



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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Submission to Select Committee on End of Life Choices in the ACT

We are making this submission in the hope that policy and law makers in Australia can make changes to:

- 1. Improve the management of dying patients – with such patients being kept well informed as to their condition, prognosis and treatment options and being given a choice in the decision making thereafter. We would like to see Advance Medical Directives become compulsory for those of sound mind.**
- 2. To enable those who wish to have their lives ended peacefully, and at a time of their choosing, to do so.**

Medical science has made it possible for so many of us to live longer but this is not always done in consideration of quality of life or the wishes of the patient. Many medical professionals are questioning the current situation and I refer you to the works of

- **Prof. Colleen Cartwright** of Southern Cross University and Foundation Professor of Aged Care Services and Director of ASLaRC Aged Services Unit at Southern Cross University.
- **Prof. Ken Hillman**, Professor of Intensive Care at the University of NSW, latest book “A Good Life to the End” 2017
- **Dr. Charlie Corke**, Senior Intensive Care Specialist, Barwon Health, Victoria, latest book “Letting Go” 2018
- **Prof. Mohamed Khadra** OA, Professor of Surgery, Sydney University and Nepean Hospital

All of these have vast experience and have written widely on the problems of the elderly. They have all been interviewed extensively on radio. All feel many things need to be done differently.

(One Case History: We first became passionately interested in the subject over 20 years ago when the 80 plus mother of a friend suffered a stroke, and whilst she appeared to be mentally alert, she had lost the ability to speak and to swallow. She was fitted with a tube through which she could be fed. She kept tugging it out and her daughter pointed out to those in charge of her medical care that she was trying to tell them that she did not want to be kept alive. This was in a rural area and she was taken by ambulance to Canberra, an hour’s drive away and surgically fitted with a device that she couldn’t pull out. Fortunately, she died several weeks later. It was an appalling treatment of a frail aged lady.)

In addition, modern technology has made it possible to keep us alive at any cost, regardless of the fact that outcomes will not be improved and suffering is increased for the patient. Ken Hillman is a passionate advocate for the improvement in management of the dying patient in acute care hospitals, arguing that in many cases the patients could have more appropriate care at home or in other hospitals (not acute care).

- He maintains that many of the elderly are being given medical treatment/s they would be better without, especially in ICU wards where care given can be inappropriate for the patient concerned.
- The systems in place for management are out of date for current conditions. (Page ½)

- Most of the elderly being admitted to ICUs have multiple health issues not just the particular one that has seen them admitted to the ICU. Often one specialist takes over and there seems to be little provision for committees of doctors to discuss and determine the most appropriate treatment. Where such committees exist, in his opinion, there is often no agenda, strategic direction or action plan.
- Many patients are not properly informed about their condition, prognosis or wishes as to treatment to be given or withheld.
- A great majority of patients would benefit more from improved community services which are often "not co-ordinated, have waiting lists and sporadic and unreliable services"
- Rapid Response systems have not been thought through with regard to the increasing numbers of frail aged expected in the next decade.
- A dying patient is often not diagnosed as such. Part of the problem here is the use of the International Classification of Diseases which was developed by accountants in the USA with the object of identifying "products" that the hospitals provide. Prof. Hillman considers that it is a financial, not a medical tool and causes problems. (Ref: page 139...Prof. Hillman, A Good Life to the End).
- He also suggests that there seems to be no name to cover the sum of all the normal age related conditions of the elderly and that a new word is needed to describe the frail aged. He suggests the word "Frailty".
- Too many of the frail aged are spending their last days in hospitals when they would prefer to be at home and it would be a better option for them to do that.
- Where doctors are paid for services and not receiving a salary it is easy to see that more tests, pills might be prescribed.
- Palliative care systems should be reconfigured and, in many cases plans should cover a longer term than the days, weeks at the very end, including home care initially when appropriate.

Regarding the **Advanced Medical Directive** (in addition to the Enduring Guardianship Agreements) and we would go so far as to suggest that they should be mandatory for any adult who is still rational as many problems arise if someone develops a form of dementia and their previously expressed verbal wishes about not being resuscitated in certain situations have no legal standing. This also would help in the cases where siblings argue as to whether to "let her go" or "do everything you can" which in many instances results in prolonging death and increasing suffering.

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(Signed copy being posted today 20/03/2018)

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