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Discussion paper on bereavement care in Tasmania:
current status and future directions

Contents

Section 1:	Executive Summary	2
Section 2:	Literature overview and key definitions	4
	2.1 Defining grief, mourning, bereavement and bereavement care	4
	2.2 Grief responses, “complicated” grief, and the need for assessment	4
	2.3 Palliative care and bereavement	5
Section 3:	The Tasmanian Landscape	8
	3.1 Key features of the Tasmanian population	8
	3.2 Bereavement care services in Tasmania	9
	3.3 Other types of bereavement care in Tasmania	10
Section 4:	Stakeholder feedback on bereavement care in Tasmania	13
	4.1 Reported service gaps	13
	4.2 Reported system-level gaps	15
Section 5:	Future directions of bereavement care in Tasmania	16
	5.1 Suggestions for future directions from stakeholders	17
	5.2 A public health approach to bereavement care	18
	5.3 Preliminary recommendations	20
	5.4 Conclusion and questions	21
	References	22

Section 1: Executive Summary

This paper draws extensively on the mapping and consultation process undertaken in *Bereavement Care in Tasmania*: a document which includes a detailed literature review and account of feedback gathered during interviews with a range of Tasmanian stakeholders working in bereavement care. Both this paper and *Bereavement Care In Tasmania* are informed by key insights from the Scottish Government's framework for bereavement care.¹ The primary goal of this paper is to prompt discussion about the current status and future directions of bereavement care in Tasmania.

This paper forms part of the Healthy Dying Framework under the BAPC (Better Access to Palliative Care). The vision of the framework is to acknowledge and support healthy dying and ensure that all Tasmanians have access to quality care as they reach the end of their life. The paper focuses on bereavement in the context of palliation, death and dying. Although the discussion touches on other kinds of bereavement, a detailed discussion of different kinds of bereavement lies outside the scope of this paper. This discussion is informed by consultation with key stakeholders in Tasmania working in bereavement care. Their input is gratefully acknowledged

The main aims of this paper are:

- To provide a snapshot of contemporary thinking about bereavement care;
- To scope current bereavement care in Tasmania and identify service and system level gaps; and
- To inform future directions for bereavement care in Tasmania in a way that is responsive to the Tasmanian population and context.

In terms of the structure of the paper, section 2 has a brief analysis of key definitions and findings in the literature on bereavement care. Section 3 includes an overview of features of the Tasmanian population and a snapshot of the main bereavement services in Tasmania. Section 4 includes a discussion of service and system-level gaps and challenges in Tasmania based on consultation with stakeholders. Section 5 concludes with suggestions for future directions in bereavement care that are consistent with a public health approach. It also includes a brief selection of questions designed to challenge Tasmanian stakeholders to consider what a bereavement care framework for Tasmania should look like.

Underpinning this paper is the idea that the bereaved require different support relative to the nature of their loss, personality, social context, culture, and ability to adapt to grief. One of the recurring themes in the literature and in feedback from stakeholders is the importance of acknowledging that bereavement care often occurs at the community level and social support is a key component of bereavement care. Most people use existing support networks such as family and friends, where this can be sufficient to adapt to loss and grief. Some people seek additional support through groups and volunteer programs. A relatively small number of people are referred for complicated grief that requires professional specialist interventions (Aoun et al 2012.) For many health professionals in Tasmania, particularly primary care providers, supporting people with grief and loss is core business even though their clinical practice may not be labelled "bereavement care." An effective systems-

¹ See *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland* (2008); Joanna Briggs Institute *Literature Review on Bereavement and Bereavement Care* (2006); and Scottish Government Health Directorates. (2011) *Shaping Bereavement Care – A Framework for Action for Bereavement Care in NHS Scotland*.

based approach to bereavement care should acknowledge that bereavement is supported at all levels of the community and health system, and aim to improve and expand on existing support networks.

There is consensus in the literature that insufficient resources compromise the quality and extent of available bereavement care. The following issues were identified by interviewees in the Tasmanian context:

- Insufficient and strained staffing resources;
- Limited access to appropriate, high need upskilling and training opportunities;
- Limited resources to research, fund and implement alternative models of care;
- Poor referral pathways and limited information about available services;
- Insufficient resources to support and debrief staff despite the risk of burnout;
- Insufficient capacity building at the community and primary care level;
- Poor access to specialised support e.g. for people with intellectual disabilities; and
- Limited access to privately practising clinicians.

The issues above are not unique to Tasmania, and there is overlap between feedback from Tasmanian stakeholders and issues identified in the literature on bereavement care in Australia and overseas. There is also overlap between evidence-based best practice and recommendations from Tasmanian stakeholders:

- Reinforcing and supporting bereavement and grief (in the community and the health system) as a part of everyday human life rather than medical conditions;
- Build a resilient Tasmanian community and health system equipped to discuss and adapt to death, dying and bereavement;
- Resource dedicated bereavement care positions;
- Develop a strategic policy to guide the development and implementation of bereavement care in Tasmania;
- Advocate for a bereavement care pathway within the Tasmanian *HealthPathways* Project;
- Expand bereavement programs such as the Hospice Volunteers South 'Walking through Grief' model;
- Expand initiatives such as the Tasmanian Association of Hospice and Palliative Care's (TAHPC) community development and education approaches;
- Develop a central access point for bereavement care e.g. gateway; and
- Develop a Tasmanian Bereavement Strategy based on a public health approach that – among other things - draws on the resources available from the Australian Centre for Grief and Bereavement.

While there are individuals and organisations in Tasmania working to achieve some of the above, stakeholders suggest that more work is required to make grief and bereavement part of everyday life, raise awareness about existing bereavement care options, build on best practice, and coordinate bereavement services. The idea is that working towards the above strategies and implementing some of the recommendations in section 5 will help to support carers, primary health care providers, and specialists to provide evidence-based bereavement care that is responsive to the needs of the Tasmanian community.

Section 2: Literature overview and key definitions

2.1. Defining grief, mourning, bereavement, and bereavement care

Despite widespread debate in the literature concerning how best to define terms such as “bereavement,” “grief,” and “bereavement care,” there is consensus that grief is normal and natural: an integral part of living (Wimpenny et al, 2006; Remedios et al, 2011). Most people will find ways to adapt to and live with bereavement in time.²

For the purpose of this paper, grief denotes normal emotional, physical, behavioural, cognitive, and spiritual reactions (Hall, 2011) to loss. Mourning is “...the social expression or acts expressive of grief that are often shaped by religious, cultural or societal norms” (Remedios et al, 2011, p. 32). 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.” (Christ et al 2003 in Wimpenny et al, 2006). 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” (Stephen et al 2006 p. 4).³ Bereavement care and bereavement support are used interchangeably in the literature, and this paper treats both as broad terms that include informal social and emotional support provided at the community level by friends, colleagues, and family members.

