

PALLIATIVE CARE IN TASMANIA: TOWARDS A FRAMEWORK

Context

Palliative care is an important component of the health and community care system. In the years to come, demand for palliative care services is expected to increase as a result of our aging population and increasing rates of chronic disease.

In recent years there has been a focus on enhancing and strengthening the palliative care system in Tasmania. This work has been led through the Australian Government funded Better Access to Palliative Care (BAPC) Program. The Tasmanian Government is also committed to ensuring that the Tasmanian community has access to high quality palliative care services.

The Tasmanian Government has committed to update the 2004 Palliative Care Report and examine unmet and future need for palliative care. This commitment will be achieved through the delivery of a Tasmanian Palliative Care Policy Framework (Policy Framework).

The Policy Framework will set the strategic direction for palliative care and establish priority areas for action to ensure the continued development of palliative care approaches in Tasmania. It will also support the Tasmanian Government's health system reforms, continue the reforms delivered through the BAPC Program, and embed national standards and best practice approaches for palliative care.

What is palliative care?

The Tasmanian Government has adopted the World Health Organisation's definition of palliative care. This approach aims to improve the quality of life of patients and their families facing challenges associated with life-threatening illness, through the prevention and relief of suffering through early identification, assessment and treatment of pain and other issues, both physical and spiritual¹.

Palliative care in Tasmania is delivered by a range of health and community care service providers.

Who has policy responsibility?

The Australian Government sets the national policy direction for palliative care. The *National Strategy for Palliative Care 2010: Supporting Australians to Live Well at the End of Life* (the National Strategy) commits all governments to develop consistent palliative care policies and services with the aim of making quality palliative care accessible to all people who are dying. The Australian Government is currently reviewing the National Strategy. Palliative Care Australia is responsible for developing National Palliative Care Standards and a suite of policy documents to support the National Strategy.

There has not been a State Government palliative care strategy or policy framework for over 10 years. In the absence of a Tasmanian framework or strategy, the program of work being delivered under the BAPC program in Tasmania (outlined below) has provided strategic direction at a system, service and community level over the past four years.

Given the significant experiences from the delivery of BAPC and the ongoing reforms as part of the *One State, One Health System, Better Outcomes* reforms, it is timely to broaden the discussion with the community on the development of a Policy Framework.

¹ World Health Organisation, 2002.

Who has funding responsibility?

With the exception of BAPC, the Australian Government does not directly fund palliative care services. Rather, it provides financial assistance to State and Territory Governments to operate services. The use of this funding and service delivery is the responsibility of individual state and territory governments².

The Tasmanian Government provides funding for the Specialist Palliative Care Service and also substantial funding through the mainstream health system, including the provision of acute health and community services such as community nurses.

The Australian Government has provided an additional one-off investment in palliative care in recent years through the BAPC program, as part of the Tasmanian Health Assistance Package. The Australian Government provided approximately \$52 million over four years (2012-13 to 2015-16) to progress work to build the capacity and enhance linkages across the Tasmanian palliative care system, and to improve access to community based palliative care.

This program is being delivered using a cross-sector partnership approach between government and non-government health and community service providers. The program partners include the Department of Health and Human Services (DHHS), the Tasmanian Health Service (THS), the District Nurses (TDN) and Palliative Care Tasmania (PCT). These partners were jointly funded to deliver key projects, including:

- \$11 million to DHHS and the THS to enhance support for existing service models and strengthen coordination and collaboration across the system;
- approximately \$38 million to TDN to pilot a proof of concept model of wrap around community packages of care (hospice@HOME) and build capacity within the community sector to support people to die at home; and
- \$2.9 million to PCT for infrastructure support services such as community development, volunteer and carer training, health promotion and professional development.

Where have we come from?

The last significant review of palliative care in Tasmania was the 2004 Palliative Care Report. The delivery of palliative care in Tasmania has evolved significantly since the release of the Report, noting that the gaps outlined in the Report informed the development of priorities for the BAPC program.

