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Anti-euthanasia laws hurt families

BY JANE CARO

“She’s in a lot of pain.”

Kay – all the names in this piece have been changed – looked at her 93-year-old grandmother who had been unconscious in her bed for what seemed like days. The old lady looked like a wizened five-year-old under the covers, with false teeth – the latest set had always been too big – adrift in her open mouth. Her struggle for breath was painful to watch but Kay was puzzled as to why her half-sister Mel thought an obviously comatose Nan was in pain.

“But she’s in a—”

Kay felt a sharp kick under the table. Mel – a retired nurse – was staring at her meaningfully. Kay shut her mouth.

“She’s in a lot of pain,” Mel repeated to the GP.

He nodded. “Well, we can’t have that. I’ll increase the pain relief.”

A short time later Nan slipped peacefully away.

Our current murky, unregulated, under-the-radar way of death hangs grieving relatives out to dry.

This is how many Australians die these days – at the end of a syringe full of morphine. It is completely unregulated and arbitrary but justified as an unintended consequence of seeking to relieve the dying individual’s pain – whether there is any actual pain or not. Usually the increase in pain relief is agreed to, in a coded fashion, by both the relatives and medical practitioners tending to the dying person. In some cases, as with Nan’s grandchildren, the response from those involved is relief when the suffering individual succumbs to the drug. The inevitable has come. The end has been peaceful. This is especially true when the person dying is very old and death, while sad, is not a tragedy.

Sometimes the end is not so easily found. Brian was 84. In his late 70s he had sustained an injury to his oesophagus from accidentally ingesting toxic fumes while cleaning his swimming pool. Over the years, the scar tissue in his throat had grown progressively worse and he found it very difficult to swallow solid food. From a fit and active man he had grown very frail and was suffering from geriatric malnutrition. He found himself in hospital after falling one evening, returning inside from the washing line at the retirement village where he now lived. He was too frail to get up so he lay on the ground for six hours until a security guard found him.

There was an operation that might help the scarring on his throat and had Brian been a little younger or a little stronger the surgeon would not have hesitated. Now the doctors were very reluctant. Brian was determined to undergo the operation. As he told anyone who would listen, including his children and grandchildren, he hoped the operation would kill him. His quality of life was so poor he now found it unendurable.

“He doesn’t want to wake up.” Brian’s son had promised his father he would convey his wishes to the surgical team.

“I can’t purposefully kill him, you know,” the anaesthetist replied, clearly affronted.

Indeed, after the operation Brian did wake up. When he opened his eyes and saw his children, he realised he was still alive. He groaned, wept and turned his face to the wall. It seemed he must go on suffering.

Max’s much-loved mother was a retired nurse. When she was diagnosed with the illness that would inevitably kill her, she knew exactly what was in store and she was terrified. She knew that in the end her lungs would fill and she’d slowly drown. Her terror was intensified by the fact that she had a morbid fear of drowning. Now her worst nightmare was going to come true. All her life she had advocated for voluntary euthanasia and she begged her son not to let her die of her disease.

When her condition reached its final stages, exactly what she had dreaded occurred. The end turned ugly. Worse, she did not respond well to the morphine she was given. Her son watched his mother struggle and suffer for five terrible days. Eventually Max could stand it no longer. He phoned his mother’s GP.

“This can’t go on. If she were an animal we would take her to the vet.”

“But euthanasia is illegal,” the GP replied.

Max thought his plea for mercy had failed but when he returned to his mother's bedside, her morphine drip had been replaced by a different medication. She finally relaxed and, four hours later, she died.

At first, Max was simply relieved that his mother's suffering had ended, but then he began to worry that he had "almost played God". His grief at the loss of his beloved mother was made doubly hard by his guilt at his feeling that he had been the cause of her death.

This is a perspective on the euthanasia debate that is seldom considered: the immense pressure we place on the shoulders of already grief-stricken and traumatised family members to make the awful decision to end their loved one's life. Our current murky, unregulated, under-the-radar way of death may protect the finer sensibilities of the medical profession – the Australian Medical Association has just confirmed their opposition to voluntary euthanasia – but it hangs grieving relatives out to dry.

Worse, it can create secrets and divisions in already grieving families. Max feels he dare not tell his sister the full truth about their mother's death for fear of her reaction. This has created a barrier between them he doesn't know how to overcome. If relatives have different religious beliefs or views about euthanasia, the family member who makes the decision may come under terrible fire. None of this is what the dying person would want, particularly if – as is so often the case – they have made their position on euthanasia clear.

Elizabeth was 86 and her life had become unbearable. Chronic osteoporosis had caused her bones to crumble. She couldn't move and was in constant pain. She had been in and out of hospital with various infections for months. She was weary and she wanted to die. Once transferred to a convalescent home, she told her daughter, Sara, that she wanted no medical intervention of any kind. She didn't want to take medication and she certainly didn't want to submit to any invasive procedures. Her GP agreed to her instructions but the doctor at the convalescent home had a very different attitude. Despite Elizabeth having an advanced care directive and appointing Sara as her legal end-of-life guardian, the doctor made his disapproval more than obvious. Sara found she had to virtually ride shotgun at her mother's bed to keep unwanted medical treatment at bay. It was clear many of the staff thought she was deliberately hastening her mother's death. What Sara felt she was doing was shortening her mother's suffering.

It is very hard to lose someone you love. Even if, as it was for Kay and Mel, the death is easy and comes at the end of a long life. For Max, his mother's terrible death haunts him, partly because he let her suffering go on so long and partly because he brought it to an end. Sara had to endure disapproval and pressure

from medical staff to help her mother die the way she wanted to. She remains traumatised by what was, in fact, an act of love. Brian's son had to find the courage to ask an anaesthetist not to try too hard to keep his dad alive. These are all loving people who wished for nothing more than that their relative could be miraculously cured. If that was not an option, then they wanted what we all want – a peaceful and painless death.

When we debate voluntary euthanasia in Australia – and a bill to legalise it in South Australia recently failed to pass by one vote – we consider the wishes of the dying person. And their wishes, of course, should be paramount. If someone wants every intervention possible and to wring every last minute out of life, then that is what should happen. But, if we are honest, most of us don't want that.

We consider the wishes of the medical profession, many of whom seem to prefer the unregulated world they currently operate in to a clear legal framework. We even consider the beliefs of church leaders and lobbyists. But there is one group that barely rates a mention. Indeed, if we do talk about relatives it is usually in a negative way, demonising them as pressuring elderly parents into ending their lives early for the relatives' gain or convenience. Such rare situations, I am certain, could easily be covered by decent legislation.

The group we never consider are those who grieve. And those are the people who – in desperate circumstances – we currently expect to shoulder the burden of making the life or death decision without any legal support and, with some honourable exceptions, not much support from the medical profession either.

The Australian way of death is in my view cowardly, hypocritical and cruel. We all know what happens, we just don't want to talk about it. This leaves the vulnerable people who we force to bear the brunt of the decision-making isolated, grief-stricken and further traumatised.

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