A BETTER ACCESS TO PALLIATIVE CARE INITIATIVE

COMPASSIONATE COMMUNITIES: A TASMANIAN PALLIATIVE CARE POLICY FRAMEWORK 2017–21

Department of Health and Human Services

Tasmanian Government

CONTENTS

ACKNOWLEDGEMENTS 2

MESSAGE FROM THE MINISTER FOR HEALTH 3

THE POLICY FRAMEWORK AT A GLANCE 4

OUR PRIORITIES FOR ACTION 5

PALLIATIVE CARE IN FOCUS 6

WHY WE NEED A DIFFERENT APPROACH 9

A NEW DIRECTION FOR PALLIATIVE CARE 12

OUR PRINCIPLES 15

IMPLEMENTING COMPASSIONATE COMMUNITIES AND MEASURING SUCCESS 20

GLOSSARY OF KEY TERMS 21

REFERENCES 22

Tasmanian Government

Department of Health and Human Services

©Copyright State of Tasmania 2017

This publication is copyright. No part may be reproduced by any process except in accordance with the provisions of the *Copyright Act 1968*.

This document may be downloaded from the Department of Health and Human Services website at: www.dhhs.tas.gov.au

BAPC BETTER ACCESS to Palliative Care Program

The Better Access to Palliative Care program is funded by the Australian Government.

ACKNOWLEDGEMENTS

Thank you to the consumers, families and carers who have shared their experiences and views, and whose wisdom and advice has been key to the development of *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017–21*. We recognise and value the voice of people with lived experience of end of life care and palliative care in Tasmania.

Thanks also to the many organisations, service providers, community groups and members of the Tasmanian community who shared their knowledge, expertise and vision for the future and helped to shape this Policy Framework.

We would also like to acknowledge the work and important contributions of the members of the Partners in Palliative Care Reference Group who continue to provide leadership and advocacy for palliative care in Tasmania.

Compassionate Communities was developed with funding from the Australian Government. It is an initiative of the Better Access to Palliative Care (BAPC) Program, which has been working within the Department of Health and Human Services (DHHS) to improve access to community-based palliative care for people in Tasmania.

MESSAGE FROM THE MINISTER FOR HEALTH

Each year many Tasmanian families experience the loss of a loved one. Caring for those at end of life, and their families and carers is an important, shared responsibility for all Tasmanians.

The Tasmanian Government is committed to ensuring that people have the best possible quality care at end of life. We are also committed to ensuring that their families and carers receive the support they need, when they need it.

To achieve this we need to ensure that we provide high quality, accessible palliative care. Supportive and compassionate palliative care must be focussed on the person at end of life and take families and carers into account. It relies on strong partnerships between the individual who is at end of life, their family and carers, friends, neighbours, local community, service providers, community organisations and government and non-government agencies.

Compassionate Communities sets out the policy and strategic priorities for palliative care delivered in Tasmania. We have identified six priorities and nine key actions for implementation over the next four years that that will strengthen palliative care in Tasmania and deliver our shared vision for the future. This Policy Framework supports the Tasmanian Government's One Health System reforms and is designed to embed national standards and best practice approaches for palliative care.

Compassionate Communities has been informed by the work of the Better Access to Palliative Care Program, 2013–16, which was funded by the Australian Government. It will continue the service and system reforms that have been delivered as part of BAPC, and provide a coordinated and collaborative approach to palliative care in Tasmania.

We must continue to build a strong palliative care system and a caring and supportive community, to ensure that Tasmanians have access to the best possible care at end of life and that families and carers are supported during these personally difficult and intimate times.

Hon Michael Ferguson MP
Minister for Health

THE POLICY FRAMEWORK AT A GLANCE

The Tasmanian Government's vision is a compassionate community that works together to ensure all Tasmanians have access to high quality, coordinated, respectful and responsive palliative care that is person-focussed and supports families and carers.