Although there are services explicitly geared towards bereavement care, much bereavement care can be invisible in the health system. For example, a psychologist may routinely provide support for grief and loss which is labelled as support for “depression” or “anxiety,” or a consumer may be referred by the Gateway to Centacare for “counselling” even though bereavement may be one of the main reasons they need counselling (see Diagram 3 for more detail).

2.2. Grief responses, “complicated” grief, and the need for assessment

Although different people have different responses to grief and loss, it is common for the bereaved to experience a range of responses including shock, pain, anxiety, guilt, anger, loneliness, and relief (Ashfield 2010). 90-95% of people experience a reduction in acute symptoms over time (Wimpenny et al. 2006). Between 5-20% do not experience a reduction in symptoms. Their grief is “complicated” as it exceeds the expected timeframe and intensity for adjustment and involves a significant impairment of function (Remedios et al, 2011).

It is worth noting that the term “complicated” or “complex” grief is contentious and can be taken to imply (erroneously) that grief is linear and there are universal symptoms of grief.⁴ Rather, “the grief process typically proceeds in fits and starts, with attention oscillating to and from the painful reality

² This notion of bereavement is consistent with the views of most Tasmanian interviewees, many of whom took issue with attempts to ‘medicalise’ grief and bereavement.

³ Although some interviewees expressed concern that there is a lack of shared understanding in Tasmania about what bereavement care is, this definition is consistent with the views of most stakeholders interviewed and with key insights in the literature.

⁴ This conception of how grief works is attributable to the Kübler-Ross model which turns on the claim that there are distinct ‘stages’ to grieving.

of death...the spectrum of emotional, cognitive, social and behavioural disruptions of grief is broad” and for many people, they learn to live with their grief (Zisook et al 2009 p 68). Despite the variability of grief and bereavement, the idea is that grief becomes “complicated” when it involves an inability to adapt to loss and a significant inability to function effectively for a prolonged period of time (Ashfield 2010). Some theorists argue that, among other things, complicated grief persists for at least six months (Hall 2011), can involve suicidal thoughts, and longstanding intense separation and traumatic distress from the deceased (Zisook et al 2009).

Most interviewees took issue with the idea that grief and bereavement are linear and many argued that recommending clinical intervention at a certain point e.g. six months is arbitrary. Bereavement is by nature complicated and grief responses differ from person to person relative to their loss, predispositions, and coping strategies. Others identified risks associated with pathologising grief, which is consistent with the view that clinical intervention is not effective for most people and could be harmful (Agnew et al 2010). The idea is that unnecessary clinical intervention can potentially “derail” a normal process of grieving (Zisook et al 2009). While the debate about complicated grief lies outside the scope of this paper, there is broad consensus that a minority of people will experience “complicated” grief responses that are best managed with clinical interventions (Hall, 2011; Hall et al. 2012).⁵

Using a systematic assessment to identify those at risk of complicated grief (Wimpenny et al, 2006; Eastman, Le & Pharaoh, 2012) is important and can help to effectively target limited resources for those most in need (Hall et al, 2012; Agnew et al, 2012; O’Connor et al, 2009). Clinicians need to understand the nature of grief to be able to make a judgement about whether a person’s grief is progressing adaptively in order to know when to intervene, if at all (Zisook et al 2009). However, assessing for risk of complicated grief is only part of the picture. Clinicians and community members need to understand that grief is complex and there is no one-sized fits all approach to supporting the bereaved. People working in bereavement need the skills and resources to tailor interventions in a way that is responsive to an individual’s needs: this requires upskilling and professional support (Boughey and O’Connor et al 2009). In keeping with this, The National Institute for Clinical Excellence (NICE) notes that clinicians “are not often adept at assessing, predicting and responding to families’ and carers’ bereavement needs, both before and after death” (Agnew et al 2010 p. 157).

2.3. Palliative care and bereavement

According to contemporary best-practice, bereavement care ought to occur before and after death (see Diagram 1). Bereavement care is a core component of palliative care (Hall et al, 2012; O’Connor et al, 2009; Hudson et al, 2012). The national definition of *Palliative Care* stems from the World Health Organisation palliative approach, which aims to improve:

*the quality of life of patients and their families facing the problems 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.*⁶

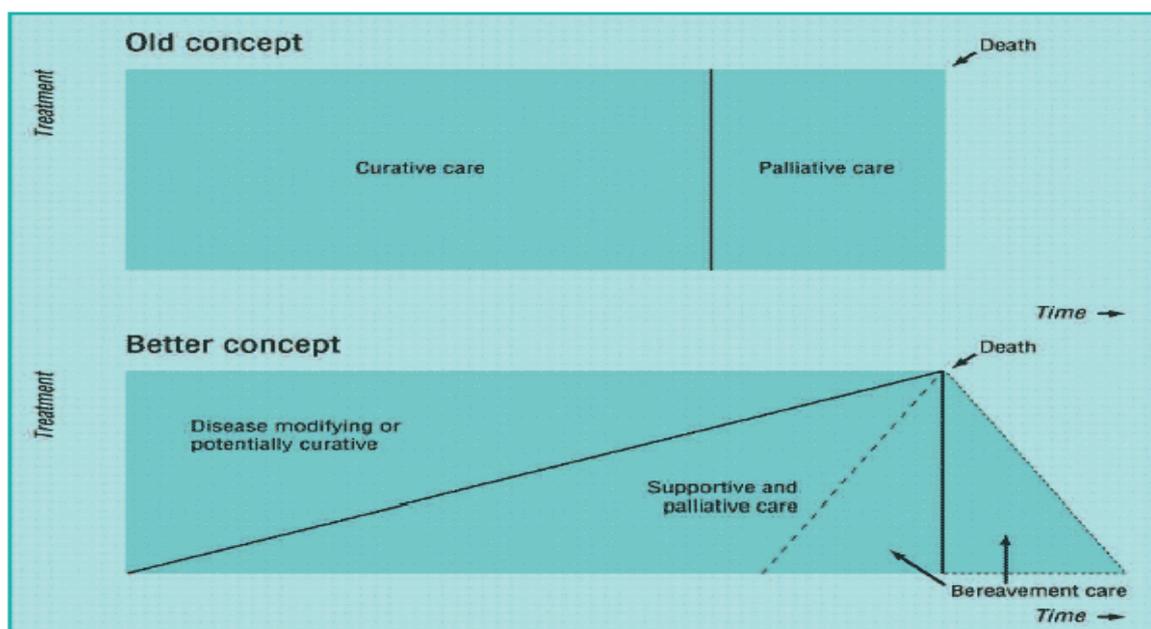
⁵ See Zisook et al 2009; Zisook et al 2010; and Shear et al 2011 for more comprehensive discussions of complicated grief and the DSM.

⁶ See National Palliative Care Strategy, 2010, p.4.

