

End of Life Choice



Newsletter on current debates

How to Stop Non Beneficial Treatments

In Oregon, USA, if you are in the last six months of life, you can choose to stay at home and have a palliative care nurse on call 24 hours a day, coming three times a week, together with an occupational therapist, a physiotherapist, a music therapist, a masseur, and someone to come and wash and bathe you. Oregon was also the first state in the USA to provide legal physician assisted dying following a 1994 plebiscite. Oregon's Death with Dignity Act has facilitated an open and transparent discussion of end of life care, to the benefit of the whole community.

'People in Australia consistently say they want to die comfortably at home, supported by family and friends and effective services. But dying in Australia is more institutionalised than in the rest of the world. Community and medical attitudes plus a lack of funds for formal community care mean that about half of Australians die in hospital, and about a third in residential care. Often they have impersonal, lingering and lonely deaths; many feel disempowered. Seventy per cent of people want to die at home, yet only about 14 per cent do so.' (Grattan Institute, 2014)

A recently published Australian-led study reviewed the records of more than one million deaths in 10 countries and found more than a third of patients nearing the end of life received invasive and potentially harmful medical treatments.

Oregon stands out as a region which provides an alternative model of care which facilitates people at the end of life to be cared for at home, and not be subject to non-beneficial treatment in the last months of life.

Non-beneficial treatment (NBT) is one of a number of terms including 'futile', 'inappropriate', or 'disproportionate' treatment (or care) concerning the range of treatment approaches at the end of life. NBT highlights the persistent culture of 'doing everything possible', even against patients' express wishes. It perpetuates an underlying assumption that the medical goal should be survival at all costs, with

disregard for human dignity and quality of life, and the repercussions for a sustainable health care system.

The analysis of 38 studies over two decades, found that doctors consistently initiate excessive medical or surgical treatment on elderly patients in the last six months of life. **The findings confirm that many elderly Australians are probably receiving invasive and potentially harmful medical treatments when they will die regardless of any treatment.** Co-leader of the study Professor Ken Hillman (University of NSW) noted that 20 or 30 years ago intensive care units supported relatively young people with curable clinical problems. Most patients in intensive care units are now over 70 years of age, with multiple clinical problems.

What's happened in the last five or 10 years is that we prolong life when there is no hope.



Ken Hillman, Professor of Intensive Care, University of New South Wales (ABC Aug 31, 2011)

Professor Hillman lists the NBT treatments as including cardio pulmonary resuscitation, radiotherapy, and chemotherapy because, as he says, 'doctors are programmed to cure you, to make you better'. Advances in medical technology have also raised unrealistic expectations of the healing power from the range of tools at doctors' disposal: especially so in the case of treatment for the elderly. Doctors wrestle with the ethical ambivalence of delivering what they are trained to do: to save lives while trying to support the patient's right to die with dignity.

Dr Magnolia Cardona-Morrell, who led the research, noted the level of invasive procedures, unnecessary imaging and blood tests, and concurrent treatment of other multiple acute conditions with complex medications. **These procedures made little or no difference to patients' outcomes, but could deny a comfortable death.**

Dr Cardona-Morrell states that although predicting death is uncertain, clinicians can be trained to use a range of 'tools' as triggers to initiate an honest end of life discussion. Timely and honest conversations empower patients and

families to cease NBTs when medicine can offer nothing more. This in no way means that clinicians or families are abandoning their patient.

The Non Beneficial Treatments review found that, for patients:

- Up to 50% had blood tests and imaging even with do-not resuscitate orders
- 33% received antibiotics, cardiovascular, digestive or endocrine medicines
- 33% were given chemotherapy in the last six weeks of life
- 30% had dialysis, radiotherapy, transfusions and other life support in their last days
- 25% had CPR even with 'not-for-resuscitation' orders
- 10% were admitted to intensive care

Other tools to support end of life conversations include the completion of advance care plans in which patients express their wishes concerning aspects of their end of life care. A recent review of 24 studies which examined older people's attitudes to advance care plans showed that most people would welcome end of life care discussions but were rarely given the opportunity.

The evidence is that the process of legalising voluntary euthanasia promotes community discussion about end of life care and the development of more informed policy and practice; it creates an environment in which older Australians are more likely to achieve their dream of a comfortable death at home, surrounded by family and friends.

References:

- M Cardona-Morrell, JCH Kim, RM Turner, M Anstey, IA Mitchell, K Hillman, Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem, *International Journal for quality in health care* DOI: <http://dx.doi.org/10.1093/intqhc/mzwo60> First published online: 27 June 2016
- Sharp, T, Moran, E, Kuhn, I, Barclay, S (2013) Do the elderly have a voice? Advance Care Planning discussions with frail and older individuals, *British Journal of General Practice*, e657-e668
- Swerissen, Hal, Duckett, Stephen, (2014), *Dying Well, Grattan Institute Report No 2014-10*
- ABC, Aug 31, 2011

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

Dying: A Memoir, written by Australian screenwriter and Miles Franklin-nominated novelist **Cory Taylor**, is the fastest book ever published by Text Publishing. Text Publishing proofread sentences as they came in; typeset pages furiously. Julian Barnes – who rarely endorses books by anyone – immediately agreed this book was worth his personal praise.

Cory Taylor died in July, from a melanoma.

In *Dying, A Memoir*, and by videolink at the Sydney Writer's Festival in May, Taylor discussed how the loneliness of dying is made worse by Australian laws that make helping someone to die a criminal offence. "It's not just that you're facing a death where – if you chose assisted dying under the [legal] circumstances in Australia – you'd face dying alone," she said, in that voice that could somehow convey intelligence, delight and being appalled at once. "It's that the whole subject is banned. **You're dying in this enormous silence about the most important thing that's happening to you.**"

In writing and in life, Taylor's pet peeves were taboos and cliché. That she was able to train her unsentimental, curious and unblinking eye on that most difficult subject is an enormous act of generosity and grace. In her book, she notes: "It takes courage to contemplate one's own death. To find companions who share your desire to know more, to take the initiative, and to laugh in the face of our shared mortality, is a gift." By her own standards then, Taylor is one of our bravest writers. (SMH, July 10, 2016)

