

Noreen Fynn

17th October 2017

The Principal Research Officer
Select Committee on End of Life Choices
Legislative Assembly
Parliament House
Perth WA 6000

Submission to the Joint Select Committee on End of Life Choices

I welcome the government initiative in establishing the Select Committee on End of Life Choices and thank you for the opportunity to make this submission.

I have chosen to address the broad question of whether there is a need for laws to allow the citizens of Western Australia to make informed decisions regarding their own end of life choices.

It is my personal view that there is a need for laws to allow for end of life choices that would enable a compassionate death for people in pain and suffering and that would enable people to have their families with them. This is based on my own experience.

It is a question of choice solely over one's own life and end of life.

“Those who oppose voluntary euthanasia all but commit some patients to an uncomfortable, undignified death” (Clive Deverall, October 2016)

I am the widow of Clive Deverall, the former head of the Cancer Council WA and former chair of Palliative Care. A brief resume for Clive is attached. It is included given the relevance of his background and knowledge and of his support in recent years for voluntary assisted dying. Also included is a personal perspective article he wrote in 2010 on voluntary euthanasia.

His personal experience was as a person who was at the end of his life and in a position of unbearable pain and suffering after more than twenty years of living with a multitude of health issues including cancer and strokes.

Just to give the Committee some idea of what he was going through – the list of health professionals involved in his care included his GP, general medicine physician, neurologist, dermatologist, rheumatologist, respiratory physician, urologist and ophthalmologist. I have only praise for the health professionals and for the health system. They were excellent, and tried everything, as did Clive himself. He wanted to live and fought for many years to retain function and some quality of life. It was a losing

battle and at the end the full force of symptoms, some of which were caused by medications, included unrelenting neuropathic pain, crippling headaches, lung damage and acute steroid induced glaucoma. I could go on but there is no point. There was no cure, no hope and unrelenting pain and distress.

It is well known that my much loved and highly respected husband chose to end his own life on 11th March, election day in Western Australia, leaving a statement that said "suicide is legal, euthanasia is not".

He had publicly said before, as has been reported in the media, that in the absence of assisted dying legislation, people will make brutal decisions. In notes for one of his talks he wrote that there was a high rate of suicide in older men in particular, some of which would be due to end of life pain and suffering.

It was a hard, sad and lonely death for a man who had given his all in life to help others, particularly those with cancer. I believe he deserved a better death and he deserved to have his family with him at the end of his life.

He strongly supported the need for legislation on assisted dying in order to allow people the choice of a more compassionate death at the end of their life. It is something I strongly support myself, even more so now given the manner of his death.

"EUTHANASIA - A PERSONAL PERSPECTIVE (Sept 20th 2010)

Clive Deverall

Former CEO of the Cancer Council of Western Australia

Former Chair of Palliative Care WA

- I have attended so many palliative care meetings where problems have been discussed in context of the experience of individual terminally ill patients. The term 'palliative care nightmare' was used frequently when despite all the best efforts - clinically and despite access to all the drugs, the patient's developing symptoms of pain, nausea, panic and breathlessness as well as emotional distress could not be controlled. So called 'nightmare scenarios' became an item for discussion at some professional meetings and conferences. (Palliative Care Australia has recently acknowledged this scenario)
- Palliative Care started well in WA. From the early 80s through to the 90s services were inspired and worked well. However, the more they became absorbed into mainstream services (which is what we wanted to happen) - so they faltered and began to suffer from lack of funding, lack of good staff and fading enthusiasm. In regional WA delivery of well structured, modern palliative care has been poor. Efforts have been made but the outcomes in too many settings have been downright bad.
- In the last 10 years much has been made of providing palliative care from within the health system. Many departmental reviews have been undertaken and reports made but the basic issues of insufficient funding, not enough trained staff and lack of dedicated palliative care beds - especially in the teaching hospitals have never been resolved. Every palliative care professional knows where the 'palliative care black holes' are within the system. Too many are in the country and even in our own

teaching hospitals after 6pm on a Friday. If you can't get access to a doctor in one of our regional hospitals - what hope of obtaining proper palliation?

- Palliative Care has been used as a mantra by politicians on all sides and health professionals to oppose euthanasia or to avoid having it debated. Even if good, modern palliative care was available for each and every terminally ill patient - we would still have the 'nightmares'.
- As part of the process to lobby for Living Wills in WA I talked to 63 community groups (over 7 years). At every meeting it was evident that there was overwhelming support for euthanasia.
- Having looked closely at how the systems work in Holland, Belgium and Oregon I am confident that we can develop a sensible system with as many safeguards as they have over here. What struck me most was Oregon where their state Palliative Care organisation strongly opposed euthanasia as it was being proposed. After 3 years they changed their minds and policy and now work in very well with the provision of euthanasia in that State. Ditto - Holland. And - most striking of all: less than 4% of those who are eligible access euthanasia but research indicates what a comfort it is to those patients who ultimately don't take the option.
- At present in our health system health professionals and especially those in palliative care know what 'Terminal Sedation' means - it is the euphemism for euthanasia and is used every day. We have an opportunity to make access to euthanasia more transparent."

