



THE *ultimate* CHOICE

Should medically assisted dying be allowed in New Zealand?
Zoë Lawton explores the complex issue that has divided the nation

“As my death has become more inevitable, I constantly worry that it could be slow, unpleasant, painful and undignified. I worry that I will be forced to experience a death that is in no way consistent with the person that I am and the way that I have lived my life. I know that it might not turn out this way, but even the chance that it will is weighing on me very heavily.

Because of this I have started thinking about what I could do to end my own life before I become physically unable. This is not a choice I want to make. I know that if I do take this action I would probably have to do that much earlier than I would if I could ask a doctor to assist me with my death. But my other choice is to face a possibly unbearable death.

I am not depressed. I have accepted my terminal illness and manage it in hugely good spirits considering that it's robbing me of a full life. I can deal with that, and deal with the fact that I am going to die, but I can't deal with the thought that I may have to suffer in a way that is unbearable and mortifying for me.

I want to live as long as I can but I want to have a voice in my death and be able to say 'enough'. I desperately want to be respected in my wish not to have to suffer unnecessarily at the end. I want to be able to say goodbye well.”

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'I have started thinking about what I could do to end my own life before I become physically unable'

Letitia Seales' heartfelt plea to the High Court last year reignited the debate on assisted dying in New Zealand. The accomplished and intelligent Wellington lawyer, at age 42, sought a landmark ruling that her doctor would not be criminally prosecuted if she assisted her to die.

While the judge determined that ultimately this was a matter for parliament to decide, not the courts, Seales' case helped set the wheels of change in motion. A petition requesting that parliament review the law gained momentum throughout the trial and shortly after Seales died, it was announced that the Health Select Committee would fully investigate public attitudes on legislation that would permit medically assisted dying in two scenarios. First, where a person has a terminal illness and second, where a person has an irreversible condition that makes life unbearable.

MY LIFE, MY DECISION

The public response to the committee's review, the first of its kind in New Zealand, has been extraordinary. The Committee is so overwhelmed with the number of submissions that it is still processing them - a whopping 16,000 have been processed so far and there are potentially thousands more. Since February 1, the final date to make a submission, 2500 of these have been published online by the Committee.

In addition to submissions from medical, legal, and other professionals, a huge number have been made by New Zealanders with strong personal views on both sides of the debate. Their submissions are reflective, angry, sad, hopeful and everything in between.

A number of people made submissions in support of assisted dying because of their own »

'There is no perfect solution so we shouldn't beat ourselves up going round in circles'

Below: Lecretia Seales' husband Matt Vickers; until her death in 2015 Seales (below) was a high-profile campaigner for the right to die with her doctor's assistance.



personal struggle with terminal illnesses or irreversible conditions. They included a young mum in her 30s with multiple sclerosis and a woman in her 50s with Parkinson's disease, right through to a grandmother in her 80s in the early stages of Alzheimer's disease. Not to mention many more in similar situations. Cancer also featured heavily in a large number of submissions made by people of all ages.

One well known submitter is Helen Kelly, former president of the New Zealand Council of Trade Unions, who has been an active campaigner in the media for workers' rights. She held the role from 2007 until October 2015, stepping down due to her ongoing battle with lung cancer.

Kelly, 51, has an incredibly upfront attitude about her situation – when I asked whether she would like to be interviewed for this article, her response was: “You had better do it sooner rather than later as I might not be around for much longer!” When I meet Kelly she is warm, friendly, very witty and articulate, although it's clear the cancer is taking its toll on her physically.

Having had a career focused on public campaigning, she said it was in her nature to go public. In addition to lending support for the assisted dying campaign she is also campaigning for access to medicinal marijuana to help her and others like her to manage their pain. She says the cancer has spread from both her lungs into her bones, heart and brain. She has undergone a range of treatments including radiation therapy to try to minimise the risk of strokes, which caused the side effect of losing her hair.



THE IDEAL DEATH

Kelly has become quite reflective and has done a lot of reading and thinking about the subject of dying. She is of the view it's time to have a more open conversation about the topic, which she has learned people are often uncomfortable discussing.

“The ideal death is to be at home surrounded by people you love and to just slip away peacefully – but the reality is that this won't happen for many terminally ill people who will have an incredibly painful death.”

Kelly also stresses the need to think about the importance of quality of life rather than quantity of life.

