Submission to the Legislative Council’s Legal and Social Issues Committee.

I have had the sad experience of watching people die slowly. Some were like my mother, a person who lived as a body without a mind in her last years having suffered Alzheimer’s for many years. I wrote an article that was published by several newspapers at the time. I will add a copy to this document.

Other relatives, who were aged 90, decided to stop eating to kill themselves. One had such severe arthritis she couldn’t even turn a page or switch on the television. The other had severe macular degeneration and so was virtually blind. Their friends and partners were already dead. They brought together their families to say goodbye and then took between five to ten days to die.

My father died aged 69 by starvation when told his liver cancer was inoperable. I stayed with him in hospital for the last two weeks of his life and witnessed his pain. This was in 1985 before palliative care was as good as it is now but my father did not want to continue living, as his pain was existential. He had been ill for too many years.

None of these deaths were easy or comfortable for the patients or their families. Medical voluntary euthanasia should have been available to these elderly people who felt they had no option but to take their own lives the slow and difficult way.

My mother was not in pain. She also had macular degeneration with very poor vision. She lay in bed and was fed like a baby with spoonfuls of a thick liquid. If she had been able to have a medical letter in place to say she should not be fed when she was in a demented state then the last few years would have been cut short giving relief to all involved.

I believe people suffering intolerable pain or distress, when they have a diagnosis of inoperable cancer or disease, should be able to access voluntary euthanasia. Of course there should be checks put in place to make sure it is the wish of the patient and they are not being coerced into asking for voluntary euthanasia by their relatives.
I take it further and say that people like my mother, if prior to their illness, were able to make a medical statement or if their medical practitioner is aware of their wishes then they too would be able to access a method of voluntary euthanasia, even if it is in fact starvation.

The following is my article published 25/3/2010.

My mother was clear: she never wanted to live this way

Date
March 25, 2010
Belinda Ramsay

Instructions were given should dementia strike, but we can't fulfil them.

Let me paint a picture. It is my mother's 91st birthday. She lives in an aged-care facility. When we were kids it was called a nursing home. It is a beautiful building surrounded by gardens and staffed by genuinely kind people who take great care of my mother.

She has broken both her hips and her pelvis in the past decade, as well as going blind from macular degeneration. She has not recognized or responded to her children for more than a year; her dementia started more than 15 years ago. She has been in dementia specific care for 10 years and high care for five years.

She is always asleep when I visit. Mouth open, snoring slightly, front teeth no longer protruding. Both her parents died before she could get braces for her teeth and they always protruded slightly. She was very proud of her teeth and she looked after them until she developed Alzheimer's. Now they are broken and have apparently disintegrated, but it is of no concern because she no longer needs them to chew her food. She is fed a protein enriched puree, which she swallows, as no doubt she did when she was an infant.

Let me paint another picture. I am 12 years old. My grandmother
has been brought out from her nursing home to visit the family. She is a beautiful 83-year-old. She had been an intelligent woman who had many talents from painting to woodwork to writing poetry. She is credited with suggesting when she was a young woman that a white line be painted down the centre of the road from Gosford to Sydney.

As she aged she developed dementia. She also had glaucoma, which was controlled with drops. A symptom of the glaucoma was seeing flashing lights. She would ask us to go to a certain spot in the room because she thought there was a fire there, and we had to put out the fire by stomping our feet.

This was a great joke for a while, but she gradually became blind and no longer saw her little fires. My mother's response was to repeat what became an often-heard request. "If I ever get like that I want you to put a pillow over my head."

Last month, a 70-year-old Englishman was arrested for doing just that to someone he loved. He admitted putting a pillow over the head of his partner who was in "terrible, terrible pain" and smothering him in the 1980s.

Author Terry Pratchett, who has Alzheimer's disease, has suggested the possibility of special panels being created to allow seriously ill people to argue their right to die legally.

In Australia, we do not have euthanasia as a legal option, but it was my mother's strongest desire to die rather than live in the vegetative state in which she now lives. My father promoted influenza as the remedy for old age, but even if she were to contact influenza, antibiotics would be administered and her life would continue - a life empty of all that we take for granted and a life my mother would scorn if she could speak.

Exploitation of the elderly and greedy children who cannot wait for their inheritance are put up as arguments against euthanasia.

When my sister was on life support after an aneurism more than 30 years ago, a system was in place so that her life support could be turned off after a panel of doctors pronounced her
"brain dead".

Why can't a similar system work for those people who wish to
die with dignity either because of extreme pain due to terminal
illness or who put in place a wish to die when they no longer
recognize their family or communicate or experience life as we
know it?

My mother never wanted to be a burden to her family or live a
life devoid of meaning. She would be horrified if she knew the
distress her children felt because of her condition.

The problem today is that there are too many opinions as to
what is right. The religious do not approve of abortions or
euthanasia, but not all of us want to live by their guidelines. The
politicians have to please the people they think will vote for them.

Until euthanasia is legal, we are denied the right to make a
choice. I do not wish to follow in my mother's footsteps, and
make a definite plea that if I succumb to dementia I want some
kind soul to enable me to go peacefully. Or, failing that, to put a
pillow over my head.

Belinda Ramsay is a Melbourne writer.