

Day One of Public Hearings
Session: The Hot Button Issues

Presentation by Neil Francis, CEO, Dying with Dignity Victoria

Thank you

Thank you for the opportunity to speak here today.

Despite the fact that death will happen to every single one of us, it is a subject that many people find difficult to talk about. It's odd, isn't it? While most people are not afraid of 'being dead,' they are quite afraid of *dying*. Why might that be so?

What happens now

Some of those with a terminal illness or the advanced stage of an incurable illness such as motor neurone disease or multiple sclerosis face intolerable suffering. Contrary to popular opinion, research shows that the majority of that suffering is not caused by physical pain, but by rather profound weakness, breathlessness, loss of appetite, and especially the inability to participate in any of life's enjoyable activities, along with loss of personal autonomy and dignity. There is often also serious mental anguish about how bad *tomorrow* might be when there is no ready and acceptable form of relief.

We can readily appreciate Woody Allen's quip: "*It's not that I'm afraid to die, I just don't want to be there when it happens.*"

What are the consequences of a lack of a human right to a peaceful death under such circumstances?

Some sufferers do indeed experience unrelievable physical pain, many experience significant psychological pain from their circumstances, and some might even regurgitate their own faeces if the bowel is blocked. Sadly, Australian Bureau of Statistics data paints an even more distressing picture. Every *week* four Australians over the age of 70 kill themselves by violent and undignified means. The most common method is hanging, but also by drug overdose, gassing, and jumping off buildings and in front of trains. Not only is this traumatic for the sufferer, but distressing for emergency workers. It causes needle-sharp anguish amongst family and delays or prevents the grieving process. These are of course not just statistics, but describe the experiences of real Australians.

Medical and social opinion

Some claim that assisted dying for the terminally ill is unnecessary because palliative care provides relief for all. However, even palliative care peak bodies recognise that this is not so. Palliative Care Australia's own policy on assisted dying "*acknowledges that while pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.*" They also "*recognise and respect the fact that some people rationally and consistently request deliberate ending of life.*"

Dr Odette Spruyt, President of the Australian and New Zealand Palliative Medicine Association, who is personally opposed to assisted dying, says that "*our palliative care resources have never been better*" and that our palliative care standards are "*the envy of many*"

countries worldwide.” However, at the same time she admits that “it is simplistic to argue that palliative care can remove all suffering at the end of life.”

Therefore, experts agree that just as there is sometimes medical futility, there is sometimes *palliative* futility, despite best practice and envied resources. So what is a society to recognise in human rights for those suffering intolerably at the end of life without adequate relief? What if a sufferer voluntarily makes a rational and considered request for medical assistance to die peacefully? Surely we don't believe that the furrowing of brow and wringing of hands is a sufficiently compassionate stance? Ought we respect the right to choose?

A 1997 research study found that 45% of physicians did *not* believe that present arrangements are adequate, 68% believed that physician assisted dying can be an act of caring, and 45% wished to have the option of physician assisted dying. Indeed, Dr Roger Hunt, head of the Palliative Care Unit at the Queen Elizabeth Hospital, Adelaide, has said, *“to talk about intentional killing and arbitrarily ending life is unhelpful and denigrating to doctors. We do not talk about stabbing people with knives when we refer to surgical procedures — to do so would be crude, emotive and misconstruing the role of the doctor in trying to help the patient.”*

What do ordinary Australians think? A national survey conducted in 2007 by Newspoll shows that 80% of Australians believe it should be a human right to seek an assisted, peaceful death for those suffering intolerably without adequate relief and no realistic chance of improvement. Support includes three out of four Catholics, four out of five Anglicans, and nine out of ten of those who follow no religion. In fact, support has been in the majority for some decades.

Protecting other rights

John Stuart Mill, said in *On Liberty*, *“The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.”*

Does a right to die with dignity violate any other fundamental human right?

Australia is legally bound by the International Covenant on Civil and Political Rights. Article (6)1 of the Covenant says: *“Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.”*

A patient suffering intolerably and without relief or reasonable chance of improvement, who makes a fully informed, rational, authenticated and tested request for assistance to die peacefully, is not being arbitrarily deprived of life. The Human Rights and Equal Opportunity Commission has ventured to argue so.

Nor should we confuse a right with a choice. A sufferer who chooses to self-administer medication to die peacefully still has a *right* to life. They have simply made a *choice* to end intolerable suffering using the one remaining means available.

Conversely, the lack of a specific right to dying with dignity may contravene the Covenant's Article 18, which conveys *“the right to freedom of thought, conscience and religion.”*

George Zdenkowski, Associate Professor of Law and Director of the Human Rights Centre of the University of New South Wales, wrote “*It could be said that it is an affront to human dignity (and indeed inhuman and degrading) not to recognise the autonomy of the individual as far as decisions as to termination of life are concerned.*”

Evidence

Opponents often point to the Netherlands and say “isn’t it awful the level of *non-voluntary euthanasia!*” However, the rate of non-voluntary euthanasia in the Netherlands is 0.7% of deaths. *In Australia, it’s 3.5% of deaths and we don’t have a physician assisted dying law—that’s five times higher!* Perhaps the rate in the Netherlands went up after their law was introduced? Formal research clearly shows that no, it didn’t.

Last year I spent a week in the State of Oregon in the USA, where a Dying With Dignity law has been in place for eleven years. I met with doctors, palliative care specialists, psychiatrists, major healthcare facilities and the Department of Human Services who collate reports of deaths under their Act. They were able to clearly demonstrate that the dire predictions of opponents have never come to pass, and wonder what all the fuss is about because they take the right as a given these days.

Other scientific study (not just opinion) has shown that the supposed “vulnerable” are in fact not so. Not the elderly, women, people of low educational status, the poor, the uninsured, the physically disabled, the chronically ill or people with a psychiatric illness.

Recommendation

In conclusion, the human right to a dignified death—whatever that means for you—is not currently enshrined in Australian law. It should be. Doing so does not erode other fundamental human rights, yet to fail to do so does undermine other rights.

On behalf of all State and Territory dying with dignity societies, and the overwhelming majority of Australians, I urge the Federal Government to enshrine in a Charter of Human Rights not only the right to life and to self-determination, but also specifically the right to *die* with dignity. Let’s get on with it.

Thank you.

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Dying With Dignity Victoria