

# The people likely to be excluded from a voluntary euthanasia law in Victoria

By Julia Medew

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Jay Franklin knows the limits of medicine. Since he was born, the Melbourne man has endured nearly 150 operations to remove most of his bowels due to a congenital condition known as Hirschsprung disease.

As a result, the 40-year-old has a bag attached to a small part of his remaining intestines to catch waste products, and requires a catheter in his chest to feed him and deliver medicines.

He has lost the pleasure of tasting and eating food, sleeps up to 15 hours a day, cannot work, and feels almost constant pain in his abdomen from scar tissue.

"The pain is 24/7," he says. "It's a twisting, gripping, stabbing sort of pain."



Jay Franklin wants medical assistance to die. Photo: Justin McManus

Mr Franklin wants medical assistance to die at home with his mother Bertha there to hold his hand. But at the moment he is one of many people likely to be excluded from potential euthanasia laws being discussed in Australia.

Despite moves towards assisted death legislation in Victoria and South Australia, neither state government is set to provide access to people like Mr Franklin or others who say they have intolerable pain but who are not dying.

Euthanasia advocates say this means people with degenerative conditions such as motor neurone disease, multiple sclerosis and Parkinson's disease will be overlooked because the predicted timing of their natural death is often unclear.

The issue has prompted Jocelyn Downie, a professor of law and medicine at Dalhousie University which advised the Canadian government on its recently enacted laws, to warn Australian governments about potential consequences of this approach.



Jay Franklin says he is living in constant pain. Photo: Supplied

Professor Downie said after the Quebec government restricted medically assisted death to people who were "at the end of life" - the same approach since adopted for the whole country - one man decided to starve himself for 53 days to qualify.

The 61-year-old man who was living with severe disability after a stroke, Jean Brault, also reportedly refused water for eight days so his body would deteriorate to the point where he was eligible for doctor-assisted death.

In another cruel twist, Professor Downie said the wording of Quebec's law meant Mr Brault had to do it slowly so he would retain enough mental capacity to re-confirm his request immediately prior to a doctor giving him a lethal drug - a legislated requirement.

In June, a Victorian parliamentary inquiry recommended the government introduce legislation to allow adults with "decision making capacity, suffering from a serious and incurable condition who are at the end of life to be provided assistance to die in certain circumstances". It describes end of life as "final weeks or months of life".

The state government has until December to respond to this recommendation but already Health Minister Jill Hennessy has said she supports law reform based on her mother's experience of multiple sclerosis, a neurological condition that can slowly rob people of physical and mental function.

In an interview with *The Age* last month, Ms Hennessy said her mother has at times expressed a desire to control her own death but instead "has to literally wither away until an infection takes her, or she chokes, or pneumonia comes by virtue of her body breaking down internally". "It's unbearable to think that will be the end of her life," Ms Hennessy said.

Professor Downie said the Victorian government should consider that people with such conditions may not qualify for a law that is restricted to people dying, and that some of these excluded people might resort to desperate measures to qualify.



Jay Franklin at hospital in 2016. Photo: Justin McManus

Another practical problem that has arisen in Canada is that people receiving strong painkillers leading up to a medically assisted death have to be "lifted" out of their medication to ensure they have the mental capacity to re-confirm their request immediately prior to receiving the lethal drug.

"Can you imagine that?... You bring somebody... back into a state of excruciating pain in order for them to say that's what I want," she said.

Ms Hennessy declined to comment this week on who should qualify for any future law, but chair of the committee that recommended the legislation, Edward O'Donohue, said six of the eight committee members agreed to restrict any potential law to people in the "final weeks or months of life".

"Decisions at the end of life are a difficult and complex area and we were seeking to limit suffering while respecting the sanctity of human life," he said.

Mr Franklin is disappointed with this and says if the South Australian government allows people without a terminal illness to access its potential law, he will move interstate immediately to try and qualify.

He says over the past 10 years he has thought a lot about ways to die because he is not eligible for an intestinal transplant and his pain is escalating without adequate relief. Mr Franklin says there is no prospect of his condition getting better, and that he often requires hospital care to get intravenous painkillers, and treatment for infections that enter his blood stream through the catheter in his chest.

He fears an infection could take his life in an intensive care unit where he is hooked up to machines with wires coming out of his body, or that a painful bowel obstruction will occur.

"That's not the way I want to go," he says, adding that he could also continue to live for decades in increasingly distressing pain.

Mr Franklin says he also faces another conundrum.

He says he has obtained a lethal drug to take his own life, but isn't sure the dosage is sufficient to ensure his body absorbs enough to die. Even if he does come across an adequate dose, he says he would have to strongly consider taking it alone to prevent loved ones being suspected of assisting a suicide - a criminal offence with penalties of up to five years' jail.

In the meantime, he is hoping the Victorian and South Australian governments will sympathise with his plight.

"At the end of the day this should be my choice. Nobody wants to force this on other people if it's not what they want," he said.

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