

**From:** [REDACTED]  
**Sent:** Monday, 17 August 2015 11:46 AM  
**To:** LSIC  
**Subject:** Submission on End of Life Choices

Thank you for the opportunity to make a submission to your inquiry.

My submission is very brief and relates to my personal experiences.

However I would also draw to your attention the novel "The Fixed Period" by Anthony Trollope (readily available from Book Depository). I am drawing the book's attention to you not to recommend a *Fixed Period* but to draw attention to the personal, moral, political and societal dilemmas the book poses; and it is a "good read". Here is what author David Lodge says of Trollope's very slim volume:

*"The Fixed Period" ... (is) also oddly relevant to some of our own current social, economic and ethical concerns. Due to advances in medicine and public health, Britain, like many other countries, has experienced a rapid rise in life expectancy in recent decades, which means that more and more old and retired people must be supported for longer by the working population, a situation that has been exacerbated by the global credit crisis, with a consequent rise in unemployment and fall in the value of pension funds. At the same time there is increasing public controversy and private uncertainty about the legitimacy of assisted dying in certain circumstances. It is fascinating to see an astute Victorian mind exploring these issues in the form of fiction.... The aim of compulsory euthanasia is to convert death into a civic duty carried out with honour and dignity. For one year before their demise the old "would be prepared for their departure, for the benefit of their country, surrounded by all the comforts to which, at their time of life, they would be susceptible, in a college maintained at the public expense; and each, as he drew nearer to the happy day, would be treated with still increasing honour." It is a kind of utopian (or dystopian) version of the almshouses in "[The Warden](#)" (1855), Trollope's first successful novel. As to the expense of such a system, the narrator calculates that the savings that would accrue to the community by the elimination of its non-productive members would more than compensate.*

My personal experience during the last weeks of my mother's life, and during my husband's eight months of suffering before his death from a brain tumor, show hard it must be for those responsible for making decisions towards the end of a person's life to respect both previously recorded wishes and that person's current state of mind.

My mother had recorded her wishes on the appropriate forms saying she did not want any interventions that would prolong her life. She had previously gone many days without eating in accord with her wishes but eventually was persuaded to take sustenance when the medical staff said that starving herself could lead to organ failure and much physical distress. In her last 3 weeks of life when she was very obviously dying she asked at one stage "Where's Philip Nitschke when you need him?". This confirmed her wishes made and written when she was fully competent.

On a later occasion, she was struggling for breath and asked me to bang her back to help her breathe. When the staff asked me not to do this because it would bruise her she replied "I'd rather be bruised than dead".

In maybe 2 weeks after this she had passed away "peacefully" but experiencing dreadful nightmares and periods of extreme pain waiting for medications to be administered and then to take effect.

If in those last weeks medically administered euthanasia had been available to her to ease the final pain and terrifying dreams I believe she would have chosen that way to go. On the other hand anyone witnessing her struggle for breath and her wish to be "bruised rather than dead" would have faced an incredible dilemma if then asked to administer voluntary euthanasia.

In my husband's case he was diagnosed with a Stage 4 Glioblastoma Multiform brain cancer, underwent an operation and then consulted with a specialist neurologist/chemotherapist.

He was told the average time he could expect to live was 15 months. One of the first questions he asked the specialist was if he could be assisted to die peacefully when the time came.

As a family we went through all the "life choices" information available and he chose only palliative care.

Yet, to our surprise, and the specialist's, he still made the choice, choosing hope over a strongly predicted limited time to live, to have radiotherapy and chemotherapy. The chemo- and radio- therapy caused so much distress particularly awful vomiting and diarrhoea that he declined any further therapy.

Later he asked to be admitted to hospital, about 6 weeks before he passed away, hoping he would be able to move quietly into a medically induced coma, but this was not to be.

The hospital experience was horrible with one nurse in particular insisting that he get up and go to the bathroom on his own though he had been expressly told not to as he was having extreme problems with balance. This one night was the only time he had been on his own for many months as the admitting doctor had said to me not to stay over as it was obvious I needed a day or two to get back my strength. This same nurse told my husband his family should have been with him if he couldn't care for himself. He could not stay in hospital after this experience, and came back home.

Throughout most of these last months he described his state of mind as being in despair.

There were happy moments but, like my mother's situation I believe had there been a "way out" sooner he would have taken it. However those caring for him would have known that, even though he had asked for a peaceful death and had written his wishes on the appropriate forms, he had also made a decision to undergo chemo- and radio- therapy, and had asked to come home from hospital when he had specifically gone into hospital hoping that his life would end in hospital at that time.

In both these cases the dilemmas for the responsible staff are extremely difficult, even when people have written their wishes quite explicitly. I hope your committee's inquiry can draft some recommendations that will assist all involved to make better, more humane decisions for people facing some of the most challenging situations of their life.

If this submission could be kept confidential within your committee I would appreciate that. I am happy for you to use my submission with a pseudonym or in any other anonymous way.

[REDACTED]