

Death wish list

The right to “assisted dying” is bringing a sense of relief to many New Zealanders. But one year on from its introduction, there is frustration over the law’s tight confines.

by RUTH NICHOL • photograph by HAGEN HOPKINS

“I love her!” says Gerry Molloy of the doctor who has been assigned to accompany her through the assisted dying process. They first met in June, just a few days after Molloy emailed the assisted dying service to inquire about whether she would be eligible for it.

“They rang me back within five minutes, and by the Monday, the doctor [her attending medical practitioner] had been assigned to me. It happened so fast it kind of blew my husband away, but I was so grateful for how quickly they responded.”

Molloy contacted the service, run by the Ministry of Health, shortly after she learnt that her just-diagnosed lung cancer had already spread to a small bone at the base of the skull called the clivus, and it was terminal. The pain from the secondary tumour was excruciating, much worse than the symptoms she was experiencing from her primary cancer. Radiation treatment and other palliative care have kept the pain largely under control – at least in the meantime.

“I don’t think it will be lung cancer that will get me, I think it will be the pain from that tumour,” she says, adding with a laugh that most of the doctors she has seen have no idea what a clivus is. “They all have to go home and google it.”

After being assessed by the first doctor, Molloy, 71, was assessed by a second one, known as an

independent medical practitioner, whose job is to provide independent confirmation that a person has not been pressured into seeking an assisted death, and that they are likely to die within six months.

Soon, she had been approved for an assisted death. She has nominated the latest possible date to do it – six months after she got her approval, though she can bring that forward if necessary.

She’s already decided where she wants to die (in her own bed) and who she wants to be in the room with her – four immediate family members, though she expects that close friends will be elsewhere in the house. “I’m so sad to be leaving them, as they are the people who have supported me for many years and I really want them to be there. Also, my husband will need some support – I know it’s not going to be easy for him.”

For Molloy, knowing she can have an assisted death has been a huge relief. A long-time supporter of assisted dying, she made a submission on the End of Life Choice Bill and, like 65.1% of those who voted, chose ‘yes’ in the referendum that eventually saw the legislation take effect on November 7, 2021. That’s partly because she has Parkinson’s disease and one of her big fears was

“This is an easier route as far as I’m concerned. I’m so grateful to have this option.”

Gerry Molloy: would have preferred the law to allow an advance directive in cases of dementia.





WHO'S CHOOSING TO DIE IN NZ?

Since the law came into effect on November 7 last year, 214 New Zealanders have had an assisted death. By the end of September this year, another 382 had applied. Of these, 294 were confirmed as eligible and another 68 were in the process of being assessed.

Of those who applied:

- 78.8% were Pākehā and 4.8% were Māori.
- 56.9% were women and 43.1% were men.
- 74.8% were aged 65 years or older.
- 65.6% had a cancer diagnosis and 9.4% had a neurological condition.
- 77.9% were receiving palliative care at the time they applied.

Most of those who had an assisted death chose to die at home or at another private residence. Seventeen died in an aged-care facility, 14 in a public hospital and nine in a hospice.

As at September 30, 38 GPs were available to act as attending medical practitioners for their own patients. 132 doctors, psychiatrists and nurse practitioners were on the SCENZ list as being available to provide some part of the assisted-dying service to people other than their own patients.

To qualify for an assisted death, a person must meet all of the following criteria. They must be:

- Aged 18 or older and a citizen or permanent resident of New Zealand.
- Suffering from a terminal illness that is likely to end their life within six months.
- In an advanced state of irreversible decline in physical capacity.
- Experiencing unbearable suffering that cannot be relieved in a manner that the person considers tolerable.
- Competent to make an informed decision about assisted dying.

that she would develop dementia and lose her quality of life. She was disappointed that the legislation specifically excluded an assisted death in that situation. "I wanted to be able to do an advance directive for assisted dying, but that didn't make it into the act."

Under the act's provisions, a person seeking assisted dying must have a terminal illness that is likely to end their life within six months and also be competent to give informed consent throughout the whole process, including on the day the medication is administered. That rules out people with dementia, as well as people who have been approved for assisted dying but subsequently lose their mental competence from something like a brain tumour, or who lose consciousness before the appointed day, as they cannot give final consent.

