

Palliative Care Queensland (PCQ) welcomes the State Government’s Inquiry into the establishment of a Queensland Health Promotion Commission. This submission outlines a public health approach inclusive of health promoting palliative care and community engagement that PCQ views as vital for integration into the remit of a Queensland Health Promotion Commission.

1. Health Promoting Palliative Care

A key element in the care of people near the end-of-life and support of the bereaved is a health promoting approach. This model of care emerged in the 1990s and has been integrated into health care systems in many jurisdictions, including the State of Victoria and across the United Kingdom in the *Compassionate Communities* program through the NHS. The fundamental premise of health promoting palliative care (HPPC) is that the achievement of optimal health and wellbeing – even near the end-of-life – must be a partnership with government, health services and every major sector of the community. Health is everyone’s responsibility and when the World Health Organization’s *Ottawa Charter for Health Promotion*¹ explicitly states the value of lifelong learning *for all of life’s stages*, there is a clear remit for health promotion bodies, such as that proposed for Queensland, to include palliative care.

Community engagement is an important strategy in HPPC. It aims to link health services with the wider community in ways that inform, consult, involve, collaborate and empower them to a greater level of understanding and recognition of death and dying. Normalising the inevitability of death and enhancing an awareness of quality end-of-life health care will deliver improvements to the ways people experience the end of their life, both in their communities and as recipients of health care.² This will result in greater participation in the care and support of those near the end-of-life in their families, networks, neighbourhoods, schools, workplaces and elsewhere. Schools and businesses are just as likely to be engaged in changing policies and practices in matters to do with the health of students and employees as hospitals and community clinics.³

Currently, the Australian Government’s *National Palliative Care Plan*⁴ affirms the inclusion of community engagement strategies in:

- Goal 1: to significantly improve the appreciation of dying and death as a normal part of the life continuum, and
- Goal 2: to enhance community and professional awareness of the scope of, and benefits of, timely and appropriate access to palliative care services.

Further, Palliative Care Australia’s (PCA) *Standards for providing quality palliative care for all Australians*⁵ also endorses community engagement strategies as integral elements of providing palliative care services. Australian sociologist and architect of HPPC, Prof. Allan Kellehear has recently noted, “Health promotion and community engagement in end-of-life care is an extension of the growing acknowledgement of modern populations that to achieve optimal health and wellbeing in the 21st Century a community engagement approach to health must extend its active concern to the end-of-life itself.”³

2. Strategic directions in Queensland

Similarly, the Queensland Government *Statewide Strategy for end-of-life care*⁶ notes the role of public health organisations in promoting knowledge of end-of-life care. It encourages open conversations within families and friends about death and dying, and the articulation of preferences for end-of-life care through advance care planning (ACP). For example, most Australians have indicated a preference for dying at home, yet most will receive end-of-life care in hospital or other institutional settings of care, such as residential aged care facilities.^{7,8} This is noted to be prevalent in a culture where death and dying are not openly discussed. Optimal health service delivery is constrained, therefore, by this general societal reluctance to address end-of-life issues and limited public awareness of the role and benefits of palliative and end-of-life care.

Partnerships between clinicians and the community are viewed as the optimal approach to address this situation, and community engagement is crucial to this.^{9,10} The *Statewide Strategy for end-of-life care* identifies a service action component that promotes greater community awareness. It states that the Department of Health's responsibility is to "lead the development of an overarching public awareness strategy designed to address key content areas that can be implemented via social media and other mediums, considering:

- key general messages appropriate for repeating on a regular basis (cycle) e.g. 'speak to your general practitioner about your healthcare preferences/advance care planning';
- particular issues that may require more comprehensive public engagement e.g. tool kit for advance care planning;
- collaborative communications with external service providers/peak bodies; and,
- targeted campaigns e.g. culturally appropriate communication for Aboriginal and Torres Strait Islander people.^{116:p.5}

Further, it states the need for support of families and carers during caregiving *and* bereavement.

Communities are able to do more to support families and health services and to bring practical resources and important supports to both. The success of these types of contributions in wider public health movements and in end-of-life care are emerging and present an innovative approach to palliative care.

3. Palliative Care Queensland

Palliative Care Queensland (PCQ) an independent not-for-profit peak body representing palliative care providers, consumers and their families and those with an interest in palliative care in Queensland. Established in 1988, PCQ has over 350 individual and organisational members, the majority of whom are specialist palliative care doctors, nurses and allied health professionals.

PCQ's mission is to aim to ensure that every person who dies in Queensland experiences quality at the end-of-life. PCQ's principal roles are to:

- improve awareness and understanding of palliative care in the general community;
- influence the development of public policy in relation to death, dying and end-of-life;
- support the professionals and volunteers who provide palliative care;
- provide health professional education;
- develop and distribute palliative care educational resources;
- provide information, support and advocacy to people affected by terminal illnesses; and,
- provide support and professional representation to Palliative Care Queensland members.

<http://palliativecareqld.org.au/>

As the peak body for palliative and end-of-life care in Queensland, PCQ is ideally placed to facilitate partnerships between government, health services and the wider community. This is explained in addressing the Inquiry's *Terms of Reference* below.