The palliative approach is a public health approach ideally used by specialists and generalists across the health care system and community (Ibid.). Although the palliative approach is most often associated with palliative care services in the health system, it implies a degree of community development, health promotion, and social support. With its emphasis on affirming life, treating death, dying and bereavement as parts of everyday life, and supporting people and their families to cope with and adapt to grief and loss, the palliative approach is relevant to clinical and community settings. As mentioned, people living with a life limiting illness typically spend time in the community with family, friends and work colleagues, rather than in hospitals and specialist services. Although statistics vary, Specialist Palliative Care Services have been estimated to be involved with about 37.5% of the total number of people who are expected to die annually (Palliative Care Australia, 2005). Tasmanian Specialist Palliative Care Services (SPCS) estimate that they see 52% of people who need their service.⁷ This raises the question: what happens to the other 48% of the population? Do they go without service or get support elsewhere? The work of primary care providers is essential in maintaining people in the community with the support of specialist palliative care teams for those with more complicated issues related to their illness.

Specialist Palliative Care Services in Tasmania and elsewhere support people with life threatening illness through a range of measures and in a variety of settings (Victorian Government Department of Health, 2011). Palliative care services also have a critical role in providing bereavement care both *before* and *after* death (Becker et al 2007). Diagram 1⁸ provides a useful representation of the fact that bereavement care should ideally occur along a continuum from before the loved one dies to after their death. An implication of the “better concept” is that good care at and around the time of death is essential to better outcomes in bereavement and that bereavement care (where death is expected) before death results in better outcomes.

Diagram 1: Contemporary bereavement care in palliative care



⁷ This is taken from the Tasmanian Department of Health and Human Services *Palliative Care Model of Service Delivery and Integrated Networks* presentation.

⁸ Adapted from Lynn and Adamson (2003) with permission from RAND Corporation, Santa Monica, California, and USA. Cited in: The Scottish Government (2008). *Living and Dying Well: A national action plan for palliative and end of life care in Scotland*.

A survey of Australian palliative care services showed that very few services had a specifically designated bereavement counsellor or coordinator. Rather, providing bereavement care formed one component of clinician's broader roles, which can render it invisible (O'Connor et al 2009). Most interviewees cited the lack of dedicated bereavement care and coordination positions as a significant shortfall of the Tasmanian health system and highlighted the need to prioritise specific training and ongoing support for bereavement care providers (Mather et al 2008). Although there may be a correlation between the claim that much bereavement care is invisible and the suggestion that more resources are required to redress that, an alternative reading of this situation might be that insofar as clinicians provide bereavement care as part of their core business, there is a sense in which grief and bereavement may already be treated as part of day-to-day life rather than a medical condition. The claim that a dedicated bereavement care counsellor is required also raises questions about whether, if that is an accurate reflection of patient and community needs, said counsellor is best positioned in Specialist Palliative Care Services or not? It is also not clear whether a position within the hospital system is best placed to coordinate bereavement care when much bereavement care takes place outside the hospital system.

In Tasmania, there are three Specialist Palliative Care Services (SPCS) which operate as distinct, regionalised services. All SPCS's have a consultancy and liaison role: a core component of their bereavement support service involves providing literature, training, information and support to primary care providers. The SPCS typically only sees people who are referred with multiple or complex needs: they are eligible for shared care and other forms of support such as home visits, letters, phone calls and memorial services and face to face counselling sessions where indicated. Bereavement support is only available for clients of the SPCS. While bereavement care is seen as an essential function of these teams, clinicians in the SPCS report that the extent to which follow up can be provided (for "complicated" grief, in particular) varies depending on caseload demands and access to and availability of other referral options.

Although palliative care teams can provide comprehensive bereavement care (Aoun et al 2012), there is a mistaken perception at the community level that palliative care teams are a resource for *any* bereaved people. In Tasmania, community members reportedly contact the palliative care service requesting bereavement care even though it is only available to existing clients.⁹ In keeping with this, there is consensus in the literature and amongst interviewees that most people living with a life limiting illness are based in the community and supported by family, friends, and primary care providers. Specialist Palliative Care Services are only one component of a complicated array of clinical and social support for bereavement. The following section provides an overview of key features of the Tasmanian population and existing bereavement care options for Tasmanians.

⁹ Such clients currently get referred to Centacare or coached to contact their GPs to discuss a mental health plan.

Section 3: The Tasmanian Landscape

3.1. Key features of the Tasmanian population

When analysing current and future bereavement care in Tasmania, it is important to recognise the unique features of the Tasmanian context. Tasmania has a small and disaggregated population, spread across mainly rural areas. Australians who live in regional and remote areas have higher death rates than people who live in major cities, which reflect reduced service accessibility, as well as a higher prevalence of risk factors for poorer health outcomes.¹⁰

According to the *State of the Public Health Report 2013*, Tasmanians generally face higher than the national average: mortality and morbidity rates; mental health problems; adverse social determinants of health; median age (40); rates of functional illiteracy; unemployment rates (6%); aged-standardised mortality rates for cancer, diabetes mellitus, ischaemic heart disease, strokes and intentional self-harm; disability rates; ageing population; and Aboriginal and Torres Strait Islander population (second only to the Northern Territory).

Perhaps because of the above social determinants, Tasmanians incur higher rates of suicide and self-inflicted injury causing death. In 2011-12, the proportion of Tasmanian adults estimated to have been diagnosed with mental and behavioural problems at some time in the past (15%) was higher than for any other jurisdiction (*Health Indicators Tasmania* p110). Tasmania's ageing population contributes to the increased burden of mental illness, since mental illness can increase with age (*Ibid.* p113). Mental health problems can mean people are less equipped to adapt to bereavement and may need additional social and clinical support. The ageing population also has implications for Tasmania's health care system: it suggests the need for palliative care and bereavement care is on the rise. According to many interviewees, the impact of social disadvantage and poverty on people's experiences of dying, death and grief, is a significant issue in Tasmania.