- The Tasmanian Government is committed to health system reform that delivers better services in our local communities, including reforming palliative care in Tasmania.
- *Compassionate Communities* provides a framework that describes how we will achieve our vision for palliative care. It will help people, their families and carers, and the palliative care sector understand our priorities for reform that will be the focus of our work over the next four years.
- We have reflected on the existing approach to palliative care in Tasmania and, through *Compassionate Communities,* will provide a new pathway to adopt a whole of community approach to end of life care.
- There are also opportunities for better collaboration across service and community organisations, to build partnerships with consumers, families and carers to support the delivery of palliative care in Tasmania.
- We will draw on the strengths, resources and resilience in our communities and work together in partnership to provide the best possible care at end of life.
- By working together as a 'compassionate community' we will share the responsibility of caring for those with palliative care needs in our community.

OUR PRIORITIES FOR ACTION

To improve the delivery of palliative care in Tasmania the Government will focus on the following key priorities over the next four years and implementing the associated actions.

These priorities and actions have been informed by comprehensive research and input from consumers, carers, families, health and community service providers from across the State and the broader Tasmanian community.

While there are a number of immediate actions that we will deliver, work to progress these priorities and embed our reforms will continue throughout the duration of *Compassionate Communities* to help us realise our shared vision for palliative care in Tasmania.

Providing inclusive palliative care that is community and person focused by:

- Developing a *Tasmanian Palliative Care Community Charter* by the end of June 2017

Strengthening communities of care by:

- Finalising a state and sector wide strategy, *Strengthening Communities of Care: A strategy to build the capacity and capability of all Tasmanians in palliative care 2017–20*

Enhancing end of life care by:

- Developing *End of life care: Supporting Tasmanians to live well at end of life,* a consistent approach across Tasmania to delivering end of life care by the end of June 2017

Enhancing bereavement care by:

- Implementing the recommendations of *Bereavement Care in Tasmania: Current Status and Future Directions for Palliative Care* over the duration of *Compassionate Communities*
- Establishing Bereavement Care Networks by December 2017

Delivering contemporary, accountable and sustainable specialist palliative care services by:

- Commencing development of a model of care for specialist palliative care services by June 2017
- Developing a plan by December 2017 to agree and implement an associated reporting and performance framework

Providing leadership, coordination, monitoring and evaluation by:

- Developing processes to support ongoing development, leadership and coordination of the palliative care system, in partnership with key sector representatives by December 2017
- Providing an annual progress report to the Minister for Health

PALLIATIVE CARE IN FOCUS

What is Palliative Care?

The Tasmanian Government has adopted the World Health Organisation[1] definition of palliative care which is an approach that improves the quality of life of patients and their families who are facing challenges associated with life-threatening illness. This includes the prevention and relief of suffering through early identification, assessment and treatment of pain and other issues, including both physical and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

What is end of life care?

While palliative care can begin as early as the diagnosis of an illness or disease, end of life care is about the specific type of care and support people need at the very end of their lives. This period of time can last for as long as up to two years, but most importantly end of life care helps people to be as comfortable as possible and manage their symptoms, such as pain.

National and State context

Policy development for palliative care in Australia is led by the Australian Government in partnership with states and territories and the national peak body, Palliative Care Australia. The Australian Government sets the national policy direction for palliative care through a national strategy.

The National Strategy for Palliative Care 2010: Supporting Australians to Live Well at the End of Life[2] (the National Strategy) encourages all states and territories to develop consistent palliative care policies and services with the aim of making quality palliative care accessible to all people at end of life. The Tasmanian Policy Framework builds on, and moves beyond, the National Strategy, by adopting a whole of community approach. The Australian Government is currently reviewing the National Strategy.

Palliative Care Australia is responsible for developing National Palliative Care Standards and a suite of policy documents to support the National Strategy[3].

