Submission Cover Sheet

End of Life Choices in the ACT

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Dear Sir/Madam

I wish to lodge this submission to the Legislative Assembly for the ACT’s Select Committee on End of Life Choices.

I am a recently retired former federal public servant, resident in Canberra since 1981. Like my late mother, who I watched slowly and traumatically succumbing to Alzheimer’s Disease in her 70s and 80s, I have long supported voluntary euthanasia. Around the age of 40 in the mid 1990s I joined Dying with Dignity (then called the Voluntary Euthanasia Society) as a personal statement of support and commitment and have now held membership for over twenty years.

Since then I have seen several friends die from various cancers - becoming skeletally thin, throwing up constantly, having bloated abdomens repeatedly drained of fluid, in constant pain and desperately reliant on ever-stronger and more frequent pain relief to numb the worst of it. And friends and relatives respectively crippled by strokes, Parkinson’s Disease and Motor Neurone Disease. My sister-in-law, younger than I am, has experienced great distress - as was the case with mum - as she has succumbed to dementia, recently diagnosed as profound. In each case the loss of control, the indignity, the trauma, the horror of it all. Certainly not all of these individuals would have requested assistance to take their own lives painlessly before this end stage, had it been an option - often because of religious conviction. But some may have done so. Just having the option of a peaceful death, surrounded by family members, would itself be a comfort, enabling the dying person to retain an element of control in choosing to avoid unnecessary suffering.

One friend, diagnosed with early-onset dementia, announced to family and friends at an early stage that s/he had no intention of continuing to the end stage of this disease. S/he took medication to slow the advance of the illness while continuing to pursue community activities, supported by friends, while making her own arrangements to take control of her own death. S/he had a forceful personality and cheerful disposition, seeking to live life to the full, and was not subject to depression. Several years later, conscious that his/her mental decline was becoming significant though not yet beyond his/her ability to make decisions and that quality-of-life was now marginal, s/he set a departure date with his/her family for the day following a happy celebration some weeks off, farewelled supportive (if inevitably confronted) friends, and - surrounded by family - self-administered an untraumatic, peaceful means of ending his/her life. A huge crowd of friends attended his/her memorial celebration of life. This is how it should be. Except that this right should be legal, with appropriate checks and balances. Had legal assisted dying with medical intervention been available, this friend may have chosen to live a little longer.

I understand that overseas experience has demonstrated that assisted dying laws can be administered ethically, minimising any potential for individuals to be manipulated by unscrupulous family members or to utilise medically assisted dying just because they feel they are a burden to society or have a mental illness such as depression - the furphies always raised by opponents of voluntary euthanasia. I have also heard that some suffering, dying people try to end their own lives unassisted and alone, sometimes horribly and/or unsuccessfully with ghastly consequences. People should not be driven to these extreme measures.
Morality is a matter of perspective, all-too-often muddled by individual’s commitment to particular religious doctrines. Australia is a secular society, and the census has demonstrated that a large proportion of the population - myself included - hold no religious beliefs. Yet bizarrely those who hold particular religious beliefs think they have the right to dictate the rights of others - whether of women to control their own fertility or terminally ill people to die painlessly and with dignity. As a society we abhor cruelty and suffering. People are rightly prosecuted for neglect and cruelty, whether to animals or people. Many of us support the animal welfare organisations, humanitarian charities and medical research. We set high store by universal medical care, and availability of pain relief. I do not understand why we treat our domestic pets (though not other animals, unfortunately) more kindly and humanely than those humans we love and care about.

Adequate funding for, staffing levels in and scrutiny of aged care is vital - this is where most people end their lives, all too often out of sight and out of mind. Over the years we have repeatedly heard horror stories about neglect and abuse of the elderly in aged care facilities - including those in the ACT.

Palliative care is of course essential, and for many this may prove adequate in controlling physical pain. Assisted dying legislation and adequate provision of palliative care are complementary not alternatives. But all too many people experience end-of-life pain that cannot be adequately controlled medically. Current laws also do not take account of mental trauma associated with terminal disease and dying, whether of physical disease such as cancer or a brain-crippling dementia.

The recent assisted dying legislation in Victoria represents a positive first step, although very limited in its scope.

As an individual I strongly support broad assisted dying legislation, and am incensed that the federal government currently denies the ACT the option of pursuing it. Assisted dying is a right I demand for myself, should I need it at some future time.

Yours faithfully

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