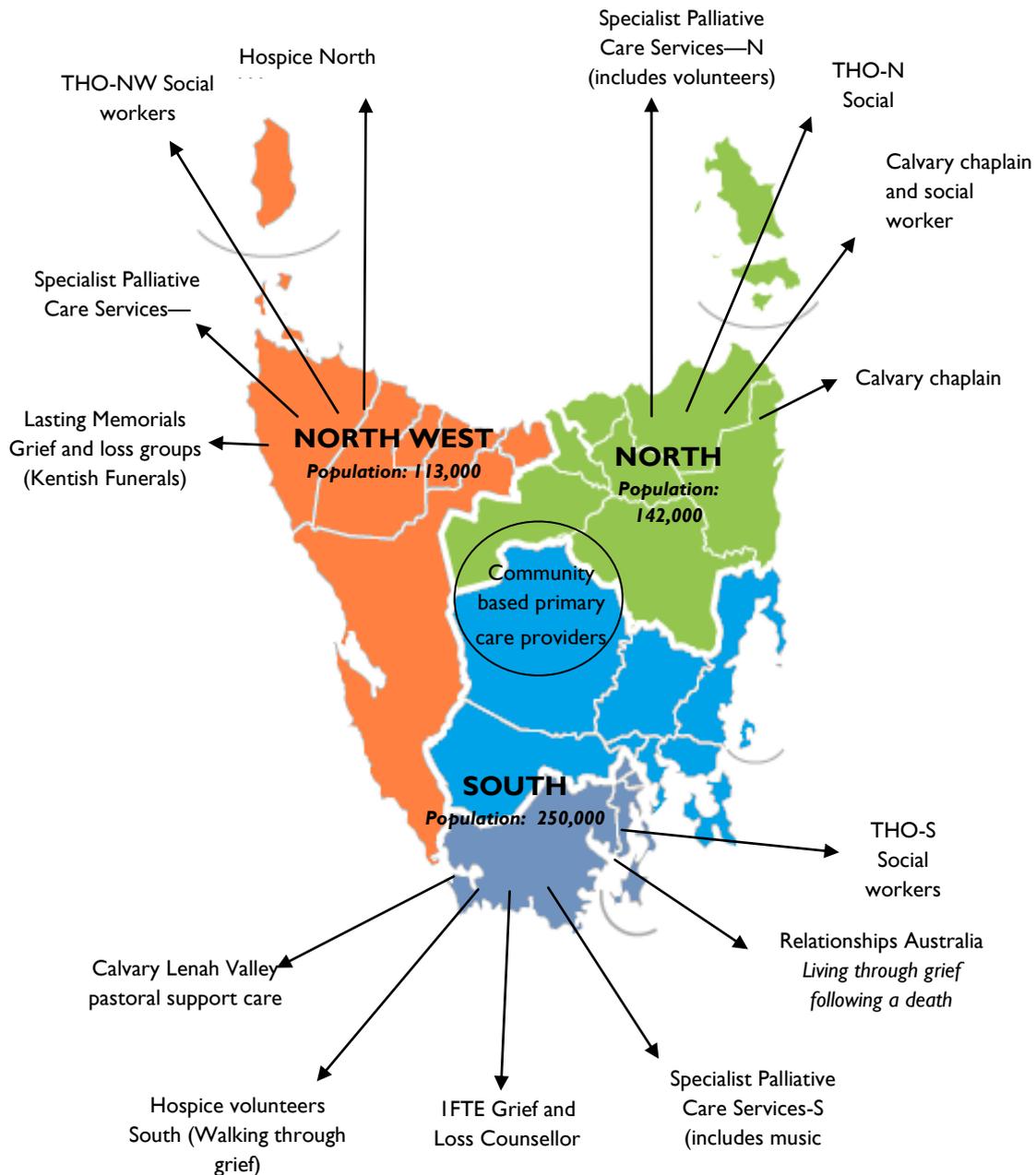
In general, the above features of the demographic profile suggest that Tasmania is likely to have a higher proportion of the population at risk of "complicated grief". If that is accurate (and more work needs to be done to establish whether it is) it might suggest that the Tasmanian health system ought to invest more in clinical support for bereavement than other jurisdictions. In any event, effective bereavement care in Tasmania will need to involve a combination of services including health promotion, community development, primary care, and specialist services to support people who cannot adapt to grief without intervention. A fundamental consideration will be to ensure access to bereavement care is equitable. It also remains to be established whether the current bereavement care options are equitable and accessible.

¹⁰National Strategic Framework for Rural and Remote Health (NSFRRH), p13

3.2. Bereavement care services in Tasmania

There was comprehensive agreement amongst those interviewed that bereavement care is fragmented, has low visibility, and does not seem to be a priority in the Tasmanian healthcare system. More work is required to determine the extent to which this indicates service or system level gaps that need to be redressed. Below is a snapshot of the main bereavement care services in Tasmania.

Diagram 2: Main Bereavement Services in Tasmania as at July 2014



As is clear from Diagram 2 there are three regionalised Specialist Palliative Care Services in Tasmania, each of which is supported by volunteers. Volunteers are able to sit with patients; provide transport to appointments and outings; provide short-term respite for carers; offer practical support in the home and complementary therapies. There are also three Tasmanian Health Organisations (THOs), each of which has hospital and community based social workers that people can access for bereavement care. The circle represents the centrality of community based primary care providers. GPs are often a first contact for people experiencing grief and a central point for further referral. Their role in diagnosis and management of grief responses is also important.

3. 3. Other types of bereavement care in Tasmania

While Diagram 2 captures some of the most visible bereavement care services in Tasmania, it does not reflect the role of the community in providing bereavement support. It also does not reflect the breadth of other resources available to the bereaved and to those whose loved ones are palliative. Below is a table that reflects a fuller picture of formal and informal bereavement care available to Tasmanians:

Diagram 3: General bereavement care resources as at August 2014

1: Informal sources of bereavement care
<ul style="list-style-type: none"> • Family members • Friends • Colleagues • Communities • Peers • Social groups • Support groups • Online resources • Churches • Men’s sheds • Neighbourhood Houses • Child and Family Centres
2. Services that can include bereavement care
<ul style="list-style-type: none"> • General practitioners • Community nurses • Nurse practitioners • Privately practicing social workers, psychologists, occupational therapists and counsellors • Community social workers • Hospital social workers • THO psychologists¹¹ • Alcohol and Drug services

¹¹ Psychologists interviewed said although they may routinely support people who have experienced grief and loss, the current structure of the Medical Benefits Schedule is inimical to accepting referrals for bereavement. In the public system, access criteria and scope of practice means that clinicians typically cannot accept referrals for people who are bereaved even if there is a diagnosis of “complicated” grief.

- THO Occupational Therapists
- Tasmania Medicare Local Access to Allied Psychological Services (ATAPS)
- Anglicare
- Uniting Care*¹²
- Gateway services (Baptcare, Mission)
- Centacare
- School social workers and psychologists
- Mental health workers
- Aboriginal Community Controlled Health Organisations
- School chaplains
- UTAS counsellors
- Chaplaincy
- Funeral homes
- Volunteers
- Australian Centre for Grief and Bereavement
- Tasmanian Association for Hospice and Palliative Care (TAHPC)
- Bears of Hope
- Lifeline
- Red Kite
- Phoenix Centre
- SIDS and Kids
- ReachOut
- Sands Tasmania
- FlourishTas
- BeyondBlue
- Legacy
- Headspace
- Relationships Australia
- Carers Association of Tasmania
- Counselling Tas
- Headspace

4. Dedicated bereavement services

- Specialist Palliative Care Services– North, North West and South
- Hospice Volunteers South *Walking Through Grief* program*
- Hospice Care Association North West
- Relationships Australia grief program*
- OneCare counselling
- Calvary Pastoral Care Service (Lenah Valley)
- Calvary Chaplains (Launceston)
- Cancer Council Life After Loss*
- Rainbow Program (Mission)*
- The Compassionate Friends

¹² The starred services are group programs and Uniting Care Tasmania has been included since they plan to implement a group bereavement program called Seasons of Change that has been successful interstate.