In Tasmania there has not been a State Government palliative care strategy or policy framework for over 10 years. The Tasmanian Government committed to update the 2004 Palliative Care Report and examine unmet and future need for palliative care. This commitment is achieved through the delivery of this Policy Framework *Compassionate Communities.*

The Tasmanian Palliative Care System

Tasmania's palliative care system involves many stakeholders, including people with palliative care needs, their families and carers, the Tasmanian and Australian Governments, health and community sector organisations, community groups and the broader Tasmanian community. As with any care system, it is subject to change as knowledge and technology advances and health and community care systems develop and respond to changing community needs.

People with palliative care needs, their families and carers

People with palliative care needs, their families and carers are the most important stakeholders in Tasmania's palliative care system. Individuals experiencing a life limiting condition best understand what their palliative care needs are and should be given as much autonomy in their palliative care as possible.

Families and carers are at the centre of palliative care. They support people with palliative care needs to live as well as possible to the very end of their lives. Families and carers also need support from the palliative care system, due to influences such as grief, bereavement, stress, social isolation or carer burden.

The significant contribution that families and carers make to the well-being of Australians, including people with palliative care needs, should not be underestimated. Recent data estimated that in 2015, 2.86 million people were providing informal care, saving the Australian economy an estimated $60.3 billion per year.[4]

Australian Government

State and territory governments are responsible for palliative care service provision, with funding support provided by the Australian Government. With the exception of BAPC, the Australian Government does not directly fund palliative care services, but provides financial assistance to state and territory governments to operate these services as part of their health and community service provision responsibilities. The use of this funding and the delivery of palliative care services in each jurisdiction is the responsibility of individual state and territory governments.[5]

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

Tasmanian Government

The Tasmanian Health Service (THS) provides palliative care across a number of care settings, with a range of services involved in the delivery of care including acute care, rural hospitals, and primary care and community services such as community nursing. The THS also has dedicated Specialist Palliative Care Services in the North, North West and Southern regions of the State, and dedicated inpatient palliative care beds at the Melwood Unit in the North and the Whittle Ward in the South.

A robust estimate of expenditure on palliative care in Tasmania is difficult to quantify. While the THS receives an allocation to deliver Specialist Palliative Care Services funding, funding for community palliative services (such as community nursing) is hard to isolate. Given the level of palliative care delivered in the community, this risks underestimating expenditure.

Health and Community Sector Organisations

Primary health care providers such as General Practitioners (GPs), General Practice Nurses and Allied Health professionals all have a key role in delivering palliative care. GPs are often the first point of contact and the primary clinical care provider for people with palliative care needs.

Residential and community aged care services across Tasmania continue to make a significant contribution to the palliative care system by providing care for people at end of life, as well as supporting their families and carers.

The Tasmanian and Australian Governments also fund health and community sector organisations to provide a range of palliative care services. This includes home and community care that provide personal care and domestic support delivered by private nursing services, government and non-government health and community service providers, volunteer groups and other community organisations.

Private hospitals also play an important role in providing inpatient palliative care services. Dedicated palliative care units operate out of Calvary's St Luke's (the Melwood Unit) and St John's (the Gibson Unit) private hospitals.

The Community

The Tasmanian community is an important part of the palliative care system and includes support groups, social networks, clubs, neighbours, local organisations, faith groups, local businesses or people living in a particular area. The Tasmanian community creates, connects and forms the natural supports that surround the person with palliative care needs, their families and carers. Well connected communities work together in partnership to enhance quality of life and help families and carers with grief, bereavement and loss.

WHY WE NEED A DIFFERENT APPROACH

For some people, Tasmania's palliative care system may be confusing to navigate and disjointed. It may not always fully account for the needs and wishes of people with palliative care needs, or their families and carers.

Coordination and communication across different palliative care services is an ongoing challenge for the health and community care system. Information gathered is sometimes not shared effectively, creating a lack of awareness of what other services are doing.

As a result, the community is not always aware of the available palliative care services or how they can work together. It is a common view that palliative care is delivered only by Specialist Palliative Care Services, but this is not the case. The bulk of palliative care is in fact being delivered by primary health and community services.

