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# TASMANIAN BEREAVEMENT CARE NETWORK AND INITIATIVES PROJECT

## FINAL REPORT

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## WHAT IS BEREAVEMENT?

Bereavement encompasses the entire experience of family members, carers and friends in the anticipation, death, and subsequent adjustment to living following a death. Bereavement care is a continuum of care from informal and formal approaches to care provided by health and community care practitioners. Grief is normal, natural and an integral part of living. Although people have different responses to grief, most seek out and are adequately supported by their existing networks such as friends and family. A small proportion of those who are bereaved do experience complicated grief which requires clinical/professional intervention.

Burnie

Launceston

Hobart

# The Regional Bereavement Care Network and Initiatives Project



## Executive Summary

The Regional Bereavement Care Network and Initiatives project aimed to link and improve support for people working in bereavement care in Tasmania through the establishment of a sustainable regional bereavement care network (BCN) across the state.

### Background

The impetus to establish a BCN in Tasmania stemmed from previous consultation, research and policy development in the broader arena of palliative care. As part of the Australian Government funded Better Access to Palliative Care (BAPC) program (2013-2017), the Department of Health and Human Services (DHHS) has worked in close partnership with the University of Tasmania Centre for Rural Health (CRH) to establish the network.

The BAPC program has resulted in a number of initiatives to enhance linkages between, and improve access to palliative care services in Tasmania, including community-based services. A significant outcome from the BAPC was the acknowledgement that bereavement care is integral to palliative care and involved both formal and informal bereavement care and support services. Recently, the Government of Tasmania released an overarching framework for palliative care, *Compassionate Communities: A Tasmania Palliative Care Policy Framework 2017-2020*, that

emphasised the need for, and importance of bereavement care across the community.

### Project Approach

The project was underpinned by Asset Based Community Development (ABCD) principles through which individuals, community groups and local service providers worked collaboratively to identify strengths and weaknesses and build connections between each other.

A multidisciplinary team of professionals implemented the project, under the guidance of a group of key stakeholder representatives. Consultations occurred with a large number of individuals across a broad range of settings and presentations made to key service providers and organisations with a direct involvement in bereavement care to seek their input and ongoing commitment to the project.

Seven regional workshops were held in Hobart, Ulverstone and Launceston to work on the development of bereavement care practice values and principles and to build the network. A state-wide BCN Management Working Group was also established to provide overall leadership and to formally take responsibility for the ongoing development of BCN. Regional meetings were held to further develop, strengthen and expand local connections.

## Project Outcomes

### (a) The Network

The project identified a large number of people and organisations involved in bereavement care across Tasmania. Despite this large number, there was limited knowledge of and connection between these services. This project addressed this problem through the establishment of a 'network'. The Tasmanian BCN is comprised of three regional groups based in the South (Hobart), the North (Launceston) and in the North-West (Burnie/Ulverstone). With support from the Centre for Rural Health (CRH), a Management Working Group has been established, comprised of key individuals working across the bereavement sector, to take responsibility for the ongoing development, administration and sustainability of the network.

### (b) Bereavement Care Practice Values and Principles

Practice standards are the underlying principles that guide the development and provision of bereavement care. Following a review of national and international practice standards, network members emphasised that these should not be overly rigid and be suitable for both formal and informal carers. A series of statements, that represented the values and principles for bereavement care practice and service delivery in Tasmania were subsequently developed and endorsed by stakeholders.

### (c) BCN Communication Strategy

Key communication messages developed for the network are:

- The BCN links practitioners and services to improve support for people working in bereavement care in the North, North-West and South of Tasmania;
- Network activities are driven by and for its members; and
- The network aims to be self-sustaining.

These messages are supported by a strategy and a website created as a communication platform for members ([www.bcntasmania.org.au](http://www.bcntasmania.org.au)).

### (d) Capacity Building and Skill Development

Capacity building was integral to all aspects of the project and stakeholders actively involved. Through workshops and regional meetings, bereavement care providers have engaged with each other

(often for the first time) and have been active in connecting across the system to build knowledge and skills and to enhance services. The capacity of the network will be strengthened by research that assesses the extent to which members are connected and how they use these connections to enhance service provision.

### (e) Network Evaluation and Sustainability Planning

A framework has been developed to evaluate the network and offers a template that can be adapted to suit the needs of regional groups and accommodates a variety of data collection methods. Sustaining networks into future will require the Management Group to identify a 'sponsoring organisation', to clearly describe the relationship between the network and any sponsoring body and to submit applications for funding to bodies such as the Tasmania Community Fund.

## Observations and Learnings from the Project

Communication: there was clear benefit in using a range of measures to engage with stakeholders (e.g. e-mail, phone, mail, face-to-face, formal and informal contact). Consistency in personal contact and active follow-up by project team members with individual stakeholders proved the most worthwhile and valuable strategy for maximising engagement. A multi-pronged communication strategy ensured all stakeholders were provided with several opportunities to engage.

Timing of events and activities: some planned project activities were delayed over the Christmas/New Year period due to the scale-down of services, stakeholder absences and lack of availability over this period. This made it difficult for some stakeholders to contribute or participate in the project to the extent they would have liked. To reduce risk and achieve high levels of participation, the project time-frame was therefore extended beyond that originally planned.

## Challenges and Opportunities

Challenges associated with the sustainability of the BCN relate to ongoing funding, governance and administration of the network, growing membership and ensuring its relevance.

Whilst strategies have been identified, each requires the ongoing commitment and active involvement of members at a regional and state-wide level. Opportunities exist for the network to be 'sponsored' or 'hosted' by a stakeholder

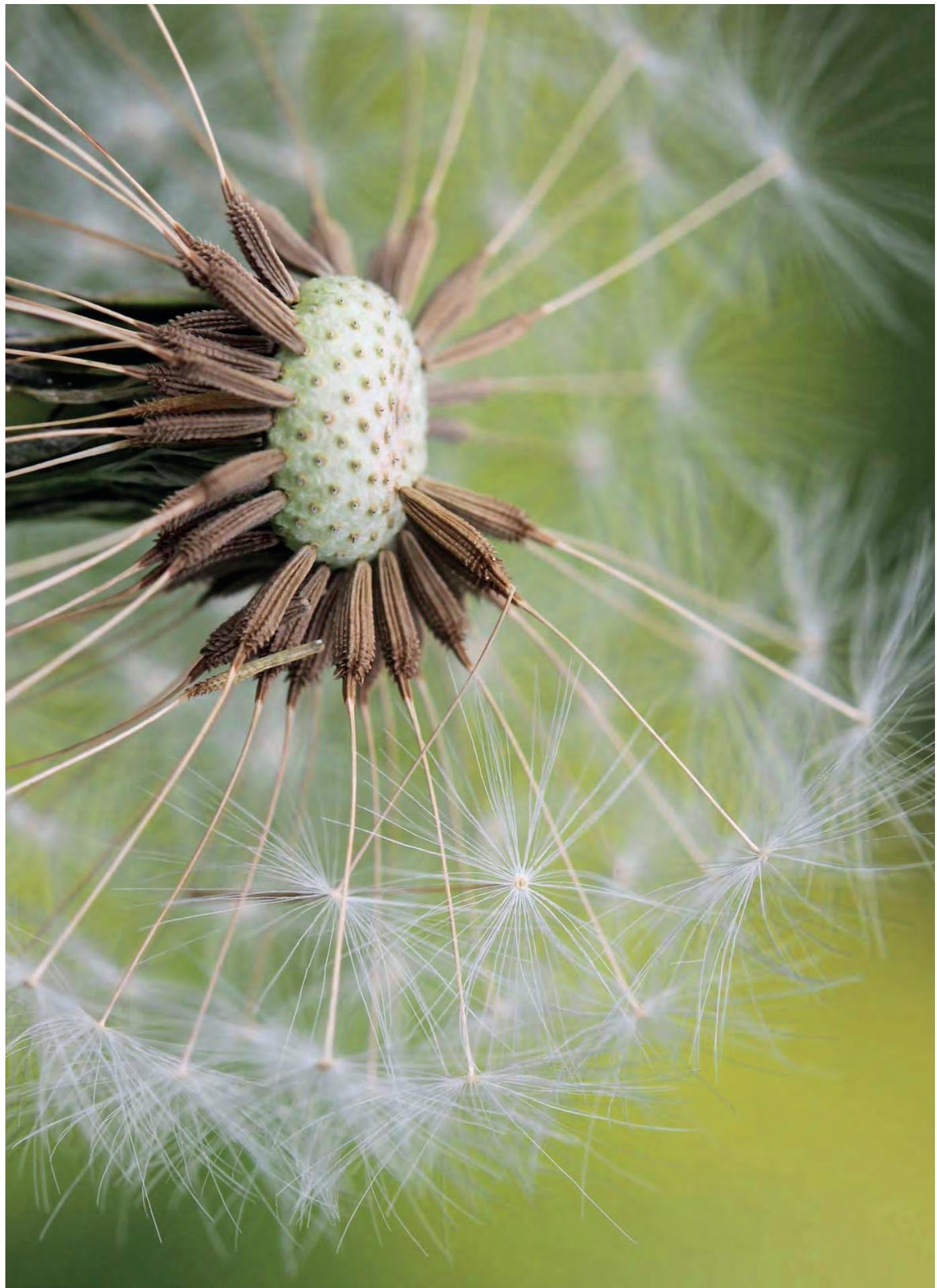
organisation (or individual), although financial support over the remainder of 2017 is required to maintain current activity, support the network as it transitions to the new auspicing working arrangements and to minimise the risk of the network faltering.

#### Recommendations

It is recommended that:

1. Funding be provided and a sponsoring organisation be identified to 'host' and help maintain the network beyond December 2017.
2. Any new arrangements for the governance and management of the BCN beyond 2017 should have a strong focus on community development and partnerships, and also adopt a broad, collaborative approach to bereavement care.
3. The BCN be evaluated mid-2018 using the proposed framework to: follow-up the initial mapping of connections between bereavement care providers; identify how well the network has functioned; and to identify strategies to enhance its impact and sustainability.
4. Health, Education and Social Service sector organisations be encouraged to publicise the work of the BCN and its role in supporting the provision of bereavement care and support services in Tasmania.
5. The BCN Management Group take a collaborative approach to secure sponsorship for events and activities, to develop applications for funding to support the ongoing work of the network and to expand its membership base.
6. Formal links be established with peak bodies and government departments, including the DHHS, to support and guide the work of the network. This could be achieved by representation on the BCN Management Group.





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## List of Acronyms and Abbreviations

ABCD - Asset Based Community Development

BAPC – Better Access to Palliative Care

BCN – Bereavement Care Network

CRH – Centre for Rural Health

DHHS – Department of Health and Human Services

EBPAC - Encouraging Better Practice in Aged Care

HPPC – health promoting palliative care

PIPC – Partners in Palliative Care reference group

PAR- participatory action research

ToR – Terms of Reference

WHO – World Health Organisation

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## Introduction

### Background

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO).

Palliative care and bereavement research demonstrates that a public health approach to palliative care, or health promoting palliative care (HPPC) is current best practice; that is, palliative care that encompasses community development, partnerships, education, harm reduction, early intervention and sustainability. In HPPC, the support focus extends outside of hospitals and formal care provision to include the dying person's family, friends, and community (Williams, 2002). The rationale is that the majority of death and dying work happens in the community, more so than in formal care, and therefore informal community care should be supported and encouraged (Abel et al., 2013; Kellehear, 2004; Rumbold, 2014). As Neimeyer (2006) notes: "Grieving is as much a social as individual process and more attention is needed into how families and other social groups can support or impede the adaptation of their members" (2006, p184). The recommendations of the 2014 Grattan Institute report into "how, where and with whom we die" state, "To meet our needs for better deaths we need to ... increase the availability of community- and home-based support for people who are dying" (Swerissen, 2014).

For every person who dies in palliative care, their relatives and close friends will experience grief and bereavement before, during and after the person's death. The needs of a bereaved person are diverse and varied and often include practical physical support, social, psychological, spiritual and community support. Bereavement care is generally widespread and effective, but under-recognised (Kellehear, 2004). It is also often poorly coordinated, and much of the information available, including on-line resources, are not accessed (Kellehear, 2004). However, research shows the provision of informal assistance in end-of-life care (for example, by family, friends and community members) is imperative. During bereavement is an intense and difficult time, but it is also a time when a range of personal strengths are mobilised (Hughes, 2015).

The current literature supports an approach that strengthens the links between informal and formal supports. Boss (2006), for example, claims networks of support beyond the immediate family and carer build resilience during times of ambiguous loss, and advises therapeutic practitioners to encourage clients to participate in shared endeavours.

