark, Jo, Christine, Bradley and Jason

## **It turns out goodbyes are important**

I wrote this account of my husband, Wayne, a year after he took his own life. I wrote it mainly for our grandchildren to read when they are older to understand why their Gramps would do such a thing. I'm hoping that by the time they are old enough to read it that it won't be considered 'such a thing'.

At the age of 65 Wayne was diagnosed with progressive supranuclear palsy (PSP). Three years later, he took his own life. He obtained with great difficulty the 'peaceful pill' – Nembutal.

PSP is an insidious brain disease slightly affecting the mind but particularly affecting the ability over around three to eight years to walk, talk, write, eat and see properly – those with it often die from choking. There is no cure. Wayne was a very active person, doing triathlons, the Ironman, marathons, and went annually on bicycling, motorbike and heli-skiing holidays. All those things came to a halt as the PSP progressed slowly but steadily. Eventually he could only walk outside with me holding on to him.

Three years into the disease, Wayne told me he would eventually have to take his own life. I completely understood. Wayne didn't believe in God. I am a practicing Catholic and although it went against everything I'd ever been taught, I felt he would be doing the right thing for him. We both knew he would have to do it completely on his own. I decided not to tell anyone – not even our son and daughter.

I told him he would have to tell me when as I would be terrified every time I came back into our apartment that I would find him dead. He said of course he wouldn't do that as it would spoil our home for me and I would afterwards have to leave.

He said we'd go to a hotel in the city on a Saturday, and on the Sunday morning he would do it while I was at Mass nearby. He said when I came back and found him I should phone our doctor and he would come and sign the death certificate and that would be that.

The dreaded weekend arrived. I was on autopilot as I got ready to go to Mass. We were relatively calm as we hugged and said goodbye. I knew this was not the time to lose it. I had a knot in my stomach and felt sick but I was calm as I walked to the church and sat through Mass. Then it was time to go back to the hotel. I'd thought about this walk during many sleepless nights for months – here I was doing it. I felt sick but calm as I walked back towards the hotel. When I was almost there I started to shake and cry.

“ I believe profoundly  
that Wayne did the right  
thing – for himself and for  
all of us who loved him ”

I'll never forget that walk from the lift to our room. I opened the door and saw Wayne lying flat on his back with his eyes open. I hadn't imagined he'd have his eyes open. I could feel myself falling to pieces as I phoned Reception and asked for someone to come as my husband was dead. They came and soon after two ambulance men arrived. By that time I was in deep shock. One of them tried for about 20 minutes to calm me down. I was taken to another room nearby where there was a young policeman. Our room had become a 'crime scene'.

If Wayne was alive today he would be in a terrible state. He would no doubt be in a wheelchair, unable to speak or see properly, and being fed through a tube. Just waiting for a long, lingering death.

If voluntary euthanasia had been legal, Wayne would not have had to take his life so early and we would have had him a little longer. Our family and his close friends would have been able to know what he was intending and to say goodbye. They had all understood and it turns out goodbyes are important. My children and I would have been able to be with him and comfort him in his last moments. It would have been hard, but not as terrible as having to leave him to do it on his own.

I believe profoundly that Wayne did the right thing – for himself and for all of us who loved him. As a practicing Catholic, it took me some time to decide whether I should go against my religion and ‘advocate’ euthanasia, but after much soul searching I believe it is my right to be in favour of it. I also believe that God is a kind God, and that he understands.

Ronda McCarthy



## We love you whatever

Three years, eight months and 28 days ago, I was left a letter from my mother's best friend, who had always been a big part of both of our lives. This was the last letter I would receive from Jo.

Johanna MacDonald was always one of my mother's closest friends. My memory of Johanna is that she had been there ever since I can remember. I remember Jo having the biggest blue eyes and the wildest blonde hair. She was always a part of our family; she was a very vivacious, bubbly and loving person. Jo had always had a passion for fitness.

About five years before her suicide, my mum and Jo's other friends started to notice she was having difficulties with memory loss, balance and choking on her food. These symptoms began to progress and worsen and she was eventually diagnosed with a rare and incurable disease: progressive supranuclear palsy.

The disease got so bad that Johanna was forced to end her life by suicide, as she had no control over her bowel movements, balance and she would often choke on her food. A month before this, she had attempted to end her life but was unsuccessful and that attempt caused her even greater discomfort.

Had Jo been able to access medical assistance in order to end her life, she would have endured a far less painful death and died with some dignity. In the letter that Jo wrote to me, she urged me to be a lovely person and to cherish my talents, remembering that not everybody can win. Her words, 'We love you whatever – win or lose', have encouraged me to be the type of person who will give things a go, even with the risk of not coming out of it on top.

Lilly Van Lent, 14 years old

## He'd said, 'life is hell'

**M**y grandfather was a proud and passionate man who really lived up to his role as the patriarch in our family. In his younger years he'd run marathons for charity, and once he set off with his dog to run the length of the North Island of New Zealand to raise funds for a needy cause.

In his later years he did everything he could do to stay fit and active – you'd often find him out playing bowls, having a game of pool, or up early in the morning swimming lengths. He loved his garden and was forever out pruning his roses and feeding the birds on his lawn. He was wise and loving, he had stories to tell and lessons to teach.

My grandfather was also a big advocate for assisted dying. He himself followed cases, attended various court hearings and got involved in supporting people's personal campaigns for medical support. He always made it clear that he thought there was a great need for change to the law to allow medical practitioners to be able to provide support, and if need be medication, to help people who were suffering to die a good death.

My grandfather was diagnosed with cancer during his 70s, and while he fought it off for a few years, he was eventually given a diagnosis of terminal cancer. So, as the cancer took its usual toll of damage and destruction, his life became increasingly unbearable. He was in incredible pain, had become incontinent, lost his appetite and could often barely eat. He was unable to do any of the things that he loved and valued in life and began struggling to stay awake or hold a conversation for any great length of time.

He documented his failing health – 'very hard to get up, hard to swallow, breathlessness, weak'. And later his wife would

share with the police investigating that matter that he'd said 'life is hell', 'this isn't living' and he was in total despair due to his increasing state of infirmity.

One Friday night, when he could take it no more, he ended his life. We didn't know his plans, nobody did. Yet no-one was particularly surprised by it either.

One of his sons was a GP, and as such my grandfather had to be very careful not to implicate him in any of his actions. He decided not to stockpile any medication of any sort, or try and get hold of a barbiturate that might potentially implicate his son.

So instead he was left with a much more horrific means of dying if he was to do so at a time and way of his own choosing: he cut an artery in his leg with a serrated kitchen knife. He did it on a Friday evening so no-one would be interrupted from work the next day. He did it quietly, he did it totally alone, in his room with his foot in a bucket and a black plastic rubbish bag wrapped around it so as not to make a mess. And as he cut deep into an artery, and his life slowly bled out of him, I dread to consider the thoughts that ran through his head, the loneliness he must have felt, the emotions – perhaps of relief, perhaps of panic, perhaps of fear, undoubtedly of pain.

His wife found him the next morning; she'd been asleep in the room next door. He'd left a note: 'I love you all more than words can say, look after one another'.

“As he cut deep into an artery  
I dread to consider the thoughts  
that ran through his head”

As a family we all feel incredibly frustrated that the current law dictated that he couldn't have had the support he needed to do this in a different way. And even more so, frustrated by the fact that a law meant he didn't have his loved ones by his side and showing all the love and support we feel for him in his final moments.

We are happy he found a release from his pain and suffering. What frustrates us is that he had to be secretive, do this by himself and in such a way as he did.

**Jess Cushing**

# **Five cases of suicide presented to the Victorian Inquiry into End of Life Choices by Coroner John Olle**

## **Case 1**

The first individual is a 59-year-old man. He had a wife of 38 years, survived by his children and his wife, with whom he shared close and loving relationships. He had no mental health documented, a medical history of metastatic colorectal carcinoma, multiple confirmed colorectal and liver metastases. About two years before his death he underwent a liver resection for confirmed liver metastases and was subsequently treated with chemotherapy. He underwent 22 cycles of treatment, and unfortunately a CT scan performed not long before his death showed evidence of progressive disease with a new liver lesion, which resulted in the cessation of his trial treatment. His GP informed the court that the cancer had now spread to his liver and his prognosis was not good.

He was admitted to hospital with a fever, dry cough, ultimately he wished to go home. He would inform his son and family members he would rather take his life than live a life dying in a bed. He was well aware of his suffering and what was ahead of him. So he would rather die than stay in a ward. Ultimately he was observed by a motorist on a major freeway in Victoria hanging from a bridge. A note indicated his intention to take his own life.

## **Case 2**

Another case I have seen was an 82-year-old lady. She lived on her own and was survived by her children, again with whom she shared a loving lifelong relationship.

Her documented medical history: hypertension, insomnia, arthritis, gastro-oesophageal reflux disease, gout and on and on and on it goes. She was feeling very poorly about it and depressed about her lot. Her vision was nearly gone. Her love of reading books, her quality of life was greatly diminished. She was described by her doctor as lonely, isolated, frustrated, impatient. Her daughter was informed by a neighbour who had told her she could not read anymore. It was the most important part of her life. She also informed her on a number of occasions she wanted to die.

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

## **Case 3**

Another, 89-year-old. Again, a man. He lived with his wife of 61 years and enjoyed a long and loving relationship with his family. He had a very lengthy medical history – no hint of mental illness. His son stated his dad's lucidity, memory and eyesight were failing. He could not listen to music, watch TV or read, which he was known to enjoy. He ended up alone, grinding

various tablets with either a mortar and pestle or food processor and died of drug toxicity.

#### **Case 4**

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

#### **Case 5**

Finally, a 90-year-old man, survived by his family, again with whom he shared close, loving relationships. He was described as a delightful gentleman. He was extremely fit for his age and a proficient iPad user. He had no documented mental health history.

A very lengthy history included back pain, chronic obstructive pulmonary disease, asbestos exposure and the like. Not long before his death he was diagnosed with a solitary brain metastasis in a setting of metastatic melanoma. He expressed his wishes very clearly to his treating clinicians; he did not wish to have any invasive procedure done. His main priority was quality of life.

In the final four weeks of his life, his doctor explained, he remained frail. He had lost approximately 6 kilograms in

the previous four weeks. He had a poor appetite. He looked malnourished and had nausea. His family stated that from about mid-December 2014 his wellbeing deteriorated. He felt generally unwell. He was dehydrated and had diarrhoea. He was vomiting uncontrollably. He had fevers. He was wobbly on his feet, even with the assistance of walking aids. He was diagnosed with likely viral gastroenteritis and was commenced on IV fluids for rehydration therapy. He improved as a result of the rehydration therapy markedly and was discharged home to the care of his grandson in January this year.

The family explained that when he learnt of his cancer he went downhill emotionally. He was depressed and angry that there was no cure. He often told his family he would rather do something to end it straightaway and that if he could no longer drive, he might as well be dead. He mentioned a nail gun. He was subsequently found dying with nail gun wounds to his head and to his chest. He died ultimately from the injuries sustained from the nail gun.



## I gave him the greatest gift I could

Ten years ago, my partner died by his own hand in the best possible circumstances. He had suffered prostate cancer that had progressed to the spine and he was in danger of suffering a broken or damaged spine which would prevent him from being in control of his end. He did not wish for any further treatment.

I was complicit in the arrangements and was proud to help him in his plight. We planned our last times together and a final celebratory dinner. Everything went according to plan. We were both brave – it was extremely difficult, but we did it. I think I gave him the greatest gift I could by my understanding and support and his immense gratitude to me helped me through the abyss of grief.

I wrote intensively after the death – much of what we did was ‘illegal’, but we walked our own path. The key point was *he* did what he wanted and *we* did it in complete agreement. We were beholden to no-one. And *it was right*.

Catherine Bainbridge

One of many poems which sums up the last days...

## **Anniversary**

Walking those same May steps.

Leaves colour  
pomegranates split  
seeds glisten and tumble.

He turns grey  
the pain increases  
I stiffen, bracing.

Reprieve, briefly, he smiles  
the sun is out  
We laugh, it's a miraculous escape.

Jagged pain once more  
and he declares the end.

No dispute  
my love is acceptance, respect,  
admiration.

And then  
each to our own inevitable abyss.