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

A clear understanding of roles within a complex health and community services system is critical to ensuring consumers and service providers are able to navigate the palliative care system. Consumers must be able to access care and support that is appropriate to their needs, at the time they need it and as close to home as practicable.

There is a need for leadership to build and maintain strategies that support and foster coordinated palliative care. There are opportunities to better promote collaboration across service and community organisations and build partnerships with consumers, families and carers.

The scope and demand for palliative care

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

According to analysis from the Australian Institute of Health and Welfare, demand for palliative care in Tasmania is greater and likely to increase more rapidly than in most states and territories. This is due to Tasmania having the highest overall incidence of cancer, the second highest rate of burden of disease as a result of chronic disease, and a rapidly ageing population.[6]

Greater involvement of primary health care and community services

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

Community based palliative care represents the majority of the palliative care accessed by and provided to people with palliative care needs. DHHS estimates that 70 per cent of palliative care is delivered by health and community service organisations and groups. This can include community nurses, general practice, aged care services, community care organisations, volunteers and many other non-government and community groups.

A change in setting

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

This means we need to focus less on hospital-based care and more on supporting people to live well at the end of their lives and receive care in the place of their choosing, including at home if they wish.

What we've learned through the Better Access to Palliative Care Program

The BAPC program brought considerable focus to how palliative care is designed and connected to deliver services in Tasmania. The objective of this program is to build the capacity and enhance linkages across the Tasmanian palliative care system, and to improve access to community based palliative care.

Throughout the DHHS BAPC project, extensive stakeholder consultation has occurred to inform key project activities and system development. We listened to feedback from consumers, their families and carers, clinicians, service providers, GPs, private providers, volunteers and other key stakeholders about palliative care, end of life care and Tasmania's palliative care system.

Some of the key learnings from this extensive consultation process demonstrated there is a need for:

- A collaborative and coordinated palliative care system;
- End of life care planning;
- Informed, supportive and capable communities;
- Early engagement with palliative care services;
- Support for the families and carers of people with palliative care needs;
- Inclusive and coordinated palliative care;
- Support for the bereaved;
- Access to services and information;
- A capable and skilled palliative care workforce; and
- Strategic leadership and accountability.

The BAPC project also conducted an extensive literature review of relevant local, national and international palliative care policy and related research to consider the best available evidence to help us improve palliative care services in Tasmania. This review demonstrated the similarities between issues raised by stakeholders during the consultation process and key concepts and recommendations from the literature. This has helped to inform our new direction for palliative care in Tasmania into the future, and has guided the development of this Policy Framework.

Contemporary approaches to palliative care

The last significant review of palliative care in Tasmania was the 2004 Palliative Care Report. The delivery of palliative care in Tasmania – and around the world – has evolved significantly since its release.

Contemporary approaches to palliative care now encourage a whole of community approach, which considers everyone's needs and enables people affected by life limiting conditions to take ownership and control of what they and their families and carers require for end of life. In palliative care this inclusive community approach is known as *Compassionate Communities*. The approach focuses on:

- Health promotion, prevention and harm reduction;
- Building community capacity, participation and partnerships; and
- Connecting and strengthening linkages within communities.

Contemporary palliative care is person focused and supports family and carers. This approach recognises the importance of understanding the unique needs of each individual at end of life and the needs of the people who are important to them. In this context, emphasis is placed on improving the quality of living by addressing the needs and preferences for people at end of life and providing bereavement support for families.

The broadening of palliative care to include the needs of those with life limiting conditions, including dementia and chronic diseases such as cardiovascular and respiratory disease, requires earlier engagement with consumers, their families and carers.

Experience has shown that when individuals are engaged in planning and decision making at end of life there is a significant improvement in their quality of life. We know that greater participation and engagement in end of life planning results in better palliative care that is delivered when and where people need it.

A NEW DIRECTION FOR PALLIATIVE CARE

What is Palliative Care?