Over the past 10 years there have been considerable developments and challenges in the health and community service system that have impacted on palliative care in Tasmania. There is growing recognition of the need to update current approaches to palliative care and find new ways to support for people at end of life.

² Senate Community Affairs Reference Committee Report: *Palliative Care in Australia: October 2012*

Demographic changes – changing demand

Traditionally palliative care has been associated with caring for cancer patients. However, as the population ages and life expectancy increases, so too do life limiting conditions such as dementia, cardiovascular, and respiratory diseases. This is also consistent with a broadening of the understanding and approach to palliative care, which is now inclusive of chronic disease and other life limiting conditions.

According to analysis from the Australian Institute of Health and Welfare, demand for palliative care in Tasmania is greater and likely to increase more rapidly than in most states and territories. This is due to Tasmania having the highest overall incidence of cancer, the second highest rate of burden of disease as a result of chronic disease, and a rapidly ageing population³.

A shift in focus

Moving from specialist services to health and community providers

For many years the delivery of palliative care has been viewed primarily as a part of the health care service; in particular, specialist palliative care services, hospitals and other medical specialities such as cancer services. This is despite the fact that a large proportion of palliative care is delivered outside these settings in our communities by primary care providers, such as GPs, health and community services, aged care services, and community and volunteer organisations and groups.

A change in setting – from acute care to community

As the demand for palliative care rises, there is an increasing focus on the role of primary care and health and community services that provide palliative care in our communities and who routinely work with patients at the end of life⁴. This approach is consistent with an increasing preference expressed by people to die in their homes, whenever possible.

Community based palliative care represents the majority of the palliative care accessed by and provided to individuals with a life limiting conditions. DHHS estimates that 70 per cent of palliative care is delivered by health and community service organisations and groups including community nurses, general practice, aged care services, community care organisations, volunteers and many other non-government and community groups.

Contemporary approaches

Contemporary approaches to palliative care encourage reorientation towards a whole of community, inclusive approach, known as ‘compassionate communities’. This approach focuses on:

- health promotion, prevention and harm reduction; and
- building community capacity, participation and partnerships.

³ Australian Institute of Health and Welfare, 2013, *Palliative Care services in Australia 2013*, HWI 123 Canberra

⁴ Frey R., Gott M., Banfield R. (2011) *Systematic review- What indicators are measured by tools designed to address palliative care competence among “generalist” palliative care providers? A critical literature review* Faculty of Medical and Health sciences, University of Auckland, Auckland New Zealand

This approach recognises there is a need to better understand the unique needs of each individual and to support the person at end of life, and their family, to make decisions about their care based on personal preferences and overall well-being.

