

Inquiry into end of life choices:

Systemic issues:

Many of the public submissions to this Inquiry make for sobering reading; however, they are no different in the distressing issues raised in submissions to the Victorian Parliamentary 'Inquiry for Options for Dying with Dignity'¹ in 1987. It is thus concerning that there have seemingly been so few advances in developing end of life expertise as a routine aspect of health care in all that time.

More recent writings add to my concern. An article in The Age on Wednesday 8th July 2015², written by a medical doctor, described how he only got good end of life care for his father, when he revealed that he was a doctor. He suggests that it is not good enough that only those 'in the know', get to access the care that is everyone's right. Dr Karen Hitchcock, in her recent Quarterly Essay³, noted the endemic ageism in the care of older people in our health care system; ageism which assumes to know what older people want in the last stages of their life; which does not give them choices; which will not grapple with the difficulties of prognostication; which raises arguments about the futility of overtreatment; and which too easily suggests that care of older people is unsustainable.

In addition, despite the majority of Australians stating that they wish to die at home, only about 14% actually do, with 30% dying in nursing homes and more than half dying in acute care settings. Among other reasons, there is insufficient political muscle to move inappropriate care out of inpatient settings; care at home remains an expedient alternative to inpatient care, rather than supported as an equal and positive choice and funded as such; and funding for palliative care lags behind demand, so much so that some home-based palliative care services maintain a waiting list. Not only is it expensive for people to unnecessarily remain in an acute hospital or to die there, the setting is inappropriate and, as noted above, the skills seem to be lacking.

The worry in all this reading is that active ending of life may be reflective of the basic fear that some people feel, of being caught in a health care system, where their wishes will not be heard and their care inappropriate; and thus they fear a death where their pain and/or suffering will not be managed. This reading represents concerning and consistent anecdotal evidence about the health care system, that professional skills in managing end of life care seem vastly inadequate. Any wonder then, that people fear the end of their life, when they cannot be guaranteed that expert symptom management and holistic support will be routinely given within our health care system. This is not complicated care and the problems don't seem to have changed in almost 30 years!!

End of life care services:

However, over a similar time frame, the palliative care sector has developed its expertise and received significant Australian government funding and policy support (although as noted the funding has not kept up with demand). Palliative care in Australia is world class and the quality, economics, policy and cultural perspectives which all contribute to a good death, are second only to the United Kingdom (http://www.lifebeforedeath.com/pdf/Quality_of_Death_Index_Report.pdf). Drug availability is as good as anywhere in the world; and so if an Australian is dying in pain, it is probably a reflection on the lack of skill of the health professional, rather than there being 'nothing more we can do'. There is no excuse for an Australian to be in pain!

In Victoria, there are excellent palliative care services across acute, hospice and other inpatient settings, as well as in people's homes and other community settings (even if as noted, the services' reach is inadequate to meet demand). The federal government has advocated policy that would broaden the expertise of palliative and end of life care across the country, beyond that of a model of expert care for a fortunate few. Over the last few years palliative care has adopted a public health approach and been marketed as being 'everyone's business'.

In addition, the federal government has funded programmes aimed at educating and developing health professionals. PCC4U (<http://www.pcc4u.org>) is a national curricula, developed to ensure that all undergraduate health professional courses have palliative care content. It has been well utilised by some disciplines more than others. The Guidelines for a Palliative Approach in Residential Aged Care (www.nhmrc.gov.au/guidelines-publications/ac15) were written specifically to develop the skills of those who work in aged care settings. Together with advance care planning, these resources need to be more widely utilised.

Why is it then, that palliative and end of life care is still so extraneous to mainstream health?

What is needed?

The issues raised are not easy to address; many, like education and professional attitudes, require systemic change. The myriad of choices around the end of life are complex and not often appreciated as being so in generalist health care settings. Health professional education is an urgent need and funding is required to provide a balanced inpatient and home care system.

There have always been and will always be, people who seek control over ending their life. However, it would be a sad indictment on our community, if people were driven to seek an active end to their life because they think there is nothing more that can be done for them, they lack trust in the health care system to ameliorate their symptoms, or fear their wish for a good death will not be met.

People need to be enabled to think about where they wish to receive their care as well as where they wish to die; they need support to work through who they want to be involved; they need encouragement in thinking through what is important for them at the end of their life; and many people wish to plan their funeral and other rituals before they die. Issues of control come into all these areas, and having control over the timing of one's death is just one aspect.

Thus it is incumbent on this Inquiry to take a broad approach to addressing potential changes to the legislative framework; not only to review the legality of euthanasia, but to examine social and health care issues that may also contribute to a person ultimately making a choice to actively end their life. The Inquiry needs to ascertain the need for euthanasia against the range of issues, and not just in isolation. This will involve:

- giving high priority to engaging the community in developing a broad approach to discussion of end of life care issues, including euthanasia. This should involve a public health approach to community engagement, utilising marketing strategies;
- continue the government's commitment to palliative care in both policy and funding, particularly in ensuring a comprehensively funded system that offers real choices to people, to receive care

and/or die at home or in an inpatient. This will require immediate new funding to expand the current services; and

- work through the Australian Health Ministers' Advisory Council and discipline-specific accreditation bodies, to ensure end of life care is mandated in education curricula, including Certificates 3 & 4 for Aged Care workers.

Emeritus Professor Margaret O'Connor AM

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References:

1. Parliament of Victoria, Social Development Committee (1987) *'Report upon the Inquiry into Options for Dying with Dignity'*. Parliament of Victoria.
2. Orford Neil (2015) 'Give death its due in a system focused on life'. *The Age* July 8th, p18
3. Hitchcock Karen (2015) 'Death Life – on caring for the elderly'. *Quarterly Essay* Issue 57, March