- Standby Response Service

Although the above table is not an exhaustive list of bereavement care options in Tasmania, it demonstrates that bereavement care is provided by a range of organisations and individuals working at all levels of the health system and community. It also illustrates the sense in which how people grieve and where they seek support for bereavement is evolving (Ruthven 2012). Stakeholders interviewed suggested there is merit in making such services and resources more visible, and making it explicit that primary health care services often include bereavement care even though they may not be labelled as such. The idea is that doing so may increase awareness about available support and reduce the tendency at the community level and in the health system to treat grief and bereavement as medical conditions. Many expressed concern that the resources above need to be coordinated to assist consumers and clinicians to know which options are most appropriate for them / their patients. The information in the table also speaks to the need to do some work to clarify what roles the resources above should and do play in supporting the bereaved at a whole of health system and community level.

Given the high rates of socio-economic disadvantage in Tasmania and adverse social determinants of health, it may not be possible for all Tasmanians to access the resources above. Access to GPs can be more difficult than it is in other jurisdictions (Primary Health Indicators Tasmania, 2012) and the out of pocket cost of seeing a GP can be prohibitive, let alone consulting a private grief specialist. And, although many people seek bereavement support and information online (Massimi 2013), with significantly lower literacy rates than other jurisdictions, online support may also not be a feasible option for many Tasmanians. A related issue is that functional literacy rates in Tasmania are significantly lower than they are in other jurisdictions, which means pamphlets and brochures about bereavement care options may not be the most effective method to engage and inform most Tasmanians. This begs the question: what are the most effective ways to engage and inform Tasmanians about palliation, dying, death and bereavement? This question is revisited in section 5.

Section 4: Stakeholder feedback on bereavement care in Tasmania

This section focuses on feedback from Tasmanian stakeholders working in bereavement care. What follows is a description of related service and system level gaps and issues.¹³ There are similarities between issues facing bereavement care services in Tasmania and national / international issues.

4.1. Reported service gaps

The following service gaps were identified in Tasmania:

- Lack of dedicated bereavement care positions;
- Lack of dedicated service coordinator for bereavement care;
- Limited options to refer Tasmanians with complicated grief;
- Insufficient access to privately practicing clinicians specialising in grief and loss;
- Limited support for bereaved people with specific cultural or spiritual needs;
- Insufficient access to specialised support e.g. bereaved people with intellectual disabilities;
- Limited volunteers and volunteer programs;¹⁴
- Insufficient access to practical support following the death of a loved-one e.g. help with mowing, shopping, legal documents;
- Limited access to group bereavement programs;
- Limited age-appropriate support for bereaved Tasmanians (children, adolescents, elderly people);
- Limited support for families experiencing grief and loss; and
- Insufficient targeted bereavement care programs (see diagram 4);

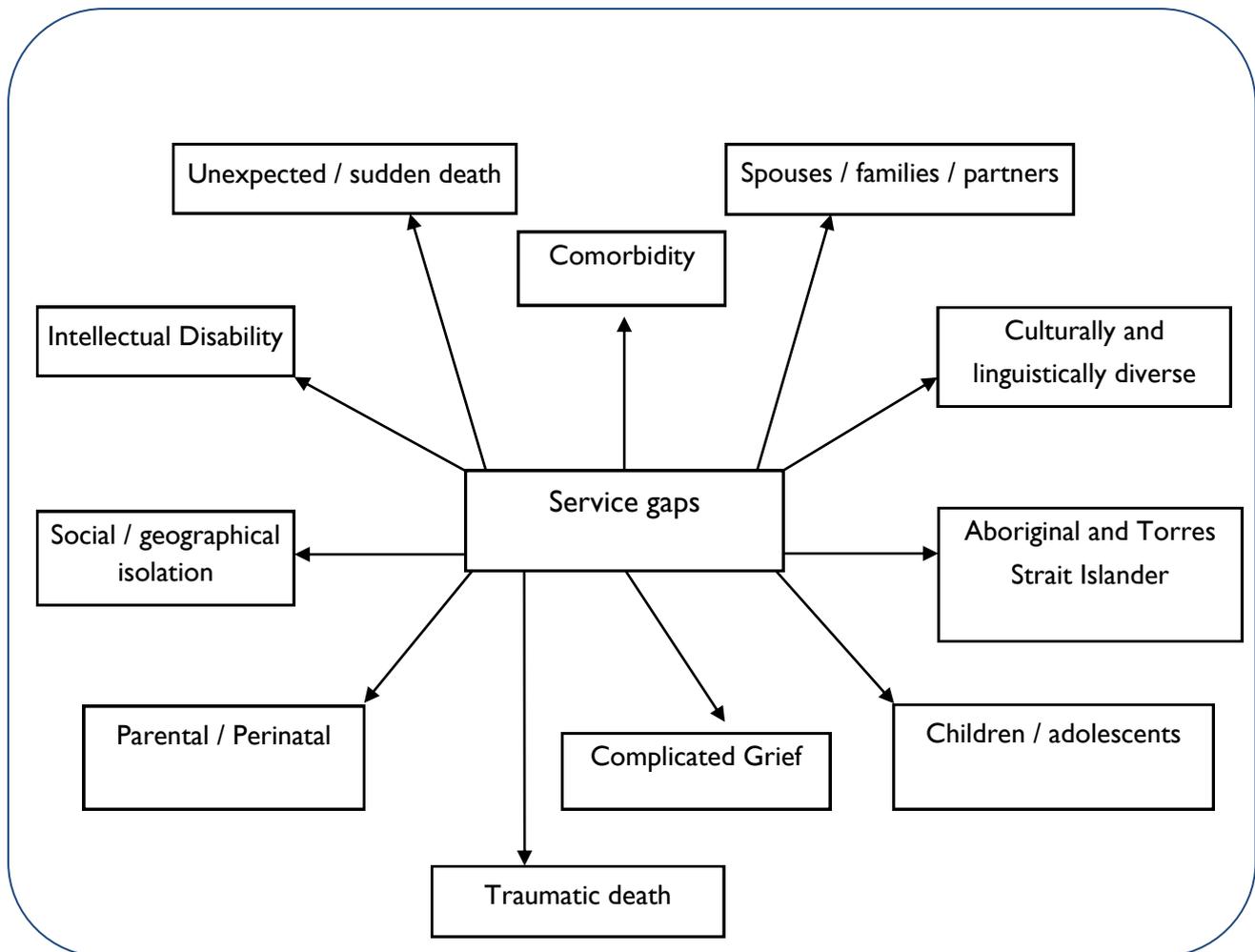
Most stakeholders consulted cited the paucity of group programs available for the bereaved as a major service gap. Many interviewees also argued that group programs are most effective when they are targeted. Some interviewees expressed concern at the relative lack of bereavement support for people whose loved ones died suddenly or were not clients of the palliative care services. It was not clear from stakeholder consultation whether the reported service gaps were actual gaps and / or gaps in people's levels of awareness about what programs and training options are on offer. Either way, it seems plausible that so-called "silos" in the health system and fragmented services play a role in service and information gaps. It is worth noting that it is unclear to what extent the views above represent the views of consumers.