4. Terms of Reference

a) Approaches to addressing the social determinants of health

The impacts of living with a life-limiting illness are profound – those who are ill and those who care for them commonly experience anxiety and depression, social stigma and isolation, premature loss of employment, financial strain, and even suicide. These key determinants of quality of life for the dying, their carers, and the bereaved cannot be solely addressed by health services.³ A HPPC approach attempts to pre-empt these issues in those requiring palliative and end of life care through

assessment of personal and community capacity to address them¹¹ and, significantly, by the implementation of a policy framework¹² which is explored below.

b) Population groups disproportionately affected by chronic disease

The Australian Institute of Health and Welfare¹³ reported that the main causes of death in 2013 were coronary artery disease, dementia and Alzheimer's disease, cardiovascular disease, lung cancer, and chronic obstructive pulmonary disease, with breast and prostate cancers prominent by gender. Whilst specialist palliative care services predominantly provided care to those with cancer, most of these illnesses follow a chronic trajectory and may be amenable to palliative care in symptom management, carer and family support.

In this way, the populations targeted by a HPPC approach are those with chronic, progressive and incurable illnesses, and therefore whole-of-population health promotion strategies are indicated. Awareness raising, open discussion and identification of choices for end of life care are relevant to whole communities and can be facilitated through engagement between health services and community members.

c) Economic and social benefits of strategies to improve health and wellbeing

There is international evidence of the cost-effectiveness of palliative care for people with chronic, progressive and incurable illnesses, particularly when this takes place predominantly in the home setting.¹⁴ Similarly, the benefits of effective support in bereavement include decreased loss of work days through sick leave and increased productivity.¹⁵ It has been reported that perhaps only 10% of those at risk of complicated grief actually required specialised bereavement support, and that for most, the support of family, friends, peers and communities may be sufficient to navigate grieving in such ways that optimise adjustment to changed circumstances through the death of family member or friend.¹⁶

Clearly, care at the end of life and in bereavement is not simply a matter for health services. A major Australian study by Horsfall and colleagues¹⁰ explored the role of social networks in supporting carers to achieve a home death for the person in their care. The relationship between this informal setting of care and health services was highly influential in harnessing (or, indeed, impeding) the capacity of these community members to support the dying person and their carers in their home.⁹ The study noted above¹⁶ also identified that social networks are a key element in bereavement support. In both cases, community engagement strategies were employed to build community capacity in end-of-life care. This capacity to develop the knowledge and skills necessary to care for a dying people to gain access to, understand and act upon end of life and death care options has been tagged "death literacy" and is a key feature of the social capital present in communities.¹⁷

d) Emerging approaches and strategies that show significant potential

A 21st Century community engagement approach to health must extend its active concern to the end-of-life itself. The HPPC approach has given rise to a public health approach to palliative care called *Compassionate Communities*. The aim of HPCC or the development of *Compassionate Communities* is a call for intentional engagement in all issues pertaining to life and health, inclusive of loss, dying, death, and bereavement. It is a movement towards the recognition that end-of-life care is everyone's responsibility.

End-of-life care is not a matter of the so-called "lottery" of geographical location or availability of services; the *Compassionate Communities* model promotes achievable social practices and not idealistic, romantic or sentimental constructions.¹⁸ In the UK, parts of Europe and other jurisdictions, this model is being embedded whereby "a conscious, planned and deliberate political and social set

of actions (are) taken by the key players in any community to enhance the support and wellbeing of everyone affected by ageing, dying, death, loss and caregiving.”^{18:p.xiv}

Compassionate Communities utilises community engagement to establish and develop comprehensive partnerships between government, health and social services, social groups, communities and others to promote optimal quality of life in end-of-life care and bereavement. In this way, it can effect policy development, organisational reorientation, and community capacity building, and address the strategic goals of jurisdictions such as Queensland, whilst simultaneously eliciting the social benefits noted above.

e) Ways of partnering across government and with industry and community including collaborative funding, evaluation and research; and

A HPPC approach to death and dying, loss, grief and bereavement and a focus on social change, lends itself fully to partnerships across governmental departments, industries and community. In service delivery, we often reference, ‘wrap around services’ yet we exclude the informal networks of carers, friends and extended family who provide essential support that if valued and promoted enhances the experience of those requiring palliative care and potentially decrease the need for formal services. This could leave palliative care services more time for complex case management. By implementing the principles of creating *Compassionate Communities* (and other approaches such as Alzheimer’s Australia’s *Creating Dementia Friendly Communities*¹⁹), hosting forums that can attract the community, people living with chronic and/or life limiting illnesses, carers, service providers, schools, workplaces, places of worship, the mass media, businesses and other peak bodies provide awareness, support and care for those experiencing loss, dying, death and bereavement in practical caring ways.

f) Ways of reducing fragmentation in health promotion efforts and increasing shared responsibility across sectors

This submission takes a whole-of-systems approach to integrating HPPC to assist in reducing fragmentation. PCQ is well-positioned to assist Queensland Health to operationalise its *Statewide strategy for end-of-life care (2015)* and achieve the benefits noted above.

This submission proposes PCQ takes the lead in forming partnerships with other industry representative groups, government, and community stakeholders to drive a social change campaign. Specifically, it proposes to:

1. Include palliative care clinicians, advocates and representatives in the development, implementation and evaluation of health promoting palliative care strategies. This acknowledges that care at end-of-life and bereavement support are also an integral part of Queenslanders’ lives and the health care journey. Partnership with government in this campaign is an important component of shifting public attitudes and actions.
2. Include Advance Care Planning in future health promotion strategies and activities as it provides a mechanism to promote conversations about future health care choices and can be offered by different health care professionals along the health care trajectory, not just for those at end-of-life. Advance Care Planning acknowledges that even when fit and healthy, we can plan for the unexpected and have some sense of control or choice in decisions even if we lose capacity to do so.

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