Although grieving symptoms are diverse and varied, they are nonetheless a normal part of bereavement, "not an illness or medical syndrome", and for the majority of the population these symptoms settle over time (Kristjanson & Lobb, 2004). Nonetheless, bereavement is associated with excess risk of mortality, particularly in the early weeks and months, and may be associated with physical and mental health issues or deterioration of existing conditions (Stroebe, Schut & Stroebe, 2007). Complicated or complex grief can occur in a significant number of bereaved people (literature suggests 5-18% of bereaved, particularly close relatives, spouses and carers). There are a number of risk factors that increase the risk of complicated grief namely, age, personality, relationship, and factors around the person's death. Improving the identification of and support for people experiencing, and/or at risk of complicated grief is one important point at which volunteers, carers and professionals connect. Community, informal bereavement care does not sit in isolation from clinical and/or formal bereavement care.

Networks are valuable assets to bereavement support. Tagliaventi and Matterelli (2006) found evidence that working alongside others with common values provides a firm base for transferring knowledge amongst professionals. Networks that involve a mix of professional and community members, who share a common goal, interest and passion for what they do, are also sometimes called communities of practice. The benefits of these types of network groups are numerous: ensuring access to relevant knowledge; improving the quality of shared knowledge; access to expertise; facilitating collaboration and improving sustainability of projects (Skalicky, 2005). Scotland's national action plan for palliative and end-of-life care is an example of the public health approach in practice which has a strong focus on collaboration between the formal and volunteer sectors of the palliative care community. The Centre for Rural Health (CRH) has extensive networks, as well as experience in using and analysing networks (Barnett, Hoang, Cross & Bridgman, 2015).

## Context and Timing

As part of the Australian Government funded Better Access to Palliative Care (BAPC) program (2013-2016), the Department of Health and Human Services (DHHS) has led much work in the broader palliative care arena. The BAPC program in general has resulted in many program initiatives to strengthen palliative care services in Tasmania, and to improve access to community based palliative care. A significant focus of the BAPC program has been the acknowledgement that while bereavement care is integral to palliative care, there are often gaps in service provision, and therefore strengthening the formal and informal bereavement care supports available is crucial.

In May 2017, *Compassionate Communities: A Tasmanian palliative care policy framework (2017-2021)* was released by the Minister for Health <http://cwmtaf.wales/wp-content/uploads/2016/08/bereavement.jpg>. Enhancing bereavement care has been identified as a key priority of the Policy Framework. This new policy framework has been informed and reflects key pieces of work completed by DHHS and the Partners in Palliative Care Reference Group:

- *The Tasmanian Palliative Care Community Charter*
- *Strengthening Communities of Care: A Strategy to Build the Capacity and Capability of all Tasmanians in Palliative Care 2017-2020* (draft); and
- *Bereavement Care in Tasmania: Current Status and Future Directions for Palliative Care*

In brief, the *Tasmanian Palliative Care Community Charter* is a statement of principles to underpin palliative care in Tasmania. The principles have arisen from stakeholder consultations, and are consistent with a compassionate communities and a public health approach to palliative care. Specific to bereavement care, the current draft states: "Our carers need ... support after our death, both immediately and in the months following our deaths. They should never feel abandoned" (p2).

The *Strengthening Communities of Care: A Strategy to Build the Capacity and Capability of all Tasmanians in Palliative Care 2017-2020* sets out a pathway for enhancing and building palliative care capability, confidence and skills for everybody in the palliative care workforce, including supporting them to respond to the experience of death, dying

and bereavement. It aims to provide a direction for workforce development, to boost the capacity of communities of care and strengthen palliative care networks and linkages. All of the priorities and action areas outlined in the document are relevant to a BCN, in particular the following:

1. Build skills of communities of care so they are able to talk about and support people to plan for death, dying and bereavement
    - 1.1 Develop and provide opportunities that equip people to talk about death, dying and bereavement
    - 1.6 Implement strategies to develop skills and knowledge in bereavement care
  2. Build the capacity and capabilities of carers, volunteers and community support networks
  - 3.5 Create and support networking opportunities for volunteers across the state.
- Drawing on a literature review and stakeholder consultations, *Bereavement Care in Tasmania: Current Status and Future Directions for Palliative Care* details current thinking about bereavement care and outlines the service and system gaps in Tasmania. The paper states that stakeholders identified four key needs:
- For an effective state-wide, coordinated approach to bereavement care;
  - To develop effective pathways for bereavement care;
  - To increase workforce development; and
  - To increase consumer and clinician awareness about available services and resources.

It is the impetus of the current project to extend on this earlier work of the BAPC program and to address the specific needs outlined above by establishing a Bereavement Care Network (BCN) in Tasmania. A Tasmanian BCN is consistent with a public health approach to palliative care, and advocates for adequate and appropriate bereavement support for family, friends and community members prior to and following death.



## Aims

The Regional Bereavement Care Network and Initiatives Project aimed to improve bereavement care and support in Tasmania. The goal was to enable all members of the Tasmanian community who are experiencing grief and bereavement to be appropriately supported through the establishment of sustainable regional bereavement care networks across the state. Through, communication, consultation and collaboration with bereavement care network members, this project aimed specifically to:

1. Identify current bereavement care service providers across Tasmania and determine the level of connectivity that exists between these service providers;
2. Establish and provide time-limited support to build sustainable and functional bereavement care networks in the North, North West and South of Tasmania;
3. Develop statewide bereavement care values and principles (or equivalent), in consultation with network members;
4. Develop a communication strategy to raise awareness of and access to existing bereavement care services and supports;
5. Examine strategies to ensure the established bereavement care networks can be self-sustainable;
6. Identify capacity building and skill development activities for network members;
7. Develop an evaluation framework, to support the ongoing and future evaluation of the bereavement care network initiative.

The achievement of these aims will greatly strengthen both the formal and informal bereavement support services operating in Tasmania, assist people working in those services, and ultimately increase the quality and accessibility of support for Tasmanians who are experiencing grief and bereavement.

## Project Approach

### Scope

Although grief is a natural reaction to loss or the threat of loss, it incorporates a variety of feelings and behaviours that vary between individuals and cultures and is associated with loss in a wide variety of forms. The scope of this project was on improving bereavement care and supports in situations where death is expected, that is, in the context of palliative care. Bereavement is a response to a state of loss which includes psycho-social processes and adaptation which maybe expressed in different ways.

### Methodology

The project was underpinned by Asset Based Community Development (ABCD) principles. The ABCD model operates on the belief that local communities are best placed to identify not only their own weaknesses or gaps, but importantly to also identify their strengths and assets. It is these strengths and assets which are then harnessed to drive the desired community changes. An important complementary element of the ABCD approach is that individuals and various local service providers work collaboratively with each other. As well, the community-based groups and individuals liaise and build connections with external providers and agencies.

Central to the methodology was also a participatory action research (PAR) approach. PAR complements community development practices. One of the key principles is that participants are active and informed members and they share an end goal of producing "action and knowledge that is directly useful to a group of people" (Liamputong, 2009, p171). This model is well suited to projects and research that involves community-based involvement in health care (Law & Urry, 2011). The project methodology was also informed by the following principles:

- A public health and community development approach to palliative care is current best practice;
- Bereavement care is a critical component of palliative care;
- For the majority of the population grief is a natural and normal part of bereavement;
- Bereavement care is diverse in nature and services require improved visibility and access;

- Collaboration between informal and formal providers facilitates better service delivery and support; and
- Workforce training and support is essential to good quality bereavement care.

### Project Team and Reference Group

To implement the project, a multi-disciplinary team of professionals was formed. The project team met regularly to seek advice and support from the DHHS project sponsor. (see Appendix A for a listing of the project team). A Reference Group was convened to assist, guide and inform the project team on project implementation. Broadly, the role of the Reference Group was to:

- communicate the aims and purpose of the project with participants;
- identify and engage project participants in the planned consultations;
- ensure that the project aligns with the requirements of service providers;
- provide advice to ensure the quality of the outcomes and outputs of the BCN project; and
- assist to identify and address any risks that may have major implications for the project.

The Reference Group met twice with the project team over the project period and were provided with written reports on progress (for more information on Reference Group membership, please see Acknowledgements section).

### Stakeholder Engagement and Assessment of Connections

Individuals employed within organisations responsible for providing bereavement care services across Tasmania, who had been identified by the DHHS from previous BAPC project work, were initially invited to participate in the project via email contact. Over 100 positive responses were received (see Appendix B for examples of services and organisations contacted). Each respondent was then subsequently contacted by a project team member to ascertain their interest using a semi-structured conversation schedule (see Appendix C). Collation of conversations held with each respondent indicated that many had a

small number of well known (often local) contacts whilst others felt they were operating in "silos" in relation to bereavement care. Many reported that they were resource/time poor so suggested the network should make strong use of communication technology to connect people and services.

Subsequently, the project team formally explored existing connectivity between bereavement care service providers across Tasmania to identify existing connections between service providers and to identify opportunities for new connections to be made. Following approval from the Tasmanian Health and Medical Human Research Ethics Committee (Ref. H0016218 ) stakeholders were sent a short on-line survey seeking information on the connections they had with other bereavement care services and their professional role in this area.

Participation in the survey was voluntary and because the information collected was in either identifiable or re-identifiable form, participants were asked to provide their consent to have one or more of their details reported and shared with others. A total of 52 of the original 100 respondents completed and returned the survey. Most (56%) responded reported that they had no connection with others with respect to bereavement care services. Overall, this highlighted the very limited connectivity between individuals sampled and who were working with bereavement care service providers across Tasmania. This could also suggest that bereavement care is underpinned by a very broad base of providers, not all of whom are necessarily associated with palliative care services. Of the 23 respondents to the survey that did provided details of one or more connections, 10 indicated they had contact with only one other person or organisation in relation to bereavement care services and 2 indicated that they had at least 5 connections (Table 1). First listed connections were more likely to be contacted 'frequently' or 'often' than those connections reported later in the survey.

<b>Number of respondents</b>	<b>Number of connections identified</b>
10	1
3	2
4	3
4	4
2	5 or more

**Table 1 Overview of the number of connections reported by stakeholders (n=52)**

The project team aim to continue components of this work into the future and contribute to a broader evaluation of the BCN in 2018.

#### *Stakeholder Communication Strategy*

A stakeholder communication strategy was developed that outlined what needed to be communicated to who (group), by whom and how. Reports and project communiqües were circulated to update and inform key stakeholders as the project unfolded. Consultations were held with many individuals and presentations made to key groups and organisations with a direct involvement in bereavement care to seek their input and feedback. These included: Partners in Palliative Care Reference Group, Palliative Care Tasmania, hospice@Home and Carers Tasmania.

## Regional Stakeholder Workshops

### *Content Development: Bereavement Care Networks*

A brief review of the literature was undertaken to understand and inform the relevant components of setting up community and health related networks. Several helpful resources were identified and useful components were thematically synthesised into a resource which then formed the basis of the workshop content. The resulting key components identified for developing bereavement care networks were categorised for the workshop resources under the subheadings: Network 'Purpose, People and Organisation' (see Appendix D).

### *Content Development: Bereavement Care Practice Values and Principles*

An academic literature search (see Appendix E) was conducted to identify relevant information regarding bereavement care practice standards, values and principles being used nationally and internationally. Bereavement care standards are developed as a series of stated principles regarding the care of bereaved individuals and families. Standards guide those people who deliver care and support do so safely, ethically and in ways that are consistent with the principles of evidence-based practice. Overall, the bereavement care standards identified from the search were often clinically focussed (e.g. for health care professionals and palliative care providers specifically) and there was a paucity of documents that related to those working in bereavement services more generally and in community settings. Based on this literature search, a number of key considerations were identified by the project team specifically in relation to establishing bereavement care practice values and principles for a Tasmanian BCN (see Appendix F).



### *Workshop Delivery*

Drawing on the findings from the semi-structured conversation schedules with stakeholders, together with the background literature reviews on bereavement care network development and bereavement care practice standards , an agenda was developed for a series of 7 regional workshops that were held at sites in Hobart, Ulverstone and Launceston (Appendix G and H)

Each of the workshops was delivered by project leads who had developed the workshop content (see Appendix I for full information on workshop delivery). Attendees were invited to comment on the content and delivery of the workshop by means of a workshop evaluation form (see Appendix J). When this feedback was collated, it was clear that participants across all workshops thought the format was appropriate, enjoyed participating and found them very useful. Critically, all (100%) either agreed or strongly agreed with the statement:

**I feel excited about being part of a bereavement care network in Tasmania**



## Workshop Findings and Outcomes

### BCN Network Functions

Feedback from attendees on the functions of the networks from all workshops was analysed and synthesised to inform ongoing steps to establish the format of the Tasmanian BCN. Content analysis was performed collating the raw data from the workshops and identifying all the statements relating to the network functions, and were listed in an excel spreadsheet for each region. A thematic analysis was carried out in order to identify recurring content across the three regions and to condense several similar or closely linked statements into one function.