Over the past 10 years there has been significant change and developments in how palliative care is delivered both in Tasmania and nationally. The Tasmanian Government is committed to health system reform that delivers better services, including reforming palliative care in Tasmania.

To develop a new approach to palliative care we can draw on our experiences, contemporary practice developments and learnings. Our new approach will be inclusive and coordinated, by connecting and building the capacity of existing resources in our communities, and ensuring we have skilled and capable communities of care.

We will foster a culture of partnership between health professions and community members and promote collaboration and coordination of care. Engaging people with life limiting conditions in palliative care earlier and providing more consistent high quality end of life care is also a priority.

We are going to support our communities to discuss and plan for end of life. Research suggests that not having these conversations can in fact cause distress and negative health effects for those people at end of life and the bereaved.[7]

To meet the palliative care needs of the Tasmanian community into the future we will adopt a whole of community approach. We will draw on the strengths, resources and resilience that already exist in our communities and work together in partnership to provide the best possible care at end of life.

By working together as a *'compassionate community'* we will share the responsibility of caring for those with palliative care needs in our community. This approach connects formal and informal care networks, meaning carers, family members, volunteers, community groups and organisations and health and community care providers work alongside one another.[8]

A Compassionate Communities approach

Compassionate communities are communities that are informed about end of life, palliative care and bereavement. In partnership with service providers, they support people at end of life and their family and carers through the experience of illness, dying and bereavement.

A compassionate community:

- Understands that the care and support needs of those at end of life cannot be met by health and community services alone;
- Recognises that quality palliative care requires a partnership approach between health and community care providers, families, carers and the broader community;
- Provides supportive environments;
- Enables people requiring palliative care to remain connected to and supported by their families, communities and natural supports;
- Uses public and community resources to provide palliative and end of life care;
- Respects and responds to the needs and wishes of the person at end of life, providing as much choice and control as possible to support a person; and
- Provides person focused care, addressing the social, physical, psychological, cultural and spiritual aspects of care for the person and their families.

Communities, carers, families and the person receiving palliative care must have the knowledge, skills and resources they need to meaningfully participate in end of life care and to engage as genuine partners. This can only be achieved by raising community awareness and understanding about palliative care.

We need to help build capacity for people to plan for their end of life and to take ownership of what they, their loved ones and their carers require for end of life care.

Communities of Care

To deliver high quality palliative care for all Tasmanians that is sustainable, accessible and meets the needs of our community we must build 'communities of care' that create a circle of support around the person at end of life and their family and carers.

Inclusive approaches and partnerships

A community of care includes all of us: hospitals, health care professionals, volunteers, social networks, clubs, neighbours, local organisations, faith groups, local businesses or people living in a particular area. Most importantly, it includes families, carers and local communities. A community of care is best represented by the Palliative Care Circle of Support.

Tasmanian Palliative Care Circle of Support

INCLUSIVE

An approach that connects and integrates formal and informal care networks is the key to communities of care. Community supports are critical to providing high quality person focused palliative care. This means that service providers must recognise and work more closely with carers, family members, volunteers, community groups and organisations.

There is also a need to recognise the knowledge and experience of carers and volunteers. Volunteering is important and makes a significant contribution to the support and services available for people at end of life; it can strengthen local communities and their capacity for self-help.

Service providers must recognise and work more inclusively with carers, family members, volunteers, community groups and organisations.

Capable and confident communities of care

To build a strong palliative care system into the future we are going to enhance and build palliative care capability, confidence and skills. To support our communities of care we need to create and promote access to opportunities that equip every Tasmanian with the knowledge to fulfil their role as part of a caring network.

High quality, person focused and coordinated palliative care is delivered by a knowledgeable, skilled and capable community of care. This requires the adoption of a capacity building approach that is more inclusive and moves away from traditional workforce development strategies.

OUR SHARED RESPONSIBILITY

The growing demand on the health and community service sector system is currently not sustainable. More sustainable approaches to health and community care can be achieved through greater emphasis on:

- Workforce innovation;
- Greater community engagement and participation;
- Inclusive community partnerships;
- Greater individual control of care,
- Building community resilience and support structures; and
- Community development and capacity building.