People with a range of progressive neurological conditions also find it more difficult to qualify for an assisted death. That's because even if they retain their capacity to make an informed decision, it can be extremely hard to say with any accuracy that they will die within six months.

Before her cancer diagnosis, Molloy had decided that if her Parkinson's got too bad she would take matters into her own hands: "My plan was to swim off Princess Bay [on Wellington's south coast]."

In a remarkable display of looking on the bright side, she's pleased she now won't have to resort to that. "This is an easier route as far as I'm concerned. I'm in contact with hospice, and they've been great, but I'm so grateful to have this option."

"PALPABLE RELIEF"

Molloy is not alone in feeling extremely fond of her assisted dying doctor, nor in the huge sense of relief she feels at knowing she can have an assisted death. "What comes through in all jurisdictions where assisted dying is allowed is that the minute the patient is given the green light, the relief is palpable – and everyone seems to love their assisted dying doctor," says Ann David, president of the End-of-Life Choice Society.

She's been advocating for New Zealanders' right to assisted dying since watching her mother's difficult death in 2005. Not surprisingly, she's pleased it's now available and, on the whole, she's pleased with the way the first year of the new legislation has gone. There have been some complaints – including one being investigated by the Health and Disability Commissioner – but she says the overall consensus is that the service is working well.

There had been fears that demand would outstrip the number of doctors available to deliver the service. That has not been the case, says David, though fewer doctors are available in rural areas, meaning the approval process (currently 4-6 weeks) can take a little longer.

Doctors must complete an online training course before they can provide any part of the assisted dying service. Some are inter-

"I can't think of another medical treatment that the doctor can't even mention ... at the risk of jeopardising your medical licence."

ested only in providing the service to their own patients. Others are happy to be added to a list of doctors who can provide the service to people whose own physicians are either unable or unwilling to do so.

The list is maintained by the Support and Consultation for End of Life in New Zealand (SCENZ) group. As well as doctors, the SCENZ list includes nurse practitioners, who can help people to plan an assisted death and administer the medication under the supervision of a doctor, and psychiatrists, who carry out assessments if there is any doubt about a person's competence to give informed consent.

Legally, doctors who are unable to provide assisted dying must refer patients who ask them about it to the SCENZ group so they can be assigned another doctor.

Like Molloy, David would prefer it if people with degenerative illnesses such as dementia could make advance directives to allow them to have an assisted death at a time of their choosing. That has been the case in the Netherlands and Belgium for many years, and Canada last year amended its legislation to remove the requirement for giving final consent on the nominated day (see "What others are doing", page 24).

"The New Zealand legislation didn't fulfil our mandate, which is to eliminate suffering for people who can't be helped in any other way and who have progressive diseases," says David.

Another aspect of the law that bothers her is that people seeking assisted dying have to raise the subject themselves – their doctor cannot do so. "Their doctor can tell them about palliative care and where they could





Jessica Young: “Assisted dying is really about controlling the dying period.”

dying and how the act is working. She’s also a member of the SCENZ group.

In 2020, she completed a PhD looking at the reasons people approaching the end of life consider assisted dying. At the time it was not an option here, but her findings were clear: people wanted some certainty and control over how and when they died.

“What they’re feeling is not, ‘Oh, I’m dying on Friday’, it’s, ‘Finally, there can be a closure to this.’”

“Assisted dying is really about controlling the dying period. It’s about saying, ‘I’d like to say when I’ve had enough of this very difficult period and have some say over how and when I die.’”

She is now involved in two other research projects, including one funded by the Cancer Society looking at the experiences of cancer sufferers, their families and doctors as they go through the assisted dying process.

Young, speaking in her capacity as a researcher rather than as a member of SCENZ, says her preliminary findings confirm those from her PhD – that people want an assisted death in order to have some control over the suffering they experience at the end of life. That includes social and emotional as well as physical suffering. In fact, 77.9% of people who applied for an assisted death were receiving palliative care (see panel, opposite page), either through hospices (the vast majority of which oppose assisted dying) or elsewhere.

