Submission to Parliamentary Inquiry into End of Life Choices

To: Lilian Topic, Secretary, Legal and Social Issues Committee

Parliament House Spring Street Melbourne Vic 3002

From:



Subject: Are Victorian laws adequately meeting people's expectations

regarding medical options available at the end of their life?

I write as an individual who has a strong interest in this subject, owing to the way in which both my parents died.

My husband (the Hon Dr. Race Mathews) shares these views. He is a former member of the Victorian Parliament and Minister in the Cain Government.

We are both members of Dying with Dignity Victoria (DWDV).

My father's death (John Barton Hack, 1911-1996)

My father's death is described in Dr. Rodney Syme's book *A Good Death* (MUP, 2008). Chapter ten is about a patient named 'Harold' - a pseudonym for my father. At 85 my father had a massive brain stem stroke. He was highly intelligent, scientifically trained, and a member of DWDV (then VESV). He had made it known very clearly, that he did not want to be kept alive in that state. He had given us his medical power of attorney and instructions on 'refusal of treatment'. In the hospital he was paralysed and unable to speak or swallow, but at times seemed conscious and in a 'locked in' state. His treating doctor was aware of his wishes, but fed him with a stomach tube. In this state he could have remained alive for months or years.

After ten days when there was no recovery, so we sought the help of Dr. Rodney Syme, who was able to transfer my father to another hospital and treat him. My brother as my father's agent signed the 'refusal of treatment' certificate. Dr Syme removed the tube and gave my father palliative care, with heavy sedation and morphine to prevent pain and suffering, and he died peacefully three days later. This was a case of 'voluntary assisted dying'. In our experience Dr. Syme is a man of great integrity, compassion and courage. Without his intervention our father may have lived in a vegetative, 'locked in' state in a nursing home, which was his greatest fear. We believe the law needs to be changed to allow 'physician assisted dying', for patients who have clearly stated their end of life choices.

My mother's death (Eileen Hack, 1907-2006.)

My mother was also a member of DWDV (then VESV) and gave us similar end-of-life instructions and medical power of attorney. She had a major stroke at 95 and was taken to hospital. I told the physician about her wishes and my POA, but he ignored these and treated her. As a result, she ended up in a nursing home until nearly 100; increasingly miserable and wishing she could have 'gone' with the stroke. I have told her story in my book *My Mother, My Writing and Me,* published in 2009. I am sending this book with my submission.

Recommendations

I believe the current laws need to be strengthened in two ways:

- 1. Strengthening 'refusal of treatment' legislation. We currently have 'Refusal of Treatment' legislation (The Medical Treatment Act of 1988 and 1991), but many doctors are either unaware of a patient's wishes, or ignore those wishes. This may be for religious reasons, or because they feel it is their job to treat people and keep them alive, no matter what. I believe we should require doctors to check if a patient has end-of-life instructions and a medical power of attorney, and for doctors to comply with those instructions. If the doctor cannot comply (e.g. for religious reasons) they should be obliged to inform the patient (or patient's agent) so that they can change doctors. We need greater supervision by hospitals to see that doctors comply with patients' end of life wishes, and perhaps some form of penalty if they don't.
- 2. We need legislation for 'voluntary assisted dying' in relation to end-of-life choices, and I support the submissions by DWDV. Such laws must, of course, have strict safeguards built in, so that 'physician assisted dying' could not be misused by relatives or others, eg so as to inherit.
- 3. We need an education program for doctors, nurses and families about our rights in these areas.

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