We all have a role to play as part of *a community of care* that surrounds and supports the person at end of life, as well as their families and carers.

Individuals, families, communities, health and community care providers (public, private and non-government), governments, and the broader Tasmanian community need to contribute to improving palliative and end of life care for *all Tasmanians*.

OUR PRINCIPLES

When implementing our priorities and actions, we will be guided by the following principles:

PERSON FOCUSED AND FAMILY AND CARER FOCUSED

- Palliative care is provided based on the express wishes of the person at end of life, their caregiver(s), families, and communities, based on informed decisions, with support from a system that is focused on individual need.

PARTICIPATION AND ENGAGEMENT

- All members of the Tasmanian community, in particular people at end of life and their carers and families, have the knowledge, skills and resources to meaningfully participate in all aspects of palliative care.
- They are engaged as equal partners and have the opportunity to contribute to the development of palliative care at an individual, community and service system level.

SUPPORTIVE COMMUNITIES

- Social connectedness and personal relationships and networks play an important role in helping the individual, family and carers during the caring phase and bereavement
- Supportive communities have a meaningful contribution to make, caring for one another, reducing stigma and promoting respect.

ACCESSBILE AND INTEGRATED CARE

- The right care and support will be provided at the right time, in the right setting. People know where and how to get the help, care and support they need, when they need it.
- Care is delivered in an integrated way across care settings so the person at end of life, and their families, can easily gain access to the care or information they need through any entry point.

EQUITABLE

- People with palliative care needs and their families and carers are well supported at all stages, regardless of their age, gender, culture, sexual or gender identity, spirituality, where they live or other related health issues.
- The system prioritises services to those most in need.

INNOVATIVE AND SKILLED

- The Tasmanian palliative care system is innovative and informed by best practice relevant to the local context.
- There is commitment to building a service system and a workforce (community of care) that is skilled in the palliative approach.

ACCOUNTABLE, AFFORDABLE AND SUSTAINABLE

- The palliative care system is committed to delivering safe and high quality services.
- There is a shared commitment to foster a culture of continuous improvement and accountability for achieving best possible outcomes for people receiving palliative care.

PRIORITY

PROVIDING INCLUSIVE COMMUNITY AND PERSON FOCUSED PALLIATIVE CARE

To achieve this, we will:

ACTION

1 Develop a *Tasmanian Palliative Care Community Charter* by 30 June 2017

Why has this been prioritised?

- The Community Charter will provide the 'community voice' on palliative care and articulate the needs and expectations of the Tasmanian community. It will be a community driven agreement with the health and community sector about how palliative care services are provided.
- The Community Charter will be designed to ensure that palliative care is person focused, supports families and carers, and is responsive to community needs. The aim is to continue to build ownership and agency in palliative care for the entire Tasmanian community.
- The Community Charter will provide transparency on how the service system will meet and address the expectations of the Tasmanian community in delivering palliative care.
- The Community Charter will facilitate discussions between those at end of life, along with their carers, their families and the palliative care service system.

PRIORITY

STRENGHTENING COMMUNITIES OF CARE

To achieve this, we will:

ACTION

2 Finalise a state and sector wide strategy, *Strengthening Communities of Care: A strategy to build the capacity and capability of all Tasmanians in palliative care 2017–20*

Why has this been prioritised?

- Through the strategy we will identify priorities for action to improve the palliative care knowledge and skills of all those involved in the delivery of palliative care. This includes not just those who make up the paid palliative care workforce such as primary, specialist or community care providers, but also volunteers, carers and community support networks. Along with families, these people make up our 'communities of care'.
- Through the strategy, we will encourage the sector to work collaboratively, build leadership capabilities and encourage research, innovation and continuous improvement.
- The strategy will take the next step beyond a workforce development strategy and take an holistic approach to build and maintain skilled, capable and confident communities of care. It will focus on actions that emphasise capacity building, raising community awareness, and promoting health and community and sector workforce development.
- The strategy will be released in July 2017. The actions under the strategy will be implemented over three years to 2020.

