

End of Life Choice



Newsletter on current debates

On being forced to suffer

Ian Maddocks, Emeritus Professor of Palliative Care at Flinders University and Senior Australian of the Year 2013, wrote in The Age in 2014:

Occasionally, in the process of seeking to ensure compassionate and effective care in the chosen setting (and home is clearly the best when it can be arranged), I am aware that although major discomforts of pain, nausea, confusion, frailty and exhaustion are causing minimal distress, and although loving exchanges with family and friends continue, the patient expresses a wish for control in saying, "I have had enough; I want out".

It may seem to all present, and to me, that such a request to move on to death now is logical and appropriate. We hope to affirm, in palliative care, that 'there is always something that can be done', but it may now seem that all I can offer is to increase the dose or rate of infusion of medication, assuming there is additional discomfort to address, but it will usually be days, and sometimes weeks, before death ensues.



Em Prof Ian Maddocks AM

Knowing the pathology being faced, the lack of any treatment to reverse its inevitable progress, and aware that effective palliative care is doing its best, I may recognise that a patient's option for an assisted death is logical, and is sought with clarity and respect, free from anger or despair. In such circumstances I would value an assurance that I would incur no risk of criminal action in providing assistance for that release. It should

require a full exploration and agreement within the family, a period of further review that included the agreement of another practitioner, and an open transparent report to an authority such as the Coroner.

Australia's palliative care system is highly regarded, but, as Em Prof Maddocks describes, when a person's suffering is no longer bearable, there needs to be another option. About 5% to 10% of hospice patients persistently request euthanasia. As Maltoni and colleagues (2012) state '*Despite the progress made in palliative medicine in terms of symptom control, there are still many patients who have intractable symptoms, because the treatment is either ineffective or intolerable.*'

Examples of the pain and distress at the end of life include

- severe head pain due to pressure on sensitive nerve structures, which may be accompanied by blindness, paralysis and incontinence
- some head and neck cancers which include ulceration may fungate, distort the face, and produce foul odours
- widespread abdominal cancer causes recurrent bowel obstruction, pain, nausea and abdominal distension
- an understanding of the extreme suffering associated with inoperable bladder cancer led to an old medical saying "Please God, do not take me through my bladder".

As well as the above *painful* syndromes there are other 'non-pain' syndromes that cause extreme suffering. These include

- Cachexia, commonly associated with advanced cancer, involves severe loss of appetite and weight, extreme loss of energy and severe psychological distress
- Obstructing oesophageal cancer involves vomiting back anything ingested; chronic progressive difficulty in breathing may result in coughing blood and an associated fear of suffocation
- Progressive neuropathic syndromes such as multiple sclerosis and motor neurone disease, may lead to paralysis of limbs, loss of speech, blindness, loss of control of bowel and bladder, and perhaps inability to breathe or swallow
- Total Dependence Syndrome refers to loss of dignity and independence

- Severe stroke can result in permanent paralysis, inability to communicate, inability to swallow, commonly followed by muscle contractures, incontinence and bedsores; this state of total dependence can last for years.

While the person's body functions disintegrate, a perfectly lucid mind may be trapped within.



Understandably, in the absence of a legal framework to end unbearable suffering, there is a resort to suicide; often by violent means. The need to resort to a lonely suicide in such circumstances is an indictment on a civilised society.

Palliative care and voluntary euthanasia are not in conflict. **In those jurisdictions where voluntary euthanasia is a legal option the evidence is that the quality and quantity of palliative care services has increased.** The European Union *Ranking of Palliative Care Development* report (2011) reveals that the Netherlands, Belgium and Luxembourg - three countries which allow voluntary euthanasia - rank 'high' in palliative care services. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=4u7qIYeJBek%3D&tabid=608>

In the USA, the Center to Advance Palliative Care reported in 2011 that Vermont, Oregon and Washington ranked 'A' and Montana ranked a 'B' in relation to their provision of palliative care services - four states which permit physician assisted dying. <http://reportcard.capc.org>

In 2011 Dr Scott Blackwell, then President of Palliative Care Australia, argued "In some ways I think let's legislate it (voluntary euthanasia) and let it just find its place."

There is neither justice nor compassion in denying choice for voluntary euthanasia, which provides a release to patients whose suffering cannot be relieved.

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, 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

"Recently I sat by my father's bedside as he died. He was unconscious, in a fog of sedation and painkillers, and I had the privilege of a long goodbye. In the end he had a peaceful death, but my family had to fight for it. ***Fight the passive resistance to providing care focused on a comfortable death, rather than care focused on cure.*** Fight the lack of recognition that we could simultaneously love this man, while advocating for care that allowed him to die without agitation and suffering. Fight the insidious guilt this conflict let creep into our last week with him.

"In itself this is not a remarkable story, our difficulties navigating the end-of-life landscape have been shared by countless other families. ***What is remarkable is that our experience was so difficult despite my role as a senior intensive care specialist in the Australian healthcare system, a clinician who regularly deals with grief and dying.*** I had imagined I would be able to smooth the bumps for my father and family. I was wrong, and there are lessons I have learnt. I have learnt it can be hard to be heard. My father had his second fall in a few months, occurring on a backdrop of progressive dementia, and had a bleed on the brain. We asked to talk about treatment options. Cruelly, his deterioration left him with enough presence to feel alone in hospital, wishing he were home with the woman he had loved for more than half a century.

"We wanted to say we didn't want him to receive care that would prolong his life, only to see him die away from home soon after. We were told he would get full resuscitation, that the doctors involved in his care were not available to talk to us about treatment limitations until the next day, or the day after that. We were not heard. I have learnt it is easy not to get good end-of-life care. ***At his most vulnerable my father suffered and we were treated clumsily.***"

Neil Orford, The Age, July 8 2015