

# End of Life Choice



Newsletter on current debates

## Dying by Starvation and Dehydration

*A SAVES member has written of her mother's last weeks, when her suffering had become unbearable and hopeless.*

**My 92 year old mother died in August 2016 in a South Australian residential care home after electing starvation and dehydration as the only legal alternative to a life of increasing suffering that had lost all quality.** She had drawn up an Advance Care Directive which explicitly laid out her end-of-life choices. She was a stoic and positive woman who always made the most of her personal situation and was neither inwardly-focused nor depressed.

My mother had been a particularly active woman in her earlier years but had become paraplegic a few years before her death as the result of complications associated with numerous orthopaedic procedures that had impacted her spine. She also had glaucoma, macular degeneration, was high-level hearing impaired; and had developed leg wounds from poor circulation that could not heal despite the best nursing care. She remained cognitively alert and tried to continue reading and watching television but this became more and more difficult and her suffering became even greater.

Due to her paraplegia she needed to be hoist-lifted to take her to the bathroom to be toileted and showered. This action caused her pain even though appropriate pain management was being delivered through a Fentanyl patch, a range of oral pain and other medications, heat-packs and a hospital bed with undulating air pad and mattress: all facilitated by high-quality nursing care.

However, my mother needed to carefully calibrate the level of medication in her pain patch to accord with her wish to remain alert and to avoid associated chronic constipation that was exacerbated

by her paraplegia. She began to dread the 'lifting routine' that had to occur at least three times daily, and her perception of a lack of dignity associated with personal care needs being attended to by others. While this reality is experienced by many it was something she was never able to reconcile with her own sense of self. The prospect of continuing to live in this situation constantly played on her mind and she wished to be able to die at the 'right moment' according to her own conception of dignity; surrounded by her loved ones in a spirit of life-celebration. Sadly, she also clearly understood that this choice would be denied her due to our current legal end-of-life framework.

**My mother was a Christian and was therefore angered and perplexed knowing that it was largely a vocal, well-funded, yet small minority of Christians both inside and outside parliament who were behind the thwarting of any law that would grant her the choice to die on her own terms. She could not identify such cruelty with Christian 'charity' or love.** She had reconciled the possibility of having to take this future drastic action (of dying through starvation and dehydration) with her Christian faith after lengthy discussions with her own very caring Minister. She also informed the pastoral care worker and others at her residential care home of her intentions. She recognised that this decision may possibly be difficult for the staff with whom she had formed very good relationships and friendships over the years.

She enquired about options available to her under palliative care and was informed of the legal limitations and what she would likely experience through enduring starvation and dehydration. She was also told that she would be offered the best possible pain management and palliative care to alleviate the inevitable suffering that accompanies this necessarily slow and painful death.

Her loving family were naturally saddened by her need to take this action but determined to support and advocate for her throughout her ordeal, and stay by her side till the end. She ceased eating (having previously stopped futile medication), but soon realised that unless she also stopped drinking, the dying process would be even

more drawn-out and harrowing. Five days later she stopped drinking. Part of the palliative process was to refresh her mouth with mouth swabs and initiate low-level sedation and pain relief which was open to review.



**Jean Davies, a long term campaigner for law reform, starved herself to death two years ago. from Oxford, England, starved herself to death two years ago. It took five weeks.**

**It took my mother nearly three weeks to die, being bed-toileted and bathed, and turned by staff every two hours; day and night.** This appeared to sometimes cause her pain and associated anxiety preceding the next turning event; necessitating further 'top-up' medication. She received the best professional care and pain relief at all times; albeit carefully monitored to ensure that there could be no question of 'hastening' her elected death. This occasionally meant that provision of 'top up' pain relief was reactive rather than proactive even though staff always acted in her best interests within an end-of-life legal framework that so easily criminalises them.

Even though my mother was very well cared for she did not die according to her wishes. She did however avoid the worst of what Allan Kelleher, Professor of Sociology, refers to as truly 'shameful deaths, racked with pain and indignity'. Elected members should refuse to collude with this cruelty: as a compassionate society we can do much better. To reiterate the words of medical ethicist Dr Brian Stoffell:

***Cruelty is the principal vice and institutional cruelty is worse than odd cruel episodes. Laws that cause cruelty by perpetuating unwanted and unnecessary anguish, pain, degradation and fear must be swept away.***

# 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.

## Doctors for Voluntary Euthanasia Choice

[drs4vechoice.org](http://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.

## Christians Supporting Choice For Voluntary Euthanasia

[christiansforve.org.au](http://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.



## Lawyers for Death with Dignity

[saves.asn.au/lawyers](http://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.



## 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](https://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.



## BREAKING NEWS...BREAKING NEWS..BREAKING NEWS..BR

A Perth GP who admits to giving an elderly woman a lethal injection wants other doctors to speak up about how they have helped terminally ill patients.

Dr Alida Lancee said that five years ago she gave an injection to hasten the death of a woman in her 80s with emphysema, and had to get the patient's family to cover up for her.

"It's time for people not to hide and to openly challenge the law.

"We're talking very specifically about people who are actively in the dying process, where we're just hastening the natural process and shortening the suffering. We should have proper legislation, with safeguards in place, to assist people in those circumstances."

Dr Lancee, who is a member of Doctors for Voluntary Euthanasia Choice, said she wanted to find at least 10 doctors who would state they had hastened the dying process, to relieve the suffering of patients at their expressed wish.

"I've seen the harm when that option is not available, and I'm in the process of bringing people like me together, who've had to go outside the law to help their patients," she said.

"This is to challenge whether any prosecution occurs, because if it doesn't happen, that will show the law is failing and needs to change.

"If prosecution does occur, it will demand public debate."

She believed most Australians supported a change in laws but politicians were not listening to them.

*The West Australian, 20.8.16*



Dr Alida Lancee