PRIORITY

ENHANCING END OF LIFE CARE

To achieve this, we will:

ACTION

3 Develop *End of life care: Supporting Tasmanians to live well at end of life,* a consistent approach across Tasmania to delivering end of life care, by 30 June 2017

Why has this been prioritised?

- We want to address the need for better end of life care planning in Tasmania. This priority will focus on preparation and planning for end of life and promoting a more consistent approach to end of life care, with application across the State.
- This work will facilitate processes to encourage and support all Tasmanians to participate in advance care planning for end of life, should they wish to do so.
- Building on work already underway across Tasmania, a standardised approach to advance care planning will be established, which will include standardised tools, information and education resources for the community and health and community service providers. Community awareness and capacity building will be critical to ensuring better planning and responsiveness to palliative care needs.
- Implementation of strategies to enhance end of life care across Tasmania will occur throughout the duration of *Compassionate Communities*.

PRIORITY

ENHANCING BEREAVEMENT CARE

To achieve this, we will:

ACTION

4 Implement the recommendations of *Bereavement Care in Tasmania: Current Status and Future Directions for Palliative Care* over the duration of *Compassionate Communities*

5 Establish Bereavement Care Networks by December 2017

Why has this been prioritised?

- Most people affected by grief and loss are adequately supported through their personal, family and community networks. However, for some people they need additional support from specific services during this difficult time. Actions under this priority will help improve access to bereavement care that meets individual needs, including specialist services for those who experience complex grief.
- As part of this priority, the Department of Health and Human Services will implement the recommendations outlined in the paper *Bereavement Care in Tasmania,* which was published in April 2016. This work will strengthen and value the role of natural supports in our communities, increase community awareness and understanding of bereavement as well as building the skills of existing services and support networks.
- This work will be delivered by regional Bereavement Care Networks which are currently being established in the North, North West, and South. These Bereavement Care Networks will improve access to bereavement care in our local communities and raise community awareness of available support to those who are grieving.

PRIORITY

DELIVERING CONTEMPORARY, ACCOUNTABLE AND SUSTAINABLE SPECIALIST PALLIATIVE CARE SERVICES

To achieve this, we will:

ACTION

6 Commence development on a model of care for specialist palliative care services by 30 June 2017

7 Develop a plan by December 2017 to agree and implement an associated reporting and performance framework

Why has this been prioritised?

- Developing a model of care will deliver a more consistent approach to the delivery of specialist palliative care across Tasmania. This work will be developed and implemented in consultation with the THS over the duration of *Compassionate Communities*.
- The model of care will be supported by the development of a reporting and performance framework for Specialist Palliative Care Services within the THS. The reporting and performance framework will enhance our data reporting capabilities and improve access to information.
- The reporting and performance framework will promote effective and efficient service delivery of specialist palliative care services that meet the community's needs.

PRIORITY

PROVIDING LEADERSHIP, COORDINATION, MONITORING AND EVALUATION

To achieve this, we will:

ACTION

8 Develop processes to support ongoing development, leadership and coordination of Tasmania's palliative care system, in partnership with key sector representatives, with a plan in place by December 2017

9 DHHS will provide an annual progress report to the Minister for Health

Why has this been prioritised?

- To continue to build and strengthen palliative care in Tasmania it is important to ensure ongoing leadership and commitment. Providing leadership to build system capacity, accountability and sustainability will be a key strategic priority throughout the duration of *Compassionate Communities*.
- This priority will require government stewardship and will include a partnership arrangement between the DHHS, THS, Primary Health Tasmania and the Partners in Palliative Care Reference Group (PIPC Reference Group).
- The Department of Health and Human Services will provide guidance and support the ongoing development of the palliative care system, promoting and maintaining system connections and partnerships that are critical to improving collaboration and coordination.