## I was traumatised for 10 years

Father loved to do practical things and that included building houses. At the time, fibro was a popular choice for internal and external wall covering. Unfortunately its side effect was asbestosis. My father's lungs were shot to pieces and when he reached the age of 72, fluid built up in those lungs and he was in excruciating pain. I took him to have blood tests and X-rays and finally the doctor said to take the X-rays to Westmead Hospital to have them read. My father had had enough. He was terrified of dying like a lot of his friends and on this night he decided to take his own life. He used a shotgun to his right temple. It did not kill him immediately; his brain was shot to pieces as the bullet ricocheted within his skull. The events that followed were harrowing; ringing the ambulance, the intensive care ambulance, and the police as a gun had been discharged, and all the events that had to follow. He was taken to Westmead and was given medication, oxygen and tube feeding. Then they wanted to perform a tracheotomy on him. I was appalled...I said he wanted to go, just let him go. But no, that wasn't what they wanted to do. I checked for myself to see how his wishes should be carried out. I found out that I could have his medication stopped.

I told the registrar that was what I wanted. He said, 'What more would you like...cut the oxygen and the food?' I said no, just the medication. He came back later and said he checked and that it was within my rights to refuse medication.

It took a week for my father to eventually pass away; at least he was finally at peace. I was traumatised for the next 10 years over all this, but now I can at least tell this story. Voluntary euthanasia would have been the answer.

Coralie Richmond

## He was helpless and he hated it

**T**his is the story of my brave, sensitive and loving father. Russell Alfred Walker was born in Parramatta to a working-class family. He was one of five children. During his young life he was hospitalised for long periods with asthma. Frequently debilitated by the illness, doctors told his parents that he would be lucky to see his teens. But he did.

My grandmother used to sit next to Dad during his hospital stays, telling him to breathe. She also told him that he could do anything he wanted, if he really put his mind to it. Dad survived, and took Grandma's message to heart. He was determined to overcome the obstacles that had been placed before him. He was told he would never be able to play sport because of his asthma, so, stubbornly, Dad ended up playing football and squash. He also became a keen surfer and swimmer.

Dad married at age 21, and had two daughters and a son. In February 2008 my daughter Ruby was born, and she was 'Poppy's Little Princess'. Sadly, it was in the same year that Dad was diagnosed with Parkinson's disease. He had noticed little things – for instance, it became difficult to comb his hair and to clean his teeth. When he walked he didn't swing his right arm. When he was finally diagnosed, Dad was devastated.

He enrolled in a six-week Catholic adult education seminar, and seemed to get some comfort from this. Always a fighter, Dad was motivated to keep pushing himself physically and mentally. As other medical problems emerged, he rose to the challenge. In May 2014, he had a knee replacement, which gave him more mobility and made him feel much better. However, soon afterwards he contracted influenza type A. This completely debilitated him and he was unable to do even the smallest task.

Once again determined to recover, Dad did everything he could to find an answer. He went to more doctors and lung specialists, had PET scans, MRIs and numerous blood tests. He completed a rehabilitation program for Parkinson's disease patients at Calvary Hospital, and changed his medication (which unfortunately made him vomit and created a metallic taste in his mouth).

Everything my dad loved to do – surfing, swimming, cooking, walking his granddaughter to school – had been taken away from him. He became totally debilitated, unable to do more than sit in a chair, for days and weeks at a time. Dad always had a fighting spirit, and was determined to overcome any obstacles that came his way, but now he was defeated. Once a very proud, energetic and brave man, he was now totally helpless and he hated it.

On Sunday 12 April 2015, my beautiful generous father hung himself in his bathroom. He was only 73 years old. Our hearts are broken and our lives will never be the same.

It's bad enough that my dad had a progressive neurological illness and a range of other medical complications. Much worse than that was the terrible way that he ended his life. Previously I have never thought much about euthanasia, but I now strongly believe that everyone should have the choice to die with dignity when they are hopelessly ill and suffering. I hope that one day there will be a change in the law so that other people will not have to go through what Dad went through. No-one should have to end their lives violently and alone when they are hopelessly ill.

Tracey Walker

“Everything my dad loved to do  
had been taken away from him”

## **My father shot himself through the heart**

**W**e always knew it would happen. Our father said many times that they treat animals humanely and put them down when there is no hope. He made it clear that this is what he believed should be the choice of human beings, to the point that if necessary he would take his own life.

And he did. On 14 June 1994, our father shot himself in the heart with a rifle. He was in the bedroom; our mother was in the kitchen no more than 5 metres away, my 12-year-old nephew in the lounge.

Dad was diagnosed with inoperable prostate cancer at the age of 54 with a 10 to 15 year prognosis. He had always been so healthy and active, and in his words: 'I've always been able to fix anything, but I can't fix this.'

And so began his long battle with an exploratory operation that ended in a careless removal of the catheter that left him 'leaking' constantly, but he didn't give up due to that little hurdle. He devised his own special 'nappy' so that he could continue to play his beloved golf. I don't think they had Tenas then!

I can't remember the exact point when he started to decline but I do remember distinctly his last couple of months. He had been admitted to the palliative care ward of our local private hospital and was cared for so wonderfully by the nursing staff. At the beginning, he would entertain other patients, and us when we came to visit, by playing the piano (totally self-taught and unable to read music). But he was being given painkilling drugs that had him hallucinating and we could sense his frustration at his lack of control. He couldn't conduct a reasonable conversation when friends came to visit.

Even though he had the best of care at the hospital, he was desperate to come home and in the end refused to go back. I learned after his death that he had begged his doctor to give him enough medication to allow him to safely and gently end his life when he knew all hope was lost.

After the initial grief, the anger set in.

Why did he have to do that at home?

Why did he choose to do it when his grandson was in the lounge room barely 10 metres away?

Why didn't he give me the chance to say goodbye???

Why wasn't he allowed to choose his inevitable end???

Why did they *make him do this* to all of us?????????

“ Why did they make  
him do this to all of us? ”

In amongst all this anger was a realisation of just how brave he actually was. He had written a note which I still have; a small piece of paper roughly torn from a page, upper case letters, obviously written with a shaking hand:

*I LOVE YOU ALL. ALWAYS DO YOUR BEST. DAD.*

I can only wonder at the beautiful memory we could have had of Dad's last moments; whether he had chosen to have us present when he passed or not, at least he would have died with the dignity that was rightfully his.

Di Hatfield

# My father

My father  
Clever man  
Maker of things beautiful and strong

My father  
Could fix it all  
Except his own health  
Myelofibrosis corroded everything but his mind and  
his indomitable heart

My father  
Uncomforted by the world  
Trapped in a prism of distress  
His moribund body unable to walk, to sit, to stretch out  
For month  
    upon month  
        upon month

My father  
Had had enough  
Said his goodbyes  
Could endure no longer

We knew it would come  
That shot  
Ringing across the island

The recoil knocked us all out of focus

I hear its echoes every day  
But never begrudge the release it brought

Amanda Collins



## **Our gutless politicians have not acted**

**M**y father originally appointed four persons who could make a euthanasia decision for him should his physical and mental capacity fail him. The appointment was conditional on the law changing and allowing them to act.

Disgracefully our gutless politicians have not acted and the law remains.

Those deluded brainwashed minorities who believe they have a friend in the sky have forced their views on us once again.

Had the law changed, my father would not have taken his own life at that time (18 years ago) and may have lived many more years.

**Mark Pryke**

Dear Mark Nancy Geoffrey Helen Stuart  
Pam and Brian.

I have seen my wife, my brother, my three sisters, my mother-in-law, and my father-in-law all die in nursing homes in very undignified and painful ways. In the retirement village where I have lived for over four years I have witnessed many more distressing exits. I do not wish to die as they did and more than a year ago decided to take my own life when I considered the time appropriate. The time is now when my mental and physical health have deteriorated to the point where I may soon be unable to carry out the act. I have tried to hide the nature and extent of my various physical problems.

The decision is my own. I have received no help or encouragement from anyone and sincerely hope that you will understand and sympathize with my decision.

My love to you all.

John

a.k.a. Pop Dad Father Grandfather Great Grandfather etc.

## Mark died alone without a goodbye

**M**y life partner, Mark Brennan, was born in 1948, and ended his own life on 9 February 2014.

It was our current laws that dictated that he took his life and what happened after.

Mark was born in 1948 in Great Britain and moved here with his family when he was 11 years of age so his father could take up a position at Sydney University. After training at the Sydney Conservatorium on trumpet as a young teen with the prospect of a position in the Sydney Symphony, Mark decided he wanted music to be a pleasure, not a career, and went to university to study law. He eventually turned to teacher education, lecturing at Charles Sturt University in Wagga Wagga. He published books pertaining to linguistics and the law, he also ran courses in Judge Education, and was a pioneer in adult literacy courses.

After a series of unfortunate accidents and illnesses over the course of some years Mark was diagnosed with multiple sclerosis (MS) and ankylosing spondylitis. His professional career was cut short, and he moved to Raymond Island in the Gippsland Lakes. He set up a choir on the island; this is where we met and after a few years our relationship began.

Mark set up his own small publishing business, Wind and Water Press. He wrote and published poetry and also edited and published the works of others. As his ability to work complex tasks diminished, he turned to his more creative side and took up bookbinding, making quality art books and journals for writers and artists. He also greatly enjoyed restoring old books. People would bring their most treasured family books for Mark to repair.

I guess people who are not familiar with the intimacies of MS could think that it's just about people whose legs don't work any more. MS is a mystery illness, it manifests differently for everyone. Mark's walking and balance were affected and were the most obvious symptom. His feet and toes had no feeling, and while he still could walk, he would walk barefoot down the street to our boat and not notice he had taken chunks out of his skin on the rough gravel road. In contrast to his feet, his skin elsewhere became extremely sensitive, making wearing clothes uncomfortable.

“His greatest fear is that he would get to a stage where he could not end his life because his hands would not work”

Mark experienced shooting pains through the left side of his body. He had spasms that often came at night. He had short sharp pains that would wake him. Pains under the skin that he called snakes and spiders. He had bladder infections. He gradually became incontinent. His bowels stopped working and he relied on fierce medications, which would suddenly send him exploding to the toilet, too bad if you were out and about! Some days his eyes were reluctant to focus.

By December 2013 he was assessed as high needs which meant if he was admitted to nursing care he would have been in the high care side of the nursing home, and they would have kept him alive against his wishes. The most devastating loss to him was when he began to lose the dexterity of his hands. He never

complained about pain but experienced a lot. Towards the end he was unable to sleep in a bed due to the pain and spasms when he lay down. He slept in an electric recliner chair.

His greatest fear was that he would get to a stage where he would not be able to end his life because his hands would not work.

Mark had always been an advocate for assisted dying, dying with dignity. It was not a rash or spontaneous act, rather the considered position of a highly intelligent person facing a disease that wouldn't let up.

If we had laws that allowed a system where people could choose to end their life on their own terms Mark may still be alive today.

Mark died alone and without a word of goodbye because he had to protect me.

That is what upsets me the most – he had to die alone and in an unnecessarily violent way.

This has affected me in many ways. People seem to think that now I am not a carer I am free to live a new life. I am not, I am mourning the loss of my life partner and I am dealing with the shock of finding him dead. I should have been able to be with him and hold his hand – it would have been a comfort to both of us.

Terri Eskdale



# **Taken to Court**

## Finally I put a pillow over his head

In 2005 nurse Cathy Pryor was convicted of the attempted murder of her mother and assisting the suicide of her father. Both were grievously ill, her father in the last weeks of liver cancer. In a decision imposing a two-year non-custodial sentence, the Tasmanian Supreme Court judge found that Cathy had acted out of love and compassion.

These excerpts are from Cathy's interview for the podcast *Better Off Dead*.

Dad knew his death was going to be horrible; he was going to die of liver failure. You become poisoned, basically, you become distressed, you become agitated, you lose your mind, and he just didn't want that.

He was having bronchial spasms, where you choke. Your throat constricts and you cannot breathe and you choke. There is nothing they can do about that either. So, some nights he would spend two or three hours choking.

Dad started talking about trying to either drown himself in the bath or to try and wrap the bell cord around his neck, because by this stage his legs were swelling but he also had terminal hiccups, which is where you just hiccup for hours and hours on end, and it is exhausting.

I went in one day and he said, 'Last night I choked so much I lost consciousness. And I had a near death experience.' He said it was wonderful. He said it was just amazing and he said, 'I so want to go. I just want to go.'

So I said, 'Look, Dad, if you really want to go that badly, I'll take you home and I will help you.'