Following analysis of stakeholder responses, there was overwhelming preference for a state-wide BCN to enable broad communication, with regional branches to be established to address local needs. As summarized in Appendix K, participants proposed the following:

*"The network should be state-wide though supported by strong, well-connected regional or local community-based groups. A network 'management-working group' will be established to guide development of the network, to ensure connections are maintained within regions and local communities, and to determine the ongoing functions and membership of the network. A network administrator will manage the directory, communications and the day-to-day business of the network in close consultation with a management group and regional 'leads'".*

It was also suggested that key stakeholders who were active in the sector who were passionate about bereavement care be identified and invited to participate in a state-wide BCN management group. This management group could be established to provide leadership, to contribute and take responsibility for the ongoing development of the BCN.

### Practice Values and Principles

Workshop participants felt strongly that bereavement care should be guided by a statement of shared values and principles. These were identified and articulated during each workshop then summarised and thematically analysed by the project team. The identified values and themes were reviewed and refined by the team, until they were considered to best represent

the ideas presented by the workshop attendees. These themes were then also compared with PallCareAust core values, the DHHS Charter and the DHHS review of common principles in charters to ensure congruency.

### Endorsement of Workshop Outcomes

Following the workshops, a summary of the workshop findings was disseminated to all attendees as well as the BCN management group. This summary (see Appendix K) included a proposed structure for the Tasmanian BCN, terms of reference (ToR) and bereavement care practice values and principles that had been developed from feedback from the workshop participants. As can be seen in Appendix H, regional meetings were then held with stakeholders to garner feedback on the work achieved in the workshops and provide an opportunity to review, provide feedback on and endorse the structure of the Tasmanian BCN, ToR and bereavement care practice values and principles. The workshop summary was also provided to the Project Reference Group for review and comment. All other potential BCN members were also given the opportunity to offer feedback on the workshop findings.

Overall, positive feedback was received by attendees of the regional meetings, as well as from other potential members of the BCN, the Project Reference Group and the BCN management group. Only minor wording amendments were suggested to the proposed ToR and bereavement care practice values and principles. Therefore, it was concluded that the proposed structure of the Tasmanian BCN, the proposed statement of values and principles and ToR all received endorsement and were therefore formally adopted.

### Project Stages and Time Frame

The project commenced in October 2016 using a staged, team-based approach and ended with submission of the final project report in August 2017 (see Appendix L for full details of the implementation of individual stages of the project).

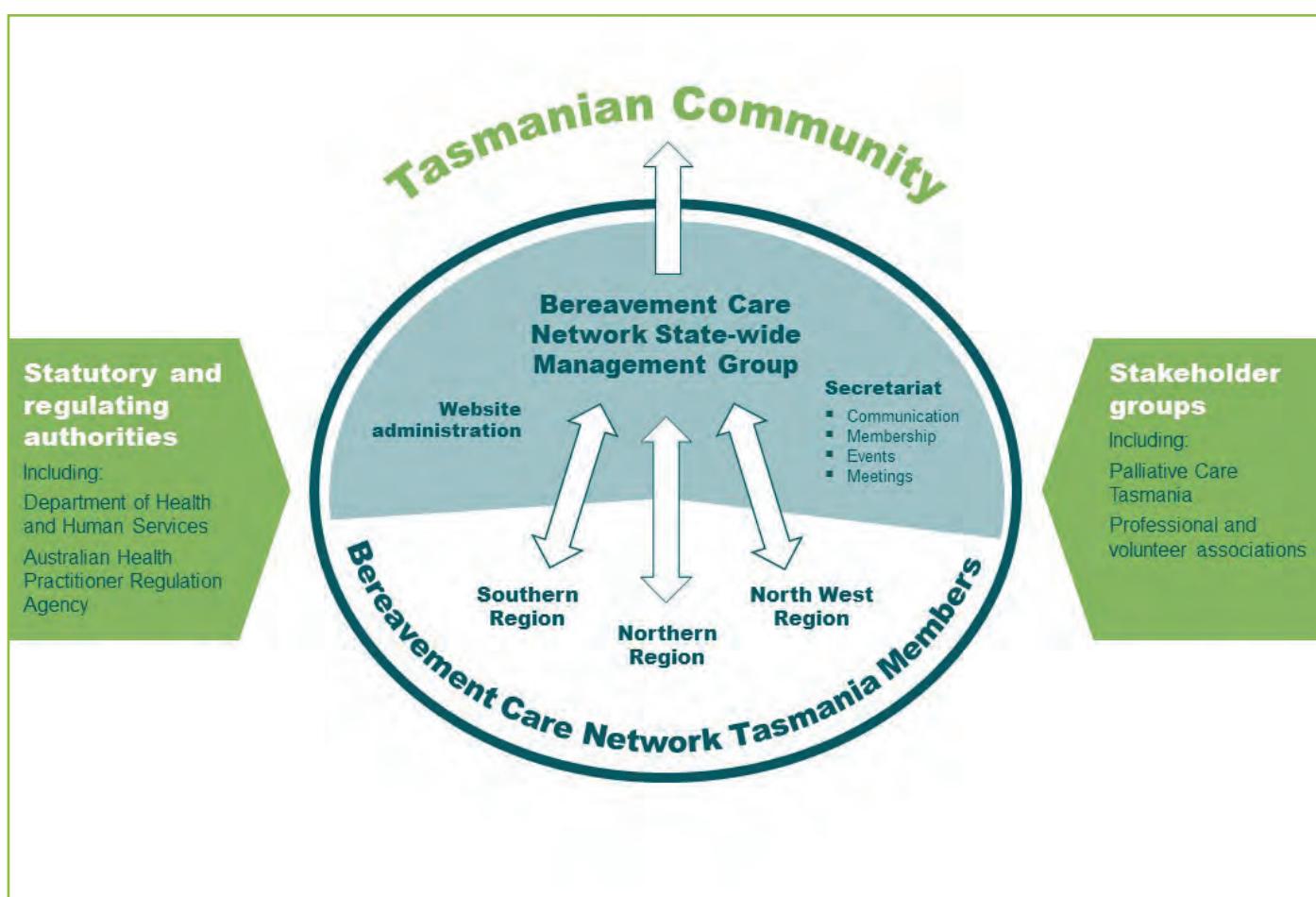
## Project Outcomes

### Establishment of the Tasmanian Bereavement Care Network

Following the work conducted as part of the regional workshops, the Tasmanian BCN was formally established and contextualised within existing structures (Appendix M). As can be seen in Figure 1, the Tasmanian BCN has been developed as a state-wide entity, comprising of three regional BCNs based in the South (Hobart), the North (Launceston) and in the North-West (Burnie/Ulverstone), with support from the CRH at the University of Tasmania.

Although the Tasmanian BCN has evolved with support from the CRH, it is expected that over time, the BCN will become more formalised and self-sustainable (see Figure 1 below). It will therefore be the sole responsibility of the state-wide management group to guide matters of network membership and development, as well as maintain the BCN website. Support will continue in

the short term from the CRH to help establish and strengthen roles and connections within the BCN, and to continue building the dedicated Tasmanian BCN website. As the involvement from the CRH reduces, however, it would be beneficial for a local bereavement organisation or service provider to host/sponsor each regional BCN to facilitate the ongoing development of the Tasmanian BCN. Currently, the state-wide BCN management group are considering the submission of grant applications (for example, Tasmanian Community Fund) to secure funding to support a Tasmanian BCN administrator to help undertake the work needed to continue the BCN development. Alternatively, a fee could be set for members to join the Tasmanian BCN and these fees could be used to support the ongoing establishment and work of the Tasmanian BCN.



**Figure 1 Contextual framework of the Tasmanian Bereavement Care Network**

## Value Statement and Principles for the Tasmanian Bereavement Care Network

Following the regional meetings, Tasmanian BCN members endorsed the following value statement:

**'We will offer services that are safe, person-centred and delivered within an individual's scope of practice and capabilities; informed by an understanding of referral pathways for clients who need additional or specialist services'.**

Tasmanian BCN members also endorsed a list of principles to underpin the bereavement care they deliver to clients across Tasmania. These values were:

- **Accountability:** we are accountable to our clients, caregiver/s, families and the community.
- **Respect:** our care will be non-discriminatory and delivered without prejudice. We will treat people as individuals – with empathy, compassion and respect for their culture, values and beliefs, in ways that value diversity and are sensitive to their particular situation.
- **Person-centred care:** our clients will be at the centre of care at all times, with support to make their own decisions without pressure from providers to take a particular path.
- **Communication:** we will communicate honestly and in ways most likely to be understood by the client.
- **Informed choice:** clients will be informed about the options available to them. We will assist them to manage their own situation according to their preferences.
- **Awareness and access:** We understand our boundaries and limitations. We will refer clients to more specialist services as appropriate.
- **Evidence based care:** we draw on current best evidence in providing care to clients.
- **Safe and ethical practice:** we adhere to the codes of practice and ethics of our profession and our organisation. We welcome feedback and reflect on what we do.
- **Advocacy:** we advocate for our clients, their families and communities



### Network Communication Strategies and Plan

The Tasmanian BCN communication plan is summarised in Appendix N. The plan will be responsive to changes in the external environment and the needs of members and their clients. The BCN state-wide management group will review the plan at least annually. A small number of key communication messages have been developed for the Tasmanian BCN. Each of these is supported by a number of communication objectives for BCN members, external stakeholders and the general public.

#### Key communication messages

- The Tasmanian BCN links practitioners and services to improve support for people working in bereavement care in the North, North-West and South of Tasmania

- Tasmanian BCN activities are driven by, and for its members
- The Tasmanian BCN aims to be self-sustaining

#### *Identification and Engagement of New BCN Members*

Additional persons and organisations that deliver or support the delivery of bereavement care services will be identified by existing BCN members who will in turn provide information about the Tasmanian BCN via the BCN flyer (see Appendix O) and/or be directed to the Tasmanian BCN website ([www.bcntasmania.org.au](http://www.bcntasmania.org.au)). Existing Tasmanian BCN members will then follow up to *inform, consult and involve* those who may be interested in joining or supporting regional BCNs (see Appendix P).

### Tasmanian Bereavement Care Network Website

As part of the current project, the CRH has developed a dedicated Tasmanian BCN website [www.bcntasmania.org.au](http://www.bcntasmania.org.au) to provide information and resources on bereavement care for health practitioners, community service providers and the general public. The CRH will build and maintain the website until December 2017, after which it will transition the ongoing management to the BCN state-wide management group. Additional organisations or persons will be needed to support the Tasmanian BCN website, and several possible user groups and roles have been identified for its ongoing running and maintenance (see Appendix Q).

### Strategies for Self-sustainability

Strategies for self-sustainability have been an integral consideration for all aspects of the planning and development of the BCN. Specifically, the strategies for self-sustainability include:

- The identification and fostering of leadership roles
  - Both regional and state-wide BCN champions
- The structure of the network promotes self-sustainability
  - The control of the network is distributed amongst many BCN members
  - Regional BCN members operate with and in response to local information
  - State-wide linkages are built on strong regional groups
  - All network members have created and promoted a shared vision and values for the BCN
  - Establishment of a state-wide management group
- The established connectivity of the network
  - Building stronger connections and trust
  - The network is an avenue for sharing/creating knowledge
- Delivery of the ToR and practice values for the BCN, which in the long-term can

be used for ongoing policy discussion to support a self-sustainable BCN

- We have promoted the capacity of the network to plan for and identify avenues to obtain funding to establish the network
- Working towards identifying a lead/sponsoring organisation
- Identifying and exploring potential funding sources to support the network into the future

### Capacity Building and Skill Development

Capacity building has been integral in all aspects of the Regional Bereavement Care Network and Initiatives project through active stakeholder involvement in developing a vision and strategy, values and organisational structure for the Tasmanian BCN. Through workshops and regional meetings, bereavement care service providers have been engaged with each other (often for the first time) and have been active in connecting across the system to build skills and enhance services.

Many participants have regarded the regional workshops and follow up meetings as worthwhile for several reasons including:

- Increasing their understand of other local services and providers in their community
- Opportunities to explore ways to connect and empower participants
- Opportunities for debriefing and recognition of the importance of self-care
- Exploration of use of technology to provide bereavement support (i.e. telehealth)
- Increased appreciation of the diversity of bereavement response (e.g ethnic/migrant groups, minority groups)
- Increased recognition of normal and abnormal grief and potential referral options
- Increased understanding of best practice standards of care across different settings and contexts
- Collation and dissemination of a library of evidence-based bereavement care resources that have been available to date and will be located on the BCN website for network members

Additional feedback from BCN members indicated a need for ongoing capacity building and skill development activities. Specifically, members commented that access to group and individual supervision with 'specialists' in the field, peer supervision, education regarding different styles of bereavement support and information about the latest international trends in bereavement research and self-care in the bereavement context would be beneficial. The BCN Management Group should seek advice and direction from the regional groups regarding specific profession and skill development needs of network members and, in consultation with training providers, develop an appropriate professional development program to meet these needs annually.



