



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Enquiry into End of Life Choices in the ACT

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Enquiry into End of Life Choices in the ACT

I have been a passionate advocate for better end of life care which includes options for both palliative care and voluntary euthanasia since the death of my parents. I first became interested in this topic over ten years ago following the personal experience of my parents deaths who both received "futile" treatment in their 80s which prolonged their lives unnecessarily, which was against my mother's wishes for herself. My father was unable to comment as he had dementia for the last few years of his life.

- My father was in his 80s when he was admitted to a nursing home with dementia. He had a heart attack about one year after he had been in the nursing home. They rushed him up to the local hospital where he was admitted to the coronary care ward. Unfortunately, because of his dementia he could not remember where he was and kept pulling out the IV (intravenous fluids line) and the other attachments to his body. After that disastrous episode, we, his family, got the message across that he was not for transfer to acute care and he died a year later from pneumonia.
- My mother died following a stroke. My mother was petrified of having a stroke and being incapacitated in a nursing home as had happened with a friend of hers. So when the doctors in the stroke ward told me that my mother's latest stroke was very serious and that she would have major handicaps, I advised them that she wanted palliative care only, which was agreed. So I was astounded the next day to arrive and find that my unconscious mother was receiving intravenous fluids. They informed me this was "palliative" and who was I to argue although I did think it was odd. Anyway, after 3 days, my mother woke up and she had such major cognitive damage, that she was not eligible for rehab and we organized for admission to an aged care facility where she died 6 months later.

I have since learned from the palliative care people here in the ACT, and from an Alzheimer's Australia publication in 2011 by Prof Colleen Cartwright on end of life care that you do not need fluids as part of the dying process and that, to quote Prof Cartwright:

"To continue artificial nutrition and hydration when the person has reached this stage of their illness (*i.e.* dying) can actually increase their suffering"

And certainly, this is what happened with my mother – her suffering was increased by their artificial hydration but the stroke ward specialists were not around to see it.

These experiences of my parent's deaths greatly increased my interest in what has now been label as futile care – *i.e.* treatment that will not improve the outcome for a decent recovery. Also, I have a reasonable chance of ending up with dementia in my 80s as did my father and his mother and I do not want futile care to prolong that experience.

So as an activist, I looked around at how I could act to improve the situation. I joined Dying with Dignity and I became an advocate for Advanced Care Planning as the latter was the only option we had then to try and have some control of our end of life care. I became a consumer representative on the ACT Respecting Patient Choices committee which works to improve advance care planning through ACT Health services.

About that time, UNSW Professor of Intensive Care, Ken Hillman, published his book *Vital Signs* (2009) which documented the change in dying practices in intensive care in acute hospitals. Whereas intensive care had been the place where young people were saved, he reported that it now had become the graveyard of the old. Tellingly, research has shown

that clinicians who are dying are less likely to receive futile treatment than non-medical people who have limited knowledge of the health system.

A similar argument about intensive care has been put recently by the President of the College of Intensive Care Medicine, Charlie Corke, in his book released this year, *Letting Go – How to Plan for a Good Death*. Corke notes that “When I started in medicine 40 years, we didn’t admit end-stage, very ill, very frail patients to intensive care. It was something for young people with reversible illnesses. Now we feel compelled to use it because it is there.”

Acute hospitals are designed to save and extend lives and medicine is much more complex than it was in the past. For many clinicians, their motivation to do all to save and extend life is challenged in the face of expected dying. It is often difficult for doctors and nurses in the culture of an acute hospital to adapt to a situation where patients are dying and all hope of a cure or meaningful recovery has gone.

This situation and the possible harm to patients was recognised by the Australian Commission on Safety and Quality in Health Care in their scoping study into Safe and Quality End of Life Care in Acute Hospitals. As a result, the National Consensus Statement: *Essential elements for safe and high-quality end-of-life care* was endorsed by Australian Health Ministers in 2010. It informed the development of programs to improve the involvement of patients and their families in end of life decisions. At Canberra Hospital, a program called *Goal Setting and End of Life* developed documentation for patients and clinicians to be used for patients at risk of dying in the next 12 months. The documentation and related new protocols were introduced in 2016, but changing the culture of all high-end acute care hospital from concentrating on saving people to supporting dying patients as well is proving quite difficult. An education session with new doctors was planned for early this year, but did not eventuate because there were no educational resources. Resourcing and funding for palliative care and other end of life projects is difficult in the competitive acute care environment. I note that 44 intensive care beds are planned for the new SPIRE building at Canberra Hospital but there is no reported planning for more palliative care or end of life programs.

Talking to my friends in old people organisations such as University of the Third Age and Council of the Aging, I find the majority do not want to be kept alive if their quality of life is poor (such as no longer able to feed or dress themselves). But there are some people who fear death and so seek heroic measures to stay alive. Corke notes that about “7 per cent of the population are determined to live, whatever it takes. Feeding tubes, bedpans, bed sores, ventilators – any thought of retreat is anathema to them.”

So it is really important that clinicians talk to patients and document their end of life wishes thru advanced care plans and resuscitations orders such as are used in the goal setting and end of life documentation. Otherwise, patients can get on a conveyor belt of escalating care as happened with my parents.

Also providing adequate palliative care options is a priority. Since 2013, when I was selected by Health Care Consumers Association (HCCA) as the consumer representative on the newly created ACT Palliative Care Clinical Network, I have also become an advocate for palliative care services. I am also an ambassador for Push for Palliative, a NSW palliative care organisation which has had some success in improving palliative care services in NSW with the help of the CWA.

Regarding palliative care in the ACT, there is still much work to be done. There is a growing recognition that Canberra Hospital would benefit by having a dedicated palliative care ward, as about 30 people a month die in Canberra Hospital. The recent HCCA study into

consumer perspectives of palliative care documents some of the palliative care needs. Additionally, the changes in funding models means that since activity-based funding was introduced, almost all the patients in Clare Holland House are now the imminently dying. Some patients who are expected to die in the coming months but not in the next week are advised to apply for a nursing home bed. This did not happen five years ago.

The ACT Health Palliative Care Services Plan 2013 -17 predicted the expected increased needs in palliative care but the findings were not implemented. The result could have been predicted - an increased demand for palliative care services without the needed resources to service the increasing demand over the last 5 years. The creative palliative care staff have learned how to make use of beds in the private hospitals for palliative care but this means that public patients are disadvantaged.

In relation to the Terms of Reference of this enquiry, I support the improved availability of choice for people by:

1. Improving palliative care services as discussed above
2. Supporting the introduction of voluntary assisted dying (VAD) in the ACT

I do not see the addition of a VAD dying system as posing additional risk for terminally ill people as the safeguards in the Victorian scheme and other such international schemes are well covered. The Canadian scheme seems to offer the best choices for people who wish to use VAD, particularly as it does not have the same time restrictions as the proposed Victorian scheme.

The main problem is that Federal legislation prevents us ACT citizens from having some control of important laws that regulate our personal lives such as dying and marriage.