



Developing and Growing Communities of Care in Tasmania

PROJECT OVERVIEW

The delivery of palliative care relies on both informal and social care networks as well as formal service providers. Therefore, the development of robust systems that support high quality, accessible and responsive palliative care is essential for the wellbeing of people living with a life limiting illness and their family/carer(s).

Research funded by Palliative Care Tasmania (PCT), on behalf of the Department of Health, and conducted by the University of Tasmania aimed to identify strategies to grow and support sustainable communities of care across the state. The research was conducted with palliative care providers, volunteers, family caregivers/friends of people living with a limiting condition.

It involved:



Online Surveys | **148** respondents completed



Workshops | **11** participants attended (across three)



In-depth Interviews | **6** participants



A rapid review of the literature was also conducted to identify existing models of communities of care and strategies that have been used to support their development.

The survey, workshops and interviews sought to understand knowledge, attitudes and perceptions about palliative care broadly and the establishment of communities of care.



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What is a community of care?

Communities of care are networks of relationships that provide a foundation for a whole-of-community approach to palliative care. In a community of care, social/informal relationships surround the person with the life limiting illness and their family member/carer(s)¹ to support their everyday practical, emotional and social needs, while service providers contribute more formal support in partnership with these social networks.

Core components of a community of care are:

- > the person who has the life limiting illness and their family/carer(s) (center of the community),
- > a primary (inner) web of informal/ social relationships that provide practical everyday support to the person with the life limiting condition and their family/carer, and
- > an outer web of formal service providers and support services that are accessed when needed.



¹ Family/carer(s) are considered here as informal support people who may or may not be related (e.g., friend, partner) to the person with a life limiting illness but are responsible for providing primary support and care.

How can the development of communities of care be supported?

This study found a lack of understanding about the concept of communities of care and a broader whole-of-community approach to palliative care. Participant accounts suggest that care networks in Tasmania predominantly comprised formal service providers, with only limited acknowledgment of caring networks as emerging from social/informal connections. Moreover, stigma associated with communication about death and dying was also raised by participants as a barrier to people having more open discussions about palliative care and accessing it in a timely manner.

Recommendations:

- 1 Raise community awareness about the core components of a community of care as part of a broader whole-of-community approach to palliative care.
- 2 Establish coordinator/connector roles to support the development of communities of care across the state.
- 3 Palliative Care Tasmania provide leadership in co-designing community coordinator/connector roles in consultation with key stakeholders to support/promote communities of care.