## Evaluation Framework

Social-professional networks are being increasingly recognised as essential components to enhance group-oriented services (Braithwaite, Runciman & Merry, 2009; Carswell, Manning, Long & Braithwaite, 2014; Short, Phillips, Nugus, Dugdale & Greenfield, 2015) and improve health care quality

and safety (Cunningham et al., 2011). There is a general understanding that services to patients and workplaces cultures can be improved where cohesive and collaborative social-professional networks are strengthened, whether these have been purpose designed or have informally occurred (Braithwaite et al., 2009; Cunningham et al., 2011).

At the same time networks have the potential to cause negative impacts if they marginalise, create siloes, foster in or out-group rivalries (Braithwaite, Runciman & Merry, 2009) or over-rely on central individuals or agencies (Cunningham et al., 2011). Whilst more is known about professional networks, understanding of the way in which cross sector networks involving consumer and community perspectives develop and operate is limited (Short et al., 2015). It is therefore vital to incorporate a framework to evaluate the contextual factors and outcome variables of a network to assist in guiding the Tasmanian BCN's establishment, growth and maintenance phases (Short et al., 2015).

An evaluation framework will also to inform outcome delivery, and identify strengths and weaknesses (Braithwaite, Runciman, Merry , 2009). An evaluation framework has been developed for the BCN (see Appendix R) adapted from the Commonwealth's Encouraging Better Practice in Aged Care (EBPAC) program. The EBPAC initiative aimed to encourage and support the uptake of evidence-based, person-centred, better practice in aged care services, through a focus on improving staff knowledge and skills and developing supporting resources.

This framework takes a strong public health and "whole of system" approach, elements of which resonate strongly with the principles underpinning the BAPC program. The framework identifies five main areas to assess including program delivery, program impact, sustainability, capacity building and dissemination. The framework recommends assessment of these five areas from the perspectives of consumers (care recipients), providers (professionals, volunteers, organisations) and the system (structures and networks, relationships). The framework offers user friendly questions to address indicators and outcomes and will function as a mechanism for annual network reflection and quality improvement. The framework offers a template that can be flexibly adapted to suit the needs of the Tasmanian BCN over time and can accommodate a variety of methods to answer key questions.

## Conclusion

### Summary

The Regional Bereavement Care Networks and Initiatives Project aimed to improve bereavement care and support in Tasmania through the establishment of a sustainable regional bereavement care network across the state. The project commenced in October 2016 and was completed in May 2017. Using a collaborative, team-based approach, the following objectives were achieved:

1. A bereavement care network covering the North, North West and Southern regions of Tasmania was established with time-limited support provided by the University of Tasmania Centre for Rural Health.
2. A statement of principles and values was developed to guide both formal and informal bereavement care practices.
3. A communication strategy was developed to raise awareness of and access to existing bereavement care services and supports. The platform for this was a purpose built website [www.bcntasmania.org.au](http://www.bcntasmania.org.au)
4. A number of capacity building and skill development activities were undertaken by Tasmanian BCN members through workshops and regional forums.
5. An evaluation framework was developed to support the ongoing and future evaluation of the Tasmanian BCN initiative.

### Limitations

Although efforts were undertaken to engage with all stakeholders, participation in the project was lower than expected, possibly due to the timing of the project. Activities were scheduled just prior to the Christmas/New Year period, and many stakeholders commented on the closure of many services, stakeholder absences (due to other prior commitments and holidays) and the natural build-up of work prior to this time of year as reasons preventing them from contributing or participating in the project to the extent they would have liked.

The project team also encountered technological difficulties after the introduction of new communication tools. This led to frustration from some participants in accessing the project team,

and therefore may have influenced their willingness to participate. Efforts were taken to resolve this issue by using a range of communication strategies to engage stakeholders (e-mail, phone, mailings, face-to-face, formal and informal contact). Consistency in personal contact and active follow-up by project team members with individual stakeholders proved the most worthwhile strategy for maximising engagement.

Finally, the current network connectivity identified between bereavement care providers may underreport the true level of interaction between existing services. This was considered after regional meetings, where conversations with stakeholders identified existing links between service providers that had not been reported as part of the written survey. In particular, it was noted that there was inconsistency amongst stakeholders with regard to the terminology used to refer to individuals, services and organisations within the bereavement and palliative care arenas. Following discussions, it became evident that individuals and service providers often called services and organisations by different names, meaning that they did not realise the extent of their existing connections with other service providers.

### Future Directions and Opportunities

Given the positive response to the establishment of the Tasmanian BCN, comprehensive evaluation of its performance after a period of twelve months would be highly beneficial to ascertain its strengths and weaknesses, as well as identify strategies to enhance its impact and sustainability. In the meantime, collaboration with health, education and social service organisations would be advantageous to publicise the Tasmanian BCN and its role in supporting the provision of bereavement care and support services across the state. In part, this would include establishing communication and reporting links with peak bodies and government departments that are relevant to the Tasmanian BCN that may benefit its members. Such collaboration would facilitate the identification of opportunities for support and sponsorship of events and activities of the Tasmanian BCN. Furthermore, a collaborative approach would assist the submission of grants and applications for funding to support Tasmanian BCN activities and to expand its membership base.

## Recommendations

### It is recommended that:

1. Funding be provided and a sponsoring organisation be identified to 'host' and help maintain the network beyond December 2017.
2. Any new arrangements for the governance and management of the BCN beyond 2017 should have a strong focus on community development and partnerships, and also adopt a broad, collaborative approach to bereavement care.
3. The BCN be evaluated (mid-2018) using the proposed framework to: follow-up the initial mapping of connections between bereavement care providers; identify how well the network has functioned; and to identify strategies to enhance its impact and sustainability.
4. Health, Education and Social Service sector organisations be encouraged to publicise the work of the BCN and its role in supporting the provision of bereavement care and support services in Tasmania.
5. The BCN Management Group take a collaborative approach to secure sponsorship for events and activities, to develop applications for funding to support the ongoing work of the network and to expand its membership base.
6. Formal links be established with peak bodies and government departments, including the DHHS, to support and guide the work of the network. This could be achieved by representation on the BCN Management Group



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## Appendices

### Appendix A

#### Bereavement Care Network and Initiatives

##### Project Team

- 1. *Project Leads* were assigned who had extensive experience in clinical and practitioner-based activities, networks, research and evaluation related to health care services. The project leads collectively have long-standing experience of working in, and with the Tasmanian Health Care system, government, non-government, private and community organisations.
    - Dr Tony Barnett
    - Prof Madeleine Ball
    - Dr Heather Bridgman
    - Dr Pauline Marsh
  - 2. *Project Advisors* were engaged to offer input and feedback on specific aspects of the project, both initially and as the project progressed. Advisors contributed to the broad multidisciplinary expertise of the team and provided input and perspectives on specific aspects of the project such as bereavement care and support for persons with particular needs, e.g. LGTBI, Aboriginal Tasmanians, people with disabilities, migrants and refugees.
    - Dr Katherine Kent
    - Dr Pathma Namasivayam
    - Dr Terry Cox
    - Sharon Dennis
    - Caitlyn Street
    - Dr Helen Lord
    - Robyn Wilkinson
    - Dr Iain Robertson
    - Pamela Cornish
    - Greg Roberts
    - Dr Christine Clifford
    - Dr Chona Hannah
    - Dr Ha Hoang
    - Dr Lyndsey Quarmby
    - Dr Jon Mond
    - Darren Grattidge
1. *Project Officers* were allocated to state-wide and regional responsibilities including communication and coordination of activities and to ensure there was local community input. All project officers had extensive experience in clinical and health service support activities.
- Greer Maine,
  - Dr Stephanie Thompson,
  - Dana Endelmanis
  - Jessie Bynon,
  - Rosy Green



## Appendix B

### Bereavement Care Service Providers and Organisations Contacted

- Advocacy Tasmania
- Ambulance Tasmania
- Anglican Diocese
- Anglicare
- Baptcare
- Bears of Hope
- Calvary Pastoral Care Service
- Cancer Council
- Canteen
- Carers Tasmania
- Catholic Archdiocese
- Catholic Care Tasmania
- City Mission
- Council on the Ageing,
- Aged and Community Services Tasmania
- Department of Veterans Affairs
- Flourish
- Hospice volunteers
- Legacy
- Li Vi (Live) Tasmania
- Lifeline
- Mental Health Council (Tas)
- Mission Australia
- Neighbourhood Houses Tasmania
- Newport and Wildman
- Onecare
- Palliative Care Tasmania
- Positive Solutions
- Presbyterian Care Tasmania
- Redkite
- Relationships Australia
- Retired Servicemen's League
- Richmond Fellowship
- Miscarriage, Stillbirth and Newborn Death Support (SANDS)
- Spiritual Care Australia (Tas)
- St Giles
- Tasmanian Council of Social Services
- Tas Medicare Local
- Tasmanian Aboriginal Centre
- The Compassionate Friends
- The Hobart District Nurses (hospice@Home)
- The Migrant Resource Centre
- Uniting Care
- Walking Through Grief groups



## Appendix C

### Tasmanian Regional Bereavement Care Network and Initiatives Key Stakeholder Conversation Schedule

**Do your homework:** check website/reports etc. Relevant information about the service may already be available (avoid asking unnecessary questions).

**Introduce** self and purpose for the call

- Follow-up on "Bereavement Care Networks" e-mail sent to stakeholders by DHHS on 24/10/2016.
- To ascertain level of interest in the project, to be part of a bereavement care network and willingness to provide some information about their service/practice/involvement in bereavement care.
- 3 simple questions (with conversation prompts)

**Time allowed:** Suggest 10-20 minutes. Ask if OK (can call them back at a more suitable time)

Brief outline of project (if required – refer to flyer) and respond to any initial questions

Definition: Bereavement encompasses the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one. Bereavement care is a continuum of care ...from informal and formal befriending approaches to care provided by health and social care practitioners before, at the point of death and beyond, to that provided by mental health practitioners for those who develop complicated grief" (para-phrased from: Bereavement Care in Tasmania, 2016, p.4).

**Q1.** What is your current role in providing bereavement care?

- paid vs un-paid?
- provide what type of care to whom [type/s of client]?
- How do clients access this care/get to know of the service?
- When/where is the service provided, how often?
- Does your service have any guidelines/standards that are in place to guide the delivery of bereavement care? (If yes, please describe).
- Would you be interested in contributing to the development of state-wide practice standards or guidelines for bereavement care?

**Q2.** What other formal or informal services are you (or your service) currently linked with or make use of (in terms of bereavement, palliative care or similar services)

- Name of person or organisation
- Frequency and nature of contact



**Q3.** Could you share your thoughts about /interest in being part of a “bereavement care network”?

- What would an effective network look like to you? What would be the key features? (eg. to extend contacts and knowledge of available services, share resources, access information, training/CPD opportunities, provide support).
- If you are already involved in a good network, what has contributed the success of this network?
- How would you like to be involved? (e.g. kept in the loop [only], provide feedback on proposals, attend a regional workshop or meeting)
- What would you consider to be the best ways to establish and maintain a network such as this?
- What might you consider to be some of the challenges in setting up and maintaining a local network?

**Close:**

- Do you have any questions (or concerns)?
- Would you be happy if I/we contacted you again about this project? (if so, do we have your correct contact details). This may be to seek further information by phone or questionnaire for example, or to invite you a workshop etc.
- Thank you so much for your time in talking to me.

**Supplementary Questions** (only if time allows/ person fully engaged/wants to talk)

- Are there any “champions” for bereavement care in your community that we should be talking to about this project? (who)
- Are there any particular groups in the community that are underserviced or may find it difficult to access bereavement support?
- How can we raise community awareness of bereavement options and support services in this area (ideas please?)
- How can we best identify and best support those at risk of “complicated grief”?

Different people have different responses to grief and loss including shock, pain, anxiety, guilt, anger, loneliness, and relief. Most people experience a reduction in acute symptoms over time though between 5-20% do not experience a reduction in symptoms. Their grief is “complicated” as it exceeds the expected timeframe and intensity for adjustment, involves a significant impairment of function and generally requires clinical intervention (para-phrased from: Bereavement Care in Tasmania, 2016, p.4).

- Do you have any particular professional development/learning needs in this area (Topics? How best to promote and deliver etc.)?

**Key Reference**

Department of Health and Human Services (2016). *Bereavement Care In Tasmania: Current Status and Future Directions for Palliative Care*. DHHS, Hobart, Tas.



## Appendix D

### What is a network?

‘Network’ is a word used extensively in healthcare research and in health services delivery. It is used as a synonym for ‘partnership’, ‘collaboration’, ‘alliance’ and ‘group’, or more specifically to describe the relationships between people, groups or organisations. (Cunningham et al., 2011)

A network is a group of multiple entities which are tied together with some form of structural peer-to-peer interdependence and common interest. They jointly coordinate their activities without subordination and form relatively stable, flexible working relationships. A network is characterized by open-ended relationships and distributed tasks requiring input from several members. Networks typically help with knowledge translation and promote diffusion and sharing of information and resources (Short et al., 2015).”