I collected him (from the palliative care unit) and we went

home to his house, and we walked around the garden. He had a walking stick and off we went. He was so calm. We looked at all of his fruit trees and he told me how to prune the fruit trees to make sure people ate the apples and what to do with raspberries. It was quite surreal and finally he said, 'No, I've had enough. Let's go and have a glass of wine.' So we had a glass of wine, and he said, 'Now'. I said, 'Dad, do you really want to do this?' And he said, 'I am so happy. This is wonderful. I am going.' He said, 'You are so brave to help me do this.' And I just said, 'Look, hopefully when my time comes, someone will help me.'

*Cathy assisted her father, a retired GP, as he injected himself with a cocktail of drugs.*

I remember him saying, 'I feel really sick, I feel sick as cat.' He said, 'Quick, give me some more.' Finally – we did not talk much – he lost consciousness. One thing he had said before he died was, 'Don't let me survive. Whatever you do, do not let me survive.'

I went home and got rid of the syringes and all the rest of it and came back and he was still alive, I mean deeply unconscious but he was alive...finally I put a pillow over his head until he died.

Enough time has gone by that I can reflect on what happened. I'm still angry. I mean it has faded. I have a conviction for attempted murder, there are a lot of jobs I cannot get. It still affects me like that, but I think overall I'm angry at the suffering.

People shouldn't have to suffer. Why, if someone's got two weeks to live and they are in agony, they know they're going to die, why do they have to endure the agony to the end? If I could have my parents back I could look them both in the eye and I'm sure they would say thank you. I don't have any regrets: I just regret that it was not allowed to happen in a legal way.

Cathy Pryor



## Her very last wish

Margaret Maxwell was diagnosed with breast cancer in 1994. She researched the disease and pursued a regime of alternative medicines, hoping to not only cure herself but also provide guidance and inspiration for others.

These proved unsuccessful, however, and Margaret underwent a double mastectomy. In 2002, she was diagnosed with massive tumours and, told she had only months to live, decided to take her own life by ceasing to eat.

Margaret's husband, Alexander, persuaded her to end her starvation, but she made him promise to assist her to end her life if her health did not improve because she was terrified of becoming comatose as a result of a failed suicide attempt.

Margaret's health deteriorated, with frequent bouts of vomiting and coughing, breathlessness and insomnia. Unable to wash, dress or feed herself, she asked Alexander to help her die. He complied.

Alexander Maxwell was convicted of aiding and abetting suicide and received a wholly suspended sentence of 18 months imprisonment.

These are excerpts from the judge's decision, delivered in the Supreme Court of Victoria.

There can be no doubt that this was a terrible time for you. Not only did you witness your wife's physical suffering from the ravages of cancer, but also the devastating psychological effect upon her of the failure of the campaign she had waged against that illness. Nonetheless, you persevered.

Having earlier discussed voluntary euthanasia with friends, Margaret had been provided by them with a book entitled *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for*

*the Dying*. The method your wife chose to employ in order to bring about her death is set out in that book. It involved the use of medication to effectively drug the person wishing to commit suicide and the use of an inert gas such as helium. ... The utilisation of the medication was to ensure that the ensuing death by asphyxiation was a peaceful one.

You told the police that when Margaret read about the technique and realised that she would be incapable of performing the necessary acts alone, she burst into tears and stated that she would have to hold you to your promise to help.

About 1.00 p.m. you carried your wife to your van, laid her on the back seat and set out for the caravan at Phillip Island – the location that she had chosen for her death. You arrived around 3.00 p.m. And carried your wife into the caravan. At her request you crushed the tablets and dissolved them in some water. Margaret drank the mixture and then asked you to put her into bed. You put on a CD which you had both chosen and, having made her comfortable, you sat with her. After a couple of minutes Margaret fell asleep. She was always terrified that if her attempt to end her life failed, she might be rendered comatose, so she had made you promise to follow the procedures detailed in the book *Final Exit*. You did so, placing the bag over her head and shoulders, securing it with a piece of sash and introducing the tube into the bag. You turned the helium on slowly and your wife went into a deeper sleep before apparently ceasing to breathe. You left the gas running for some time as she had instructed, before checking her pulse and breathing and ascertaining that she had in fact died. In the record of interview you told the police:

Her very last wish was that she wanted to lay down in nice clean pyjamas in a nice clean bed and cuddle up under the doona. So I did that and I stayed with her for a little while longer and I packed everything away and then the idea was that I would ring the funeral home and they were supposed to ring the doctor that Margaret was under down here and the death certificate would be written and then I could bury her. Nobody was supposed to know about it and then my idea was that when I got back home and Daniel was finished with his exams, I would write a full report on it and hand it to the senior officer at Kew police station and they could do what they wanted then. It wasn't going to matter. Daniel would have finished his exams in a couple of weeks and Margaret would be at peace.

I accept that you loved your wife intensely. You were desperately hopeful that a cure for her illness could be found.

You have a history of hard work and you have been a good family man. Up until this incident you have lived an unblemished life and there is no reason to believe that you will ever again transgress the law.

Further, the trauma of having initially been charged with the murder of your wife, together with the period of 26 days you have spent in custody, have constituted a measure of punishment for you.

“ I accept that you loved your wife intensely ”

## **An inhumane and horrific way to die**

**M**y story is on behalf of and in memory of my mother, Dorothy Joan Meikle, a staunch believer in euthanasia and supporter of the right to die with dignity for over 20 years. A qualified English teacher, she achieved a degree in psychology and also worked as a librarian in the latter part of her teaching career, until retirement age. She then achieved a diploma in art and also qualified as a yoga instructor. She was a very articulate and intelligent woman to the day of her dying.

Sadly, at the age of 70 she contracted motor neurone disease shortly after an accident/fall whereby she broke her ankle. Unfortunately, at the time of her diagnosis, my mother was given a prognosis of about five years. She was faced with the prospect of the next five years whereby this disease would travel up her body and she was likely to die slowly and possibly painfully. She would slowly lose muscle functions and they would be depleted in her lower and upper limbs. We all knew that this would progress until she was unable to talk, swallow or breathe.

My mother really came to her decision to die at home with dignity shortly after the death of her loving husband of 55 years (he was aged 87). I watched him in agonising pain – he was gripping my hand and groaning to his last breath in the early hours of the morning.

Our requests for more morphine were often denied and to this day, those two days can only be described as appalling and horrific. Our family had felt they had witnessed an inhumane and horrific way to die. So when Mum started finding it much harder to cope with her deteriorating health, her need to die with dignity became paramount to her. She felt she had held on

for so long and with the progression of her disease, there was now very little muscle holding her small frame together. It was frightfully painful and debilitating. She had been confined to a wheelchair for years, she was receiving 24-hour pain relief and 24-hour home care and she knew that within months she would choke to death.

“ I was arrested, interrogated,  
and received many threatening  
phone calls ”

I respected and loved my mother so much and I wanted to support her decision to die at home and not alone. Being the youngest but closest of the three children, I was fraught with sadness and fear.

The legal implications and repercussions made my decision to be with my mother the day she wanted to die extremely distressing. I felt absolutely torn between two very strong ethical situations; an innate daughter's need to love and support her mother as she was dying and the legal repercussions I would endure because of it. Most importantly, I was also a single mother of my only daughter, aged 12. I chose whole-heartedly to be with my mother just as I also chose to be with my father when he died in hospital.

I wanted my mum's death to be a better experience for her, but overall simply wanted them both to not die alone. For them and me both, my most simple and purest wish was for them to not suffer. My want to hold their hand so tightly so that they knew I was with them was essential.

However my life totally changed the day my mother died. And it still has to this day. I was arrested a few days after my mother's passing, on a murder charge. I was interrogated by a police officer and received many abusive threatening phone calls. I was constantly harassed by news magazines. My family abandoned me. I was reduced to only a few close friends and I had to vacate my home.

Eventually I moved to a country town and became a recluse. It impacted hugely on my life and in ways I had not even thought about or prepared myself for. Two years later I was informed that the DPP had decided that I had assisted in my mother's death, however, no further charges were to be laid. I endured two years of quite extreme distress.

From my experiences, I do not wish upon anyone who is gravely ill to be denied the right to die or to have their family and friends by their side to comfort them, to celebrate their life or to say goodbye if and when they so wish.

**Miriam Meikle**





# **Nurses and doctors**



## A damn good death

Isn't it strange, the various pathways that lead us to the world of voluntary euthanasia? I suppose some see it as a good cause and cautiously enter. Others, facing their own mortality, may step into the stream. My family and I were thrown in at the deep end.

In March 1990, Gavin, my 37-year-old brother, was standing in the cockpit of his yacht, off the south coast of NSW, taking a land bearing. Suddenly the yacht heeled, the boom swung unexpectedly and struck the right side of his head. His skull was severely fractured. By the time he was moved to shore and transported to the closest tertiary hospital, the golden hour had well and truly passed. He died 36 hours later, when we stopped life support. Fortuitously an organ retrieval team was in town, so in some way, he lives on.

He was a marine biologist. We returned his ashes to a wild stretch of the north coast where we had played, and fished, as kids. Shared some whisky. Said goodbye. Wept for the waste.

This unexpected and traumatic death forced my parents, my sister Tina and myself to discuss and mull over our own individual plans, hopes, fears, expectations. Death was more relevant for my mother Meg (69) and father David (73). Both were independent and adamant they didn't want to die in hospital, be left as a vegetable, or rust away in a nursing home. Subsequent conversations over the ensuing years reinforced these wishes, and clarified intent, for all of us. The stage was being prepared to die at home, respecting their wishes.

I then started to ponder how I could actively help them achieve these ends. At this time, about 2003, I was working on remote Aboriginal communities in the Western Desert region. Pharmaceutical stocktaking was a regular part of a clinic routine,

and consequently I was able to progressively set aside a growing supply of out-of-date medications, complemented by my personal Doctors Bag supplies. I discussed these acquisitions with my parents, and we progressively formulated plans for a well-managed death, at home. Their plans. Their home. My help.

Unfortunately, in 2004 my mother suddenly developed convulsions due to a cerebral tumour. The subsequent left-sided brain biopsy damaged her speech area, and we were unable to finalise her plans to die at home. She was inoperable, and soon became unconscious. Terminal sedation, and a hospital death, was her final pathway. We were thwarted. It took a week. She was 83. My father was shattered.

We took her ashes to that same stretch of coast. She joined Gavin. A sunny day, an offshore wind, another toast. Meg went graciously on her final journey.

Meanwhile, my father's chronic lung disease progressed relentlessly, with numerous hospital admissions for tenacious chest infections. He received excellent clinical and nursing care, and otherwise remained living alone at home, independent, with some home nursing and meals on wheels. But he missed Meg terribly, his autonomy was eroding, he was weakening, and dreading the return to a hospital bed.

He was tired of living.

At his final hospital admission late in 2006, we decided he should come home. He signed the 'discharge against medical advice' form, packed his bag, gathered his papers and pens. His treating physician didn't understand or accept this move and warned David he would be found collapsed on the floor at home, in a day or so, and readmitted. 'Go to buggery,' I mused to myself, 'we have a better plan.' So we trotted off home together. David sat on his couch in their sunroom, and rested in his own bed.

I slept in the nearby spare bedroom, with an electric buzzer for night calls. It didn't take long. On the second evening I invited a few of his old mates over for biscuits and cheese, some whisky, and a chinwag. You don't comfortably do that in the hospital environment. They were delighted.

The next night was rough – hard coughing, severe chest pain, distress with his breathing. I helped him to the bathroom a couple of times, and at 3am we sat on the bed together, had a hot buttered crumpet each, and a couple of whiskies, his favourite drink. Good home care. Proper love. At 6.30am he buzzed me – 'I've had enough, JW.' We had rehearsed this scenario, documented, dated and jointly signed our many conversations over the years. From here on it was simple – a butterfly cannula into his left arm, swabs, syringes and necessary medications laid out on his bedside table.

I told him I loved him. 'I love you too, JW.' The midazolam was gentle and quick, and the rest of the drugs followed taking their course. Some 20 minutes later he was gone. Peaceful. At peace. In his own bed. In his home. He was 87.

I sat quietly with my father for over an hour. Reflecting on his life, our family times together. Later I rang his doctor – 'Dad died earlier this morning. Had a rough night, coughing and a lot of chest pain. Perhaps he had a heart attack...'

So he was cremated, and we took his ashes, a bottle of his favourite single malt and a few family members. Back to that familiar, rocky stretch of coastline to rejoin his beloved Meg and son Gavin.

A life well lived, and a damn good death. I miss you old fella.

