

The Secretary
Standing Committee on Community Development
Parliament of Tasmania
Parliament House
Hobart TAS 7000

June 24, 2016

Inquiry into Palliative Care

In this submission to the Standing Committee I would like to address issues in palliative care provision. Thus my comments fall under (iv) of the terms of reference, but have implications for the other matters listed. I write on behalf of the Unit I direct at La Trobe University, but have not sought the university's endorsement for this letter.

For almost a century we have been treating dying as primarily a health service responsibility. Increasingly death has occurred in institutions, not people's homes. Even the 1970s revival of public interest in dying, expressed in community based hospice programs that aspired to provide holistic care, has been channelled into health service-based palliative care programs (Rumbold 1998). Current discussions about end of life decision-making are thus predominantly about receiving or refusing medical treatment, or requesting medical provision of assisted death.

Already the Australian healthcare system is struggling to provide palliative care to the minority of citizens who can access it. As the recent Grattan Report documents (Swerissen & Duckett, 2014), demand will increase markedly in the coming decades, with the number of deaths in Australia predicted to double by 2030. New models for end of life care need to be found to ensure equitable provision of services, and to meet people's expressed preferences to die at home.

The assumption that discussions of dying are best located in healthcare contexts has narrowed the scope of the discussion. Even the healthcare discipline that deals directly with end of life care, palliative care, reflects this narrowing. Most palliative care discussions of emotional, social and spiritual dimensions of care, for example, focus on professional delivery of services to those already enrolled in a palliative care program for attention to their physical symptoms. This focus on delivery of care by professionals however ignores the fact that most people spend most of their time living with terminal illness in the company of family, friends, colleagues, and neighbours. That is, their major emotional, social and spiritual support, as well as much of their physical care, is provided informally (to use the healthcare term). I argue that end of life care would be substantially improved by paying attention to these informal care networks as well as formal care provision; and conversely that attending to formal provision whilst ignoring informal care is neither efficient nor effective.

The Tasmanian Department of Health and Human Services puts forward a four-phase model for palliative care provision (DHHS nd.). It's a well-recognised pyramid model for health service delivery, but it does not address the need for action beyond the health services. Public health models seek to integrate formal and informal care provision, recognising their complementarity and drawing upon the strengths of each. One representation of this approach is the circles of care model (Abel et al 2013). To adapt this representation to the existing Tasmanian DHHS model, a public health model would portray the health services pyramid of care as immersed in informal care and self-care; or represent these elements as the base of the pyramid, extending it to a five-phase model of care.

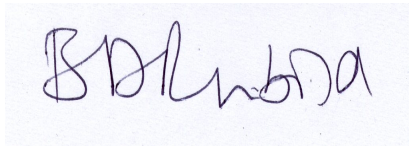
In essence a public health approach to end of life care recognises that healthy dying depends upon the community in which the death takes place. It's an extension of the public health assertion that health is created in communities. In this understanding health services address the problems that arise from illness, but cannot of themselves achieve healthy living or healthy dying. Health is created through action in all domains of social life. Equally a healthy end of life policy must engage all aspects of community life.

A public health approach to palliative care was first articulated by Allan Kellehear (1999, 2005), who was at that time director of the La Trobe University Palliative Care Unit. His health promoting approach has become the basis for an international 'compassionate communities' approach, so called because he argues for assets-based, socially inclusive strategies that have compassion (mutual recognition of our human connectedness) at their core. Tasmanian palliative care practitioners have adopted aspects of this approach and developed local applications of it. That is, they have articulated the relevance of a public health approach for Tasmania (Ashby 2015, Johnston 2015) and have demonstrated it particularly in the Better Access to Palliative Care project. The BAPC program (<http://www.tas.palliativecare.org.au/content/better-access-palliative-care-bapc-project>) shows the diverse creative responses that local communities can make to end of life issues, and the sorts of conversations that can be initiated beyond the boundaries of the healthcare system.

I would like to encourage the Standing Committee to adopt both the public health reorientation of palliative care that has been suggested by Tasmanian palliative care leaders, and the work that has been initiated through the BAPC program. Support for such action, in the form of advice or resources as required, is available both nationally (Compassionate Communities Network Australia <http://compassionatecommunities.net.au/>) and internationally (Public Health and Palliative Care International <http://www.phpci.info/>).

I would be most happy to supply the Standing Committee with any further information or materials that you might require.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'BRumbold', on a light blue background.

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