Collaborative networks by definition, seek to bring different groups together so that they can work effectively and synergistically together. Networks are increasingly seen as an optimal structure which both organise, and think conceptually about, clusters of diverse individuals, groups or organisations who aim to work together collaboratively (Long et al., 2013)

Networks can be formal or informal; built through social media; be put together purely to access funding, or can be built from grassroots. But networks always require resources - time, energy, practical things such as space to meet and support to travel (Scottish Association for Mental Health n.d.)

### Considerations when developing a network

Considerations when developing a network may relate to purpose, people and organisation, as described below (synthesised from Short et al., 2015; Castello et al., 2011 & Scottish Association for Mental Health n.d.)

#### PURPOSE

- **Shared analysis, vision, interest, and identity** - It is important to have or develop a shared analysis, a shared understanding of the challenges that the network is coming together to address. Related to this are a shared vision, a collective identity, a shared interest, and a shared sense of place. A sustainable network can be about diverse people with a common goal, which helps to focus activities and outcomes. These goals, which might be broad and flexible can help members feel as if they are achieving change.
- **A Purpose or a Goal** - Expectations about setting up a similar network need to be flexible and realistic, and common aims are an essential foundation for an inter-organizational network. Network development is not a linear process. It is important to set shared goals, develop collective plans, create a shared measurement system, and work together on a coordinated, strategic body of work.
- **Shared Event** - An event which forms a cultural ‘artefact’ of the inter-organizational collaboration maybe used as a vehicle to focus the network and promote networked activity. Concrete artefacts such as collaborative events may also be used to measure the success of the network. Such an artefact which engages the inter-organizational network may then further embed the effects of the network into the community.

- **Members** - Be clear about what members bring and not become over reliant on one organisation or individual. Does it need to have mechanisms in place to be sustainable? Is it dependent on key people? Does it need a leading group or organisation? Membership structures need to remain flexible and inclusive.
- **All Round Participation** - A sustainable network can increase participation, mental capital and community development. It will make sure hard to reach people get to participate. A sustainable network should not be a clique and seen as exclusive from the outside.
- **Clear benefits for member organizations** - Network members are most engaged when there are clear and strong benefits for their organizations and their work.
- **Trust and relationships** - Trust and relationships are the glue that holds a network together. They are built over time as network members work shoulder-to-shoulder on coordinated work that meets their organizations' and their communities' interests. Building trust enables networks to take more risks and share resources more willingly.
- **Power Balance** - A sustainable network develops, nurtures and challenge relationships between partners. Networks may need facilitation to build a sustainable future. Networks operate most effectively and efficiently when power, control, and leadership is dispersed and balanced. Network managers, network staff, or staff at the network's sponsoring organization find ways to share decision-making, direction-setting, and planning with working groups and network members.
- **Interprofessional Collaboration** - The network is stronger with a foundation of Interprofessional Collaboration which may also be described as multi-disciplinary working together and sharing of information depending on the language culture of participating organizations. This concept needs to be embraced by all members of an inter-organizational network in order to promote positive working together.
- **Leadership** - In terms of leadership, there needs to be a driver, or driving group, who are credible and respected by potential members. Distributed leadership is essential in order to avoid imbalances in network engagement.
- **Non-judgemental** - Be radically non-judgemental and non-hierarchical. Everybody has a contribution to make.

## ORGANISATION

- **Share Good Practice** - Share good practice and information in a way that partners find easy to access and enjoyable to engage with.
- **Adaptable** - A sustainable network must be organic and change according to circumstances. Conditions will change, and change is the only constant - so a sustainable network needs to be organic to be able to respond to change. Networks must always be creative in their communication and stay fresh and new to attract people.

- **Strong network management** - Strong network management is essential for networks to grow, thrive, and accomplish their goals. Having a capable, committed, skilled network management team is necessary rather than optional.
- **Communication** - Communication within a network is important. People need to be in the loop and feel like they're part of the loop. Conversations among network members need to be focused on things that are of value to them, rather than getting together just to talk and share information.
- **Enough structure, but not too much** – There needs to be a balance between having enough structure and having too much.
- **Resourcing** - A network requires adequate resources for its development.
- **Mutual accountability** - Network members need some way to hold each other accountable for moving the work of the network forward. This accountability can be either formal or informal, but it needs to be effective.

### Sustainable Networks Dos and Don'ts

(appropriated from the Scottish Association for Mental Health, n.d.)

- Do stay flexible. Change Networks respond to the environment around them and are co-produced with communities, which means they need to remain responsive, but the values of the network need to be stable and unchanging.
- Don't rely too heavily on key members. Sharing responsibility and building capacity of network members throughout can help make the network more sustainable.
- Do invest in people. People continue to invest and participate in change processes when they feel fulfilled by the process. Supporting people to learn new things and develop in their role means they feel invested in.
- Don't underestimate the challenges of transient groups. Learning from projects who worked with transient groups (students, the prison population) showed that sustainability was a challenge to achieve and measure. Sometimes, more time is needed for recruiting and retaining network members. However, we also saw this as a strength as new and diverse voices are included.
- Do dream. The nature of short term funding and a drive towards measuring concrete outcomes could draw away from what drives people and their vision.
- Don't rush. There is a fundamental incompatibility between taking a sustainable approach to change, and one-year funding.
- Do identify what you need to sustain your network. Sustainability cannot always rely on enthusiasm of network members, but may need resources to maintain momentum. This might be in terms of new membership, money, admin support or space.

## Examples of Bereavement Networks

The Australian Centre for Grief and Bereavement - <https://www.grief.org.au>

Loss and Grief Practitioners' Association - <http://www.lgpa.org.au/membership>

WA Cancer and Palliative Care Network -

<http://www.healthnetworks.health.wa.gov.au/cancer/home/>

## Further Reading

Castelloe, P., Watson, T., & Allen, K. (2011). Building a Sustainable Network: A Toolkit. Asheville, NC: Rural Support Partners.

<http://www.ruralsupportpartners.com/docs/BuildingASustainableNetwork-AToolkit.pdf>

Cunningham, F. C., Ranmuthugala, G., Plumb, J., Georgiou, A., Westbrook, J. I., & Braithwaite, J. (2011). Health professional networks as a vector for improving healthcare quality and safety: a systematic review. *BMJ Quality & Safety*.

Long, J. C., Cunningham, F. C., & Braithwaite, J. (2013). Bridges, brokers and boundary spanners in collaborative networks: a systematic review. *BMC Health Services Research*, 13(1), 158.

Short, A., Phillips, R., Nugus, P., Dugdale, P., & Greenfield, D. (2015). Developing an inter-organizational community-based health network: An Australian investigation. *Health Promotion International*, 30(4), 868-880.

Scottish Association for Mental Health (n.d) [www.seemescotland.org/our-movement-for-change/change-networks/building-sustainable-networks/](http://www.seemescotland.org/our-movement-for-change/change-networks/building-sustainable-networks/)

## Appendix E

### Bereavement Care Standards

The Tasmanian Department of Health and Human Services (DHHS) and the Centre for Rural Health (CRH) at the University of Tasmania are currently conducting a review of ‘bereavement care standards’ that are in use nationally and internationally. This is the first step in a process to identify which features of bereavement care standards may be useful in a Tasmanian setting.

#### *What are bereavement care standards?*

Bereavement care standards are developed as a series of stated principles regarding the care of bereaved individuals and families. Standards may ensure that people who deliver care and support ‘do so safely, ethically and appropriately’ or they may provide a practical means of achieving principles of good practice. Only a relatively small number of organisations have developed bereavement care standards or identified bereavement care principles to guide bereavement support in the community and in the palliative care environment. Standards are generally composed using a series of steps, including the formation of a steering group, a stakeholder event that brings together representatives from statutory, voluntary and commercial sectors, a review of existing literature and through consulting a range of key people in the field.

Overall, the bereavement care standards we identified were clinically focussed (e.g. for palliative care providers specifically) and there was a paucity of documents that related to the general community. As there were a limited number of bereavement care standards identified, and they were so diverse, it has been difficult to synthesise and summarise their key features. Consequently, the identified documents have been described according to their target audience: national, organisational, and community. The types of terminology used and their main features are listed below.

#### *National Bereavement Care Standards*

An example of national bereavement care standards are [Bereavement Care Service Standards](#) developed for the UK by the national organisations ‘Cruse Bereavement Care’ and the ‘Bereavement Services Association’. These were developed to be applied by any sector dealing with bereavement care including hospital, hospice, community, commercial and bereavement support organisations.

The national documents are generally very long and detailed (~30 pages), and aim to provide guidance for improving service provision via ‘standards’. These documents are generally referred to as standards and charters. Some key features include resource allocation, access, and systematic assessment of bereavement care services.

#### *Organisational Bereavement Care Standards*

An example of organisational bereavement care standards are [Bereavement support standards for specialist palliative care services](#) developed by the State Government of Victoria, which specifically apply to the professionals working in all Victorian government-funded, adult,

specialist palliative care services, including community, inpatient, acute and consultancy services. Organisational standards are fairly long (~10 pages) and generally provided guidance on how staff should perform within their roles. The documents are generally referred to the guidelines or principles. Some key features include coordination of service provision, and improving training and support.

### *Community Bereavement Care Standards*

An example of community groups principles is the [Nottingham Child Health Organisations Principles Of Bereavement Care](#). These are principles that are applied to all areas of their community based organisation, including volunteers. The common terminology used for community bereavement care standards are principles, vision, mission, code of conduct, or code of ethics. The documents are generally short and sweet (~1-2 pages), and written in easily accessible wording. Some key features include the provision of ideal and unifying statements – e.g. ‘treating people with dignity’; every child is part of a family; privacy will be offered...

### *What is happening in Tasmania?*

The Tasmanian Department of Health and Human Services have recently produced a comprehensive document [Discussion paper on bereavement care in Tasmania: current status and future directions](#). The purpose of this paper was to provide a snapshot of contemporary thinking about bereavement care and to prompt thinking about the future directions of bereavement care in Tasmania. The report provides an overview of current bereavement care options in Tasmania and identifies service and system level gaps reported by stakeholders working in the area.

Whilst currently there are no specific ‘bereavement care standards’ for Tasmania, the Tasmanian DHHS via the Better Access to Palliative Care initiative has recently consulted widely with the Tasmanian community to inform the development of the [Tasmanian Palliative Care Community Charter](#). The draft Charter encompasses key statements regarding bereavement care, which may be useful in informing the development of Bereavement Care Standards for Tasmania.

A recent evaluation of the “Walking Through Grief” program undertaken by Palliative Care Tasmania proposed that guidelines or a charter be developed for the Walking Through Grief program. They concluded that an important consideration when developing TAS specific standards may be:

‘That there should be some form of guidelines, though again, this should not be too long. In an attempt to remain “un-bureaucratic”, recommendations of no more than 1-2 pages were made. This charter should contain elements including respect, communication and confidentiality.’