Dr JW

## **Later I discovered what I had done was illegal**

She was the first person who ever asked for my medical opinion, so I suppose that made her my first patient, although I was only a final year medical student at the time. She took my advice, and as a result she died as planned. Later I discovered that what I had done was illegal.

Cle was short for Cleonea – the only one I have ever heard of. She said her mother made up the name. Cle was 42, working as a secretary and mother of three boys aged 17, 19 and 22. She was separated from the boys' father and her de facto partner, Bill, lived with her and the boys. Three years earlier Cle had undergone an operation for bowel cancer. When she consulted me she had just been told that the cancer had returned, in the form of secondary tumours in her liver and lung. These were discovered during routine antenatal care. A termination at 20 weeks had been performed so that she could access further treatment for her cancer. She understood treatment was unlikely to be curative.

She had many fears about her future and we discussed these at some length. Her greatest fear was of losing control over her body in the final hours and days leading up to her death. She asked me to advise her on a way she could end her life, at a moment of her choosing. She said she would know when that moment came.

I did some research and advised her that an overdose of barbiturate was the best way to achieve a reliable, painless death. Since I could not prescribe for her, I coached her on how she could obtain a supply of barbiturates, for a fictitious insomnia, from her general practitioner. Within a few weeks she had a supply, which

she hoarded. I calculated the dose she would require, based on her body weight and the potency of that particular drug. When she had saved enough tablets, she stashed them away in a safe place. She was ready.

Three months later, Cle had tried every avenue she could to find a cure. She had completed the palliative therapy prescribed by her oncologist without any apparent benefit. She had flown to Germany to try laetrile therapy. She had spoken to alternative practitioners at home in Brisbane. Nothing she tried had any benefit. She became weaker, lost weight, lost energy, and lost hope. She now spent most of her time resting at home, supported by her family.

An episode of shortness of breath saw her admitted to hospital with a diagnosis of heart failure brought on by the tumours in her lungs. Oxygen and medication to make her heart beat more strongly relieved her symptoms. At visiting time that night, her family were treated to a vibrant, energised Cle. She wore make-up, she did her hair and she told jokes and stories, laughing as she had not done for weeks. Each of her family members had time with her alone, to share their thoughts and feelings at an intimate level. When visiting hours were over, she stayed in the hospital and slept well.

The first visitor the following day was her partner, Bill. Cle told him that she had taken the tablets ten minutes earlier. He knew which tablets, and he rushed to a public telephone to call me. Fifteen minutes later when I arrived at the hospital she was dead. No autopsy was performed. Cle was buried a few days later.

I have had many patients since, some of whom have been approaching death. None since Cle has asked me for advice on how best to end their life at a time of their choosing. If and when

that question comes again, I hope I can help them without fear of prosecution. I believe that laws need to be changed, so that each of us when we face our death can take at least a little control. As did my first patient, my mother, Cle.

**Dr Michael Cameron**

## The guilt is still with me

I'm a retired physician. I had been working for over 50 years in my profession, first in Poland, later in Australia. I strongly support euthanasia as the way to end unnecessary suffering of the patients without any hope for recovery. In such cases, with the right safety guards in place, it should be a patient's choice when he or she wants to end his/her life.

My mother suffered from emphysema and the last few weeks of her life were just a torture for her and also for those who loved her, especially for me. During that time, she begged me to end her suffering. I didn't do it, but the guilt is still with me.

Dr Barbara Westwood

## **Drops of Mercy**

You begged

I didn't do it

there was no strength  
in my hand to push  
the shaft of that syringe to add  
drops of mercy to your cup

you begged and I couldn't

was it cowardice  
behind a screen  
of Hippocratic oath  
did I not love enough?

**Barbara Westwood**



## His eyes would fill with tears

I had a fully paralysed patient on life support with end stage neuromuscular disease who could only communicate through eye movements. Once he realised he would never get off the ventilator, his mental status deteriorated to extremely fragile and he repeatedly indicated that he wished to die. His eyes would well with tears on mention of his home, family and pets.

The problem with ceasing artificial ventilation was that he would need almost an anaesthetic to overcome the feeling of suffocation as he died. Family members expressed strong opinions ranging from 'it's his life and his choice' through to 'nobody should play god'. If artificial ventilation is ceased as strong intravenous sedation is given, causing rapid death, some may believe this to be murder. In intensive care units people from all cultures and beliefs are suddenly thrust into life and death situations often with no prior experience. It's a high-tech, confronting environment and people respond in many ways: fear, anger, or false expectations are common. The potential for litigation is always present and may influence outcome, as in this case where a conflicted family could not reach a consensus and whatever medical staff did would be criticised. The patient remained on life support for 11 weeks until he died from pneumonia.

I can scarcely imagine what went through his mind, immobilised, staring at the ceiling for months, unable to say where he was hurting, with tubes in his windpipe, arm, stomach and bladder, 24-hour machines and alarms, no hope of recovery, begging to end it all and finally an awful septic death. Current laws failed to protect both this patient's right to control his own fate, and the medical staff's freedom to implement his wishes.

**Dr Geoff Wall**

## He then shot himself

I am now retired but one case of the unfortunate result of the lack of an option for assisted dying sticks in my mind. He was a fit man in his forties who worked in the local council office and who was a low handicap golfer at the local club. He developed a rapidly aggressive form of multiple sclerosis and within eighteen months had become very disabled and only able to walk with difficulty using a walking stick. At a visit to his home, in the presence of his wife, he asked me if I would assist him to die. I wanted to but my mind froze with the thoughts of a possible murder trial and the loss of my licence to practice.

He was a practical man so did without my input. He asked his wife to go into the town to buy some magazines then called the police to say he was going to kill himself so that his wife would not find his body. He then shot himself. That a man should have to do this in civilised society is a great indictment of the maturity of that society.

Another case which has worried me is a man in his sixties with late stage pharyngeal carcinoma with all its horrors. I was looking after him in the local 20-bed hospital but I did not bring up to him the possibility of my hastening his death and he was unable to speak due to the choking effect of the malignancy. He asked to be transferred to a private hospital in Launceston where he died a couple of weeks later – I gather very uncomfortably. I spoke to his wife after as to whether he would have liked me to help him out and she said, ‘Didn’t you see him jabbing at his arm like you injecting him?’ By this stage I would have arranged something. There is no palliative care for pharyngeal carcinoma apart from long-term complete sedation.

Dr Geoff Trezise

## I do not fear erosion of trust

Emeritus Professor Ian Maddocks is an eminent palliative care specialist and Senior Australian of the Year 2013. In an online article for MJA InSight, he advocated for more open debate on assisted dying law within the medical profession. In response some doctors stated helping patients die would erode trust in the medical profession:

**Submitted by semi retired doc on Tue, 24/11/2015 – 9:13**

There is little discussion in the euthanasia debate about who administers or provides the means to end life. If you provide the patient with the means to end their life then, as their doctor, it is ethically no different to administering it yourself, although it may protect you legally. Once we start this process we are going to lose a fundamental trust from the community in the medical profession that will be almost impossible to regain.

This was Professor Maddocks' reply:

**Submitted by Ian Maddocks on Wed, 25/11/2015 – 9:04**

Dear semi-retired one,

I do not fear an erosion of trust if assisting dying under clearly defined circumstances is decriminalised; rather it might increase patient trust. I think of two instances where single aged female patients with terminal cancer died suddenly and unexpectedly at home. I felt sure that they had taken accumulated analgesia/sedatives. My regret was that they had not been able to share the decision to do that with me, and I was not able to be there to ensure that no disaster of half-death occurred. When I can sit with patient and family through the last hours it is a moving and very comfortable experience for all. These women had to deny that opportunity for themselves, their loved ones and me.

**Professor Ian Maddocks**

## People know when they've had enough


People's bodies at end of life do amazing things. Bones break. Organs fail. Even our neural receptors, our pain receptors, are hypersensitive, so we may have apparently little reason for pain but yet feel it and experience it. And often we see at end of life no amount of pain relief can relieve that, and people will ask the question. They ask you to help them end it, to finish it, to kill them. They will use all sorts of language but there is no mistake about it. People know when they've had enough. It can be very difficult for the nursing staff to, I guess, experience that imploring and begging to assist them to end their suffering when it happens.

I would go the pan room and cry for 10 minutes because I didn't know what to do or say. There was nothing I could do about it. Saying that to a patient who is begging you to die doesn't help. It doesn't change their view to tell them that it's against the law and that there is nothing you can do. They don't see anything other than their own distress and their own suffering. Sometimes you just had to sit there and hold the hand of the person dying so that they could squeeze it and ease their own pain.

Many of the deaths I've seen are extremely undignified. I can assure you starving to death or dying of dehydration is not dignified. It's just not. And the levels of pain — people can scream for the last hours of their death in agony despite very high doses of opiates, morphine and other forms of relief. It's less than dignified I think when you're in a public place surrounded by people that you may not know very well, when other people can hear you, hear your trauma, hear your suffering, and you're generally in a strange environment. To me that's not dignified.

**Nurse Coral Levett**

## **I have nightmares about their tragedies**

n too many occasions as a Division One Registered Nurse off duty, and on duty, I have been overcome with inner distress over the prolonged inhumane, unrelieved suffering, particularly of the incurable patients known to be terminally ill and in their final stages of life. Even more sadly, several of my friends have become such patients.

One friend was diagnosed with end stages of asbestosis and was in an acute general hospital for around six weeks then transferred to a nursing home, where he died within weeks. Before he became ill he had much pride in his appearance. For the above period he suffered terribly. He never got relief from the constant cough that sounded like he was choking, nor relief or way of removing the huge ribbons of yellow-green-brown tenacious mucus accumulating and dripping from his mouth, throat and nose, and was constantly soiling his pyjamas and bedding. He had no energy. Continuous oxygen via nasal tubes seemed to add discomfort and annoy him with his unbearable, unrelieved, dreadful pain. Loudly he yelled out with the pain, and for staff who rarely responded to him, perhaps knowing they couldn't help him.

After being transferred to the nursing home he continued to thrash around the bed so much that his leg nearest the wall was bleeding from deep abrasions, caused by him desperately and repeatedly hitting it. He did a lot of screaming out with the pain, and 'can't someone help me?' My asking the staff made little difference. Repeatedly, when he got enough energy, he begged me to try and get the law changed to prevent others like him suffering.

Too often pain breakthrough occurs in the suffering, terminal patients already receiving analgesia. With disbelief I observed the above situations also in acute public and private hospitals, some also under palliative care, and in ‘modern’ aged-care facilities.

Each friend had terminal medical conditions and was incurable. In the care of professional medical staff they felt mostly unheard and that they didn’t matter. Perhaps unsatisfactory responses when begged through tears or pain and desperately calling out, ‘please can’t you do something for my pain?’ or ‘please end my life I can’t bare it anymore’. Now they are all dead, but I have nightmares about their end of life tragedies.

**Nurse Flora Metcalf**

## **Trapped, traumatised, by a hopeless existence**

**W**hile on my first placement as a student nurse in a nursing home I cared for a patient who a couple of years earlier had suffered a catastrophic stroke which left him in a dreadful state with no possibility of recovery.

Rob required full nursing care – all he could do was move his head from side to side, was tube-fed into the stomach, and he constantly made loud, angry, incomprehensible mumblings when frustrated, angered, or agitated by his condition. He fully understood his circumstances...he just wanted to die. He made that very clear by the resistance to everything we tried to do for him – he didn't want to be here anymore.

Prior to the stroke he was a very active 60-year-old who had an interesting career as an engineer, looking forward to his retirement sailing the seas in his newly acquired 55 foot cabin cruiser. Rob couldn't walk, talk, swallow or enjoy anything remotely resembling a normal life but he certainly made his thoughts and feelings known.

Rob lay on his back looking at the framed photo of his much-loved boat on the wall behind his bed. Hopelessness surrounded Rob – the active life he once knew was now gone. He felt trapped in a body that let him down.

Nursing Rob was not easy, the helplessness and hopelessness he felt made him non-compliant with many of his ADLs (activities of daily living). In order to be heard and understood he would self-mutilate by biting down on his bottom lip until it bled, causing the skin to rip and tear. This was Rob's only way to express himself...to have some control over his situation, to convey how he felt, traumatised by this hopeless existence.

When I returned to continue caring for Rob a few weeks later, I was shocked to see his teeth had been surgically removed.

Later that year when I returned for my second placement, I received news Rob had died. While it had been a privilege and pleasure caring for Rob, living in a body that let him down is not what he wanted.

As I progressed in my nursing career I met many Robs, but none as feisty and determined as he was to get the point across. I remember him and admire him for his conviction and courage.