“They have wonderful things to say about hospice care but assisted dying is very much another tool in the toolbox. It’s not a replacement for palliative care, it’s another option.”

UNEXPECTED ISSUES

Young’s research has highlighted some slightly unexpected issues. One doctor talked about being unsure how to behave during their first assisted death. “There’s no etiquette for how you turn up and provide the service – do you stand in the corner of the room or do you go to the room next door, for example?”

Similarly, a few families of those who have had an assisted death have told her that

go and the possibility of hospice, but they can’t tell them that they could also organise an assisted death.”

It’s a requirement that also bothers Doug Jones (not his real name), one of 132 doctors, psychiatrists and nurse practitioners on the SCENZ list. He describes it as absurd. “I can’t think of another medical treatment option that you cannot even mention, that you’re literally legally prohibited from mentioning at the risk of jeopardising your medical licence if you talk to a patient about it.”

The names of doctors on the SCENZ list cannot be published, though individual physicians can name themselves if they want to. However, Jones has decided to maintain his privacy as a SCENZ provider for now. He registered for the list as soon as it was possible and has now attended four assisted deaths and helped several dozen more people work through the application process in terms of counselling, family conversations and second opinions.

For him, assisted dying is just another

type of medical treatment and one he would want to have access to himself. “If I had unbearable suffering that couldn’t be relieved and I had a terminal illness that I knew was going to cause my death within six months, I would love to have an assisted death. Why would we not want that for our patients as well?”

As to the process itself, he’s been asked whether people are scared or upset at the end. The answer is a very firm “no”; the main emotion he’s witnessed is a profound sense of relief. “What they’re feeling is not, ‘Oh, I’m dying on Friday’, it’s, ‘Finally, there can be a closure to this.’”

Sometimes there’s even laughter: in one case, he says, everyone was in stitches – including the person who was about to die.

CONTROL AND CERTAINTY

Jessica Young, a postdoctoral research fellow at Victoria University of Wellington School of Health, is one of a number of academics carrying out research into assisted

What others are doing

Overseas trends may be influential when NZ's assisted dying law is reviewed in 2024.

When the End of Life Choice Act became law, New Zealand joined eight other countries, 11 American jurisdictions and two Australian states that allowed assisted dying.

In Australia, laws allowing what is called voluntary assisted dying have now been passed in all six states and will gradually start operating over the next year.

Switzerland is often seen as the trail-blazer in the field; what is called assisted suicide has been legal there since 1942. Unusually, even non-residents can access the service. This has led to what some critics call "suicide tourism", where non-Swiss residents travel to Switzerland to die, often through voluntary organisations such as Dignitas. It comes with a hefty price tag: Dignitas charges 7500-10,500 Swiss francs (NZ\$12,800-\$18,000) for what the organisation calls accompanied suicide. While Swiss doctors can legally supply life-ending medication, they cannot legally administer the drugs: the patient must administer them themselves.

Here, assisted dying is provided free through the public health system. New Zealanders wanting an assisted death can choose to take the medication themselves (by swallowing it or intravenously) or to have it administered by a doctor, either by injection or directly into their stomach through a tube. Nurse practitioners can also administer the medication under the supervision of a doctor.

Information about exactly what is in the medication cannot be made public.

Most of the 214 New Zealanders who had assisted deaths up to September 30 chose to do so in a private residence (81%).

That compares with 44.2% in Canada, where what is called medical assistance in dying (MAID) has been legal since 2016. The number of Canadians taking advantage of the provisions has been slowly rising. In 2021, MAID accounted for 3.3% of all deaths, up from 1.9% in 2019. The average age was 76.3 years, and as here, cancer was the most common reason for seeking an assisted death.

In March 2021, Canada extended its assisted dying legislation to remove the requirement for giving final consent on the nominated day. This makes it possible for some people to effectively make an advance directive while they have the cognitive ability to do so.

From March 2023, the Canadian legislation will be further extended to include people who have mental illness as their

sole underlying medical condition, providing they meet all eligibility requirements.