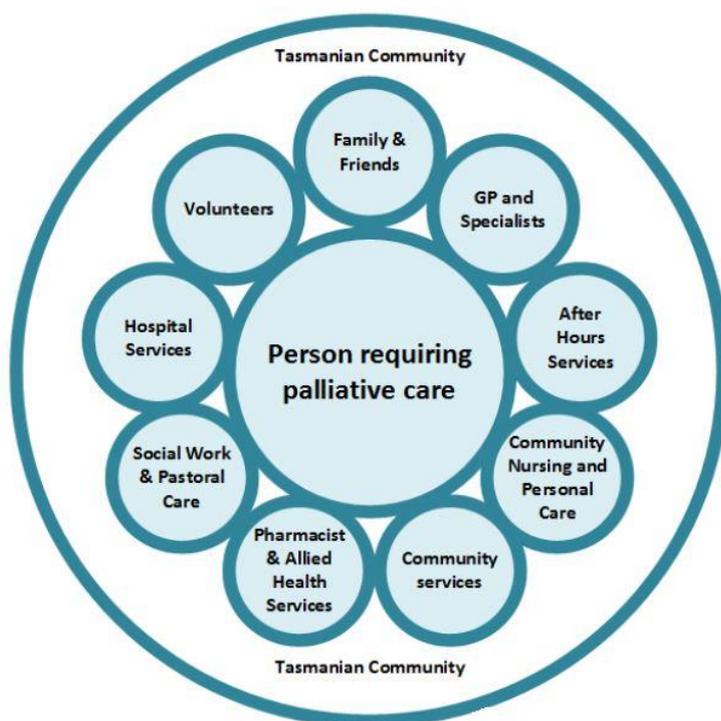
Where we are now

A more inclusive Tasmanian palliative care system

There is greater recognition and understanding that palliative care services in Tasmania are delivered in almost all health and community care settings, including acute, primary, community, and aged care sectors. These come together to create a circle of support – a ‘community of care’ - that surrounds and supports the person at end of life and their family by maximising quality of life and well-being.⁵

Communities of care include hospitals, health and community care providers, volunteers, social networks, clubs, neighbours, local organisations, faith groups, local businesses or people living in a particular area. Most importantly, it includes families, carers and local communities. These communities can provide practical support and care for those who are dying, have experienced loss, or are bereaved.

Figure 1: Palliative Care Circle of Support



⁵ Community Participation: What is it? (2002) Community Participation Volume 14, No 3., <http://advocatesforyouth.org/component/content>

The progress made over the life of BAPC and key achievements to date

The BAPC program has brought considerable focus on palliative care at both a system and service level in Tasmania. It has been delivered using a whole of community approach (including system, service and community) and has focused on the development of key partnerships between DHHS, THS, TDN and PCT.

The BAPC program has made a significant contribution to improving access to community based palliative care. A number of innovative system and service reforms have been delivered.

Program Partner	Progress/Achievements
DHHS	<ul style="list-style-type: none"> DHHS has focused on systems level work, which has included the establishment of a Partners in Palliative Care Reference Group to increase coordination and engagement across services, updated the Tasmanian Palliative Care Formulary and implemented a patient administration/registration system within community health. DHHS has also progressed significant consultation and commenced development of strategies for bereavement care, end of life care, building community capacity and workforce, a community charter to articulate community expectations of palliative care, and a model of care for the Specialist Palliative Care Service.
THS	<ul style="list-style-type: none"> The THS has extended practice placements for non-specialist professionals to advance their palliative care skills and knowledge, enhanced the multidisciplinary care approach, and built capacity to more comprehensively address both individual and carer needs across the THS (acute, community, rural and regional).
TDN	<ul style="list-style-type: none"> There are 600 active clients receiving hospice@ HOME packages across Tasmania, with an average length of care of 99 days. Approximately 50 per cent of clients receiving hospice@HOME packages die at home, with 56 per cent of those expressing a desire to die at home able to do so.
PCT	<ul style="list-style-type: none"> PCT has provided education and information to over 7 000 Tasmanians (including on King and Flinders Island), reaching diverse communities and populations. PCT established strong networks with more than 100 organisations, peak bodies and community groups. This has included the provision of \$950 000 in grants to 72 community organisations, who have facilitated approximately \$1.5 million in community projects.

What has this taught us?

With the focus on palliative care in Tasmania, there has been an opportunity to review and reflect on how palliative care is being delivered and identify opportunities for further development. There has been consultation with the community and service providers, including members of the Partners in Palliative Care Reference Group.

The BAPC Program has highlighted the following:

- the value of an approach to palliative care that is inclusive of the broader health and community system, and that defines and recognises the larger network that is part of palliative care in Tasmania;
- the value of working at the system, service and community level concurrently and in an integrated way to achieve consistent change and development;
- the need for a consistent state-wide approach to palliative care;
- the need for strategic leadership at a system and service level across Tasmania;
- the value of a state-wide palliative care reference group in developing and informing palliative care direction in Tasmania.

Where are we going?

Strategic direction

The palliative care system requires a strong strategic direction to provide a coordinated, inclusive and whole of community approach to palliative care. The three key areas below are critical to articulating and achieving this direction.

1. Service coordination and collaboration

Coordination and communication across different services is an ongoing challenge for the health system and also for palliative care. Information gathered is sometimes not shared effectively, creating a lack of awareness of what other services are doing. As a result, the community is not always aware of the available palliative care services or how they can work together. Therefore, they will often assume that the Specialist Palliative Care Service is responsible for delivering all palliative care, which is not consistent with what we know about the bulk of palliative care being delivered by the primary and community sector.