**Appendix E**
**List of bereavement and palliative care standards documents**

	<b>Country/Region</b>	<b>Developed by...</b>	<b>Developed for...</b>	<b>Link</b>
<b>Bereavement Specific</b>	Australia, VIC	Department of Health, State Government of Victoria, Melbourne	Professionals working in all Victorian government-funded, adult, specialist palliative care services, including community, inpatient, acute and consultancy services	<a href="#">Bereavement support standards for specialist palliative care services</a>
	Australia, organisational	Lifeline, Suicide Bereavement Support Groups	Suicide Bereavement Support Groups	<a href="#">Standards and Guidelines for Suicide Bereavement Support Groups.</a>
	UK, national	Cruse Bereavement Care (Cruse) and the Bereavement Services Association (BSA),	Any sector (hospital, hospice, community, commercial and bereavement support organisations)	<a href="#">Bereavement Care Service Standards</a>
	Scottish, national	Scottish Government Health Directorate	Service provision by NHS Scotland	<a href="#">SHAPING BEREAVEMENT CARE: Consultation on A Framework for Action for Bereavement Care</a>
	New Zealand, national	<b>MDHB Palliative Care Bereavement Support</b>	The Guidelines are designed to be used by health care professionals working in the MDHB who care for the families, whānau and friends of people who are dying.	<a href="#">Palliative Care bereavement support guidelines</a>
	BBA, organisational, UK	BBA – voice of banking	Clients of banks	<a href="#">BBA bereavement principles</a>
	USA, national	American Association of Suicideology	Suicide support groups	<a href="#">Guiding principles for suicide bereavement support groups</a>

<b>Children/Maternity</b>	Ireland, national	HSE	Maternity settings	<a href="#">HSE National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death</a>
	Ireland, organisational	Ireland Hospice Foundation	Maternity settings	<a href="#">Bereavement care standards for maternity settings</a>
	Ireland, organisational	Irish Childhood Bereavement Network	ICBN members	<a href="#">The Vision, Mission and Principles of the Irish Childhood Bereavement Network</a>
	UK, organisational	SANDS – Stillbirth and neonatal death charity	Parents' perspectives and collaborative working with healthcare professionals have informed these principles of bereavement care.	<a href="#">Sands principles of bereavement care</a>
	UK, organisational	Winstons Wish	Children/adolecents	<a href="#">The charter for bereaved children</a>
	Australia, National	Palliative Care Australia		<a href="#">Standards for Providing Quality Palliative Care for all Australians.</a>
<b>Palliative (including a statement on bereavement)</b>	Australia, TAS	The Tasmanian Department of Health and Human Services		<a href="#">Tasmanian Palliative Care Community Charter Draft</a>
	Australia, national, nurse-specific standards	Palliative Care Nurses Australia		<a href="#">Competency Standards for specialist palliative care nursing practice.</a>
	United Kingdom, national	National institute for health and care competency (NICE)		<a href="#">NICE – end of life care for adults</a>
	Canada, national	Canadian Palliative Care Association Standards Committee		<a href="#">Proposed Norms of Practice for Practice for Hospice Palliative Care</a>
	Canada, national,	Canadian Hospice Palliative Care Association Nursing		<a href="#">Canadian hospice palliative care nursing standards of practice.</a>

<b>Standards not written in English</b>	nurse-specific standards	Standards Committee	
	USA, national	National Consensus Project for Quality Palliative Care	<a href="#">Clinical Practice Guidelines for Quality Palliative Care</a>
	New Zealand, national	Palliative Care Nurses New Zealand (PCNNZ)	<a href="#">National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand (2008)</a>
	Ireland, national	The All Ireland Institute of Hospice and Palliative Care	<a href="#">Palliative Care Competence Framework</a>
	Ireland, organisational	Ireland Hospice Foundation	<a href="#">Quality standards for end-of-life care in hospitals</a>
	Scotland, national	Healthcare Improvement Scotland and the Scottish Partnership for Palliative Care.	<a href="#">Scottish Palliative Care Guidelines</a>
<b>Standards not written in English</b>	Hungary	Hungarian Hospice-Palliative Association	<a href="http://www.hospicjum.waw.pl">www.hospicjum.waw.pl</a>
	Moldova	Ministry of Health, Moldova	Request via email <a href="mailto:secondbr@beltsy.md">secondbr@beltsy.md</a>
	Romania	Romanian National Palliative Care Association	Request via email <a href="mailto:hospice@rdslink.ro">hospice@rdslink.ro</a>
	Spain	SECPAL Consensus group	Request via email <a href="mailto:rartigas@ico.scs.es">rartigas@ico.scs.es</a>
	Switzerland	Arbeitsgruppe "Standards" der Schweizerischen Gesellschaft für Palliative Medizin	Request via email: <a href="mailto:frederic.stiefel@inst.hospvd.ch">frederic.stiefel@inst.hospvd.ch</a>

## Appendix F

### Considerations when developing bereavement care practice values and principles

Considerations	Specific questions to guide development
A well-defined purpose and target audience	<ul style="list-style-type: none"> <li>• Who will the practice values and principles be for (individuals, organisations, health professionals, community groups)?</li> <li>• Will the developed practice values and principles be appropriate for application in a wide range of settings?</li> <li>• If one set of values and principles is not appropriate for all settings, would multiple standards be suitable?</li> <li>• Will the values and principles be developed to be 'minimum standards', 'ideal practice' or 'norms of practice'?</li> </ul>
Regional considerations	<ul style="list-style-type: none"> <li>• What regional evidence/accepted social norms are specific to Tasmania?</li> </ul>
Contributions to development	<ul style="list-style-type: none"> <li>• Will the public be invited to comment?</li> <li>• Who will form a consensus group of professionals?</li> <li>• How will data contributing to the development of bereavement care standards be collected?</li> </ul>
Ranking of practice values and principles	<ul style="list-style-type: none"> <li>• Is the ranking of statements a consideration? What is the most important consideration for Tasmania?</li> </ul>
Reviewing practice values and principles	<ul style="list-style-type: none"> <li>• How will Tasmanian standards be published, reviewed and assessed/audited?</li> </ul>
Access and appropriateness	<ul style="list-style-type: none"> <li>• What is the scope for accessibility, and adequate resources?</li> <li>• Do the standards need to be developed with the current 'climate' in mind?</li> </ul>

## Appendix G

### Bereavement Care Networks Tasmania Workshop Agenda - Northern

DHHS Better Access to Palliative Care, with the Centre for Rural Health are running workshops in three regional areas to assist in establishing Tasmanian Bereavement Care Network/s (BCN). The workshops will provide you, as an individual involved in bereavement care, with an opportunity to contribute to the establishment of these networks in Tasmania.

There are three workshops being run for the Northern region. Please register your attendance at one of the workshops:

**Date:** Monday 13<sup>th</sup> February;

**Times:** 9am – 12pm OR 1pm-4pm OR 5pm-7:30pm;

**Location:** Cancer Council building, Training Room, 69-71 Howick St, Launceston

#### Workshop Agenda

At each workshop we will work on identifying and establishing the core components of the BCN, including the:

- Functions
- Vision
- Benefits
- Governance
- Communication strategy
- Membership
- Sustainability
- Operations

We will also seek input regarding the potential for developing bereavement care standards in Tasmania.

If you cannot attend the workshop, we still want your input. Each workshop will be structured similarly so that the results can be collated and disseminated for your feedback via an online survey.

#### Next steps

Please register for the workshop you will attend:

<http://www.utas.edu.au/rural-health/news-all/news-items/bereavement-care-networks-workshops>

Or follow the links via the CRH website: <http://www.utas.edu.au/rural-health>

Further information and background readings regarding networks and bereavement care standards is available via the link below.

<http://www.utas.edu.au/rural-health/news-all/news-items/bereavement-care-networks-workshops>

If you cannot attend the workshop but wish to remain informed and provide feedback on the workshop outcomes, please contact the Northern Project officer:

Greer

[Greer.Maine@utas.edu.au](mailto:Greer.Maine@utas.edu.au)

6324 4010

**Appendix H**
**Bereavement Care Network workshop and meeting details**

<b><i>Location</i></b>	<b><i>Dates</i></b>	<b><i>Participants</i></b>
<b><i>Workshops</i></b>		
<i>Hobart</i>	9/2/17 PM	19
	10/2/17 AM	12
	10/2/17 PM	15
<i>Launceston</i>	13/2/17 AT	12
	13/2/7 PM	10
<i>Ulverstone</i>	16/2/17 AM	12
	16/2/17 PM	12
<b><i>State wide Management Working Group</i></b>		
<i>27/3/17 teleconference</i>		22 attendees 13 apologies
<i>25/05/2017 Campbelltown</i>		12 attendees 19 apologies
<b><i>Regional Group Meetings</i></b>		
<i>Hobart</i>	20/04/2017	16 attendees 10 apologies
	1/06/2017	9 attendees 10 apologies
<i>Launceston</i>	28/04/2017	10 apologies 11 apologies
<i>Burnie</i>	28/04/2017	7 attendees 8 apologies

## Appendix I

### Bereavement Care Network Workshop Delivery

The format of the workshops was designed to elicit stakeholder input to assist in establishing the Tasmanian BCN as well as state-wide practice standards.

The primary workshop aim was to identify and establish the core components of the BCN, including the functions, vision, benefits, governance, communication strategy, membership, sustainability and operations. Stakeholders that couldn't attend the workshops were invited to offer their input through a follow up survey.

During the workshops, participants offered examples of interstate bereavement based networks:

- The Australian Centre for Grief and Bereavement <https://www.grief.org.au>
- Loss and Grief Practitioners' Association - <http://www.lgpa.org.au/membership>
- WA Cancer and Palliative Care Network - <http://www.healthnetworks.health.wa.gov.au/cancer/home/>

Two local, successful Tasmanian network examples, the North West Providers Forum and the Tasmanian Allied Health Network were also showcased as potential local models for workshop participants to consider:

*The North West Community Providers Forum is a network of 700+ community service providers. The network grew from a need to raise awareness of function and availability of community services on the North West coast of Tasmania and to encourage 'warm' referrals and connections. The forum has a dedicated facilitator and is funded by Catholiccare. The forum operates with a moderated email list and bi-monthly face to face themed forums at Devonport and Burnie. The continued growth and success of the forum is attributed to a dedicated administrator and continual input from network members into planning forum topics annually.*

*The Tasmanian Allied Health Network has 300 allied health professional members of a public Facebook page. The Network originated as an Exercise Physiology network then expanded to encourage all allied health professionals to connect and share professional development events and other opportunities of interest. There is a dedicated facilitator and small committee who support the page.*

During the workshops, participants were asked to consider how a Tasmanian BCN may be facilitated to suit the Tasmanian context. Participants collectively offered feedback for the following prompts:

#### Purpose

- What purpose/function should the Tasmanian BCN have?
- What is the main benefit you see coming out of the BCN?
- Are there important 'shared values' for the BCN?

#### People

- Who should it involve? (e.g. membership)
- How might leadership roles be handled?
- How would the BCN ensure diversity and inclusion?

#### Organisation

- How would it work? (Resourcing, Governance, Accountability, Communication)
- What are some features of successful networks you are involved in?
- What are some challenges and how can these be addressed?

A short presentation was made to communicate the main features of current bereavement care standards (described above) and the important considerations relating to developing practice values and principles within Tasmania to participants in the regional workshops (see below for BCN workshop PowerPoint presentation). This presentation was supported by summaries and a tabulated list of relevant links to full text documents disseminated both prior to the workshop and collated in a workshop participant pack.

It was also highlighted that whilst currently there are no specific ‘bereavement care standards’ for Tasmania, the Tasmanian DHHS via the BAPC initiative has recently consulted widely with the Tasmanian community to inform the development of the Tasmanian Palliative Care Community Charter (DHHS, 2016). It was communicated to participants that the Charter (still in draft form at that time) encompassed key statements that could be ‘translated’ into a bereavement care setting, and that these may be useful in informing the development of bereavement care standards for Tasmania. The main themes identified from this document were:

- Relief
- Respect, Dignity and Person-Centred Care
- Good communication
- Coordination of care
- Choice
- Fair access
- Support
- Help with planning care
- Cultural respect

A group activity in the workshop was conducted to collect information regarding bereavement care standards based on the following questions:

- What types of standards relating to bereavement care are you aware of?
- What features of bereavement care standards are important?
- Do you think that standards will be useful or applicable? If so, for whom?

These questions were discussed in small groups and the ideas generated by participants was verbally confirmed by a member of the research team and transcribed onto butchers paper. At the conclusion of the workshop series, the raw data from the butchers paper was transferred into a Microsoft Word document by a research team member from each region respectively.


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## Tasmanian Bereavement Care Network Workshops



## Bereavement Care Networks and Initiatives

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The Better Access to Palliative Care program is funded by the Australian Government.  
 Proud Program Partners are Tasmanian Association for Hospice & Palliative Care,  
 The District Nurses, hospice@HOME and the Tasmanian Government.

[www.dhhs.tas.gov.au/palliativecare/better\\_access\\_to\\_palliative\\_care\\_project](http://www.dhhs.tas.gov.au/palliativecare/better_access_to_palliative_care_project)



## About BAPC

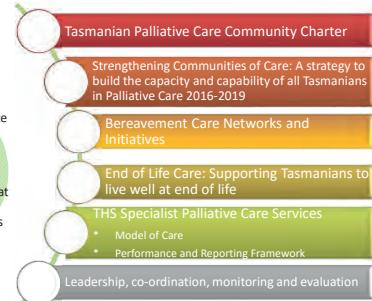
### Four key areas for action:

- Tasmanian Palliative Care Policy Framework – developing and implementing a strategy for co-ordination and collaboration;
- Strengthening the networks and linkages between palliative care providers (primary and specialist);
- Enhancing palliative care system (public private, primary, secondary, tertiary); and
- Enhancing the capacity of specialist palliative care teams.



### Our Vision

Tasmania is a compassionate community that works together to ensure that all Tasmanians have access to high quality, coordinated, respectful palliative care that is person-focussed and supports families and carers



## Bereavement Care Networks and Initiatives

*Bereavement Care in Tasmania: Current Status and Future Directions for Palliative Care, (DHHS, April 2016)*

### Four key themes emerged:

- The need for a state-wide, co-ordinated approach to bereavement care
- The need to develop effective pathways for bereavement care.
- There is a need for increased workforce development, and
- There is a need to increase consumer and clinician awareness about available services and resources

[http://www.dhhs.tas.gov.au/palliativecare/better\\_access\\_to\\_palliative\\_care\\_project/project\\_activities](http://www.dhhs.tas.gov.au/palliativecare/better_access_to_palliative_care_project/project_activities)



## Bereavement Care Networks and Initiatives

### Action Plan/Deliverables:

- Establishment of Regional Bereavement Care Networks
- Capacity Building and Skills development
- Awareness Raising: Communication Strategies and Activities
- Bereavement Care Practice Standards/guidelines

The Better Access to Palliative Care program is funded by the Australian Government.  
 Proud Program Partners are Tasmanian Association for Hospice & Palliative Care,  
 The District Nurses, hospice@HOME and the Tasmanian Government.





