

Dr Graeme Robson

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Legislative Council Standing Committee on Legal and Social Issues  
re Inquiry into End of Life Choices

Dear Committee Members,

During the last two years four acquaintances of mine died, each having different experiences. My submission will be in respect to the end of life choices or lack of choices they experienced.

One friend had been ill for some time with cardiac, respiratory and neurological problems. He had been admitted to hospital twice in the last two years with life threatening complications. His wife was his carer and they had assistance from other carers. Due to his previous experiences in respite institutions and his personal sense of disability he and his wife had agreed that if he should again become critically ill she was not to call for an ambulance so that he may die at home. They chose not to involve the hospital, which would try to preserve his life, when he did not wish to live any longer.

Another friend had a most unfortunate end of life developing Pancreatic cancer with constant penetrating pain which could not be controlled by opiates or spinal anaesthetic blocks. He developed frightening hallucinations from the opiates, and finally the Palliative Care institution sent him to an Acute care hospital for sedation which terminated his life. He had uncontrolled pain for some months. There was poor communication between the different Heath organisations he was being treated by; the family, did not know who was really in charge. He died a miserable death. Well before he died, when he knew he had inoperable cancer, and cancer not appropriate for treatment, he wished he could be put out of his misery. He just bore the pain and the complications of palliative care until he was finally given some assistance to die. I, as a retired doctor, felt upset he should be submitted to so much, before he was able to die.

My next experience was the death of my mother-in-law. She died in a Nursing-home with dementia at the age of 97 years. This was something she had always feared, and had made an Advanced Directive in order to avoid this. Eighteen months before her death she developed pneumonia and was admitted to a hospital when, despite having her Advance Directive attached to her 'history', she was treated for the pneumonia as it was reversible condition, the doctor completely ignoring the Advance Directive. During the last years of her life she was looked after very well in the nursing home. However she was incontinent, unable to recognise her daughter who visited her regularly, and was in a pitiable state.

My next friend to die had brain cancer and coped with his demise relatively well. His wife looked after him for as long as she and the family could manage, before he was put into palliative care, his final management being compassionate. It is, of course, impossible to know what an individual thinks when the ability to communicate is lost.

What End of Life Choices did they have ?

They were limited to refusing treatment - if they were mentally and physically capable

Some time ago my father died from a bleeding gastric ulcer, after advising his surgeon he did not wish to be treated. He had at the time Bulbar Palsy from Motor Neurone Disease, a terminal disease which the muscles of the throat and causes daily fear of choking to death. The only advice I could give him was to not attend a hospital should he become ill, advice which was impractical after he had the haematemesis. The family was fortunate he was well enough to make that decision to refuse treatment, and his decision was respected. As a family it would have been impossible to refuse an operation to stop the haemorrhage, despite the knowledge of his morbidity due to the Motor Neurone Disease.

It seems that Advanced Directives are increasingly being recognised, but without legal backing health workers and people with Medical Power of Attorney are still in a difficult position; different family opinions can cause a problem. When patients whose autonomy is already diminished by mental or physical infirmity are institutionalised, as in Palliative Care institutions and Nursing Homes, the autonomy of the individual is further diminished, by the institutions own policies with respect to care, and sometimes influenced by personal beliefs. A legal authority for the Advanced Directive would be helpful.

The limitations imposed on the individuals choice are unsatisfactory, with some illnesses leading to a final outcome, little different to torture. For some religious people suffering is an expected form of acknowledgement of their 'god', but our society is not a Theocracy. It is a secular society, where personal responsibility with respect to property, harm or injury to others, care of our fellow citizens is acknowledged in our legal system.

Personal responsibility should surely include the ability to expect a more liberal End of Life choice.

Thank you for having the opportunity to express my views

Yours sincerely

Graeme Robson