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Why we need to talk about death

Medical intervention is a default response instead of allowing people in the last stage of life to make the most of the time left. One family's experience shows what might be gained if we do.

By NATASHA ROBINSON

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There are so many things Melissa Reader wishes she could have said to her husband Mauro Bertolini, the father of her three tiny children, before he died. Chief among them is a simple acknowledgment that death was inevitable.

“That would have been very hard to hear, of course, but I think probably pretty transformative for the decisions we would have made,” Reader says.

Bertolini was only 39 when his abdomen began to swell and his body filled up with fluid. A scan revealed kidney cancer that had been growing silently and had already spread to his liver and lungs. Reader and Bertolini’s eldest child was just five and the youngest only nine months old when the diagnosis of renal cell carcinoma rocked their young family’s world.

“You just go into an absolute fog,” Reader, now 49, says. “Everything you thought you knew to be true changes overnight. We never really understood the severity of his diagnosis. Nobody really explained that to us.

“They immediately put Mauro on treatment, which you think is going to potentially correct this or at least help him stay as well as possible. But there was certainly no conversation that this is life limiting, this is terminal.”

Much of the last 18 months of Bertolini’s life were stressful and traumatic for the whole family as he cycled in and out of hospital.

“There was just a constant flow of treatments and interventions,” Reader says. “His lungs collapsed multiple times, so he would go and have procedures to try and reinstate that. And it just meant that he was in hospital for weeks at a time away from us.

“The kids were really frightened going to hospital, he was really lonely and frightened. And he should have been at home with us, we should have been receiving care at home.

“I felt like I was kind of carrying the weight of betrayal because if I had ever tried to tell him that I was really concerned about where things were going, if I had stepped out of that space of hope and positivity, I really felt like I would have been betraying him. I didn’t have the skills to do that. I didn’t know where to get the help.

“For my kids, they didn’t see their dad very much in that last six months. And when they did, they were pretty frightened to see him, you know, hooked up to a bunch of machines in a pretty clinical, frightening setting.”

Bertolini died on February 11, 2011, intubated, in an acute care bed in the Royal North Shore Private Hospital in Sydney. The night before, Reader had received a hurried call in the middle of the night from the hospital, wanting to discuss a do-not-resuscitate plan that she struggled to understand and didn’t have time to process.

Before Bertolini’s consciousness began slipping away, he was administered increasing doses of morphine as his pain escalated, and he was terrified. His two youngest children did not get to say goodbye in those final moments. The scene was too confronting.

The lead-up to Bertolini's death was so stressful and overwhelming for the family that the unfortunate but essential legal business of death was not attended to. He died without a will. A decade later, Reader is still tying up loose ends from his estate.

"The death that Mauro had was not what anybody would have wanted," Reader says. "All of that precious memory-making and time that we should have spent together, that would have meant so much to the children now in their teenage years, didn't happen.

"There was not a single conversation about care planning, or financial or legal planning. I was in an absolute blur and a whirlwind, and I was trying to get through one day at a time, I didn't know how to approach it any other way.

"Even now, having to push the death certificate over the counter in front of strangers constantly over and over and over again, it's a horrible experience."

Now Reader, who has a background in business and brand strategy, is on a mission via the Violet Initiative, a national not-for-profit organisation that she founded, to bring the realities of death out of the shadows. The Violet Initiative, which has an associated technology platform that helps people talk about and plan for the last stage of life, is chaired by former ACT chief minister and former businesswoman Kate Carnell.

It's a mission aimed squarely at improving the human experience of millions of people facing one of the most stressful and emotionally devastating experiences of their lives, but it's also a project of critical importance to the sustainability of the nation's health system.

"We are all going to die," says Carnell. "The youngest baby boomer will turn 60 this year. And so this big chunk of the Australian population is now moving into the expensive part of healthcare. We've got to create a better system and a better experience for people in the final stage of life. It's bleedingly obvious really."

With the number of deaths each year expected to double by 2040 as Australia's population continues to age, the health system will be crippled if the way we manage death and dying does not transform.

Already, 11 per cent of the federal health budget is spent on the 1 per cent of people who die in any given year, with the costs estimated at $4bn annually. Much of that expense relates to the fact many people die in hospital in acute care beds, despite surveys consistently revealing most people want to die at home.

Too often medical intervention is the default response in the care of terminally ill people, without the time or space for an honest reckoning of the utility of such treatments that often simply delays the inevitable without consideration of the human cost.

“In the Western world we have created a death-denying culture, which seems unwilling to acknowledge and allow for planning a high-quality death,” says Australian National University professor Imogen Mitchell, executive director of research and academic partnerships at Canberra Hospital.

Mitchell’s thoughts are contained in a foreword to a research report, launched last week by the Violet Initiative, entitled Too Little, Too Late: The Experience of the Last Stage of Life Across Australia.

They are based on her decades of experience as an intensive care unit specialist physician, bolstered by academic research she has led that indicates medical records tend to document formally that a patient is dying only a very short time before death.