The following diagram depicts the main reported service gaps identified by stakeholders in the health system. Many stakeholders thought group programs for the bereaved and upskilling for clinicians targeted to specific types of bereavement would be beneficial. This suggestion is consistent with Palliative Care Australia's view that effective bereavement care services must respond to community needs and diverse groups in society including the marginalised and disadvantaged.

¹³ Most of the feedback aligns with issues raised in the literature and work previously undertaken in Tasmania. See Leipoldt (2006), Eagar et al (2004); Jaffray et al (2003); Jaffray (2002); and Ellis (2014).

¹⁴ The literature demonstrates that Australia uses relatively few volunteers compared to the UK and US and would benefit from more volunteers (Arthur et al 2011 and Stephen et al 2009).

Diagram 4: Service gaps in Tasmania relating to specific types of bereavement care



There was overlap between the service gaps identified and gaps reported in upskilling and training. Most interviewees cited the lack of high quality, appropriate, professional development, and training opportunities as their main concern e.g. upskilling to support bereavement for intellectually disabled people or refugees with co-existing Post Traumatic Stress Disorder. These concerns resonate with key findings in the literature that quality bereavement care depends on training and support (Remedios et al 2011). There was considerable overlap between the issues identified by Tasmanian stakeholders, and some of the key themes that emerged from the *Literature Review on Bereavement and Bereavement Care* (2006) which informed the Scottish bereavement care framework. That said, more work needs to be done to establish which of the areas above are relevant to “palliative” bereavement care and which are not.¹⁵

¹⁵ This paper has not specified what constitutes palliative bereavement care but seeks to prompt key stakeholders to discuss what it is and how it relates to other forms of bereavement care.

4.2. Reported system-level gaps

Below is a list of the main system-level issues identified with bereavement care in Tasmania, many of which are similar to issues identified in the literature:

- Insufficient and strained staffing resources;
- Insufficient coordination between bereavement care options / services;
- Limited access to professional development, upskilling, and training opportunities;
- Lack of a strategic Tasmanian policy to guide the development and implementation of bereavement care;
- A tendency amongst some clinicians to treat bereavement and grief as medical conditions;
- Limited resources to research, fund and implement alternative models of care;
- Unclear referral pathways and limited information about available services;
- Insufficient resources to support and debrief staff despite the risk of burnout;
- Limited capacity building at the community and primary care level;
- Insufficient community education campaigns to treat death, dying and bereavement as part of everyday life;
- Insufficient up-to-date directory of bereavement care options;¹⁶
- No central gateway for community members and clinicians to access information about bereavement care;
- Generally poor linkages between public health system and privately practising clinicians; and
- Limited access to privately practising clinicians.

Stakeholders identified staffing resources across the continuum of bereavement care as an issue in Tasmania. In the public system, FTEs in palliative care teams and allied health departments have largely remained stagnant despite burgeoning caseloads. Limited staffing resources can mean that there are limited opportunities to provide face-to-face support or develop and implement group programs, even though evidence suggests that group programs are effective (Leipoldt 2006). Interviewees also report increased risk of burnout in part caused by limited resources.

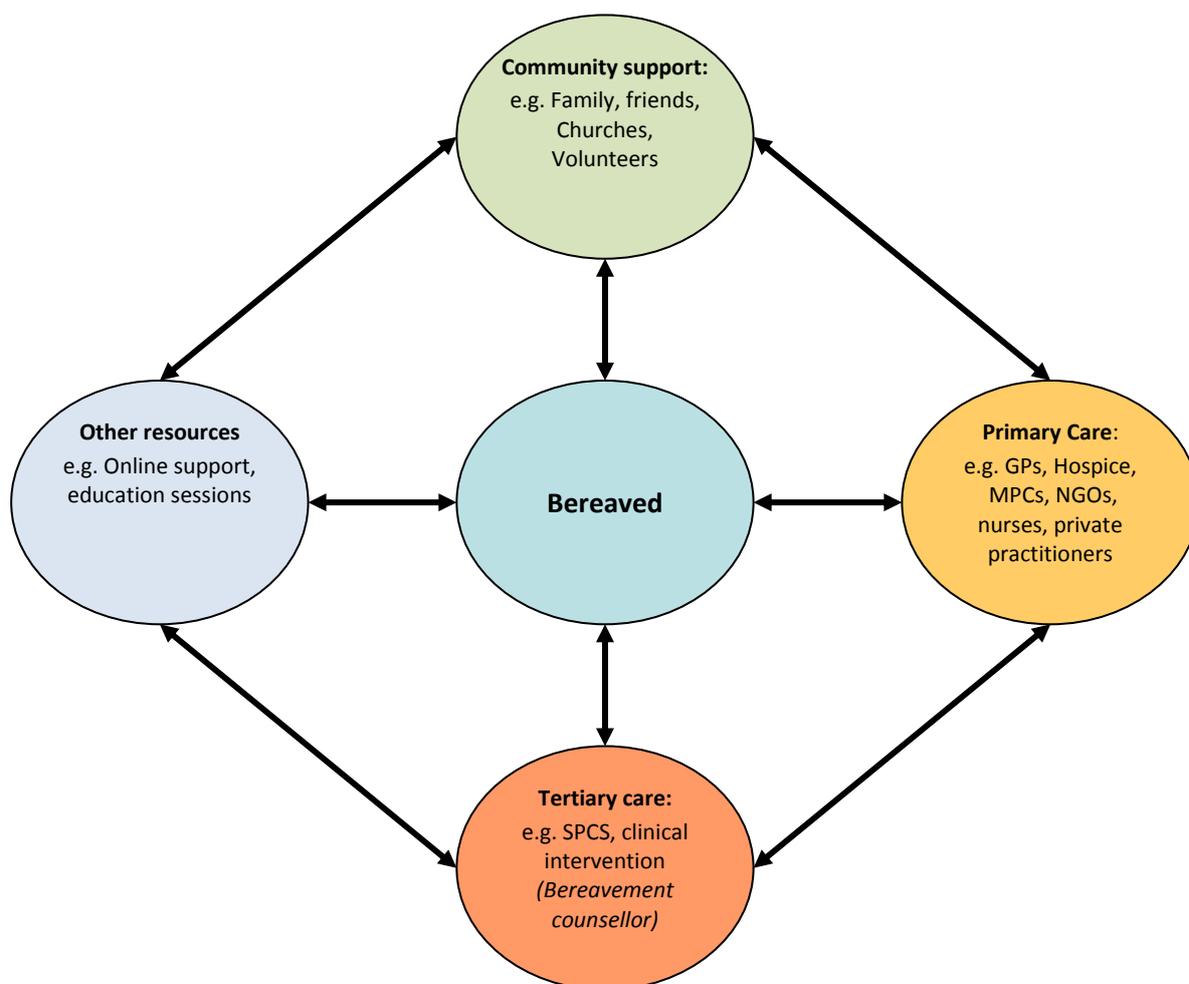
A recurring concern was the lack of 'pathways' and referral entry points for people who need bereavement care. Effective partnerships and pathways are required to ensure clinicians and community members have a better understanding of what is available and how to access appropriate care. The Tasmania Medicare Local is responsible for health pathway development in Tasmania. Several stakeholders suggested it is timely to advocate for consideration of a bereavement care pathway. Ideally, any pathway developed should be simple and reflect the various entry and exit points that exist as different people respond differently to grief and loss (Arthur et al 2011).