**Nurse KS**



## **The GP took the risk on our behalf**

**M**y father's death was kind and loving. I had the support of an understanding GP, many years ago now, who understood that the suffering served no purpose and a prolonged death was the end result.

I was fortunate, as I was a nurse of many years standing and my father's GP had confidence in my ability to care for him. My father was 71 and had suffered many strokes and was completely incapacitated and in a lot of pain. He was a pilot in the RAF during the Second World War and had suffered head injuries and severe burns and had poor health throughout his life. His determination to provide for his five children, along with his loving wife, made us a united family in understanding that we needed to care for our father at home and away from the hospital environment, where he lay in pain and discomfort for hours on end even with the ongoing attention from the hospital team.

I, along with the total support of my mother and sisters and their husbands, was able to take Dad home and care for him in the dining room of his own home, surrounded by family and friends. My father was skin and bones when my husband carried him into our home. Dad was never left alone night or day. I was given the necessary medications (injectable) to end my father's terrible suffering.

My father died very peacefully over two days and we watched him slip away, without the agony that we had witnessed whilst he was hospitalised.

From that time onwards I have supported the need for proper legislation for assisted dying. I was very fortunate to, one, be a nurse; two, have the support of a GP who was enlightened

and took the risk of leaving with me the required drugs (his final words to me were, ‘just let me know when you need the death certificate and I will come’); and three, have a family who supported the need for us to bring about a kinder death for my father than the one we were witnessing.

At the time of my father’s dying the medical profession had no legal way of dispensing the necessary drugs to aid his death in his family home. The GP took the risk on our behalf in his strong belief that it was a better way to die than a very slow demise in a hospital ward. The comfort it gave us all was overwhelming, for we knew Dad’s time had come, but we were able to give him a well-rewarded loving kind end to his hard life – one he so richly deserved. I no longer nurse as I am now 69 years of age and hope to enjoy my retirement with my husband, and when my time comes, may I receive the help from an enlightened GP as my father had.

**Nurse Juliana Clemesha**

## **Nothing except death gave her release**

I have been a practicing GP for close to 30 years after several years working in the hospital system. My wife died of pancreatic cancer aged 54 in 2010, and my mother died of stomach cancer in 2012.

I have witnessed the illness, suffering and deaths of many patients over the years. Many deaths have been well managed with palliative care but there is a misconception that modern palliative care can alleviate most suffering and allow a dignified and reasonably comfortable death in nearly all cases. This is simply not so.

The vision of a dying patient on a morphine drip surrounded by family and slipping away peacefully is not the reality in a significant proportion of patients. Patients can suffer both physically, psychologically and existentially for weeks or months and can die in great suffering, often alone in the middle of the night and often in confusion, fear and distress gasping for breath or choking on their own fluids. But for the sake of a small proportion of the community who will not accept a more humane way (including some doctors), this is how things will continue.

In my mother's case of linitis plastica (a form of stomach cancer), she had absolutely intractable and intolerable nausea and could not eat, and this was not adequately palliated despite maximum involvement of palliative care services. It was dreadful to see her suffer without adequate relief. She asked me several times to be put out of her misery but she had to endure it to the end.

I can recall several other patients who were unable to be adequately palliated. In particular, I vividly recall one unfortunate

young woman. She was dying of advanced vulval cancer and had the most awful ulceration with severe pain at the slightest movement or touch and offensive discharge, bleeding and odour. Fifteen years on her suffering still makes me feel sick. Nothing except death gave her release and death did not come peacefully despite morphine and palliative care. Patients dying of advanced motor neurone disease are also faced with unbearable suffering, witnessing in full alertness a body that is paralysed and fearing choking to death as they lose every last vestige of independence and dignity. For some this is intolerable, yet our society demands that they endure the full course of their illness no matter what their wishes.

Why allow intolerable suffering when it is within our power to give people a choice to relieve it? My experience convinces me that I would want that choice. Many doctors feel the same and are placed in legal limbo by placing relief of suffering above the anachronistic laws in this state.

I have seen it first hand and my considered opinion is that we need law reform in this area.

Dr X

## Sometimes one needs to stand up for what's right

**A**s a female semi-rural GP involved in palliative care for the past 25 years, I have helped many patients and their family attain a 'positive' death experience through psychological, spiritual and medical support.

The option of assisted dying was always a very important and reassuring part of this care to both the terminally ill and their loved ones. This option was not always called upon, but when used it was a beautiful relief to an agonising crawl into death. The dying person and their loved ones were always most grateful for this service and went through great lengths to protect me from any legal ramifications. Unfortunately this included scheming and lying and not discussing issues with third parties. This was by far the most traumatic part of the situation for everyone concerned.

Legalising this most humane part of medical care (which I believe is commonly practised by many of my compassionate colleagues) would avoid the isolation, scheming and 'backyard' aspect to this service. I liken it to abortion, which is carried out in all countries whether it is legal or not, but legalising it has allowed safe and supportive care.

Some five years ago, a 55-year-old woman came to see me in my clinic. She was distraught and desperate for help. She explained that her mother, who was in her 80s, had severe emphysema, was breathless at rest and any activity caused her to gasp for air. The respiratory physician had suggested home oxygen and inhalers, none of which relieved her severe breathlessness.

She went on to explain, through tears of distress, that on three occasions she had found her mother in bed with a plastic

bag over her head. The bag had not been tied effectively and her mother's suicide attempts failed each time. Did I have any suggestions to help, she asked?

What to do? My bags of tricks in my palliative care repertoire are mostly useless for severe breathlessness. I could try low dose morphine, but this would create hypoxia and confusion which would be very distressing in itself.

Could I, as a compassionate human being with skills and ability to relieve another human being's severe distress, deny this because some bad rules were in place in our society that could land me in trouble? My answer was: NO. Sometimes one needs to stand up for what is right, despite the potential personal sacrifice.

I went to visit the mother, who lived with her daughter on a rural property, and confirmed her medical condition to be terminal and associated with severe distress. The mother confirmed a passionate wish to die and end her suffering, and a mental state examination confirmed she was of sound mind.

Over the coming weeks I did try the morphine to allow at least an attempt at symptomatic treatment and to give me, the patient, and her family, time to consider her options. The treatment did not relieve her symptoms and the mother was persistent in her wish to die.

After confirming the family's support of the mother's decision and their support for my position from a legal point of view, it was decided for me to arrive at 6.00 one morning to provide a lethal injection with the family by her side. The mother died a beautiful peaceful death with a smile on her face.

I went back home to have breakfast and went to my clinic to start the day. To cover myself, I had asked the daughter to call my clinic at about 9.00 to inform the reception that she

had found her mother deceased in bed that morning and could I come over please. At lunchtime I went back to the house to debrief the family, certify the death and help arrange the funeral arrangements. The family was very grateful for my help.

As for me? How did I cope?

Over the years it has been a very lonely road. I was unable to discuss this emotionally charged part of my work with any colleagues or other health professionals. My husband was a great support, but this is not the same. It was also very difficult to determine and access the right mix of medications to allow for an effective gradual peaceful passing. I know I have done the right thing for my patients and this knowledge is the best reward.

**Dr Alida Lancee, MBBS, FRACGP**

## Where was the caring for Diane?

**D**iane was one of the most courageous persons I have ever known. She was a fighter who beat the odds and lived through great pain with a smile on her face and unfailing humour.

My friend, Diane, would not follow the doctors' advisement to go home to die when she was diagnosed with advanced metastatic breast cancer. She had to seek another oncologist's opinion as her first refused her request for chemotherapy. She was determined to fight this cancer. She had two young boys, a loving husband and a life worth living. The second oncologist agreed with the first but finally supported Diane's decision to fight and arranged for the chemotherapy and radiation. She was given four to six weeks to live. She lived ten years. We made a joke about doctors' prognoses; 'You've had so many expiration dates stamped on you!' I said. And we laughed as she lived past those dates. It was a hard ten years. Repeatedly the cancer returned and she fought back again and again. Words like courage, strength, determination, spirit – well they just aren't enough to describe this woman's unfailing efforts to live.

I am still deeply affected by the memory of how she had to die. When her time came, her bones were riddled with metastases and fractures. Breathing broke her ribs. Can you imagine this type of pain? Multiple fractures throughout her body. I can't imagine it. No-one should be forced to live through it. I will never forget her words the day I called her at the hospital. Without saying hello or the usual pleasantries one begins a phone call with, my dear friend, the strongest, most courageous woman I have known immediately said, 'Oh my God Cheryl, my body won't



stop. My body won't die. Oh God, Cheryl.' I'll never forget my friend begging for her agony to end.

She had lived with a great deal of pain and suffering from chemotherapy, radiation, surgeries and metastatic fractures and met it head-on with humour and strength. She was inspiring. I cannot comprehend the torture she would have gone through. She didn't deserve that. No-one does. It was completely unnecessary. No-one benefited by forcing her to have to live that last month. I cried every day for that month. The first day I didn't cry was the day her husband called me and told me she had passed away.

I'm a doctor who went into medicine because I want to help people live the best lives that they can. Today as I write to you about health care, I have one question: Where is the Caring in Diane's story?

Voluntary assisted dying is not about giving up. It's not about someone else's religion. It's about the right of a person to not suffer unnecessarily. A person making the decision for themselves. She suffered cruelly. Her family suffered watching helplessly as she would cry out in pain. We are all scarred by this. Our current legislation enforces unnecessary cruelty on some people. We vowed not to cause maleficence. We are failing.

Ask yourself if you would be happy to die that way. If your answer is no, then you know it is wrong. It's time to make a change. It's time.

Dr Cheryl Wilson, RACGP

## The patient in cubicle 4

**M**y intern asked me to see the patient in Cubicle 4. She had been transferred by ambulance from the nursing home she lived in with a note saying she had been refusing to eat or drink for the last five days. She was 42 years old, had a rare disease affecting mitochondria meaning she could no longer move or talk, but was wide awake and aware of everything around her. Beside the bed sat her husband, who was able to fill me in on the history.

They married years before, when she was well and had no idea that this awful disease was her future. She had been an intelligent and attractive woman, with a career she excelled in and a wide circle of friends. Then the disease had made itself known, in a small way at first but causing increasing disability as time went on. A diagnosis was made, her prognosis bleak. There was no treatment. This disease was irreversible and would lead to her death.

Her husband had managed her at home for as long as he could, but his capacity to care for her was finite. Reluctantly he had to admit her to a nursing home four months before I met her. At that time she was still able to speak, and she told him over and over that she hated living there and that she wanted to die rather than face the already severe but ever increasing disability her disease brought. She made him her Enduring Power of Attorney (EPOA) for health matters and made it clear that he and only he was to decide about health issues for her. She had said that her mother should not be involved in those decisions. The responsibility was to be only his.

I examined her in the Emergency Department cubicle. She was skin and bone. She was unable to move her body or

speak, yet was clearly aware from the way her eyes followed the conversation between her husband and me. She was dehydrated, and had some tenderness of her abdomen.

Her husband was clearly distressed by the situation. We talked about what options there were for her care. I suggested that sometimes when people in her situation refuse to eat or drink that it is the only way they can control what is happening to them and that they are seeking release. I asked him if that could be what she was doing. He cried, and said that he thought that was exactly what she was doing. Her eyes followed our conversation, back and forth.

I suggested that one option was to palliate her. I explained that this meant accepting her choice of refusing food and fluid, but making sure we treated any pain she may exhibit and keeping her comfortable in hospital. Another option we discussed was for her to be returned to her home and for the same plan to be followed, with his care being supported by community nurses. She looked at me with what I saw as hope in her eyes.

A third option was to put a needle into her arm and run intravenous fluids to rehydrate her, to investigate her with blood tests and abdominal scans to clarify the cause of her abdominal discomfort, and to treat whatever we found that may need treatment. He cried some more, and said she would hate that, and would prefer to be kept comfortable and allowed to die naturally. Her eyes told me she agreed.

Then he explained that he did not feel he had the authority to make the decision alone. He told me her mother was coming to the hospital, and could I please speak to her about it. Her mother wanted her to live as long as she possibly could. She had clashed with him over her care on many occasions. He expected that she would disagree with palliation.

I told him I thought that was why she had made him the sole EPOA. He looked at me blankly and asked if I would speak to her mother when she arrived. She was due in half an hour.

An hour later I was asked to go back to the cubicle. Sitting beside her husband was an older lady, her mother. I repeated the conversation I had with her husband, again followed closely by my patient's eyes. I saw the wall between her mother and myself building, word by word. When I finished what I had to say, I suggested that I leave the three of them alone to discuss the way forward.