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- Workshop aims
  - To establish core components of a BCN including the purpose and function
  - To input regarding potential bereavement care standards
- Goals of the session
  - Get all thoughts up and on the table – all ideas welcome
  - Notes will be distributed for feedback and consensus afterwards
- What did the initial phone interviews identify?
  - A wide interest in establishing an active BCN
  - That respondents
    - Are often time poor
    - Want to connect with peers (especially external) and to link services
    - Want greater access to shared resources and education



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#### Ice-breaker

- Who you are
- Your role in bereavement care
- Your involvement in other networks
- One ‘front of mind’ idea regarding a BCN



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## Networks Session



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### Networks:

- synonyms: ‘partnership’, ‘collaboration’ and ‘group’
- multiple entities tied together by common interest
- help with knowledge translation, sharing of information and resources
- brings different groups together to work effectively
- can be formal or informal
- require resourcing



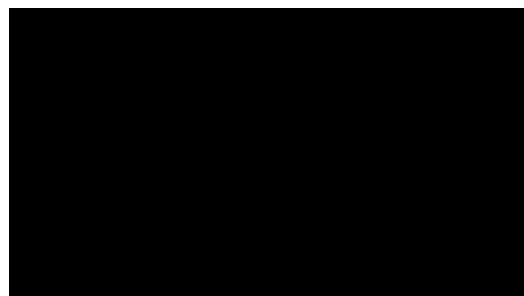
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### Local Networks Video Examples

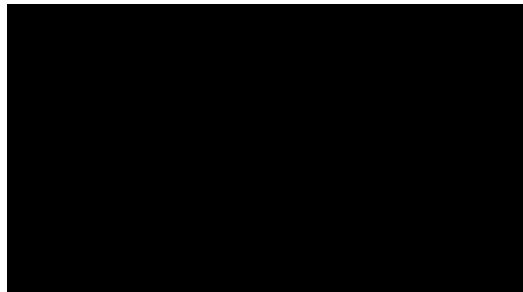
The “North West Community Providers Forum”

The “Tasmanian Allied Health Network”

### North West Community Providers Forum



### Tasmanian Allied Health Network


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### Examples of Bereavement Networks

- Victorian Bereavement Support Network  
<http://www.vbsn.org.au/information-on-membership/>
- The Australian Centre for Grief and Bereavement -  
<https://www.grief.org.au>
- Loss and Grief Practitioners' Association -  
<http://www.lgpa.org.au/membership>
- WA Cancer and Palliative Care Network -  
<http://www.healthnetworks.health.wa.gov.au/cancer/home/>


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### Network Group Activity


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### Purpose

- What purpose/function should the BCN have?
- What is the main benefit you see coming out of this network?
- Are there important 'Shared Values' for the BCN?


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### People

- Who should it involve? (e.g. membership)
- How might leadership roles be handled?
- How would the BCN ensure diversity and inclusion


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### Organisation

- How would it work? (Resourcing, Governance, Accountability, Communication)
- What are some features of successful networks you are involved in?
- What are some challenges and how can these be addressed?

## BREAK

Refreshment break – 15 minutes



## Network Activity Feedback



## Bereavement Care Standards Session



### What are bereavement care standards?

- A series of 'stated principles' to ensure service provision is safe and effective
- Can be used for:
  - Developing high quality services
  - Assessing the quality of existing services
  - Uniting bereavement care services
- Developed for national, state-wide, organisational or community groups

### Existing bereavement care standards

Can be known as: Standards, charters, guidelines, principles, codes, vision or mission

	National	Organisational	Community
<b>Aims</b>	<ul style="list-style-type: none"> <li>• Improve service provision (e.g. resource allocation &amp; access)</li> <li>• Assessment of services</li> </ul>	<ul style="list-style-type: none"> <li>• Coordination of service provision</li> <li>• Staff training &amp; support</li> <li>• Guidance for staff performance</li> </ul>	Provide ideal and unifying statements for all
<b>Features</b>	Very long and detailed (~30 pages)	Fairly long (~10 pages)	<ul style="list-style-type: none"> <li>• Written in easily accessible wording</li> <li>• Short and sweet (~1-2 pages)</li> </ul>
<b>Example</b>	<a href="#">UK Bereavement Care Service Standards</a>	<a href="#">VIC Bereavement standards for specialist pall care services</a>	<a href="#">Nottingham Child Health Principles of Bereavement Care</a>

### Tasmanian Example

- The DHHS have developed '*Tasmanian Palliative Care Community Charter*' which outlines principles of care:
  - Relief
  - Respect, Dignity and Person-Centred Care
  - Good communication
  - Coordination of care
  - Choice
  - Fair access
  - Support
  - Help with planning end of life care
  - Cultural respect


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## Bereavement Care Standards Group Activity


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## Group Activity

- What types of standards relating to bereavement care are you aware of?
- What features of bereavement care standards are important?
- Do you think that standards will be useful or applicable?
  - If so, for whom?


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## BREAK

Refreshment break – 5 minutes


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## Workshop Wrap Up

Do we know....

- What would we like the network to do?
- How many there would be?
- What will it look like and how will it work?
- Who will be involved (as members...or “other”)?
- What the essential elements are(got-to-haves) for network to succeed?
- What bereavement care ‘standards’ are and how they could be used?


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## Workshop follow up

The CRH team will

- Collate and circulate notes from all workshops
- Canvas and confirm main ideas
- Facilitate input from stakeholders unable to attend

We will develop and implement an action plan

This will be done by...


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## Thankyou!



## Appendix J

### Bereavement Care Workshop Evaluation.

Which workshop did you attend (please tick)?

- |   |   |
|---|---|
| <input type="checkbox"/> Hobart (9/2) 1-4pm       | <input type="checkbox"/> Launceston (13/2) 1-4pm    |
| <input type="checkbox"/> Hobart (10/2) 9-12pm     | <input type="checkbox"/> Launceston (13/2) 5-7:30pm |
| <input type="checkbox"/> Hobart (10/2) 1-4pm      | <input type="checkbox"/> Ulverstone (16/2) 9-12pm   |
| <input type="checkbox"/> Launceston (13/2) 9-12pm | <input type="checkbox"/> Ulverstone (16/2) 1-4pm    |

Please indicate (tick) the extent to which you agree or disagree with the following statements:

**1. I enjoyed participating in the workshop.**

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

*|Comments: and if you responded "Disagree" or "Strongly Disagree", please tell us how we can improve.*

**2. I found the workshop very useful.**

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

*Comments: and if you responded "Disagree" or "Strongly Disagree", please tell us why*

3. The workshop format was appropriate.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

*Comments: and if you responded "Disagree" or "Strongly Disagree", please tell us how we can improve.*

4. I feel excited about being part of bereavement care network in Tasmania

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

*Comments: and if you responded "Disagree" or "Strongly Disagree", please tell us why.*

5. Are there any other comments/suggestions would you like to make?

**Thank you for your time**

## Appendix K

### Bereavement Care Network Project: Workshop Outcomes

DHHS Better Access to Palliative Care, with the Centre for Rural Health is working with palliative care service providers, volunteers, community organisations and carers to establish a Bereavement Care Network.

As follow-up to over 100 positive responses and interest in the project from individuals and organisations across Tasmania, a series of seven workshops were held to discuss the functions, membership and organisation of the network. A summary of the outcomes from this work follows:

#### What is bereavement?

Bereavement encompasses the entire experience of family members, carers and friends in the anticipation, death, and subsequent adjustment to living following a death. Bereavement care is a continuum of care from informal and formal approaches to care provided by health and community care practitioners. Grief is normal, natural and an integral part of living. Although people have different responses to grief, most seek out and are adequately supported by their existing networks such as friends and family. A small proportion of those who are bereaved do experience complicated grief which requires clinical/professional intervention

#### Vision

That all members of the Tasmanian community are able to access and receive appropriate, compassionate bereavement care when needed.

#### Mission

To value, connect and support both formal and informal providers of bereavement care who live and work in our communities.

#### Aim and Functions of the Bereavement Care Network

To improve co-ordination and strengthen partnerships to support the delivery of bereavement care by connecting people; identifying services; and promoting education and support for people involved in bereavement care.

The specific functions of the bereavement care network will be to:

1. Collate and maintain a **directory of services** on a regional and state-wide level. This will include up-to-date information such as the service location, contact details, and service parameters including client restrictions and costs.
2. Manage an accessible **list of members and organisations** comprising the bereavement care network. Inclusion of a description of their background, credentials, expertise and service/s offered will facilitate 'warm' referrals.
3. Provide a listing of relevant educational **resources** that are accessible to formal and informal bereavement care providers.
4. Distribute relevant information on **current news and events**. This may include upcoming forums, workshops, conferences, CPD events, grants, tenders and job opportunities.

## Values and principles

We will offer services that are safe, person-centred and delivered within an individual's scope of practice and capabilities; informed by an understanding of referral pathways for clients who need additional or specialist services.

Our members subscribe to the following values and principles in the care they deliver:

- **Accountability:** we are accountable to our clients, caregiver/s, families and the community.
- **Respect:** our care will be non-discriminatory and delivered without prejudice. We will treat people as individuals – with empathy, compassion and respect for their culture, values, and beliefs, in ways that are sensitive to their particular situation.
- **Person-centred care:** our clients will be at the centre of care at all times, with support to make their own decisions without pressure from providers to take a particular path.
- **Communication:** we will communicate honestly and in ways most likely to be understood by the client
- **Informed choice:** clients will be informed about the options available to them. We will assist them to manage their own situation according to their preferences.
- **Awareness and access:** We understand our boundaries and limitations. We will refer clients to more specialist services as appropriate.
- **Evidence based care:** we draw on current best evidence in providing care to clients.
- **Safe and ethical practice:** we adhere to the codes of practice and ethics of our profession and our organisation. We welcome feedback and reflect on what we do.
- **Advocacy:** we advocate for our clients, their families and communities

## Membership

The network will be open to individual and organisational providers of bereavement care services in Tasmania. Members will be required to subscribe to the networks' core values and, in providing bereavement care to clients, observe relevant legal, ethical and professional standards and codes of conduct.

Application for membership will be made to the network administrator and include details of experience, qualifications, nominator or referee/s, a description of services offered and a statement confirming acceptance of the principles and values of the network.

## Governance and organisation

The network should be state-wide though supported by strong, well-connected regional or local community-based groups. A network 'management-working group' will be established to guide development of the network, to ensure connections are maintained within regions and local communities, and to determine the ongoing functions and membership of the network.

A network administrator will manage the directory, communications and the day-to-day business of the network in close consultation with a management group and regional 'leads'.

## Communication platform and awareness raising

The network will create and maintain a dedicated website for members to provide information and resources on bereavement care for health practitioners, community service providers and the general public.

## Funding and resourcing

The aim is for the network to be self-sustaining. Initially, the network will be supported by the DHHS, BAPC program and the Centre for Rural Health. It is anticipated that the network administrator will be identified and supported by a member organisation with the capacity to release someone for this task. This could be on a rotational (annual) basis.

The network will actively pursue ongoing resources to further its objectives and to achieve its mission.

## Quality improvement

The network is committed to the improvement of bereavement care consistent with its vision and values. It will establish mechanisms to receive feedback from members, clients and other service providers on its functions and will undertake a self-review of its functions, operation and membership every 12 months.

## Bereavement care practice standards or guidelines

Members of the network recognise current practice standards, guidelines, charters and codes of practice developed for the professions, individuals and organisations providing bereavement care to safeguard the public and promote evidence-based practice. Given our diversity, members will practice in accord with codes/standards relevant to their profession/role and deliver bereavement care in ways that articulate those values shared by all members.

Further work on the establishment of bereavement care guidelines or standards will be investigated as part of the ongoing work of the Network.

[http://www.dhhs.tas.gov.au/palliativecare/better\\_access\\_to\\_palliative\\_care\\_project/project\\_activities](http://www.dhhs.tas.gov.au/palliativecare/better_access_to_palliative_care_project/project_activities)

## Appendix L

The Regional Bereavement Care Network and Initiatives project had five stages (with some overlap) commencing with project planning (October, 2016) and ending with completion of submission of the final project report (August, 2017). Within each stage, activities and milestones were identified to monitor progress, reporting and achievement of the project aims (see Table 4).

