

# End of Life Choice



Newsletter on current debates

## Pre-emptive suicide: premature, lonely, violent

**"I may never use the option of Voluntary Euthanasia if it becomes legally available here in SA, but if it becomes legal, it would be a huge relief to know that if and when my worst nightmares come about, then I could resort to a dignified pathway to end my unbearable and hopeless suffering, without involving my loving husband and family in any illegal activity."** (Judith King)

SAVES Member Judith King is sixty-nine years old and lives in Evandale, SA. Nearly two years ago Judith was diagnosed with an incurable medical condition, MSA – Multi Systems Atrophy. It affects about 2,500 people in Australia. It is a rare, progressive, degenerative neurological disease. The disorder is a combination of Parkinsonism, autonomic failure (which normally controls the body-regulating part of the nervous system such as blood pressure, digestion and temperature) and cerebellar atrophy.



**Judith King**

The health issues Judith faces include movement, balance and coordination, orthostatic hypotension (postural instability so she cannot stand for more than a minute or two, with blacking out or collapsing), heart rate, tremor, urinary incontinence, faecal incontinence or constipation, abnormal sweating, sleep disturbance, use of feeding tubes, depression, cognitive impairment, breathing disorders, muscle weakness, dystonia (where muscles contract involuntarily and out of sequence), loss of

speech ability, difficulty swallowing, and other impacts on internal organ functions.

Judith is hoping that Members of Parliament debating the *Voluntary Euthanasia Bill 2016* will be aware of the "unbearable and hopeless suffering" that people like herself face each day.

**DEMOS**, an independent British cross-party think-tank, following research on suicide in Britain, concluded that

***Suicide amongst terminally and chronically-ill people is more prevalent and a much greater problem than public policy currently recognises.***

In a 2011 study, **DEMOS** correlated reported suicides with medical records, using data from Primary (Health) Care Trusts, interviews with 15 Coroners, and a detailed study in the District of Norwich. **DEMOS** found that 10% of people who died from suicide also had a chronic medical condition, such as Parkinson's disease, motor neurone disease, or chronic arthritis. In 2% of cases the disease was terminal, usually cancer. **DEMOS** found that these figures were an underestimate, partly because many institutions do not collect the data and because Coroners commented that they sometimes chose not to investigate a case which they suspected may be 'assisted suicide' because their investigation may incriminate surviving friends and family. This practice was particularly relevant in relation to older people and suicide.

A similar outcome was established by the Victorian State Coroner in 2015.

In a study led by Justice Ian Gray, the Victorian Coroner investigated suicide and irreversible deterioration of physical health, using records from 2009 to 2012.

The investigation defined three categories of deteriorating health:

1. Diagnosed terminal disease, such as metastatic cancer or endstage respiratory disease, where death was expected within a specified time
2. Incurable chronic disease where death was not expected in the near future
3. Permanent physical incapacity from accident or injury.

Justice Gray's investigation specifically excluded mental ill-health, isolation and fear of loss of independence, and cases where there was insufficient evidence to make a diagnosis.

***The Victorian Coroner found that 8.6% (297) of the people who died from suicide in Victoria between 2009 and 2012 had a history of chronic or terminal illness.***

***The largest group were aged over 65.***

The most common method used was poisoning, with firearms next. The most recent ABS statistics on suicide confirm these findings.

The Coroner's Court concluded that in Victoria between 2009-2012, ***at least 50 people each year committed suicide in the context of irreversible deterioration in physical health due to disease or injury.***



**Dr Rodney Syme**

**Dr Rodney Syme, vice-president of Dying with Dignity Victoria**, has said:

"Australia's rapidly ageing population means the numbers of such suicides can be expected to increase. The tragedy is not that these people take their own lives; it is how they are compelled to do it in the absence of compassionate legislation permitting medical advice and assistance."

**Hon Marshall Perron, former Northern Territory Chief Minister**

who introduced Australia's only voluntary euthanasia legislation in 1995, has said that as a result of being denied choice for voluntary euthanasia many of these deaths are premature, lonely and violent.

"Premature because the individual has to act while they have the physical and mental capacity. Lonely because the individual is aware that assisting a suicide is an offence and they do not want to implicate family or friends. Violent because they must use whatever means to die they can access."

Their lives are robbed of time, ended by necessity, compared with lives lived longer where assisted dying is legal. In Oregon, as an example, one third of the people given prescriptions for medication that will end their lives do not take it. The insurance of having the choice to peacefully end their suffering if it becomes unbearable is a recognised form of palliative care, giving them valuable time to live another day.

**DEMOS, *The Truth About Suicide***, <http://www.demos.co.uk/files/Suicide>

# 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 expectancy may bring.



## BREAKING NEWS BREAKING NEWS BREAKING NEWS

**John Paynter describes his wife's last seven days in Hospital.**

**April 2016:** My wife had stage four cancer and other medical issues including a broken hip that were causing her much pain.

I had no idea what palliative care involved. They removed anything that would help her stay alive, including saline drips and antibiotics.

One staff member told me she would virtually die of thirst and that it could take several days or even weeks. She was given a steady infusion of morphine, a sedative a few times a day and a drug to dry out her throat.

**Days 1-4:** For the first few days she was constantly gurgling and coughing in an attempt to clear her throat. She appeared terrified. (Mr Paynter constantly implored the staff to provide relief.) It was horrible to watch her with her face crunched up in pain and trying to breathe through liquid and desperately trying to cough – but she was just too weak.

**Day 5:** Still groaning and trying to cough, sometimes almost screaming. Finally they increased her medication, but too little too late.

**Day 6:** She was getting weaker and sometimes just couldn't get a breath. When I asked for more relief to stop her needing to cough up the liquid at about midnight I was told: "We can only give that three times a day and she had some an hour ago". My god! Were they afraid it might make her sick? I felt I was living in a Stephen King horror novel.

**Day 7:** She finally got so weak that she stopped trying to cough and just breathed more and more shallowly. Finally she stopped breathing. At last, she had some peace – after 7 days of unnecessary and unbelievable cruelty.

**Religion:** My wife was an atheist and as such deserved the same right to her belief as any Christian, Buddhist, Muslim or any other religion. However, I was told by one of the staff that "only God can take a life". This is despite the fact, as the member for Fraser Andrew Leigh told the House of Representatives in August, that: "Three out of four Catholics, four out of five Anglicans and over nine out of 10 Australians with no religion say they, in principle, support voluntary euthanasia".

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