End of Life Choice

Diagnosis: terminal medical condition

These are the stories of Patricia and David, two people diagnosed with terminal medical conditions. Their stories show the human face at the heart of voluntary euthanasia legislation.

Patricia, Inoperable Lung Cancer

Patricia is 65 years old, happily married to Robert. Patricia and Robert have two adult children, and one grandchild, aged 9. Patricia lives a very active life and spends a lot of time with her grandchild.

Six months ago, Patricia noticed that she had a persistent cough and swollen ankles. She went to her GP of twenty years, who undertook routine x-rays and tests. Patricia's chest X-rays showed there was 'fluid around the lungs' (pleural effusion). Patricia was referred to a Respiratory Consultant and then admitted to hospital. Patricia was not experiencing breathing difficulties, but her cough persisted. In hospital, Patricia had a series of diagnostic and symptom management procedures to relieve the fluid around her lungs. A CAT scan confirmed a diagnosis of Stage 4 Lung Cancer - inoperable.

After extensive consultation with Patricia and her family, respiratory and oncology specialists suggested the only option was symptom relief (palliative) with chemotherapy, giving her a prognosis of six months to live.

Patricia, Robert and her family, in consultation with her GP and specialists, made the difficult decision to return home and have Patricia's care managed with the visiting community specialist, nursing and palliative care teams.

During home treatment Patricia's breathing deteriorated and she needed constant home oxygen. She was fatigued but, as was her way, Patricia did not complain about pain.

Patricia had always been the organiser and head of the household; she prided herself

on being the one to determine her path in life.

Knowing her condition would continue to rapidly deteriorate, Patricia investigated all options available to her. She acknowledged that she was receiving excellent care. However Patricia wanted to make her own choice and decisions about her life. She did not want to let the cancer make choices for

Patricia had dinner with her family and spent important time with her precious grandchild. They laughed at family videos and shared treasured moments.

When the house was quiet, Patricia wrote a note to her family stating how wonderful every member was and how she cherished them.

Robert found her the next morning, hanging from a tree in the backyard. Police were called and her death was referred to the Coroner.

David, Motor Neurone Disease

Motor Neurone Disease (MND) is a progressive, terminal neurological disease. It can affect anyone, both men and women, and nearly 60% of people with MND are younger than 65 years of age. There is no known cure and no effective treatment.

People with MND progressively lose the use of their limbs and ability to speak, swallow and breathe, whilst their mind and senses usually remain intact. MND symptoms and progression varies significantly from person to person.

In Australia two people die from MND every day, and another two people are diagnosed with the disease. The average life expectancy after diagnosis is 2.5 years.

Hon Gordon Bruce, Labor President of the Legislative Council, 1989-1993, was a strong advocate for voluntary euthanasia.

He died with MND.

David is a 49 year old former bank executive, married to Susan. David and Susan have two adult children, both completing university studies. Eighteen months ago, David complained to his GP about falling and stumbling at home, dropping things, cramps, slurring his speech and on occasions, experiencing difficulties in swallowing. David was previously fit, ran marathons and had no pre-existing health conditions.

Newsletter on current debates

After a series of blood tests, nerve conduction studies, electromyography (insertion of a needle electrode into muscles to measure their electrical activity) and an MRI, David was diagnosed with MND.

David opted to remain at home with his family, under the care of his GP, neurologist, palliative care, home nursing and allied health care teams.



Former SA Liberal leader, **Hon Dale Baker**, who died from MND, wanted the choice to end his own life.

Over the next six months David's physical health and condition deteriorated significantly. He had difficulty breathing, was always tired, and experienced significant pain and discomfort due to the pain from his stiff joints and muscles. David found it difficult to sleep due to excessive saliva and breathing difficulties. Eventually David could not walk and had difficulty speaking. When he could no longer chew or swallow, David - in consultation with his family and medical/nursing team - had a permanent gastrostomy (PEG tube inserted).

David and his family were aware that his prognosis was very poor; that there was no cure for MND.

David communicated with his family, medical, nursing and allied health team that he wanted to be "in charge" and have the choice and the legal right to bring his suffering to an end in a dignified manner surrounded by his loved ones. He wanted the opportunity to share precious moments and say goodbye while he still could.

David's MND continued to progress. His family's lasting memories are seeing their dearly loved husband and father suffer and waste away to a shadow of his former self.

Voluntary Euthanasia legislation would have enabled Patricia and David - and many others like them - to end their life with dignity and on their terms.

Stories documented by the ANMF, SA Branch

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 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 in quality of life a longer life expectancy may bring.

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

An Australian Doctor survey of 366 doctors and 26 nurses found

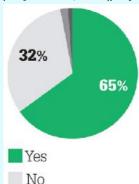
that 65% supported legal reforms allowing patients to end their own lives and 49% would be willing to assist patients to take their own lives.

Almost half said they would assist in a patient's suicide if they were terminally ill and facing intolerable suffering.

The survey was based on a model for euthanasia recently put forward by the Victorian parliamentary report, Inquiry into End-of-Life Choices, which says requests for assisted dying should be restricted to terminally ill patients with enduring unbearable pain and suffering.

Victorian Health Minister Jill Hennessy said too many people were dying in unnecessary pain. She has called for reform of existing end-of-life laws in the Don't know 1%

Q: Do you support laws which would allow doctors to end the lives of terminally ill patients, facing intolerable pain / suffering?



Other 2%

When she was three-years-old, her mother was diagnosed with MS. "At different points in time she would say that she wanted to have control of her own death," she told the Sunday Age newspaper earlier this month.

"But we're not legally or medically able to do that for her, so she's denied that choice - she has to literally wither away until an infection takes her, or she chokes, or pneumonia comes by virtue of her body breaking down internally. It's unbearable to think that will be the end of her life." (Australian Doctor, 14.10.16)