

# A tale of two deaths

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**T**his is the story of two elderly women who died. One was lucky. One was unlucky. One was my mother. One was my wife's mother. But the only relevance of that for the story is that the details of their respective final illnesses are fully known to me.

Audrey had been a schoolteacher. She lived in London all her life which included two world wars, and saw amazing advances in technology, science and medicine. She enjoyed the technology because she was able to drive and keep herself busy for the 33 years of widowhood following her husband's sudden death in his prime. She never really got over that catastrophe, but she kept busy and got on with life well enough for most of the time. She was the lucky one when it came time for her to leave the world.

She had always had good health, been a bit of a worrier with minor complaints after her husband died, but nothing serious. Eventually, however, it became apparent that she was becoming increasingly forgetful, she began to rather neglect her appearance and general cleanliness, and she started getting through kettles at an alarming rate, whistles notwithstanding, through forgetting she had put them on the gas stove. Shortly before her 89th birthday, a urinary infection rendered her unable to cope at all and she was admitted 'temporarily' to a nursing facil-

ity near where she lived. She had 'lost the place' entirely by now, but settled happily enough into an affable state of dementia, well cared for in her nursing home. On admission, a thorough medical uncovered a nasty feeling breast lump. This was almost certainly a breast cancer but the diagnosis remained 'almost certain' as she was otherwise asymptomatic and, after discussions between doctor and family, no one could see the point in subjecting her to painful investigation and treatment which she was no longer capable of understanding. She was a little unsteady now and one day fell and hurt a rib. She may have fractured it—it might, I suppose, have been a pathological fracture given the clinical diagnosis of breast cancer, but investigation was not taken up and her pain was well enough controlled with oral analgesics.

Things were not looking good for the longer term and it was readily apparent that she was nearing the end of her life—not that she seemed bothered by that herself. One day there was a call from the nursing home to say that she had become more unwell, had become more than usually confused, and had a slight fever. Her doctor had seen her and she was comfortable, but the nurses felt that "family might wish to visit as, with her degree of frailty it was possible that any infection might prove fatal". Her son visited again and found that she no longer

knew him, was rambling in her speech, mildly febrile, possibly a little dehydrated and with a rather rapid pulse. She was in no apparent distress, but obviously ill. She had refused food and medication for 24 hours or more and was taking only sips of fluid. She died peacefully that night. Her infection, site unknown, had not been treated with antibiotics, her dehydration had not been treated with parenteral fluids, and restlessness—possibly due to pain—had been controlled with small doses of morphine mixture. Her nursing care had been exemplary. The death certificate read "senile dementia". Her family were grateful for her care and that her illnesses had not been made worse by investigations and treatment for a breast lump that would have been distressing to her and possibly futile, given that she had already lost her mind and her independence.

It was, to use contemporary medical parlance, a 'good death'.

Joyce was in her 80th year when she died, but she had not had particularly good health. Her life was blighted by a severe postnatal depression requiring hospital admission and ECT. She had had a breast cancer in middle age successfully treated with local radiotherapy, and had been free of recurrence for many years. Her husband had angina and underwent open coronary artery

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The **ETHICS** column explores issues around practising ethically in primary health care and aims to encourage thoughtfulness about ethical dilemmas that we may face.

**THIS ISSUE:** Northland GP Stephen Main presents two personal cases of end-of-life care which illustrate the ethical dilemmas implicit in deciding when to treat or not to treat conditions which may shorten life.

surgery but he survived into his seventies, finally succumbing to bowel cancer. She nursed him till he died, at home, with help from family and community nursing services. Within a year after his death, things were not right with her. Mentally she was coping well but she started having falls, getting difficulty with fluency of speech and lost the ability to play her piano and also to swim.

Everyone feared cerebral secondaries from her previous breast tumour, but it wasn't that. After specialist investigations the diagnosis was cerebellar degeneration, cause unknown, outlook progressively increasing disability but without significant dementia, leading to death after an indeterminate period of anything from months to a few years, depending on individual situation and comorbidities. Not a cheerful thought. She and the family discussed making an advance directive to the effect that excessive invasive treatments and resuscitation attempts were not to be made in the event of her being ill and unable to communicate her wishes. Unfortunately (in retrospect) this was never formally put in place.

As expected, she gradually lost the ability to walk unaided, her speech deteriorated and conversation became increasingly difficult. She developed a pneumonia—a common complication of progressive motor loss in neurological disease. She was admitted to hospital and her pneumonia treated. However, her recovery was prolonged because of her underlying problems. By now she was unable to care for herself and it was clear she was never likely to regain her independence. She had no real choice but to be admitted to a high dependency care home.

Her progressive neurological illness was inexorably disabling her, gradually and unstopably, but also predictably, locking her in, cutting off communication with the world. Because she couldn't speak, friends tended to stay away—

visits were too difficult to sustain for more than a few minutes at a time on an infrequent basis. The rest of her time, for over a year, she lay paralysed in bed in her single room on the top floor of her high dependency nursing home, visited frequently but briefly by family and rather over-worked nurses, and in between times unable to move, unable to change position herself, unable to scratch an itch or move limbs to relieve pain. She suffered. She was unlucky.

Some weeks later she developed another chest infection and she remained unlucky. The on-call doctor did not know her well and decided to treat her pneumonia with antibiotics, thus dragging her back from death yet again. In

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the event she had another three months of staring at the ceiling, unable to speak, cry out or in any useful way enjoy quality of life. Finally a third chest infection supervened and, in consultation this time with her family, she received symptom relief only and death released her from torment.

Joyce's situation illustrates the dilemmas that often result in futile treatment. In retrospect it is a shame that her pneumonia had been treated so well in hospital. But that is what hospitals do and you cannot fault them for that—can you?

At no point did she receive anything short of good nursing care, but maybe her medical decisions could have been done better. In Audrey's situation the decisions were perhaps easier and in retrospect wiser, but who is to say what

should and should not be treated? How can you really know what a patient who cannot speak for herself actually wants?

What was the ethical test here? Was the continuing treatment of infections in Joyce's best interests? Did it do no harm? Was her autonomy respected, or even able to be respected?

It is arguable that three cornerstones of ethical principles were violated and yet at every stage her professional carers would have felt that indeed they were doing their best for her. By cruel twists of fate her illness failed to kill her before she had suffered months of living hell which could have been avoided if her physicians had had the courage not to do

so much. She had not, herself, made a formal legal advance directive about this. Poor woman—I think she was afraid to. We cringe these days from what is regarded as paternalism from doctors. But, as yet, death is not optional and often it can be kinder to allow it to occur rather than to attempt increasingly futile treatments which merely prolong suffering.

I make no judgments here. The facts are as I have told them. It is hard to say what should or should not have been done for either of these women, and opinions will differ. What will you do when you are faced with similar cases in future? What would you want for your mother? What would you want for yourself?

Morphine can be wonderful stuff—God's own medicine according to William Osler.