It didn't take long. I was called back into the cubicle after ten minutes. Her husband told me that I was to rehydrate her with an intravenous drip, and investigate her as outlined with blood tests and scans. I asked if he was sure, and through tears he told me he had no other choice. Her mother had insisted.

I prepared my equipment for the intravenous drip, and blood tests. When I turned back to the bed, she was looking straight into my eyes. For the first time, they were full of tears. So were mine. I did what I had to do and she went to the ward.

Two weeks later my intern pulled me aside in the corridor. She had followed up on the case. Her husband had finally decided that enough was enough. The investigations and treatment were stopped. She finally died her natural death.

**Dr Michael Cameron**





# **Living the dying**

## A good death

I have melanoma. I've kept it at bay for 10 years but it is now untreatable.

To me the concept of a good death is at the core of this discussion. I don't think the desire to die well can be dismissed as akin to a lifestyle choice (an oxymoron if ever there was one). It is a far more complex desire than that. It is a desire to have some real say in the matter of how you die. It is the desire for your wishes to be respected and acted upon. It is the desire for yourself and your family to be spared futile and unnecessary suffering at the end. It is the desire to be fully present for those you love at the moment you leave them. This is the kind of death I would choose if I could. It might not be everyone's idea of a good death, but it is mine.

“It is the desire to be fully present  
for those you love at the moment  
you leave them”

Of course it is possible and legal for me to take my own life at any time by whatever means. But a lonely and potentially messy suicide is a difficult prospect to contemplate, and that is the coercive power of the current legal framework. It offers no information, protection, or support for terminally ill people who might choose the kind of death I have described above. Nor does it protect and support their families. In fact it would seek to punish them. In this way the current system mandates the kind of death where decisions about the timing and manner of dying

are made by others, within the framework of a medical system that, to the uninitiated, is unpredictable and obscure.

I doubt that anyone who hasn't been handed down a terminal diagnosis can ever fully grasp the depth of anxiety that the prospect of inevitable death induces. The loss of your own life is unlike any other kind of loss. Surely it is time for this to be understood, and for the dying to be paid the compliment of assuming that they are capable of intelligent decision-making at the time of their greatest need.

Cory Taylor



## Death by a thousand cuts

The following are extracts from the diary of 90-year-old Eileen Dawe. She was diagnosed with terminal cancer and wrote of her wishes for a different kind of dying.

### ***27th July 2015***

My name is Eileen Emma Dawe born on 26/8/1925 nearly ninety years ago. After suffering nearly six weeks of strong pain I was eventually diagnosed as suffering from untreatable terminal cancer.

It is my wish to end my life whilst still able bodied and clear minded.

I have now received pain management medication for five weeks. Two weeks would have been sufficient for final goodbyes and an orderly exit.

### ***Early August***

Pain relief helpful. Getting business affairs in order. Phone out of order for eight days. Still considering overseas assistance to Switzerland. Likelihood becoming less of an option.

### ***Tuesday 25/8***

Cancelled bridge due to discomfit and hearing stress. A surprise lunch had been planned for me.

### ***Friday 28th***

Admission to hospital. It would seem to me my one option out of life is slow starvation, whilst most good folk wish to keep plying me with pain bearing food or wishes for a longer life.

***13th September***

Completed two weeks of further pain management treatment. An experience that left me astounded at the patience, kindness and caring that nurses, doctors and staff lavished on a terminally ill ninety year old woman whose wish then and now is to depart a long and happy life as soon as possible.

***Written after return from hospital***

‘I need your simpering smile and a hand to soothe my pain awhile.

My country’s laws decree “Death by a thousand cuts for me”.

My life flows away like an ebbing tide

That takes my courage and humbles my pride.

My independence stripped away as I linger on for another day.

I have no choice’

Eileen E Dawe

***21st September***

I am comfortably starving to death.

We tried to find a gentler choice – one that our fellow Australians do not approve of or permit. So I must abide by their wishes.

***Friday 25th Sept***

Over two months of pain relief. Not my choice. Another awakening to a day of medication. The threat of pain hanging over me as I wither away to that shrunken bundle being quietly discussed.

My hearing and eyesight, along with comprehension deteriorate. The perplexed eyes of a stranger return my gaze.

First moments awakening bring sadness and dismay with the realisation that my continued existence seems interminable.

***Sunday 27th Sept***

If it is illegal to shorten one's life by administering drugs, which is it not also illegal to give drugs to a patient to extend their time of dying. Both must be unnatural practice against the laws of nature. Is the desire to end suffering an irreligious act against so-called gods? Is suffering and pain something to be endured to gain access to a so-called afterlife?

***Monday 5th October***

Another restless night. 11 weeks since diagnosis. Another day of sad routine. Does it have to be so long?

***23–24th October***

Body starting to reject all food and liquid – pain (physical) not evident.

***25th Oct***

Another morning as I lapse into all that I did not want to become. Perhaps my sanity next to go. Pain is menacing.

***2nd Tues Nov***

It's like waiting for a train that never comes in.

***Friday Nov 13th***

Eyesight failing [and] early July my last real meal. Meals are a dry biscuit. Nothing really interests me for future. Sleeping a lot. Mind wanders a lot. I watch my daughter toil and my life slips away. What egotistic monster would subject another

29th SUNDAY

NOV. 1:55 wander round the house NO.

7:05 AM SUNDAY  $\frac{1}{2}$  steroids, 2 PAN -  $\frac{1}{2}$  METAL

8 AM hungry legs a bit stiff no pain (nightmares through the night should Carol caring for me at home. 11:50 SUND 2

SUNDAY, 2:30 PM I keep this record so I will see my medication as I become more vague. Carol checked medication earlier. We had a cuppa and smok. The girls so good and loving.

My treatment consists of semi-starvation release from hospital 18th Sept. Some days better others from Friday Sept 11th. I have not suffered deal of pain, some few happy days. The question ask why must it all go on for so long. I want to die, I am happy to die. Why drag out a long long suicide. How many people have it as good as me. How many in loneliness, poverty & fear. Fear of pain is all I anticipate or how long it will stretch the time ahead the grief for those behind me.

Some days I eat a little food usually ~~goes~~ diarrhoea long stretches between or lots of frothing mouth, slight vomiting. Sometimes very weak at some time very energetic. I love my little garden that gives me enjoyment & Beauty like the birds. I do so hate the ~~long~~ long long farewell I just have the life that was mine any more I am happy. SUNDAY NOV. 29th " lovely day the girls & caroline + on lunch for them quarter to noon I wake up and see and TUES & Bed again & METAL DONE 1 HOUR

human a peaceful departure with friends and loved ones. I fear for those less fortunate than me and still dread what will be my as yet unknown end will be.

***Sunday 29th November***

...My treatment consists of semi-starvation since release from hospital 11th September. The question I ask [is] why must it go on for so long? I want to die, I am happy to die. Why drag out a long, long, long suicide.

Some days I eat a little food – usually gives diarrhoea or lots of frothing from the mouth, slight vomiting. Sometimes very weak as I tire [but] sometimes very energetic. I love my little garden of plants that give me enjoyment and beauty like the birds beyond. I do hate the long, long farewell. I just do not have the life that was mine anymore. I am happy to go...

Glad did I live and gladly die.

Eileen E Dawe

“ I do hate the long, long farewell ”

## Emotionally excruciating ...almost surreal

I am a 60-year-old woman who has been diagnosed with primary peritoneal cancer, Stage IV, which is a terminal illness. I have for many years believed that clear-thinking adults who are terminally ill should be legally allowed to have the help of a compassionate doctor and drugs to let them end their lives peacefully and painlessly at the time they want to. The alternative may be weeks or months of emotional and/or physical pain and anguish.

I have had a busy and fruitful life. I have a husband and two sons and the idea of them watching me slowly and painfully waste away and die because there is nothing anyone can do to avert it is emotionally excruciating, almost surreal. It would give me enormous peace of mind to know I had some control and that I could hopefully spare them and myself a little suffering.

Ms Leith Richards

“it would give me enormous  
peace of mind to know I had  
some control”

## **This tortuous death is my greatest fear**

In 2014 I had a cold. It was very painful and on 10 November 2014 I experienced the worst pain I ever had in my life (by magnitudes). I could only imagine that my eardrum had ruptured or something.

By the 11th, the pain had only increased if anything. I wanted to go to the GP but I couldn't take myself there, so I asked my mother to drive. As we were in the carport I opened the car door and I collapsed onto the ground with a grand mal (tonic-clonic) seizure.

“Being alive as my brain literally dies will be unbearable”

I was admitted into John Hunter Hospital in Newcastle where a large mass of approx 'very large chicken egg' size was found. It was a tumour. Shortly before Christmas I received the pathology results: Grade 3, anaplastic, aggressive, malignant, ganglioglioma. Prognosis two to five years. I was 33 at the time.

For myself, I'm not afraid of death. Death is nothing, it's void, it's null. I'm no more scared of death than I am of the non-existence before my birth. What troubles me is pain. What troubles me is being alive but incapacitated. I've already felt that pain. It's horrific. I cannot put into words the feeling of that pain, that pressure pain. It's as though your entire brain is being forced out of your skull. In many ways that's what's happening. And pain meds can only treat that so far. Most opiates can't help it. Steroids are what they use, but they often have side effects.

As for losing my ‘sense of self’, I’m a hardcore nerd. I’m almost narcissistic to my brain. I like being a nerd. I enjoy knowing things. My greatest phobia is to lose my mind. So being alive whilst my mental ability goes, as my brain literally dies (grade 4 cancer is necrotic cells) will be unbearable.

The end game for my tumour, given that it’s a left-side parietal tumour, is possibly: partial blindness, right-sight paralysis, being mute, cognitive impairment, pain.

I already get headaches about daily now. I get ‘bad headaches’ about every two to three days or so. I can generally push through these but, what happens when I can’t? At the moment I just have to keep suffering and keep living. So here’s something that is rarely discussed with euthanasia. The lack of euthanasia laws depresses me. The fact that I know that, in my final days, I’m going to be forced to experience this torturous death in my greatest fear – depresses me. I’m spending my final years depressed not from ‘dying’ but from the ‘method of dying’. If, however, we had euthanasia laws and I knew I could say, ‘Right! When it gets to that point, I have a plan in place’, I no longer would be worried. I’d be happier. I wouldn’t have to face that torture.

This is a very important point so let me state it again.

Euthanasia laws, by their existence, make terminal illness easier to live with.

I doubt the laws will be in place before I die, unless I get high on the bell curve for my cancer. Odds are on I’ll have to figure out my own exit or I might get ‘lucky’ and die suddenly.

But I hope that the more I can comment on it, and leave traces of my opinion – first hand – as someone living with terminal illness, hopefully people (politicians) will start to address this dire need for law reform.

John Grayson



## Not allowed to die but allowed to suffer

**M**y name is Loredana Alessio-Mulhall and I have advanced, progressive multiple sclerosis. I am totally disabled and can't move anything except my head and my mouth. I have had a catheter for 10 years and a colostomy for 15 years and for me there is no turning back. It is too late for me. Although I can't move, I feel everything and have pain every day and nerve pain is the worst.

I live at home in my unit and I have carers for a total of eight hours per day. This is the maximum number of hours allowed and as my condition continues to deteriorate this makes my life very difficult.

I am a very positive person and I only started to think seriously about voluntary euthanasia in the last few years. People who oppose voluntary euthanasia just have no idea and they don't want to face the reality of my situation, which makes it so much worse for me. I am not allowed to die but I am allowed to suffer.

Whenever I am interviewed, I ask people to please come and speak to me – politicians, church leaders, anyone, just come and speak to me. But no-one ever does. They could call me, that would be easy, but they never do. So that proves to me that they just aren't interested, they just don't care.

Opponents can close their eyes and ears but they don't have my pain and they don't have my fear. All I want is for voluntary euthanasia to be legalised so that people like me have a choice when my suffering becomes unbearable.

There are many people like me but not everyone can speak up. Some are too sick, some too shy or too scared, or some are

just very private...and that is fine, of course, but I want to talk. I am tenacious and I will never give up.

When people say that legalising voluntary euthanasia will change the role of doctors as healers, I think, what a quantum leap that is. Doctors should help alleviate suffering when they can't heal. Nurses understand and that is why so many of them support voluntary euthanasia law reform. Doctors don't always see the suffering.

