

End of Life Choice



Newsletter on current debates

Hopeless suffering and terminal illness

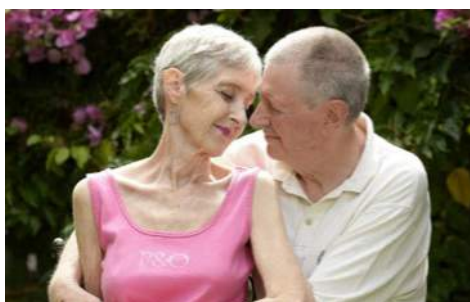
The Voluntary Euthanasia Bill 2016 establishes 'unbearable and hopeless suffering' as the criteria for requesting assisted dying. Other Bills have required a diagnosis of 'terminal illness'. This Newsletter discusses how a doctor is required to confirm a person's condition is 'hopeless' before they are eligible to request assistance to die.

The moral case for voluntary euthanasia is based on three major principles: respect for personal autonomy; compassion for those who are suffering with no prospect of relief; and concern for the dignity of the individual. With advances in medical technology, the number of people facing the prospect of prolonged and hopeless illness has increased over the last few decades.

The central focus in this discussion is on the needs of patients for whom no acceptable treatment is available. The function of medicine is not only to sustain biological life but to relieve suffering. Forcing a patient to suffer when such suffering can only be alleviated by death, is arguably doing harm. The medical literature acknowledges that doctors have a particular responsibility towards patients who are either hopelessly ill, dying, or in the end stage of a terminal illness (Wanzer, 1984). Courts around the world now accept that patients have the right to die, whether or not they are terminally ill or suffering. There is already a right to withdrawal of treatment for those who are permanently unconscious, or being kept alive through medical intervention, such as a respirator or feeding tube. This right applies even if the patient is not perceptibly suffering or close to death.

South Australia's Voluntary Euthanasia Bill 2016 focuses on people experiencing 'unbearable and hopeless suffering': a prognosis made within the close relationship between a patient and his or

her doctor; subsequently confirmed by a second medical opinion and with other safeguards. Other proposals for voluntary euthanasia law reform have focused on the terminally ill or dying. Perhaps this is based on a pragmatic view that law reform would be easier if strictly confined to terminal illness. But this ignores the plight of those who are not expected to die imminently: those people with such a quality of life that they have a rational case for requesting assistance to die.



Judith King of Norwood, who has a degenerative disease, multi system atrophy Photo, Sunday Mail, March 13

It is also arguable whether it is possible to consistently distinguish between patients who are dying and those who are not. Predicting imminent death is not always easy, and this has led to a lack of clarity in related terminology. For instance **South Australia's Consent to Medical Treatment and Palliative Care Act 1995** uses the term "terminal phase of a terminal illness", as if this settles the point. Use of the term 'terminal illness' is arguably most appropriate in the context of malignant diseases. Advanced incurable cancer is usually associated with a rapid, progressive, predictable and inevitable path to death. And around the world, most people who use assisted dying laws have cancer.

Terminal illness is defined by four basic characteristics that may, or may not, be associated with intolerable and unrelievable suffering:

1. No chance of recovery
2. Certain progression to death
3. Rapid progression to death
4. A short time-frame to death

'Hopeless illness' shares only one of these characteristics – no chance of recovery. It is characterised by permanence: the patient will never recover. The associated severity of the condition leads to intolerable suffering, such as that experienced in mid-

brain stroke, motor neurone disease and multiple sclerosis. In the **Voluntary Euthanasia Bill 2016** currently before the South Australian Parliament, a person's medical condition must be unbearable (to the person) and 'hopeless' before a request for voluntary euthanasia can be made. S4 of the Bill defines 'hopeless' to mean that neither of the doctors can identify any further reasonably available treatments which would relieve the person's suffering "to a level bearable to the person".

It is for these reasons that unbearable and hopeless illness should be the criteria for voluntary euthanasia law reform. If a thorough medical assessment and exploration of all available treatment options finds that there is no hope of an end to suffering and regaining any acceptable quality of life, a patient should have the choice to relinquish his or her life with compassionate assistance.



Em Prof Ian Maddocks, AM, first Professor of Palliative Care, Flinders University, writing on voluntary euthanasia, said "we need compassionate consideration for those outside the setting of major disease and imminent death"

Regular Australian scientific polling conducted on this issue since 1962 (eg Morgan Poll) confirms this view. In 1962 47% supported law reform with the percentage increasing to above 70% in the 1990s. In 2012 it was 82%. **The Morgan Poll makes no reference to 'terminal' illness but poses the following question (1):**

"If a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering, asks for a lethal dose, so as not to wake again, should a doctor be allowed to give a lethal dose or not?"

The unequivocal response to this question highlights the overwhelming view of the electorate, that we each have the right to face death in our own way with the assurance that it need not be preceded by intolerable pain and suffering, senility, and loss of bodily functions. Death with dignity is the right of every person who faces an incurable, painful or degrading future.

(1) Newspoll uses similar wording

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

Speaking with doctors in Belgium, the Netherlands and Oregon, Andrew Denton learnt that in those places, palliative care and assisted dying are seen as things that go together – and assisting a patient to die may sometimes be the ultimate offer of help for those beyond the skills of even the most dedicated palliative care experts.

Without a law to protect or guide doctors and nurses, Denton wondered: how does palliative care in Australia deal with those same kinds of patients?

Richard Chye is the director of palliative care at St Vincent's Hospital in Sydney. When Denton asked him if he could spend a week in his unit to learn what it is they do, he was upfront, telling him that he believed there should be a law for assisted dying in Australia and that it would be one of many things he'd like to discuss with him and his team.

To Denton's surprise, and to his credit, Chye agreed. By the end of the week, two things struck Denton about the doctors and nurses of Sacred Heart. First: their deep commitment to, and compassion towards, their patients. And second: the universal acknowledgement of how hard they found it when a patient was beyond their help.

'I think we do provide dignity and good care, and the majority of the time, symptoms are managed well. But there are occasions when a symptom isn't controlled, or someone has a rough journey – for whatever reason, you know – and you do think about that.' (Nursing unit manager Ken Webb) (Source: Wheeler Centre, Better Off Dead, Podcast 10)



Spencer Ratcliff had never witnessed such pain as he saw during his partner Deb's final days – pain which palliative care staff were unable to relieve: 'I said, "What are we supposed to do? Just sit and watch her scream herself to death in pain?"' Photo: Andrew Denton