“In acute care hospitals, healthcare professionals are programmed to ‘fix’ patients even in their last stage of life,” Mitchell writes.

“The consequence of such a paradigm is that patients who are dying receive non-beneficial treatments, which can often be invasive and painful, in lieu of ensuring patients are comfortable, relieved of suffering and in an environment of their choice at the time of death.

“With the acute care hospitals bearing much of the load of the dying, it places an additional burden on to the already constrained public healthcare system.

“There is a burning platform for the need to change, given the significant increase in the elderly population over the next 20 years and the number of people dying.

"Without changing the way we care for our dying, individuals and their carers are unlikely to routinely experience a safe and high-quality death."

The "burning platform" of which Mitchell speaks is already aptly demonstrated in every public hospital in the country, where an average of one in four beds is taken up by the often frail elderly.

An Australian Medical Association report last year found that 20,000 patients at any time nationwide were stuck in public hospitals waiting to be discharged into appropriate residential or in-home care, and about 10 per cent had been waiting more than 35 days.

Sadly, some of these patients never make it out of hospital, with the experience of being stuck in a ward leading to rapid deterioration.

Hospital exit block not only means thousands of elderly people are denied the death at home they want, but across the system the knock-on effects are crippling: there are fewer beds for inpatient services, ambulances ramp with patients who cannot be offloaded, emergency departments are clogged, and elective surgery lists frequently must be cancelled.

Canberra grandmother June Emblen was 92, fit and independent when a fluid build-up in her body triggered a hospital admission during the October long weekend in 2021. Although the immediate issues were resolved, she was experiencing heart failure and doctors did not believe she could live at home any longer.

But finding an aged care place amid such significant health challenges was almost impossible, says daughter Sheryle Moon. And palliative care usually is provided, sometimes in a hospice, only at the last possible moment, meaning many people miss out on being provided it at all. Emblen deteriorated rapidly in hospital across the course of three weeks and died in November 2021.

"I think the majority of Australians want to go to sleep one night and not wake up the next morning," Moon says. "It certainly would have been a preferred option for Mum. I think Mum realised she wasn't going to go home to her own house. And maybe she just gave up the will. But she did want to die at home."

Despite society's modern obsession with longevity, as ICU professor and end-of-life expert Ken Hillman notes in the Violet Initiative research report, "the priorities … of the elderly often do not include living longer. Instead, their needs are society-based, such as a sense of self-worth, loneliness and a community support network."

And the terminally ill generally also want to die at home, but it is not usual that any clinician has the time or inclination to embark on a frank end-of-life discussion. These patients instead are often "subject to a conveyor belt from home to hospital, often ending on life support in an intensive care unit", Hillman says.

The Productivity Commission, in its report Caring for Older Australians, outlined the challenges in end-of-life care as long ago as 2011, but little changed in the intervening period. The commission described fragmented and uncoordinated healthcare delivery and governing systems.

"What we have found in Australia currently is that the investment in palliative care tends to be only in the last month of life," Palliative Care Australia chief executive Camilla Rowland says. "We know that the investment in palliative care made by states and territories and the commonwealth is not keeping up with demand. We anticipate that there is a significant percentage of people who would benefit from palliative care who are not able to access it.

"So I would say to government, have a look at your in-home care packages, and ensure there's sufficient funding to enable people to be supported, to be cared for and to die at home. From an economic perspective, also, it is much more cost effective to care for people in their home."

Reader concurs with the call for greater funding, but she says the narrative on palliative care must be expanded significantly to take in not just discussions on how to support people in their final weeks and days but to lift what is effectively a society-wide veil of silence on discussing death.

To assist the process, the Violet platform is a sophisticated digital resource that harnesses artificial intelligence to help people answer universal questions surrounding death. There is information on everything from how to have tender conversations with dying loved ones to estate planning and wills.

"There's indisputably a huge taboo that still sits over this whole experience," Reader says. "Conversations around last stage of life, death and dying remain really taboo.

It's often thought about to be one of the hardest conversations you'll ever have.

"The current system is not serving anybody. It's not serving the people who are in the last stage of life who are not having the experience that they want or deserve. It's not serving their families or caregivers well, and it's putting enormous pressure on our health and aged care systems.

"And I wonder whether some of these medical interventions and treatments that are routinely given are just a response to the fact that the conversation is so hard, because it's too hard to create the time and the space and the support to help people understand the health decline of someone that they love.

"I'm really interested that we've seen things like menopause and miscarriage move into the zeitgeist, and I think this is probably the last human social and health issue that needs to be drawn into the light.

"We've got to find the courage to talk about it. If you can open the door to these conversations, and it might take multiple attempts, if you can open it up and make it safe, it is really transformative. I think it connects people at a deeper level, and it helps to really make the most of the time you have when time is the most precious thing."

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Natasha Robinson began her career at The Australian in 2004. A Walkley awards finalist and a Kennedy Awards winner, she was appointed Health Editor in 2019, and has covered rounds including national affairs, indige... Read more

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