“If you can't move, get out of bed, talk, eat, feed yourself – have you already in a sense died?”

In terms of changes to the law, Kelly says it's important to consider all of the people who would be affected – those with terminal illness, chronic illness, disabilities and children. It's also important to look at what other countries are doing. However, as with any complex issue, “there is no perfect solution so we shouldn't beat ourselves up going round in circles. We just need to start somewhere.”

As for herself, at this stage she is unsure whether she would ultimately choose to end her life with medical assistance; she just wants to have the option available to give her peace of mind and some control.

“At the moment, I don't regard myself as dying; I am living, but the uncertainty of how I might die weighs on my mind. I just want to be able to decide when enough is enough.”

THE SUPPORT OF FAMILY

In addition to submissions by people about their own illness or condition, many were made by people who had witnessed the suffering of loved ones – grandparents, parents, partners, siblings, and friends. Often they were involved in their care in their final few days, months or years.

They spoke about the range of palliative care their loved ones had received, from the appalling right through to the incredible. There was a range of views about whether all pain could be effectively managed or not, but often it was the psychological battle and dealing with a deteriorating quality of life that they say their loved ones struggled with the most. In other words, they were less afraid of death itself and more afraid of the process of dying. They dreaded the loss of bodily and medical functions, as well as the loss of autonomy and dignity.

Often this experience had a profound effect on women caring for others and had caused them to change their views on assisted dying. This is the



case for Ngaire Riley, whose husband has had Parkinson's disease for the past 20 years. She believes the time is well overdue for a person to be able to make the choice to die when suffering is enduring or overwhelming.

"We have been able to care for our beloved pets in this way for years. Having supported my husband through his decline has given me years to see that, should I need to, I want to be able to choose to end my suffering."

Others spoke of how the anguish of a slow, painful death was too much for their loved ones, who had begged them to help them end their lives. Some refused food or fluids in hospital in order to starve and dehydrate themselves to death, or took their own lives by other means while they were still physically able to.

One woman, who cannot be named due to a current coroner's inquiry into her father's death (compulsory for all suspected suicides), says she strongly supports a change in the law. Her father's death last year came as a devastating shock to her, her siblings, and his wife of more than 40 years.

"Dad's health was deteriorating rapidly, he was having seizures due to the cancer and had lost his sense of taste and smell. He was then told that he would soon no longer be able to wash, feed, or clothe himself. Dad was a strong, quiet, and proud man who wanted to maintain what dignity he had left.

"At times we had spoken about euthanasia and I know that if he could have, he would have opted for this path, which would have enabled us to be there with him, supporting and loving him right until the very end. Instead, he died alone. We have to live with that forever."

THE OTHER SIDE

There are always two sides to every debate and this one is no exception. The submissions against assisted dying were varied and again came from people of all ages and backgrounds.



Clockwise from left: Assisted dying campaigner Helen Kelly; Professor Stefaan Van Gool discussing euthanasia in Brussels; a divided world – euthanasia protests around the globe.




Some voiced their opposition to assisted dying on religious or cultural grounds. Some expressed the view that legalising euthanasia would send a confusing message to people struggling with mental illness, who do not have a terminal illness or irreversible condition.

This could potentially be dangerous and increase the number of suicides in New Zealand.

Others spoke of the excellent palliative care that their loved ones had received and thought that this was effective for managing all physical pain, as well as the psychological challenges associated with dying. Further, concerns were raised that assisted dying would eventually replace palliative care, or reduce its funding and availability, because assisted dying would be the cheaper and 'easier' option. Expecting doctors to assist people to die was also said to be counter to the patient/doctor relationship.

The final overriding concern expressed was that people would opt for assisted dying when it was, in fact, not what they wanted. People might feel obligated to end their lives because they did not want to be a burden on their families. Others, particularly the elderly or those with >>

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disabilities, might feel subtle or overt pressure from their family, doctor, or wider society to choose assisted dying when they would prefer to die naturally and with palliative care.

AVAILABLE OPTIONS

The New Zealand Health Select Committee is not the first to consider the arguments for and against this issue, as well as the legal options available.

Several countries have already gone through this process and currently either allow euthanasia or assisted dying, or both.

There is a slight difference between the two: euthanasia is often regarded as a doctor administering life-ending medication, whereas assisted dying is when a doctor prescribes life-ending medication, but the patient has to take it themselves in order to end their life.