IMPLEMENTING *COMPASSIONATE COMMUNITIES* AND MEASURING SUCCESS

We will continually monitor progress towards the implementation of the *Compassionate Communities* Policy Framework through the following methods and processes.

Implementing *Compassionate Communities*

Implementation of *Compassionate Communities* will be led by DHHS in collaboration with the PIPC Reference Group. The PIPC Reference Group has broad state and sector wide representation.

Implementation will occur in partnership with consumers and their families and carers, the THS, health and community providers (both private and public), peak bodies, together with the Tasmanian community.

Governance

A governance structure will be established to support the implementation of *Compassionate Communities* and will include processes for reporting, monitoring and evaluation. This will require Government stewardship and partnership arrangements between the DHHS, THS and other key stakeholders such as the PIPC Reference Group.

Monitoring, evaluation and reporting

DHHS will guide and support the implementation of this Policy Framework and will be responsible for monitoring and evaluating progress towards implementation.

To ensure that *Compassionate Communities* remains relevant and contemporary the priorities and key actions will be reviewed mid-way through implementation and new priorities and key actions will be recommended for the remaining years of the Policy Framework if required.

DHHS will provide an annual progress report to the Minister for Health.

GLOSSARY OF KEY TERMS

Advance care planning
The process of preparing for likely scenarios near the end of life. Advance care planning usually includes assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences and personal and family resources to provide care. Advance care planning supports an individual to communicate their wishes about their end of life care.

Advance care directive
A written record of a person's advance care plan. The Tasmanian Government has developed a standard form titled *Advance Care Directive for Care at the End of Life (Tasmania),* which can be found by following the links at www.dhhs.tas.gov.au/palliativecare

Bereavement
Bereavement, or grief, means normal emotional, physical, behavioural, cognitive, and spiritual reactions to a loved one's death. 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.

Capacity building
Supporting local communities to develop, implement and sustain their own solutions to problems in a way that helps them shape and exercise control over their physical, social, economic and cultural environments.

Community development
A process where community members come together to take collective action and generate solutions to common problems.

End of life
The last part of our lives, which can be a long or short period of time, with deteriorating health, increasing chronic disease, pain, symptoms and dependence. This phase can last up to two years or more before death.

End of life care
A palliative approach to providing care at the end of a person's life, which involves the person and their family in decisions about their care. End of life care aims to reduce inappropriate and burdensome healthcare interventions and to offer choice of place of care where possible. For a person to receive quality end of life care, person focused and proactive clinical decision making, communication and care coordination are important.

Palliative approach
Aims to improve the quality of life for people with life limiting illnesses and their families by addressing their physical, cultural, psychological, social and spiritual needs. The palliative approach focuses on comfort and care.

REFERENCES

[1]World Health Organisation, Definition of Palliative Care, available at: http://www.who.int/cancer/palliative/definition/en/

[2]Australian Government Department of Health, The National Strategy for Palliative Care 2010: Supporting Australians to Live Well at the End of Life, available at www.health.gov.au/palliativecare

[3]Palliative Care Australia, The National Palliative Care Standards, available at www.palliativecare.org.au

[4]Deloitte Access Economics. *The economic value of informal care in 2015,* June 2015.

[5]Senate Community Affairs References Committee. Palliative care in Australia. Commonwealth of Australia; 2012.

[6]Commonwealth of Australia. Palliative Care services in Australia,. In: Australian Institute of Health and Welfare, ed. Vol HWI 123. Canberra; 2013.

[7]McNamara B, Rosenwax L. Which carers of family members at the end of life need more support from health services and why? . Soc Sci Med 2010;70(7) 1035-1041.

[8]Kellehear A. *Compassionate Cities. Public Health and End of Life Care.* London: Routledge; 2005.

Tasmanian Government

Department of Health and Human Services

www.dhhs.tas.gov.au

Published June 2017
©Copyright State of Tasmania 2017