

Submission – Inquiry into end of life choices

Nicolette Smith.

16 October 2017

The Principal Research Officer
Select Committee of End of Life Choices
Legislative Assembly
Parliament House
Perth WA 6000



Dear Sir or Madam:

I submit my reflections to the committee as someone who has been working in this field for a few years as an end-of-life doula and community educator and who strongly values community empowerment. I support our community to consider their choices at the end of life and to act on those choices with the resources, courage, and grace that enables them to embrace death in a more wholistic way.

I am adamant that people have the right to informed choice in all their healthcare, I believe that West Australians should be provided with more options and support for the way they die, where they die, and the way their bodies are treated and disposed of after death.

Recently Australia has seen a groundswell of interest and advocacy to improve our death literacy, death awareness, and our personal empowerment for managing the end of our lives. I submit that many of us wish to take back the responsibility and honour of attending to this powerful life event. Research is indicating that 70 – 80% of Australians express a desire to die at home (Gomes et al, 2013; Palliative Care Australia, 2011). However, only 16-20% of people can do this. The Natural Death Care Centre suggests that 50% of us will die in hospital and another 30% in an aged care facility. There is a demonstrated need to dovetail palliative care with medical treatment earlier, and to streamline the transfer of people from hospitals into home or hospice care.

In response to these considerations, Parliament should:

- a) Maintain legislative protection of people's right to refuse treatment;
- b) Ensure there are mechanisms through which people know they can exercise this right;
- c) Expand Advanced Care Planning through government support, providing community outreach and assistance to prepare the relevant legal documentation;
- d) Improve support, education and funding for community-based care networks to maximise the quality of the end-of-life care environment.

Death and dying has rapidly become removed from our homes and communities as the funeral industry has grown over the past few generations. Nowadays many of us have no personal experience of caring for our dead, and much of the ritual and sacred work of the family and community at the end of life has been forgotten. We separate the ailing and elderly from our ordinary everyday lives and many of us feel that this takes away from our whole experience of being human. The time of dying has become less personal and sacred as we have surrendered our personal connection with death to the medical, aged care, and funeral industries.

The shared vision of many people involved in the natural death movement is to increase the availability and access to information, resources, and tools for individuals, families, and groups to provide empowerment and choices around the end of life. The principles of natural death care aim to improve and extend palliative care, embrace death rituals and traditions from many cultures, and strengthen communities.

People all over the world are re-embracing natural community-based death care and bereavement through the crafting of home-built coffins and shrouds, providing end-of-life care at home, and conducting DIY home funerals. Along these lines, there are many and varied alternatives being explored and developed for eco-burial and bio-cremation.

End-of-life doulas, or 'death midwives' are joining religious and spiritual leaders, social workers, funeral celebrants, lawyers, doctors, and entrepreneurs to build a network of natural death support.

It is important to review any existing legislation that impedes on these choices. In particular, Parliament should:

- a) change the hefty permit costs for Single Funeral Permits and make the process of conducting your own funeral simpler and easier for people to access
- b) change the current legislation and process to allow more people the opportunity to choose to have natural burials on their own properties with permission granted prior to the person dying and not dependent on the Ministers approval
- c) change legislation to embrace and allow various eco-burial / eco-cremation options including shrouding

Sincerely,

Nicolette Smith
The End of Life Care
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References:

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Palliative Care Australia. (2011). We need to talk about dying – survey (media release). Ret. Nov2013. Available from <http://www.palliativecare.org.au/Portals/46/National%20Palliative%20Care%20Week%20Media%20release.pdf>.