Euthanasia and assisted dying is legal in the Netherlands, Belgium, Colombia, Luxembourg

and soon in Canada. Assisted dying is legal in Switzerland and the US, where it is limited to certain states including California, Oregon and Washington. There are a range of legal processes in these countries that could be considered by the New Zealand committee.

In order to provide necessary safeguards there are essentially two fundamental thresholds that a person wishing to opt for assisted dying would need to meet. First, they would need to meet a medical threshold. In other words, a doctor must be satisfied that they have a terminal illness or an irreversible condition that makes life unbearable. A definition or guidelines of what both of these mean could be provided to offer some clarity, but ultimately each person may need to be assessed on a case-by-case basis. This is because, for example, what may be unbearable for some people may not be for others. Second, people would need to meet a psychological threshold. More specifically, they

A final consideration is whether assisted dying should be an available option for children and teenagers, as in Belgium. There's no denying this is a complex ethical issue

would need to have the mental capacity to make the decision to end their life.

Consideration could be given to whether consent to assisted dying would need to be provided by the person at the time they go through the sign-off process or whether consent could be provided in an advanced directive, particularly for people with conditions like Alzheimer's disease.

WHO DECIDES?

A strict requirement for valid consent would protect people who are potentially being pressured into the decision. This is because their consent would be invalid and not accepted if it were found they were under pressure from family, or anyone else, to end their lives.

The next question is who decides whether the person wishing to opt for assisted dying meets both these important thresholds.

One option is that the person's doctor decides by themselves. However, this could be too much of a burden to put on one person and not provide enough checks and balances. Alternative options could be that the person's doctor makes the initial assessment and this is then assessed by one or two independent doctors, before sign-off can be given.

Another option is the decision is made by a panel including people from a range of backgrounds, for example an independent doctor, a lawyer, a psychologist and a layperson.

Alternatively, Family Court judges could ultimately make the decision after considering reports provided by a doctor and a psychologist who has assessed the person. The judge could also hear from the person themselves in court or in hospital, where judges currently assess mental health patients in a more informal setting. The judge would be in a position to make an assessment as to potential pressure exerted on the person, something they are already skilled at doing in a range of contexts.

An additional safeguard could be the appointment of a lawyer, funded by the court, to represent the person, express their views and raise any potential red flags.

The more people involved in a process the longer it may take, so there would need to be a realistic time frame

within which a decision should be made so the person seeking assisted dying is not left waiting for an unreasonable amount of time, or dies before a decision is made.

Once everything is signed off, there is the question of who will undertake the physical act that will end the person's life. Should this be the doctor, by administering life-ending medication through an IV drip, for example, or should the person themselves have to swallow life-ending pills? Consideration will need to be given to whether individual doctors can refuse to assist their patients to die due to their own personal views.

A final consideration is whether assisted dying should be an available option for children and teenagers, as in Belgium. There's no denying this is a complex ethical issue, but equally there's no denying that they can experience just as much pain and suffering, if not more, than adults.

THE NEXT STEPS FOR NEW ZEALAND

The Health Select Committee, made up of MPs from National, Labour, Greens and New Zealand First, has a significant task ahead. It will review all written submissions and then begin hearing from a number of people who have requested to make verbal submissions to the committee in person. Once that process is complete, the committee will draft a report containing recommendations that will be made public. At this stage no time frames have been announced.

Lecretia Seales' husband, Matt Vickers, is writing a book about Lecretia's story, which will be released this year. He says by taking her case to the High Court, Lecretia made a huge personal sacrifice so New Zealanders could have this debate.

"Lecretia was a humble person who saw what she did as nothing more than doing the right thing and as a way to start an important public discussion. As a family we're incredibly proud of Lecretia," said Vickers.

"We miss her terribly, but it is a comfort for us to know that her contribution has not been forgotten." □

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How to have your say

If you didn't get the chance to make a submission, you can still make your voice heard by contacting your local electorate or list MP, writing to the editor of your local paper, or supporting family and friends who are making submissions to the Health Select Committee in person.

For information... about hospice services and contact details for your local hospice, see www.hospice.org.nz.

For updates and news... on assisted dying from New Zealand and overseas head to www.lecretia.org.

IF YOU OR A LOVED ONE ARE CONSIDERING SUICIDE:
CALL Lifeline's Suicide Crisis Line – 0508 82 88 65 (available 24/7) or visit www.depression.org.nz.