There needs to be greater recognition of the role of the network of health and community service providers, family carers, community groups, volunteers and the broader community in delivering palliative care. In particular, the significant role of community nursing, General Practitioners and aged care services (particularly residential facilities) requires greater acknowledgement and definition.

A clear understanding of roles within a complex health and community services system is critical to ensuring consumers and service providers are able to interpret and navigate the system to access care and support appropriate to their needs, at the right time and as close to home as practicable.

The service system should be consumer focused and provide consistent approaches to palliative care. In order to achieve this, a more streamlined and integrated palliative care service is required. Shared practice guidelines and protocols across the sector would also support greater definition and clarity of role. It is noted that increased coordination is particularly required for the provision of After Hours and Rapid Response services.

2. Engaging and strengthening the capacity of our communities and building partnerships

The community is a valuable resource and has a significant role to play in palliative care. It is also the key to early engagement and planning for end of life care. There is a need to connect with and build capacity in existing resources in our communities, by acknowledging the significant contribution and role of the community in delivering palliative care.

The community is already delivering palliative care in many ways through existing community and social support structures. This is not always well recognised because of the focus on palliative care as being delivered by the health system.

Fostering a culture of partnership between health professions and community members will enable everyone to work together to achieve the best possible end of life care.

There is often reluctance in the community to discuss death and dying, yet research suggests that the absence of these conversations can cause distress and negative health effects for bereaved individuals⁶. There is a perception that palliative care is only terminal care. As a result, many are not actively aware and engaged in planning and preparation for the end of life.

We want to adopt an approach that engages our communities earlier, builds community awareness and understanding about death and dying and adopts strategies that build community capacity. This approach is emerging in palliative care literature⁷ as *Compassionate Communities* which emphasises a whole of community approach and a partnership between informal and formal palliative care service providers.

3. System coordination and leadership

There has been a lack of system level strategic direction and planning for palliative care in Tasmania. The policy focus has been on Specialist Palliative Care Services, through a traditional health service delivery lens.

As a result, the system lacks consistent policy approaches for palliative care in Tasmania that reflect contemporary practice and approaches. DHHS will continue to progress the development of the comprehensive Policy Framework to address this.

The system will need strong leadership so it can continue to build and grow in a sustainable way, and to encourage the different parts to work together better.

⁶ McNamara & Rosenwax, 2010 cited in Allan & Watts, 2012 *Promoting Health and Wellbeing at the end of life: the contribution of care pathways* International Journal of Palliative Nursing Vol. 18, No. 7

⁷ Kellehear, A, 1999, *Health Promoting Palliative Care*. Oxford University Press, Melbourne; Sallnow, L & Paul, S, 2015, *Understanding community-engagement in end-of-life care: Developing conceptual clarity*, *Critical Public Health*, Vol. 25 (2), pp.231-238; and Wegleitner, K., Heimerl, K., & Kellehear, A. (Eds) 2016, *Compassionate Communities: Case Studies from Britain and Europe*. Routledge: London.

Next Steps

A significant amount of consultation has already been undertaken with key community and service stakeholders, and has resulted in the key learnings outlined above. There is much goodwill in the community and a desire to see recognition of the changes that are occurring in the way palliative care is supported and accessed, and the value of these changes for the community.

The palliative care system is complex and there is a need to integrate with other key reforms such as the *One State, One Health System, Better Outcomes* reforms, the Australian Government's aged care reforms and the new arrangements for primary health services through Primary Health Networks.

In order to work towards a *Compassionate Communities* approach, our desire is to achieve a shared vision for the future of palliative care in Tasmania that is focused on integration and community capacity building. DHHS will therefore continue to progress the strategies underway (including those on bereavement care, end of life care, and refining a model of care) while bringing these together under a comprehensive Policy Framework to guide the future of palliative care in Tasmania.