

End of Life Choice



Newsletter on current debates

Personal Stories from the Victorian Inquiry into End of Life Choices

The **Legal and Social Committee** of the **Victorian Parliament** documented many cases to illustrate that too many Victorians who experience an irreversible deterioration in their physical health, many of whom are elderly and frail, take drastic and brutal measures to end their lives. These stories are based on information provided by the Coroner's Prevention Unit, an examination of case law in Victoria and statistical evidence from the Coroner. (p169)

A selection of stories are reproduced below.

A 93-year-old woman with crippling arthritis and back pain had gone into an aged care facility and smuggled a razor blade into her wallet which she used, and died of exsanguination with her arm dangling over the toilet bowl. Her daughter made a compelling statement about her mother's death. The essence of it, that from the family's point of view, if only there was a better way, that their loved ones did not have to die in such violent circumstances and alone. (p198)

Janetta Rolfe was diagnosed with vascular dementia in 2006. She needed assistance to walk and could no longer communicate. Her husband Bernard Rolfe suffered extreme anxiety and depression. He was particularly concerned that Janetta would need to go into respite care and that they would be separated. Bernard Rolfe promised his wife of 55 years that she would not end up in a home.

Police found Janetta and Bernard at home in bed, with a propane gas bottle on the floor connected to a hose leading under the blankets. Janetta had died and Bernard was unconscious. He was resuscitated by paramedics.

Bernard Rolfe pleaded guilty to manslaughter by suicide pact and received a two-year suspended sentence. *In sentencing, the judge stated, 'Your actions do not warrant denunciation; you should not be punished; there is no need to deter you from future offences; and you do not require reformation.'* (p177)

Dr Geoff Wall described treating a fully paralysed patient with end stage neuromuscular disease who could only communicate through eye movements:

Once he realised he would never get off the ventilator, his mental status deteriorated to extremely fragile and he repeatedly indicated that he wished to die. His eyes would well with tears on mention of his home, family and pets.

The problem with ceasing artificial ventilation was that he would need almost an anaesthetic to overcome the feeling of suffocation as he died ... If artificial ventilation is ceased as strong intravenous sedation is given, causing rapid death, some may believe this to be murder.

... The patient remained on life support for 11 weeks until he died from pneumonia.

I can scarcely imagine what went through his mind, immobilised, staring at the ceiling for months, unable to say where he was hurting, with tubes in his windpipe, arm, stomach and bladder, 24hr machines and alarms, no hope of recovery, begging to end it all and finally an awful septic death.

Current laws failed to protect both this patient's right to control his own fate, and the medical staff's freedom to implement his wishes. (p197)

Terri Eskdale described the effects of multiple sclerosis on her partner Mark Brennan who took his own life. She stated his greatest fear was that he would get to a stage where he would not be able to end his life because his hands would not work:

If we had laws that allowed a system where people could choose to end their life on their own terms Mark may still be alive today

... Mark died alone and without a word of goodbye because he had to protect me.

That is what upsets me the most, he had to die alone and in an unnecessarily violent way. (p199)

At a personal level, I suffer from a slowly progressive disease which, if I live long enough, can be reasonably expected to incapacitate me such that I shall no longer be able to walk, stand, and may experience loss of bladder and bowel control. If I ever do get to this stage and if I wish to do so because my life has become unbearable for me I should like to be able to end my life without breaking the law either for myself or for anyone else.

Robert Gunter, personal submission (p203)

David Scanlon wrote of his father who, in the early stages of dementia, hanged himself in his garage. Mr Scanlon described the shock for his mother who found him:

Things could have been so very different if there were proper processes in place for end of life choices. He could have lived a while longer. He could have enjoyed life, family and friends for a while longer. He could have said proper goodbyes to his family and friends. He could have consulted with his doctor as to when and how would be the best time to go. He would not have had to face and carry out the decision that he did, alone. His wife wouldn't have had to find him, hanging in the garage, the image forever imprinted on her mind. (p198)

Coralie Richmond wrote of her father who had fluid build-up on his lungs and how pain relief did not ease his suffering:

Mother rang and said "Your father has had a haemorrhage." I raced to her home and found the cause, there was the gun and father was still alive but in great distress. *His brain was a pulp, the body still alive.*

Her father died a week later in hospital. (p199)

John McEwan, a former water-skiing champion who became quadriplegic and dependent on a ventilator after a diving accident, asked doctors to withdraw the ventilator that was keeping him alive. Fearing litigation, his doctor's insurers refused. Dr J Toscano gave evidence that he received legal advice that he could not be charged with assault if he performed treatment to prolong Mr McEwan's life. This advice was contrary to the common law right to refuse medical treatment and the prohibition against medical trespass.