I support palliative care but it doesn't work for everybody and it can't ever work for me. I have been to hospital before but nobody can look after me properly in there. It is always so traumatic because I can't take my carers and the nurses don't know what to do with me. Nurses are just not trained to look after someone like me and there is no time to train them. Life is hard enough for me at home but at least it is not traumatic. Home is the best place for me. It is the only place for me.

“ I can't even suicide because  
I can't use my hands ”

With MS everything goes, all the muscles go and, after 40 years, it is now affecting my voice. What terrifies me the most is what will happen to me when I am unable to communicate with my carers. Nobody is going to say what will happen to me... they don't want to. Even now my voice is going and sometimes it is very difficult to communicate. It depends how stressed I am. Stress is my enemy. I have already reached the stage where I can't speak in a room full of people. If lots of people are talking, I can't speak at all...my voice just goes, it literally just goes. When my

voice goes and I can no longer tell my carers where my pain is, what will I do?

The big problem for me is that I can't even suicide because I can't use my hands. I can't get anyone to help me because it is illegal. So I am left feeling very frightened, very fearful and under a great deal of stress because I wonder what is going to happen to me.

I have already lost so much independence but I don't want to be a vegetable, or treated like a vegetable when I still have a brain. That is what frightens me...not dying. What really frightens me is the pain and the agony of seeing what has become of me.

That is why I need voluntary euthanasia to be legalised so that I take something and just go peacefully, when I am ready, without any concern. Wouldn't that be beautiful? To be with my family and just go to sleep.

It is hard to argue with that and that is why politicians and others just won't come and talk to me. We are fighting for something that these people, the politicians, just don't want to face. That's why we can't get anywhere with them. But we have to find a way.

With this issue, I will never give up.

As told to Shayne Higson

## I might have to kill myself

I have an incurable cancer and have been given a year or so to live. While I have never smoked I have lung cancer. I have had two years of chemo and radiotherapy and my life, and that of my family, has been on hold. We are all waiting for me to die so they can get on with their lives. It's a cruel disease – any terminal or incurable disease is – as it takes away your normal life, your sense of future, hope and the normal thoughts of getting better, and while treatments are of course welcome, they are generally unpleasant and bring unpleasant side effects that make living not great.

I want to be able to choose a comfortable, stress-free way to die. I want to see people like me having the choice to not endure horrible last stage dying. I want my family to not have to watch me suffer through horrible last stage dying.

In the absence of legal euthanasia someone like me might have to kill myself earlier than I would choose, when I am still physically able to do whatever kills, so that no-one else is implicated. That is not the choice about dying I would want to make.

Lynne Wannan, AM

“ I want my family not to have to watch me suffer through horrible last stage dying ”

## **The end is pretty grim when it happens**

I have just turned 41. A pretty big life event for many, but in my case especially. Three years ago I was diagnosed with a glioblastoma multiforme, the most aggressive and invariably fatal form of brain tumour. I have been lucky to make it this far; the median survival time is 17.1 months. The end is pretty grim when it happens. I will be victim to a creeping paralysis and increasing loss of cognitive function, until I am paralysed and delirious. There will also probably be quite a lot of pain from increased intracranial pressure. I will slip in and out of coma until I die. This process could stretch out for quite some time.

Right now life is certainly worth living. I tire easily and my cognition is not what it was, but I can enjoy life. But there is going to come a time when I am going to be paralysed and suffering and the last images my friends and family will have of me will be that, as I slowly waste away until, at last, I die. By the stage that life is no longer worth living I will be effectively unable to do anything about it. And I most certainly could not ask anyone to assist me or I would leave them open to criminal charges.

I would ask you why. Why should any human be sentenced to such a horrible ending? Why should my friends and family go through that? And why should I? When my beloved whippet was in horrible pain due to a rare medical condition with no cure or pain relief we had the option to put her out of her misery. Why do pets get more consideration than humans?

As someone who has had their life cut in half, I beg you to do all you can to change the laws to allow me, and others like me, to die with dignity.

Lachlan Smith



TO WHOM IT MAY CONCERN, I HAVE RECENTLY LOST MY HUSBAND AFTER A LONG & DEBILITATING ILLNESS, HE CONTINUALLY ASKED TO BE ABLE TO DIE. THIS IS A DECISION THAT A PERSON SHOULD BE ABLE TO REQUEST WHEN AN ILLNESS IS TERMINAL OR THERE IS NO CHANCE OF HAVING ANY QUALITY OF LIFE, THE DECISION SHOULD BE MADE WITH THE TREATING DOCTOR & THE PERSON CONCERNED PROVIDING ALL AVENUES HAVE BEEN DISCUSSED WHILE OF SOUND MIND WITH FAMILY & DOCTOR.

Yours Sincerely  
THELMA POPE



## Living the dying

**T**wo things in life are certain: death, and the fact that we must remain alive until we die. When we hear of people living their dying slowly and painfully in empty, bleak and degrading circumstances in this country, we shudder in horror. We hope that if it happened to us, we would have another choice.

For most of us it is intolerable that someone experiencing unbearable suffering should be forced to remain alive against their wishes. Most Australians want laws permitting voluntary assisted dying, but our wishes are disrespected by the politicians elected to represent us.

Carefully crafted voluntary assisted dying laws will take time to implement. If you or someone you love needs the comfort of those laws, it will be too late to turn your attention to them when that need is pressing upon you.

In 2009 I was diagnosed with primary progressive multiple sclerosis. Seven years later, I could describe the horrors of advanced MS to you, and how it has dismantled my life, piece by piece, but that would just be words on a page. Can you truly imagine the unimaginable and the endurance of the unendurable? Consider what it means to lose your mobility, your job, your driver's licence, your identity and autonomy. To be forced into a sitting position in a wheelchair all day, every day until you die, with the risk of contractures and other physical deformities, or injuries such as pressure sores, or to be bedbound, housebound, with little to do, in unrelieved pain, perhaps unable to dress, toilet, bathe or feed yourself. Can you imagine that the living of a 'dying in slow motion' could cause you to welcome death, or even long for it?

We want to believe the fiction that our institutions can ease our suffering and provide us with a meaningful existence right up until the end. Presently the only choice for many with a terminal or chronic illness, advanced old age, or degenerative cognitive decline is to suffer an unspeakable fate or commit suicide. They cannot even talk to their doctor about their wishes. Can you imagine their despair?

The barbarity of Australian law makes the only avenue of escape from intolerable suffering an act of suicide, in lonely, slow, and violent ways. Our laws prevent us from ending our lives using a medically prescribed compound that will end life swiftly and painlessly, or to do so in the company of people who care about us. Australian law says that suicide is legal, now go away quietly on your own, out of sight, and do it in the most horrifying way imaginable.

At the centre of that casually imposed cruelty is a minority who have decided that they will tell us what will happen to us at the end of our lives and how we will live our dying.

Voluntary assisted dying is voluntary. It is about personal choice and cannot be imposed on anyone. It should be available not only to the terminally ill but to the chronically and incurably ill, and to those ravaged by advanced old age. The criteria should be unbearable suffering and quality of life, not some arbitrarily chosen time left remaining before death.

Australians overwhelmingly want to define a more compassionate way of approaching death that gives choice to the person who is actually living the dying. We must not turn away.

Lawrie Daniel







# Appendices

# **Appendix I:**

## **The Parliament of Victoria's Inquiry into End of Life Choices**

In 2015 the Victorian Parliament inquired into the need for laws to allow citizens to make informed decisions regarding their own end of life choices. It was the first serious inquiry into end of life choices by an Australian Parliament. The Victorian Parliament's Legal and Social Issues Committee assessed end of life practices currently occurring within the Australian medical and wider communities. It also reviewed existing legislation, both in Australia and overseas, and considered how laws should change.

Running over 10 months, with over 1000 submissions, and hearings involving 154 witnesses over 17 days of public hearings, this is the most extensive inquiry into end of life choices ever conducted in Australia. It was also the first time an Australian parliamentary committee has travelled overseas to see for themselves how laws for assisted dying actually work.

The Committee reported to the Legislative Council in June 2016.

### **What the Committee found**

- Death is a taboo subject in Australian society. People don't like to talk about it or plan for it.
- Existing Australian laws relating to end of life care are confusing and cause uncertainty, particularly for health practitioners. Even if a person has completed an advance care plan, the law does not provide certainty that a person's wishes will be carried out when they lose capacity to make their own decisions.

- The current illegality of assisted dying can cause great pain and suffering for those who endure terminal illnesses. Inadequate pain treatment as a consequence of health practitioners' uncertainty about the law was a repeated theme.
- People experiencing an irreversible deterioration in health are taking their own lives, often in horrific circumstances that traumatise their families.
- Doctors practice unlawful assisted dying despite its prohibition and despite prospective liability for serious crimes. This is happening without regulation, without support, without transparency or accountability, and sometimes without consent.
- Although courts impose lenient penalties without jail time on people who do assist loved ones to end their lives, the potential burden of a court battle compounds carers' distress and grief.
- There are many benefits of palliative care, an area of medicine which has advanced significantly over the last decade. However, palliative care does have limitations, as described by Palliative Care Victoria, who explained that palliative care can sometimes be ineffective at relieving all suffering.
- Some doctors will do what they consider to be necessary to end a patient's suffering when they are at the end of life. This may be through continuous palliative sedation, even if this may unintentionally result in death. However, its use is not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it.
- Some people are choosing to stop having treatment, knowing that this will result in their imminent death.

Others spoke of the trauma of watching seriously ill loved ones refuse food and water to expedite death and finally relieve their suffering.

- In other countries where assisted dying frameworks have been introduced assistance in dying is, in the vast majority of cases, given to people in what would otherwise be the final weeks of their lives. Government support and funding of palliative care has not declined when such frameworks have been introduced.
- Everyone's end of life care needs differ, and that it is important that a system be in place to cater for the needs of individuals, whilst ensuring that there are safeguards in place to protect vulnerable people.

In its conclusions, the Committee rejected maintaining the status quo as an inadequate, head-in-the-sand approach to policy making and the plight of the Victorians discussed in their report. They recommended a law that would allow people to seek assistance to die. In their words, this would: 'not only enable patients' end of life wishes to be respected, but also to protect patients, particularly vulnerable people, from abuse and coercion'.

The Committee also found strongly in favour of increased resources and funding for palliative care. In so doing, they made it abundantly clear that assisted dying and palliative care were both important points on the spectrum of end of life care in general.

In emphasising this, the Committee highlighted the words of the man known as the 'father of Australian palliative care', Professor Ian Maddocks, who said: 'Rather than fighting a rear-guard action, I suggest the proponents of palliative care join forces with advocates of assisted dying, and with mutual respect

and dialogue ensure that enabling laws are framed with a care and precision that allows no abuse and promotes best outcomes.’

### **What happens in other countries?**

Five members of the Committee visited international jurisdictions in order to better understand the various procedures and regulations in place. The Committee reported that:

We were warned against change on the basis of what, purportedly, has occurred in jurisdictions that have legalised assisted dying. To evaluate these claims, five members of the Committee travelled to the Netherlands, Switzerland, Canada and Oregon. We met with academics, regulators, healthcare professionals, supporters and opponents of the different legalised assisted dying frameworks.

The Committee met with doctors, medical and legal experts, palliative care specialists and disability rights groups in jurisdictions where assisted dying is legal and who highlighted the rigorous safeguards, monitoring procedures and high levels of compliance in their jurisdictions.

While these jurisdictions differ significantly in their assisted dying models, what they all have in common is robust regulatory frameworks that focus on transparency, patient-centred care and choice. We found no evidence of institutional corrosion or the often cited ‘slippery slope’.

The Committee found that Switzerland, the Netherlands, the province of Quebec in Canada, and the state of Oregon in the USA all have legislative frameworks that enable voluntary

euthanasia and/or assisted suicide. Eligibility, safeguards and practices vary widely between jurisdictions. Despite the fact that, in some cases, voluntary euthanasia and assisted suicide remain criminal offences in principle, the systems provide legal protection for medical practitioners who report their actions and meet all due care criteria.

It has taken up to 30 years of thoughtful, ethical, medical and legal discussions in those countries to establish workable legal frameworks around assisted dying. Details of the history and legislation for each international jurisdiction is provided in *Inquiry into end of life choices Final Report, 2016*.

The Committee identified the best elements of the different systems and incorporated them into their recommended assisted dying framework for Victoria. The Chair of the Committee, Hon Edward O'Donohue MLC, wrote:

In recommending an assisted dying framework for Victoria, the Committee has sought to adopt the best elements of these jurisdictions and mould them to the Victorian context. The proposed model contains several significant checks and balances that seek to protect individuals from exploitation, while facilitating choice in certain limited circumstances.