Some Canadian provinces allow nurse practitioners to carry out assisted deaths without needing a doctor to supervise them.

Our law will be reviewed at the end of 2024 and calls for similar extensions to be introduced here are expected.

Ann David, president of the End-of-Life Choice Society, would like to see more relaxation of the current law, but she's not holding out much hope of radical change. "I guess a lot will depend on what kind of statistics come out for the next two years, including reassurances that there have been no breaches and things like that."

– Ruth Nichol



Ann David: hoping for a relaxation of NZ's law.

while they are grateful their loved one's suffering has finally ended, they're unsure how to make sense of the death afterwards. "We don't yet have any cultural rituals that help us interpret this kind of death."

That's been the case for John Smith, whose son was among the 66 people who'd had an assisted death by March 31 this year. Smith (not his real name) voted "yes" in the referendum and knew that assisted dying made sense for his son, whose quality of life had been severely compromised by the complications of cancer.

Nevertheless, he's found the grieving process hard, particularly as very few people know how his son died. "The difficult thing for me is that the person dying knows the

"The person dying knows the date and place of death – it's the ones left behind who have to deal with it."

date and place of death. They dictate that and the rest of us are left behind – we're the ones who have to deal with it."

Several overseas studies have found that the family and friends of people who had assisted deaths had fewer traumatic grief symptoms than the family and friends of people who died of natural causes. However, a Swiss study published in 2012 found a higher prevalence of post-traumatic stress disorder and depression among family members or friends who witnessed an assisted death.

A study published in the *BMJ Supportive & Palliative Care* journal in 2015 concluded that people find it easier to come to terms with an assisted death if they can talk freely and openly about it with their loved one beforehand.

If that's the case, then Gerry Molloy's husband, Mike, is well prepared. His wife's openness means they've had plenty of opportunities to talk about what is going to happen. Initially, he found it hard to get his head around the fact that eventually they would reach a point where they knew they had only a few hours left together: "It's quite a mind-bending thing."

He's found a book by Canadian doctor Stefanie Green, *This is Assisted Dying*, extremely helpful – including her thoughts about the importance of resolving any unfinished business before entering the final phase of the process. "Reading the book



has clarified my thinking and settled me down. I've always told people I completely agree with Gerry's decision regarding assisted death and I am now more at ease with the process."

TIKANGA CHALLENGE

One unique aspect of assisted dying in New Zealand is the place of tikanga Māori in the process. Although not everyone agrees with him, Te Hurinui Karaka-Clarke believes it is possible to follow tikanga Māori and also support assisted dying.

Karaka-Clarke, a senior lecturer in education at the University of Canterbury and another member of the SCENZ group, says there are oral traditions suggesting that in certain circumstances, assisted dying is acceptable within tikanga Māori.

"I don't want to talk about those oral traditions in any detail, but they're readily

available," he says.

He also takes the view that, as with any kind of cultural practice, tikanga is not set in stone. "It's got to evolve because we no longer live in the same society our ancestors lived in."

He first started thinking about how assisted dying fits within Māori traditions when he watched both his mother and his sister have very difficult deaths. "My mother was a devout Catholic and also well steeped in tikanga Māori, so I was initially surprised when she said she would have chosen assisted dying if it had been an option."

More recently, he also started advocating for Māori to become involved in organ donation as well as blood and sperm donation. "Traditionally we're taught that whatever you're born with, you keep and you take that with you. However, my

Te Hurinui Karaka-Clarke: "We no longer live in the society our ancestors lived in."

thinking has evolved about that and I have recently become a blood donor."

Karaka-Clarke says one issue that, as far as he knows, has not yet been addressed is whether marae will allow the body of someone who has had an assisted death to be taken there for the tangi. That's largely because relatively few Māori have yet had an assisted death. However, he's confident that, just as marae have different ways of dealing with the bodies of people who have committed suicide, they will develop their own tikanga when it comes to assisted dying.

"It's not something that is widely spoken about, but once it becomes an issue for marae I'm sure they will start looking at it." ■

MARTIN HUNTER