In response to the refusal of his request, **Mr McEwan went on a hunger strike and was certified insane after pleading to be allowed to die.** Only when he agreed to end his hunger strike, go on anti-depressant medication and receive counselling was the certification revoked. He was kept on a ventilator and died 10 months later. (p187)

Asked whether palliative care or other support services could prevent such suicides, **Coroner John Olle** said (p172):

... the people we are talking about in this small cohort have made an absolutely clear decision. They are determined. The only assistance that could be offered is to meet their wishes, not to prolong their life.

SAVES

South Australian Voluntary Euthanasia Society

saves.asn.au

*Compassion for suffering
The freedom to choose
Add your voice to the call*

SAVES was established in 1983 to campaign for legal, medically assisted choice in end-of-life arrangements. The aim is to relieve suffering by providing choice for people at the end of their life. SAVES works in the community and with Members of Parliament to achieve law reform.

SAVE-YA Syndicated Australian Voluntary Euthanasia Youth Advocates

Facebook: Support SAVE-YA Law Reform



A national youth lobby group which aims to provide a youth voice in support of legalising voluntary euthanasia in all States and Territories. Members between ages 18 and 35 are encouraged to join, make contact with their local MP and inform them of their support for voluntary euthanasia law reform.

Christians Supporting Choice For Voluntary Euthanasia

christiansforve.org.au

We are Christians who believe that, as a demonstration of love and compassion, those with a terminal or hopeless illness should have the option of a pain-free, peaceful and dignified death with legal voluntary euthanasia. The overwhelming majority of Australian Christians support choice for voluntary euthanasia.



South Australian Nurses Supporting Choices in Dying

Facebook: SA Nurses

Supporting Choices in Dying

We are a group of passionate nurses who believe in our patient's right to choose the end of life care they wish. The group provides a forum for the nursing voice and perspective on legalising voluntary euthanasia and other patient choices in end of life care.



MY BODY MY Choice-VE

facebook.com/pages/MY-BODY-MY-Choice-VE

MBMC provides a voice for people with disability in the VE reform debate. MBMC represents the interests of people with disabilities who wish to exercise choice in all aspects of their life, including choice at the end of life, with the view that choice and control are a fundamental human right for everyone.

MBMC argues that people with disabilities know how it feels to lose personal autonomy through their ongoing fight for self-determination, independent living and disability rights.

MBMC believes that people with disabilities, who have struggled to control their own lives and bodies, must be allowed to maintain control and autonomy throughout their life, especially at its end.



Doctors for Voluntary Euthanasia Choice

drs4vechoice.org



We are a national organisation of Australian medical practitioners, both current and retired, who are committed to having a legal choice of providing information and assistance to rational adults, who, for reasons of no realistic chance of cure or relief from intolerable symptoms, would like to gently end their lives. Assistance may be by doctor provision of medication for the patient to consume, or by doctor-administration.

Lawyers for Death with Dignity

saves.asn.au/lawyers

Lawyers for Death with Dignity

acknowledges the need for people with profound suffering to have the legal choice for a medically assisted and dignified death.

The current law says suicide is not illegal, but assisting suicide is. People in a terminal state

may have profound, unbearable suffering and be in the undignified position of being unable to end their life without assistance. Advances in medicine have improved life expectancy, but South Australian law has not changed to reflect the often forgotten deterioration of quality of life that a longer life expectancy may bring.



BREAKING NEWS BREAKING NEWS BREAKING NEWS

Elderly people dying in hospitals spend their final weeks and months tormented by a barrage of pointless, expensive and harrowing procedures, say researchers.

Speaking on ABC 891 Mornings last week (28.6.16), Prof Ken Hillman, Professor of Intensive Care, UNSW, said "when you're very frail, and towards the end of life, these interventions may be detrimental to the patient". Prof Hillman was the lead author in a review of two decades of studies covering 1.2 million patients, relatives and clinicians in 10 countries, including Australia. The findings were outlined in the *Journal for Quality in Health Care*.



"My mother was 86 when she died. In the previous six months she came into hospital 22 times. She had what would be relatively minor infections or falls in a younger patient, but they were life threatening for her. She did not like coming into hospital. Each time she spent at least 4-5 days getting all sorts of treatment. Until a very special sort of person sat us down and said 'Your mother is coming to the end of her life. What we're doing is inappropriate and cruel.' This was a huge relief to my mother and all my family."

Prof Hillman's report highlights the states of Oregon and Washington as the gold standard for talking about dying - two states where voluntary assisted dying has been legal for up to two decades. "They've got excellent systems where there is honest and transparent discussion about dying. This translates into excellent systems for the way we manage dying." (Also in *The Australian*, 28.6.16)