¹⁶ It was acknowledged that websites such as TAHPC, Australian Centre for Grief and Loss and DHHS Palliative Care provide links to useful websites, publications and other resources.

Section 5: Future directions of bereavement care in Tasmania

Three main themes have emerged from the preceding discussion: First, the need to develop effective health pathways for bereavement care. Second, there is a need for increased workforce development. And third, there is a need to increase consumer and clinician awareness about available services. There is also arguably a need to engage the community and consumers to get a sense of whether the issues discussed above are in keeping with consumer perceptions of service and system level gaps. This section expands on some of the main recommendations made in the literature and by stakeholders, which provides a platform to inform future directions of bereavement care in Tasmania. The section concludes with a series of questions designed to provoke thinking and conversations about what a strategic framework for bereavement care in Tasmania ought to take into account. Below is a diagram that represents the primary kinds of support available for the bereaved in Tasmania. This is useful to bear in mind when considering the recommendations made by stakeholders:

Diagram 5: Basic continuum of bereavement care



5.1. Suggestions for future directions from stakeholders

Stakeholders identified the following areas for developing bereavement care in Tasmania:

- Reinforce and support grief and bereavement as parts of everyday life, rather than medical conditions;
- Build resilient communities, individuals and clinicians who are equipped to discuss and adapt to death, dying and bereavement;
- Recruit and train volunteers to provide bereavement support closer to home for disadvantaged Tasmanians in rural areas;¹⁷
- Raise awareness about formal and informal bereavement care in Tasmania;
- Resource dedicated bereavement care positions in the community and the hospitals which include a service coordination role;
- Upskill communities, health professionals and individuals to support the bereaved;
- Develop a strategic policy platform to guide the development and implementation of bereavement care services in Tasmania;
- Develop and implement tailored programs for groups who share similar bereavement e.g. death of a child;
- Advocate for a bereavement care pathway within the Tasmanian *HealthPathways* Project;
- Resource more group programs for the bereaved e. g. the Hospice Volunteers South ‘Walking through Grief’ model;
- Build on and support initiatives such as the Tasmanian Association of Hospice and Palliative Care’s (TAHPC) community development and education approaches;
- Develop an accessible central access point (preferably gateway) for community members and health professionals alike; and
- Develop a Tasmanian Bereavement Strategy based on a public health approach that draws on the resources available from the Australian Centre for Grief and Bereavement.

Many interviewees noted the importance of supporting the community and individuals to deal with bereavement, palliation, and grief in an open and healthy way. Rural interviewees noted that rural communities tend to pull together to support the bereaved and many argued that enhancing community support has economic benefits minimising individual and family costs of seeking services in urban areas. There was also broad agreement that partnering with primary care providers such as GPs was key to identifying and managing physical and mental health issues associated with bereavement. A holistic understanding of the impacts of bereavement requires a partnership approach. It also requires acknowledging and building on the role of the community in bereavement support. The problem of poor health literacy was identified as an issue to address and a barrier to engaging some cohorts of the community, as was the issue of people who are isolated from the health system and others in the community. Some interviewees suggested that community social workers were best placed to try to engage isolated people who are grieving and / or to support communities to help identify and support those who are isolated.

¹⁷ The Cruse volunteer organisation in the UK was identified as a potentially suitable model for Tasmania.

5.2. A public health approach to bereavement care

The suggestions above are consistent with a public health approach to bereavement care and with the gist of the palliative approach discussed in section 2. They also share similarities with the Scottish Government's framework for bereavement care which emphasises that bereavement is a normal, natural process and – like death and dying – an integral part of life:

...from the outset it is important that we caution ourselves not to become too prescriptive about grief reactions and their effect on bereavement and to remember that bereavement as a process is affected by religious and cultural beliefs and by a range of mediators. The meaning of the loss to the person, the combination of risk and protective factors and the level of internal resilience and coping skills are important aspects. Moreover, grief is mediated by social factors such as the age of the bereaved person, the circumstances of the death, the social background of those who have been bereaved and the extent to which mourning, as the public face of grief, takes place”(2011, p. 11).¹⁸

The Scottish Framework also states that good care at and around the time of death is essential to better outcomes in bereavement and that where death is expected, bereavement care before death results in better outcomes (Wimpenny et al 2006).¹⁹

Briefly, the features of a public health approach include:

- building public policy that promotes population health improvement;
- creating environments which support healthy living and dying;
- developing and supporting communities to determine their health needs and how best to address them;
- supporting people to manage their own health; and
- ensuring the health care system promotes health.²⁰

This approach to bereavement care has considerable support throughout the literature²¹ (Agnew et al 2012; and reflects the current nature of Tasmanian services demonstrated in Diagram 3. Below is an evidence-based, systematic public health approach to bereavement that includes three target groups for bereavement: primary – all bereaved; secondary – those at risk of bereavement complications; and tertiary – those with complicated grief (Aoun et al 2012). It is worth noting that this model fits well with the picture of bereavement care represented in Diagram 5 (p. 16) and the overview of available options for bereavement support captured in Diagram 3 (p. 10).

¹⁸ See Scottish Government Health Directorates. (2011) *Shaping Bereavement Care – A Framework for Action for Bereavement Care in NH Scotland*.

¹⁹ On this model (depicted in Diagram 1), referring early to a palliative care service may have a positive impact on the anxiety being felt by family members and that providing support for home deaths ensures better outcomes for carers who have lost a family member (Wimpenny et al 2006).

