

# End of Life Choice



Newsletter on current debates

## Voices of suffering

Suffering is multi-faceted and relates to enduring different forms of pain, distress, injury and loss. The point at which suffering becomes unbearable is different for everyone. **The fact that suffering eventually becomes unbearable is the driver for voluntary euthanasia law reform.**

When the suffering becomes unbearable, even with the best palliative care support, the death can be cruel and protracted. The stories of three South Australian women who endured unbearable suffering are described below.

**Shirley Nolan OBE, the visionary founder of the Anthony Nolan Trust and bone marrow register, ended her life on her second attempt at the age of 60. Shirley wrote:**

*Today I hope to end the horror my life has become. Parkinson's disease has slowly debilitated me for some 25 years, leaving in its path an almost unrecognisable parody of my former self. No-one has assisted me to end my life and the detailed account of my deplorable condition will affirm its necessity and blessed release....Mine is a life without quality. It is a living hell. I place what is left of mine on the altar of compassion in the hope that my death will highlight the plight of others, and thus serve some purpose.*



Shirley Nolan OBE



Nancy Crick

**Nancy Crick, a 69 year old voluntary euthanasia advocate, suffered crippling effects following cancer surgery.**

Nancy Crick took her life in Queensland. She stated that despite surgery and the best palliative care, her life had deteriorated to such an extent that she felt death would be a blessed relief. Nancy argued that she did not want to die alone, and in order to avoid any one of her family or friends being implicated in her death, she gathered 21 of her family and friends around her when she died.

**Jo Shearer, a 56 year old journalist, ended her life on her second attempt.**

Jo Shearer had, potentially, another 25 years to live, and endure the relentless and unbearable suffering due to a constellation of complex and hopeless conditions for which palliative care was not an option. Scoliosis, an S-shaped spinal curvature, had developed in her thirties but deteriorated rapidly at age 54. Jo's vertebrae protruded through to her stomach, and some of the vertebrae rotated. In addition to the spinal pain, which prevented her from standing, or from lying except on hot water bottles, Jo had Sjogren's syndrome. This dried her eyes, mouth and lungs, and meant that she had to apply eye gel every 20 minutes to prevent sight-threatening ulceration. Jo had pain on breathing, painful tenosynovitis of the hands, and calcium deposits on the knees which grated when she walked. When she first tried to kill herself, she was found by paramedics who saved her despite her request to die peacefully. After being saved, she made a second attempt on her life, this one being successful. Due to her disability, physically attempting to take her own life was very difficult. She had to resort to smothering herself, a panicked and violent method of suicide which made her last moments ones of terror.

Shirley, Jo and Nancy were all victims of disease; all were hopelessly ill – there were no further medical interventions acceptable to them which could relieve their suffering - and all were experiencing *protracted, unrelievable and unbearable* suffering. Each had her own lived experience of suffering, but all understood that they would never personally benefit from voluntary euthanasia legislation that would have given them, and so many others, peace of mind. Instead, Shirley, Jo and Nancy each had to end their life themselves while they were still physically able to do so.

**Ray Godbold**, a palliative care nurse, describes the end of life for many people in the following terms:

*I've been there when lots of people have had terrible deaths... if we [care providers] all sat down and people were honest, a lot of them would come out and say: 'Look, that was a shocking death. We should have done something else to help.'... After all, who could be more vulnerable than those in unbearable suffering or in the last stages of a terminal disease? Who could be more abandoned than those begging for help who are turned away by opponents of law reform? Whose lives could be less valued than those desperately seeking a way to die, and who are told instead that 'suicide is legal, why not just do that?' And who could be more coerced than those facing no choice about how to end their lives – other than to do so violently and on their own?... The scars of ugly deaths are livid in the lives of all of us left behind who will never forget, can never forget, the terrible, lingering way in which someone close to us died; or the violent, lonely way in which others chose to take their own lives because they saw no other option.*

**Shirley Nolan, Jo Shearer and Nancy Crick all advocated voluntary euthanasia law reform**, and all refused to remain silent. They insisted on making a final stand for the right to manage their own deaths, just as they had managed their own lives. The denial of a right to an assisted death was the trigger for speaking out so forcefully for the rights of others. Shirley, Jo and Nancy all died in 2002.

**It is unconscionable that countless others will have inevitably suffered futilely over the 14 years that have since elapsed.**

# 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](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.



## 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.



## 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.

## 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



## BREAKING NEWS BREAKING NEWS BREAKING NEWS

Comedian, producer and interviewer Andrw Denton argues for assisted dying in Australia

In presenting the 2015 Di Gribble argument the organisers commented *Poll after poll reveals overwhelming support for assisted dying laws. But our elected representatives won't act, the conversation's stalled, the debate has become immovable and seemingly too hard. Meanwhile thousands of Australians are dying badly - in pain, alone, afraid.*



Eight months ago, Denton set off to try and answer the question: why can't Australia have a law for assisted dying. He spent hundreds of hours talking with nurses, doctors, politicians, lawyers, academics, priests, surgeons, palliative care specialists and activists on both sides of the debate, both in Australia and overseas. Above all, he spent time with the dying and their families.

"My starting point was an anti-euthanasia convention in Adelaide, featuring speakers from around the world. Here I heard, in detail, warnings about what was happening in places where laws to help people die already exist: of babies and children being killed; the vulnerable being made expendable; people being euthanased without their consent. Of doctor-patient trust destroyed and palliative care services degraded.

"Belgium, Netherlands and Oregon, I was told, were societies weakened at their moral core; a slippery slope where the number of people seeking to die was sharply on the rise, with ever-expanding reasons for their legalised deaths. "At its heart lay two key accusations: that the safeguards don't work; and that the elderly and disabled were threatened.

"What I found was almost the exact opposite: long-running systems, based on years of open research and debate, with multiple safeguards, and overwhelming acknowledgement that they work, from across the spectrum – the public, medical bodies, and political parties of every hue.

"Their greatest safeguards? That only a competent adult can ask for help to die; and it is voluntary." ([www.wheelercentre.com/notes/denton-s-di-gribble-argument-2015](http://www.wheelercentre.com/notes/denton-s-di-gribble-argument-2015))