Comment on the terms of reference:

- a) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;**

Notes written by Clive:

"and every day, in different settings, terminally ill patients – most with advanced malignancies and uncontrolled symptoms – are terminally sedated. Excellent. But that is the Lotto Life: the patient has to be lucky enough to find a doctor willing to help. And there is little or no transparency and a legal risk to the doctor and/or nurse."

- b) review the current framework of legislation, proposed legislation and other relevant reports and material in other Australian States and Territories and overseas jurisdictions;**

Today legislation has passed through the Lower House in Victoria and I hope that this is the forerunner to legislative change in Australia.

- c) consider what type of legislative change may be required, including an examination of any federal laws that may impact on such legislation;**

The media have carried reports of the Australian Federal Police visiting elderly people suspected of planning to import Nembutal or other lethal substances used in voluntary

euthanasia. Surely we have better things to occupy our police forces and better use of limited resources than for them to have to be concerned with an elderly person's worries about death at the end of their lives.

These substances are however illegal and Australians are not allowed to purchase or own them. Clive knew, and knew of, people who had bought Nembutal. He had researched buying it himself but would only have trusted a source where he could be assured it was the genuine article. He was concerned that there was no guarantee regarding the provenance of substances bought illegally over the internet and had read reports of some horrendous cases where the product was not genuine. He even tried many avenues to see if there were places where one could get it tested but to no avail.

Legislative change would enable people to have access to legally prescribed and controlled drugs.

At present it is legal to commit suicide, but not to have assisted dying. This is a horrible death for the people who feel they need to take this path and it is horrendous for those of us who are the family.

It is a tragedy too in that it means we lost Clive earlier than we needed to. He took the action to end his life while he felt he had the capacity to still do so, capacity that he was aware was diminishing as symptoms increased again. In the six months since his death he has missed the wedding of one of our sons, his granddaughter's second birthday and his grandson's fourth birthday. We mourn his loss and felt his absence keenly.

It is important too to recognise the wider impacts, on the police who have to attend and to then break the news to family and on the ambulance officials. The impacts can extend to members of the public, local government officials and other services.

Legislative change would enable people to make choices at the end of their life that would remove the need for them to consider ending their own lives.

There is indisputably a need for safeguards, particularly for those who are vulnerable. This has been given in depth consideration in Victoria with stringent consent processes in the proposed legislation.

I believe we could do the same in Western Australia.

Should an event have occurred which removed the ability for a person to give consent in terms of the legislation then they would need to have an Advanced Health Directive in place to give voice to their choices.

d) examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship and the implications for individuals covered by these instruments in any proposed legislation.

Clive, in his professional life, advocated for and was a strong supporter of Advanced Health Directives. His was the first Advanced Health Directive in Western Australia at their launch along with Kim Hames, the then Minister for Health.

He and I both had/have Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship in place.

The Advanced Health Directive is very important in noting a person's own wishes and choices in regards to treatment options, particularly at times when one's emotional response as a family member is to want to save a person at any cost.

Clive's for instance was very specific in not wanting treatments/interventions such as cardiac pulmonary resuscitation (cpr), artificial feeding or ventilation should he suffer some catastrophic event likely to leave him incapacitated. He was quite aware that this was his choice and others might make different choices.

I used to tell him that I was glad he had written this down because, in common with most family members, I would have wanted to save him and he would not have wanted that. He was quite clear about what was constituted quality of life for him and that was more important than merely being alive.

In summary, I support efforts to introduce Voluntary Assisted Dying legislation and urge the WA members of Parliament to make such provisions available to the people of Western Australia.

Yours sincerely

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Clive Deverall - background

- CEO of the Cancer Council WA 1977-2000

MEMBERSHIPS & REPRESENTATION

- Board member, The Cancer Council Australia (2002-2008)
- Chair, WA Government's Charitable Collections Committee (2002-2017)
- Chair, Cancer Voices WA 2003 - 2009
- Member of the Consumers' Health Forum of Australia and the Health Consumers Council of WA (1994-2008)
- Member, Research Committee, the National Health & Medical Research Council(NH&MRC), plus member of various research assessment groups (2001-2007) including Positron Emission Tomography, Brachytherapy (ref prostate cancer), M-vax(ref melanoma), and Electromagnetic Energy Committee (mobile phones).
- Member, National Cancer Strategy Group (Dept of Health & Ageing, Canberra) (1994 – 2003)
- Member of Medical Services Advisory Committee(MSAC) advising the Federal Minister for Health in assessment of new drugs and equipment plus review of tenders (1999-2005)
- Founder Member & Chair Palliative Care WA 1996 – 2005
- Member of the WA Coroner's Ethics Committee 1999-2003
- Board Member Cancer Voices Australia - 2003-2009

AWARDS

- Order of Australia, AM, in 2001 for services to cancer patients and development of palliative care.
- Centenary Medal, Commonwealth of Australia, 2003
- Cancer Council Australia Gold Medal 2004
- Presidents Medal, Cancer Council WA, 2008