²⁰ See World Health Organisation Ottawa Charter for Health Promotion (1986) and Scriven and Garman (2007)

²¹ See Agnew et al (2012); Remedios et al (2011); Wimpenny et al (2006); Palliative Care Australia (2005 and 2010).

Diagram 6: A three-tiered model of bereavement care²²

Level of Intervention	Target population	Type of support	Support provided by	Need	Proportion Bereaved ²³
Tier 1: Universal	All bereaved	Information about bereavement and relevant supports	Family and friends (information supplied by health and social care professionals)	Low	54%
Tier 2: Selective or targeted	Those at risk of complicated grief	Non-specialist support	Trained volunteers, mutual –help groups, community supports	Medium	33%
Tier 3: Indicated	People with complicated grief	Professional specialist interventions	Mental health services, bereavement services or psychotherapy	High	9%

Underpinning the model above is the idea that bereavement care must align with people’s needs and risk factors. Primary and specialist bereavement care providers must operate as part of a continuum: referral to appropriate services and support needs to occur at all points of the continuum relative to the person’s need (Aoun et al 2012). To implement an effective public health model, partnerships with primary care practitioners such as GPs are essential as are strong connections with community services and groups, including volunteers (Ibid). This model also requires community development to equip people to support the bereaved, and access pathways to assist the bereaved to transition across sectors and services when needed. According to Palliative Care Australia, a public health approach relies on health promotion and community education to build resilience in individuals and communities through reinforcing the fact that dying, death and bereavement are parts of everyday life.

Stephen et al (2009) also support a tiered model to address the varying levels of need during bereavement. On their account palliative care, including bereavement support, is centrally coordinated, integrated, and includes training and support across all sectors. With their focus on evidence-based specialist interventions and capacity building for individuals, organisations, and communities, the Australian Centre for Grief and Bereavement as an organisation that could provide guidance for such a model (Stephen et al 2009). A public health approach is also cost efficient and effective as it supports the appropriate targeting of limited resources for those most at risk rather than operating with a one-size-fits-all approach to bereavement. In recognising and supporting the fact that much bereavement care takes place at the community level, this approach also aims to develop support structures in the community to better support the bereaved, and promote healthy dying and grieving.

²² This is adapted from Aoun et al (2012) whose model is based on the National Institute of Clinical Engagement (NICE).

²³ (Sobell House Hospice in UK, 1989 – 2002)

5.3. Preliminary recommendations

Although a detailed analysis of the literature and feedback from Tasmanian stakeholders lies outside the scope of this paper, in light of the research undertaken in *Bereavement Care in Tasmania* and the feedback from stakeholders, it is possible to begin to explore preliminary recommendations. Below is a list of preliminary recommendations that stem from the discussion in this paper:

1. Develop and implement a Tasmanian Bereavement Care Strategy based on a public health approach;
 - Among other things, this will require engaging the community and clinicians in discussions about what a Tasmanian bereavement care framework should look like;
2. Develop and implement a communication strategy and policies to promote healthy approaches to death, dying and bereavement.
 - This might include developing and implement a social marketing campaign to address misconceptions about grief and bereavement as medical conditions and raise awareness about available options for bereavement support;
 - As part of that strategy, support consumers to be well-informed and partner with clinicians in making decisions about dying and bereavement;
3. Facilitate more effective integration between existing bereavement care services, clinicians who provide bereavement care, NGOs and informal bereavement care options at the community level;
 - Recruit bereavement care counsellors for each part of the state who can work across the community and the tertiary sector;
 - Recruit administrators to develop and maintain a comprehensive directory of bereavement care services and options for support in Tasmania;
4. Work with the Tasmania Medicare Local to develop a bereavement care pathway that is accessible for GPs;
 - As part of this initiative, promote and support the primary care workforce to provide bereavement care, assess for risk factors of complicated grief, and refer appropriately;
5. Investigate what bereavement care is available at the community level and where there are gaps that could be addressed with community development, training programs, and increased awareness about death, dying and bereavement.
 - This may also require community engagement to better understand consumer views about service gaps and what bereavement care is most needed to help people deal with death, dying and palliation.
6. Determine which aspects of bereavement care and resources for the bereaved ought to be included in palliative bereavement and which not;

- On the basis of that, decide which available services and resources to link those whose loved ones are palliative into.
7. Develop targeted approaches (including group and volunteer programs) for vulnerable Tasmanians;
- Fund and staff evidence-based group bereavement programs tailored to specific kinds of grief and loss;
 - Invest resources into specialised support for people / groups who need it e.g. families, people with intellectual disabilities etc.

The combination of a gateway and dedicated bereavement care positions were seen as two of the most promising means of reducing fragmentation in the health system and helping to address service gaps by clinicians interviewed. Early intervention and screening for risk of inability to adapt to grief and loss were also seen as promising avenues that ought to be developed and explored. An implication of this work is that bereavement care needs to be responsive to the population and to nature of bereavement.

5.4. Conclusion and questions

The purpose of this paper has been to provide a snapshot of contemporary thinking about bereavement care and to prompt thinking about the future directions of bereavement care in Tasmania. The discussion has provided an overview of current bereavement care options in Tasmania. It has also captured service and system level gaps reported by stakeholders working in the area, as well as provided an overview of their recommendations for the future directions of bereavement care.

Despite the broad consensus amongst stakeholders about issues and recommendations, the discussion in this paper and in *Bereavement Care in Tasmania* prompts a number of questions:

1. What are the priority areas for a Tasmanian bereavement care strategy?
2. What are the salient differences between bereavement care and palliative bereavement care?
3. What would a Tasmanian health system that provides effective bereavement care look like?
4. How does Tasmania engage community members and clinicians effectively to adapt to death, dying and bereavement?
5. Do stakeholder views outlined here reflect consumer views on what an effective bereavement care strategy for Tasmania should look like?
6. How do we ensure bereavement care in Tasmania is equitable, accessible and cost efficient?
7. Does the fact that much bereavement care in Tasmania is “invisible” mean that there is insufficient support for the bereaved, or that bereavement is already treated as a normal part of everyday life rather than a medical condition in parts of the health system and community?

8. If stakeholders are right that dedicated bereavement counsellor / service coordinators are required, how will they benefit the health system and the community, and will it make services more visible?
9. Are bereavement counsellors / coordinators best located in Specialist Palliative Care Services?
10. Does the demographic profile of Tasmania (including high rates of adverse social determinants of health) mean that Tasmania requires more clinical support for bereavement than other jurisdictions?
11. How can we better understand and map the nature and quality of social support in Tasmanian communities to improve the quality of care available for those who do not or cannot receive support from SPCS?

Any future framework for bereavement care in Tasmania will need to factor such questions into account to come up with a model that is responsive to the Tasmanian community and health system.

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