# End of Life Choice



#### Newsletter on current debates

# Victorian Parliamentary Committee recommends Assisted Dying Legislation

In the words of Committee Chair, Hon Edward O'Donohue MLC, Liberal Member for Eastern Victoria Region:

For the past 10 months I have led an inquiry looking into how people die. With seven other Victorian MPs representing four political parties, I have met the people most immediately affected by this Inquiry people facing horrendous suffering. Many spoke of their fears of dying a painful death, the toll that will take on their families and the helplessness they feel. The Committee heard disturbing evidence from the Coroner's Court and Victoria Police that people experiencing an irreversible deterioration in their health are taking their lives in brutal ways. Those deaths are happening, on average, twice a week. Those desperate, lonely deaths are the hidden toll of our current end-of-life framework.

We can no longer ignore the suffering taking place in our community — reform is needed. (Electorate website, 16.6.16)

The 444 page report released on June 9, *Inquiry into end of life choices*, has 8 chapters: I, Executive Summary and Inquiry Methodology; 2&3, palliative care; 3&4, Advanced Care Directives (SA enacted ACD's in 2014); 4&5, suicide; 8, findings and recommendations.

The summary below uses direct quotes from the Inquiry report.

# The Committee's recommended framework allows an adult, with capacity, who is at the end of life and has a serious and incurable condition which is causing enduring and unbearable suffering to request assisted dying. (p217)

People suffering from terminal illness and serious chronic and degenerative diseases gave evidence about the angst and frustration they feel at being unable to choose to end their irremediable pain and suffering, and to die at home surrounded by loved ones.

Some people are choosing to stop having treatment, knowing that this will result in their imminent death. Witnesses spoke of the trauma of watching seriously ill loved ones refuse food and water to expedite death and finally relieve their suffering.

Anne Woodger wrote of her father who suffered motor neurone disease and decided to cease percutaneous endoscopic gastronomy feeding so he would die of starvation and dehydration. The law respected his right to end his life, but gave him no help to do it and insisted he must die slowly of starvation and dehydration ... Mucous solidified in the back of his throat and was regularly prized out with cotton buds, causing him to gag. His mouth was dry and could only be swabbed with water ... He died after 12 days. (p196)

Family members, the Coroner's Court of Victoria and Victoria Police gave evidence about how people experiencing an irreversible deterioration in health are taking their own lives in desperate but determined circumstances. (p193)

#### No slippery slope

In explaining its proposed legislative framework, the Committee chose not to focus solely on arguments for and against legalising assisted dying because the various arguments put by supporters and opponents are well known and have been addressed many times in many different reports and research papers, both in Australia and internationally.

Concerns raised in arguments against legalising assisted dying — such as the inability to implement and maintain effective safeguards — have not eventuated in jurisdictions where assisted dying is legal. Rather, these jurisdictions highlight the importance of establishing a framework that suits a particular jurisdiction's medical and legal culture and of providing the appropriate safeguards within that framework. (p205)

#### Four report themes

Suffering: The Committee recognises people's suffering and resolved to consider what legislative action, if any, should be taken to best serve Victorians at the most difficult time of their lives. While several submissions suggested that all pain and suffering can be alleviated through the provision of better palliative care, the Committee heard from health practitioners that not all pain can be alleviated.

Suicide: The evidence presented by the Coroner's Court was highly persuasive, and highlighted some of the horrific ways people are currently dying under current law, particularly frail, elderly and vulnerable Victorians. Many are dying alone and in pain. They are often dying earlier than they desire because they believe they must act alone, before they are no longer capable, and so that their loved ones are not implicated in their death.

Public Confidence in the law: Some Victorians are prosecuted for acts of love and compassion towards their relatives and loved ones that violate our criminal law. Without exception, police, prosecutors and judges have used their discretion to ensure those prosecuted for helping loved ones to die do not face the full effects of the law. This threatens to bring the law into disrepute and undermine public confidence in the administration of justice.

Unregulated medical practice: Some Victorians are assisted to die by doctors. This is happening without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without their consent. (pp206-7)

The criteria and safeguards in South Australia's Voluntary Euthanasia Bill 2016 are similar to the legislative framework recommended by the Victorian Committee.

#### Committee conclusion

The evidence is clear that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not. The Committee is satisfied that assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse. (p212)

The law should enable the small number of eligible Victorians who want help to end their suffering to die surrounded by loved ones, without fear of prosecution. (p213)

It is essential that the patient must be experiencing enduring and unbearable suffering that cannot be relieved in a manner which the patient deems tolerable. In the shift towards patient-centred medicine the Committee believes it is not for others to decide what is and is not tolerable for a patient.

#### SAVES

South Australian Voluntary Euthanasia Society



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 doctoradministration.

#### 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

### ACL agrees palliative care cannot alleviate all pain and suffering

Staunch opponent of voluntary euthanasia, Lyle Shelton, Australian Christian Lobby Managing Director, has conceded that people do not wish to suffer at the end of life, and that palliative care is unable to manage all pain and suffering. Within minutes in the same interview on ABC Lateline, Shelton said palliative care was adequate, then he said it wasn't. The alleviation of pain and suffering is the principle reason for the overwhelming public support for the legalisation of voluntary euthanasia.

LYLE SHELTON: When parliamentarians having closely looked at it have opted not to legislate it (voluntary euthanasia) because it's not seen as safe, it's too dangerous, the safeguards can't be put in place to protect the vulnerable, who might be coerced or pressured, and also, the advances in palliative care have been seen to be quite adequate.

Later in the same interview

LYLE SHELTON: No-one wants to see their loved ones suffer. None of us want to suffer ... and ... no palliative care expert will say that all patients can be pain-free or have an end-of-life experience that one would want.

http://www.abc.net.au/lateline/content/2015/s4469375.htm *Lateline May 25, 2016*