Submission – Inquiry into end of life choices

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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 a citizen who values community empowerment and as an end-of-life doula. I am striving to learn as much as I can about the legal, practical, and spiritual elements of death and dying, and I hope to 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 can help us empower ourselves to embrace death in a more wholistic way. I feel this is essential to having a full experience of our humanity.

I am adamant that people have the right to informed choice in all their healthcare, from birth all the way to their last breath. I assert 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.

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.

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, 2016). However, only 13-20% of people are able to 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 dove-tail palliative care with medical treatment earlier, and to streamline the transfer of people from hospitals into home or community 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.

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 funeral licensing requirements to allow for affordable and accessible DIY community funerals;
- b) change legislation to embrace and allow various eco-burial / eco-cremation options:
- c) allow for burial on private land or in family/community cemeteries where connection to ancestors and the land can be maintained by the survivors.

Sincerely,

Kristy Ratcliffe

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References:

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Palliative Care Australia. (2016). Palliative care in the right place, at the right time (media release). Ret. Oct2017 *from* http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2016/12/20161205-productivity-report.pdf