The Committee has sought to strike an appropriate balance between respecting the end of life choices of Victorians while recommending a sufficiently robust eligibility framework for competent adults that protects against abuse.

Like in other jurisdictions, the Committee anticipates that while a comparatively small number of Victorians will die using the assisted dying framework

(approximately 0.4 per cent of all deaths in Oregon and Switzerland), many others will take comfort from its existence, knowing that another option exists.

The Committee recognises that assisted dying is contentious, that is why there should be no legal, moral or ethical compulsion on any individual or institution to participate in any part of this process, including through referral.

### **What the Committee recommended**

In its report the Committee stated that the Victorian Government should introduce legislation to allow adults with decision-making capacity, suffering from a serious and incurable condition, and who are at the end of life, to be provided assistance to die in certain circumstances. This should include amending the Crimes Act 1958 to provide the exemptions necessary to protect health practitioners who act within the provisions of assisted dying legislation.

Assisted dying should, in the vast majority of cases, involve a doctor prescribing a lethal drug that the patient may then take without further assistance. The singular exception is where people are physically unable to take a lethal drug themselves. In this case, a doctor should be able to assist the person to die by administering the drug.

The Committee set out the following criteria:

- ***Conscientious objection*** No doctor, other health practitioner or health service can be forced to participate in assisted dying.
- ***Eligibility criteria and assessment*** Assisted dying is intended to provide an option that can limit suffering at the end of life. It is not a way to end life for those who are otherwise



not dying. A primary doctor and an independent secondary doctor must approve each request for assisted dying. Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the patient's specific condition. Each doctor must independently judge whether the person's request satisfies all of the criteria outlined below. The exception to this is the suffering component. It is essential that the patient must be experiencing enduring and unbearable suffering that cannot be relieved in a manner which they deem tolerable. This is fundamental to patient-centred care, and is a subjective measure judged by the patient themselves.

- ***The person*** The individual must be over 18 years of age and have decision-making capacity about their own medical treatment. Patients whose decision-making capacity is in question due to mental illness must be referred to a psychiatrist for assessment. The person must be ordinarily resident in Victoria and an Australian citizen or permanent resident.
- ***The condition*** The illness must be occurring in the final weeks or months of life. The condition must be serious, incurable, and causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable. Suffering as a result of mental illness alone does not satisfy the eligibility criteria.
- ***A properly informed decision*** The primary and secondary doctors must each properly inform the patient of the diagnosis and prognosis of their condition, as well as the treatment options available to them, including any therapeutic options and their likely results. They must provide information about palliative care and its likely

results. It must be made clear that the patient is under no obligation to continue with a request for assisted dying and may rescind their request at any time. The doctors must explain the probable result and potential risks of taking the lethal drug.

- ***The request*** The patient must make the request personally. It cannot be included in an advance care directive. It must be completely voluntary, free of coercion and result from a properly informed decision. It must be repeated three times in the form of an initial verbal request, followed by a formal written request signed by two independent witnesses, and then as a final verbal request.
- ***Checks and balances*** The primary and secondary doctors must be independently satisfied that the patient's request has not been made on a whim, is enduring and that a reasonable amount of time has passed between the patient's initial request and the provision of a lethal drug. In making this judgement the primary and secondary doctors must have regard to the patient's particular condition and its likely trajectory. The primary and secondary doctors must also assess the reasonableness of the request. This is to ensure that the patient truly understands and appreciates the nature and consequences of the decision to request assisted dying, as well as the alternatives to assisted dying, and that the patient's request is not ambivalent. The patient may withdraw their request at any time. Once withdrawn, the request becomes void, and the primary and secondary doctor must assess any subsequent request from the beginning.
- ***Review and support*** Within its framework for assisted dying the Committee recommended the establishment of a robust oversight, review and reporting structure. An Assisted

Dying Review Board would assess each case of assisted dying to ensure doctors follow all procedures and comply with all requirements of the legislated framework. It also recommended the establishment of a new entity, End of Life Care Victoria, to provide information and guidance on end of life care to health services, practitioners and the wider community. As well, it recommended ongoing academic research into end of life care in order to provide continuing improvement in services for the community.

Source: <http://www.parliament.vic.gov.au/lsc/inquiry/402>

## Appendix II:

### Explanation of terms

***Advance care directive*** This is a written statement that sets out your wishes for medical treatment at the end of life. You must be competent when you sign it. You can list specific conditions under which you do not want particular treatments such as resuscitation, antibiotics, or artificial nutrition or hydration. You can specify what you believe would be an unacceptable quality of life, and can refuse medical treatment if your situation meets those criteria. In that instance your Advance Care Directive is legally binding and nobody can override it. Nonetheless, the Victorian Parliamentary Inquiry into End of Life Choices found in its 2016 report that ‘even if a person has completed an advance care plan the law does not provide certainty that a person’s wishes will be carried out when they lose capacity to make their own decision’.

***Advance care planning*** This process involves thinking about and deciding what sort of medical treatment you wish to receive in the future, at the end of life. It helps guide doctors, family and friends in making decisions that fulfil your wishes and are in your best interests. Advance care planning can be done at any age or level of health. One of the most important parts of planning includes the legal appointment of someone you trust to be a substitute decision-maker if you can no longer speak for yourself. Another aspect of planning involves completing a written document, called an Advance Care Directive, that clearly outlines your wishes.

***Assisted suicide*** A competent person dies after being provided with the means or knowledge to kill themselves by a friend, relative or other person. It is a crime to aid or abet another person to commit or attempt to commit suicide.

***Capacity/competency*** People are said to be competent, or have capacity, if they have sufficient understanding and memory to comprehend the nature and consequences of a decision, and to evaluate and weigh relevant information in making that decision.

***Continuous palliative sedation*** Medications administered to induce a continuous state of unconsciousness until the person dies. It is generally considered a treatment of last resort when a patient's pain and suffering can no longer be controlled. Conceptions of continuous palliative sedation, and its moral and ethical equivalence to, or distinction from, assisted dying are contested in academic literature. The Victorian Parliamentary Inquiry into End of Life Choices (2016) found that the use of palliative sedation 'is not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it'.

***Doctrine of double effect*** If doctors cannot restore a patient to health they are entitled to provide treatment necessary to relieve pain and suffering, even if that treatment incidentally shortens the life of the patient. What it means is that, if you are tending to someone who is dying, you can give them medication which may have the unintended effect of helping them die more quickly but only if your actual intention is to ease suffering. What you must not do is give them medication with the intention of helping them die. Even if only death will

end their suffering. This doctrine protects doctors where they are charged with hastening the death of patients. The doctrine of double effect's legal status in Australia is, in most states, based on English case law. The doctrine has also been accepted as law in the United States and Canada. Three Australian states – Queensland, Western Australia and South Australia – have incorporated the doctrine of double effect into legislation.

***Medically assisted dying*** A doctor provides a person with a prescription to obtain a lethal dose of a drug. Assisted dying is illegal throughout Australia but increasingly there are cases of doctors providing patients with drugs to end the patient's life, upon their request. These doctors have not been prosecuted.

***Nil by mouth*** This is a medical instruction not to eat or drink anything at all. If it is written above a patient's bed it alerts nurses not to provide food or drinks of any kind.

***Palliative care*** This includes a range of treatments that relieve a dying person's pain or suffering. It can include medical, physical, mental and spiritual comfort for both patients and their carers. The word 'palliative' comes from the Latin word *palliare*, which means to cloak. So it comes to mean alleviate or even, disguise, the pain of dying. The central credo of palliative care, 'we shall neither prolong nor hasten death', comes from the 13th century priest and philosopher Saint Thomas Aquinas. Nearly 60 per cent of Australia's palliative care services are provided by the Catholic Church.

***PEG*** This is an abbreviation for Percutaneous Endoscopic Gastrostomy. It is a way of delivering food, via a tube, directly

through the skin into the stomach. A doctor makes a surgical hole through the abdominal and stomach walls and fixes the tube in place. People who cannot swallow food temporarily or permanently can benefit from PEG feeding.

***Refuse medical treatment*** Every competent adult has the right to refuse medical treatment, including artificial feeding, hydration and respiration. Patients can include their own perception of their quality of life when deciding to refuse any medical treatment.

***Voluntary euthanasia*** A doctor injects a competent patient, at their request, with a lethal substance to relieve that person from unbearable physical pain and suffering. Voluntary euthanasia is not legal in Australia.

***Withdraw/withhold treatment*** In Australia doctors have no duty to provide treatment that is futile. They are required by law to use care and skill in determining which treatments are in their patients' best interests. Enduring Guardians in all states and territories of Australia have a right to request the withdrawal or withholding of treatment if that treatment is not in the best interests of the patient. Doctors are protected at common law from liability for withdrawing life support where the treatment is futile and confers no benefit. In Australia there is no obligation at common law to obtain a patient's consent or the consent of her or his loved ones before making this decision. Consent is not required and neither is authorisation from any other source such as a court, tribunal or statute.

## **Appendix III:**

### **For more information**

For further information about end of life choices contact:

#### **ACT**

**Dying With Dignity ACT**

PO Box 55

Waramanga ACT 2611

EMAIL [secretary@dwdact.org.au](mailto:secretary@dwdact.org.au)

WEB [www.dwdact.org.au](http://www.dwdact.org.au)

#### **New South Wales**

**Dying with Dignity New South  
Wales**

PO Box 25

Broadway NSW 2007

PHONE (02) 9212 4782

EMAIL [dwd@dwdnsw.org.au](mailto:dwd@dwdnsw.org.au)

WEB <http://www.dwdnsw.org.au/>

#### **Northern Territory**

**Northern Territory Voluntary**

**Euthanasia Society**

GPO Box 2734

Darwin NT 0801

EMAIL [ntves@bigpond.com](mailto:ntves@bigpond.com)

WEB <http://ntves.org.au>

#### **Queensland**

**Dying With Dignity Queensland**

PO Box 432

Sherwood QLD 4075

PHONE 1300 733 818

EMAIL [enquiries@dwdq.org.au](mailto:enquiries@dwdq.org.au)

WEB <http://dwdq.org.au/>

#### **South Australia**

**SAVES**

Hon Secretary, SAVES

PO Box 2151

Kent Town SA 5071

PHONE 0421 305 684

EMAIL [info@saves.asn.au](mailto:info@saves.asn.au)

WEB <http://www.saves.asn.au/>

#### **Tasmania**

**Dying with Dignity Tasmania**

PO Box 1022

Sandy Bay TA 7006

PHONE 0450 545167

EMAIL via contact form on website

WEB <http://dwdtas.org.au/>

#### **Victoria**

**Dying with Dignity Victoria**

5a/602 Whitehorse Road

Mitcham VIC 3132

PHONE (03) 9874 0503

EMAIL [dwdv@dwdv.org.au](mailto:dwdv@dwdv.org.au)

WEB <http://www.dwdv.org.au/>

#### **Western Australia**

**WAVES (Inc)**

PO Box 7243

Cloisters Square

Perth WA 6850

PHONE 0449 969 544 (Murray Hindle)

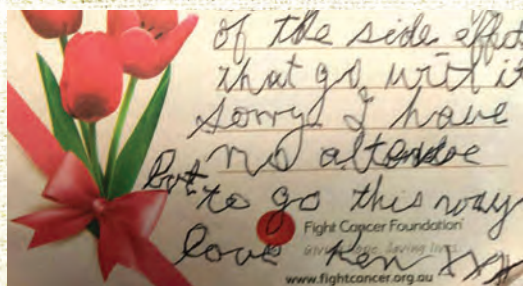
EMAIL [info@waves.org.au](mailto:info@waves.org.au)

WEB <http://www.waves.org.au/>



**‘There is a cry for help.  
It may be muted, it may be  
veiled, but it is there nonetheless  
and they all know it – including  
doctors. They know that this  
person is screaming for help,  
but no-one is going to answer  
this call; not in this society.  
So they have got to die alone.’**

**Coroner John Olle’s testimony to the  
Victorian Parliamentary Committee’s  
Inquiry into End of Life Choices**



**THE DAMAGE DONE** is a collection of testimonies from patients and families, doctors, nurses and coroners that describes the suffering across Australia created by the absence of a law for assisted dying.

Written by contributors aged from 14 to 100 years, these testimonies ask serious questions of our society.

How much longer can we allow this damage to continue? And who amongst our politicians has the courage to address it?