### Project stages and timeframe

Stage	Oct 2016	Nov	Dec	Jan 2017	Feb	March	April	May	June	July	August
1. Planning, review and consultation											
2. Establish bereavement care networks and develop state-wide practice standards											
3. Support networks to develop communication strategies											
4. Capacity building and skill development											
5. Evaluation and reporting											

## Appendix M

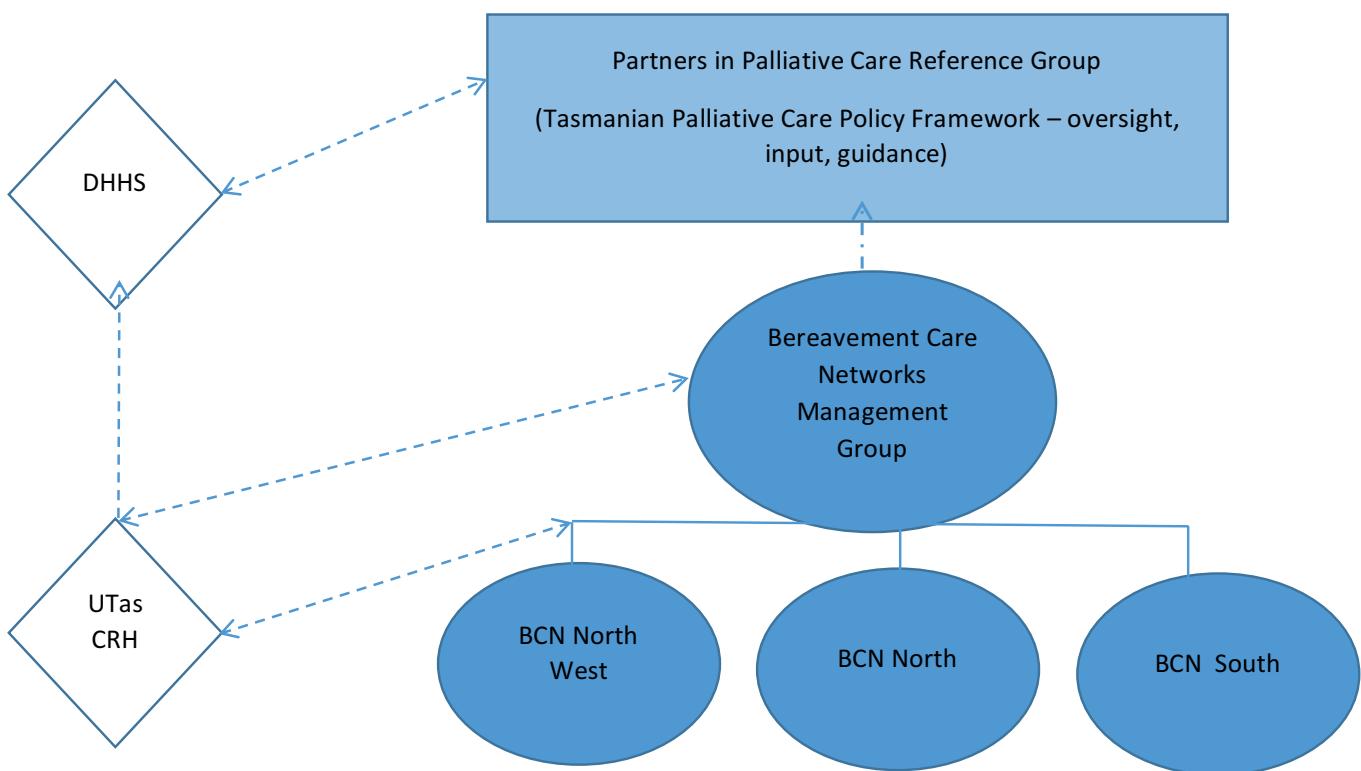


Figure 2 Relationship and role delineation map – Bereavement Care Networks

The **Partners in Palliative Care Reference Committee (PIPC)** broadly represents the Tasmanian palliative care sector. PIPC provides oversight, advice, input and guidance in relation to the implementation of the Tasmanian Palliative Care Policy Framework 2017-2021. The establishment of the Bereavement Care Networks is a key initiative of the policy framework.

**DHHS** - Chairs the PIPC and provides secretariat support and is responsible for implementing, reporting and evaluating the policy framework. Annual progress reports are provided to the Minister for Health.

**BCN Management Group** role includes:

- Statewide leadership and co-ordination of networks
- Sustainability planning for networks
- Management and moderation of website
- Evaluating networks
- Statewide events, communication strategies
- Progress reports to the PIPC
- Advocacy and community education

**BCN** role includes:

- Regional forum/network for members
- Identifying bereavement care service gaps and where possible initiating local responses to meet service gaps in regions;
- Promoting local co-ordination and building bereavement care capacity across their regions/communities/services
- Local leadership, advocacy and community education in bereavement care

## Appendix N

### BCN stakeholder communication plan

Stakeholder	Communication Objective	Responsibility	Communication Strategy
<b>BCN members</b>	<ul style="list-style-type: none"> <li>- Understand what the network is about, its aims/functions/purpose.</li> <li>- Are vested in the network and use it to connect with others</li> <li>- Contribute to the ongoing operation of the network by volunteering for tasks/roles.</li> <li>- Members are actively engaged in advocating for the network and making it successful</li> <li>- Communicate network events and information with professional colleagues and community contacts</li> <li>- Understand where to go for resources, education and training</li> <li>- Provide constructive feedback and advice on the network</li> </ul>	BCN Management Group and regional conveners	<p>Maintenance of BCN website</p> <p>Regular face-to-face and teleconference meetings</p> <p>Regular e-mail updates</p> <p>Circularise information about BCN events</p> <p>Face to Face workshops (as requested)</p> <p>Regular BCN regional meetings held quarterly (S, N and N-W)</p>
<b>External stakeholders (eg. linked services and organisations, DHHS, THS, PHT)</b>	<ul style="list-style-type: none"> <li>- Understand the purpose of the network and are able to inform others</li> <li>- Appreciate the impact and benefit to their work/service /area</li> <li>- Are actively engaged in supporting staff who are members of the network</li> <li>- Provide enablers for network success eg. posting BCN website link on their own homepage</li> </ul>	BCN Management Group and network members	<p>Targeted 'phone calls and e-mails</p> <p>Distribution of BCN flyers</p> <p>Regular project updates via e-mail and link to website</p>
<b>Tasmanian public (and potential users/clients of bereavement care services)</b>	<ul style="list-style-type: none"> <li>- Are aware of the existence of the network</li> <li>- Are able to access information via the BCN website</li> <li>- Can draw on [local] resources for bereavement care.</li> <li>- Value the range of both formal and less formal bereavement supports available.</li> </ul>	BCN Management Group and network members	<p>Dissemination of information via local community and professional groups (other networks) and services</p> <p>Raise awareness through their own bereavement care practice</p> <p>Provide public and invited talks about the network</p>

## Appendix O



DHHS Better Access to Palliative Care & the Centre for Rural Health established a **Bereavement Care Network for Tasmania** uniting carers, community organisations, palliative care providers & volunteers.

The network is state-wide, with strong regional groups in the North, North West and South.

**The purpose** of the network is to value, connect and support both formal and informal providers of bereavement care who live and work in our communities.



**The vision** of the network is that all members of the Tasmanian community are able to access and receive appropriate, compassionate bereavement care when needed.

**Visit our website** to find out more including membership enquires, a directory of services and resources, and a calendar of events.

**[www.bcntasmania.org.au](http://www.bcntasmania.org.au)**

## Appendix P

### BCN new member engagement processes

<b>Inform</b>
<ul style="list-style-type: none"><li>- Provide information about the network (via the BCN flyer and/or e-mailed the web-site address)</li><li>- Outline project purpose/aims of the BCN and potential benefits</li><li>- To ascertain level of interest in joining the and contributing to the bereavement care network</li></ul>
<b>Consult</b>
<ul style="list-style-type: none"><li>- Seek feedback on the functions of the network and how it works</li><li>- Engage to assess eligibility and willingness to provide some information about their service/practice/involvement in bereavement care</li><li>- Respond to any questions (or concerns) about the network</li></ul>
<b>Involve</b>
<ul style="list-style-type: none"><li>- Outline procedures for membership application</li><li>- Assist to make application for membership and/ or listings of service</li><li>- Introduce and explore options for contacting other members and services</li><li>- Seek input into work of the network and ascertain interest/capacity to contribute and support</li><li>- Attend and participate in regional forum</li></ul>

## Appendix Q

### Tasmanian Bereavement Care Network Website Roles

- Front-End (website) Users
  - Registered: This role will allow members to log into the website and access the discussion board and non-public resources.
  - Editor: This group allows to add and edit all articles, including those created by other users. More advanced editing requirements will be performed by administrative users (next section).
- Back-End (administration) Users
  - Manager: Managers can access the content from the back-end and create new Categories, Menus and Sections.
  - Administrator: Administrators can manage content, components and modules, site statistics and user accounts.
  - Super Administrator: Super Administrators have the highest level of access and can manage and modify all parts of the website including other administrator access.
- Forum/Discussion Board Access
  - Site Administrator
  - Global Moderator: can moderate any topics in any forums
  - Moderator: can only moderate topics for the discussion boards then are assigned to
  - User: base registered user

## Appendix R

### BCN evaluation framework

KEY AREA	IMPACTS AND OUTCOMES		
	For consumers (care recipients)	For providers (professionals, volunteers, organisations)	For the system (structures and networks, relationships)
Indicative questions			
PROGRAM DELIVERY	<ul style="list-style-type: none"> <li>• What changes were made that benefited consumers?</li> <li>• How much input did consumers have into the direction and activities of the project?</li> </ul>	<ul style="list-style-type: none"> <li>• What opportunities were there for knowledge and skills development and how did these take place?</li> <li>• How many health workforce members, and of what kind, took those opportunities?</li> <li>• How strongly did the use of practice standards feature in the project?</li> </ul>	<ul style="list-style-type: none"> <li>• How has improved/networked practice been promoted (and what was communicated) to care providers, peak bodies etc.</li> <li>• How are resources allocated to achieve maximum effect?</li> </ul>
PROGRAM IMPACT	<ul style="list-style-type: none"> <li>• What are the positive impacts on the care recipients' wellbeing?</li> <li>• How have consumers' knowledge of bereavement care services changed?</li> </ul>	<ul style="list-style-type: none"> <li>• In what ways, and to what degree, did the learnings of network members translate into better practice?</li> <li>• How have network members and service providers responded to the project?</li> </ul>	<ul style="list-style-type: none"> <li>• What models for change are the most effective in promoting better care?</li> <li>• What is unique about the outcomes of the project?</li> </ul>
SUSTAINABILITY	<ul style="list-style-type: none"> <li>• How can the positive impacts the care recipients' wellbeing be maintained?</li> </ul>	<ul style="list-style-type: none"> <li>• How is the demonstrated better care services being embedded so that it can be sustained?</li> <li>• What kinds of support does the network need to provide to promote these services in the long term?</li> <li>• How can the impact of project resources be maximised and sustained within the project?</li> <li>• Who was needed to lead change/s and what supports did they need?</li> </ul>	<ul style="list-style-type: none"> <li>• How can the main messages continue to be shared at various levels of the community and health care sectors?</li> </ul>
CAPACITY BUILDING	<ul style="list-style-type: none"> <li>• What works and what doesn't work?</li> </ul>	<ul style="list-style-type: none"> <li>• What strategies need to be implemented to optimise workforce participation in training initiatives?</li> <li>• What are the essential ingredients for success?</li> <li>• What can the resources achieve, how might they be refined further or are they in a form that is ready to be used elsewhere?</li> </ul>	<ul style="list-style-type: none"> <li>• What main messages, to share with whom, are most effective in sharing learnings and building consumer confidence?</li> <li>• What potential is there for further system level innovation and improvements?</li> <li>• To what extent are project resources shared?</li> </ul>
DISSEMINATION	<ul style="list-style-type: none"> <li>• Who and how many people know about the improvements for consumers and how has this been communicated?</li> </ul>	<ul style="list-style-type: none"> <li>• Who and how many people know about the changed practice and how it was achieved?</li> </ul>	<ul style="list-style-type: none"> <li>• What key stakeholders and media have been informed about the outcomes of the project?</li> </ul>



**IF YOU HAVE  
A NEED FOR  
CRISIS SUPPORT  
AND/OR  
COUNSELLING,  
PLEASE CALL**

**Lifeline**

 13 11 14

Confidential telephone crisis support service available 24/7 from a landline, payphone or mobile.

**beyondblue**

 1300 22 46 36

Independent, not-for-profit organisation working to reduce the impact of anxiety, depression and suicide in Australia.

**Suicide Call Back Service**

 1300 659 467

Suicide Call Back Service provides free phone, video & online counselling for anyone affected by suicide.



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BETTER ACCESS  
to Palliative Care Program

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