



OUR  
**HEALTHCARE**  
FUTURE

# Tasmanian Palliative and End of Life Care Policy Framework

2022–27



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# Message from the Premier and Minister for Health and Wellbeing

The Tasmanian Government is committed to ensuring that people have access to quality care at end of life and that their families and carers receive the support they need.



We know that quality palliative care is vital to supporting people with a life-limiting illness to live well, up to end of life. To ensure Tasmanians can access this care, we need to work together with patients, families, carers, volunteers, community organisations and health professionals to raise awareness of the role we can all play in palliative care. It is important that palliative care is person-centred, delivered with compassion, and respects the dignity and choices of our loved ones.

Over the last five years the Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017–21 has guided the development of a range of important initiatives. This includes a workforce strategy Strengthening Communities of Care, an End-of-Life Policy Statement, a Community Charter, Specialist Palliative Care Service Model of Care and establishment of a Bereavement Care Network across the state.

This Framework builds upon this previous work and aims to build a compassionate community that works together so that all Tasmanians have access to timely, coordinated and responsive palliative and end of life care. The Framework has been developed in response to the growing demand for best practice palliative and end of life care in Tasmania and aims to reflect the importance of patient choice and support for families and carers.

The Framework identifies six priority action areas for the palliative care sector over the next five years:

1. Holistic person-centred care, with family / caregiver inclusion
2. Community awareness and understanding
3. Psychosocial support and bereavement care
4. Building the palliative care workforce
5. Coordinated and integrated palliative care services
6. Evaluation and outcomes.

The Tasmanian Government has committed \$21.5 million to further strengthen a palliative care system for all Tasmanians now and into the future. This will seek to expand home and community-based care to improve end of life care and strengthen our partnerships with the palliative care sector to enhance access to high-quality palliative care services.

I would like to acknowledge and thank everyone who has contributed to the development of this Framework including members of the Partners in Palliative Care Reference Group. I look forward to working together with individuals, families, carers and the palliative care sector over the next five years to achieve our vision for palliative care and end of life care for Tasmania.

A handwritten signature in black ink, appearing to read 'Jeremy Rockliff', written in a cursive style.

**Jeremy Rockliff**  
Premier  
Minister for Health  
Minister for Mental Health and Wellbeing



# Acknowledgements

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The development of this Framework was informed by a wide range of voices in the Tasmanian Palliative Care sector. We would like to acknowledge and thank those who made contributions by sharing their experiences and thoughts about palliative care and the future needs of Tasmanians.

Contributions came from consumers, families, and carers, community service provider organisations, medical and allied health professionals, members of peak organisations in Tasmania, and those in the education sector. We value the knowledge and expertise they have contributed, and the time they have spent helping us develop this important piece of work.

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.

This Framework builds on *Compassionate Communities, A Tasmanian Palliative Care Policy Framework, 2017–21* and is based on extensive data modelling, stakeholder consultation and literature review.

*Image facing page: Buttongrass plains at Dempster Plains, south of Maytim (the Arthur River), site of the first Aboriginal cultural burn on a state managed park or reserve in Lutruwita (Tasmania) in 2021. Photographer – Jillian Mundy.*

# Acknowledgement of Country

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The Department of Health Tasmania respectfully acknowledges Tasmanian Aboriginal people as the traditional custodians of the land on which we live, work and play and pays respect to Aboriginal Elders past and present.

## Recognition statement

Tasmanian Aboriginal people's traditional lifestyle promoted physical and emotional health and wellbeing, centred around Country, Kin, Community and Spirituality. Aboriginal people continue to value the importance of culture, community connection and being on Country as vital components of health and wellness. Through colonisation, Aboriginal people experienced displacement and disconnection, which has significantly affected their health and wellbeing.

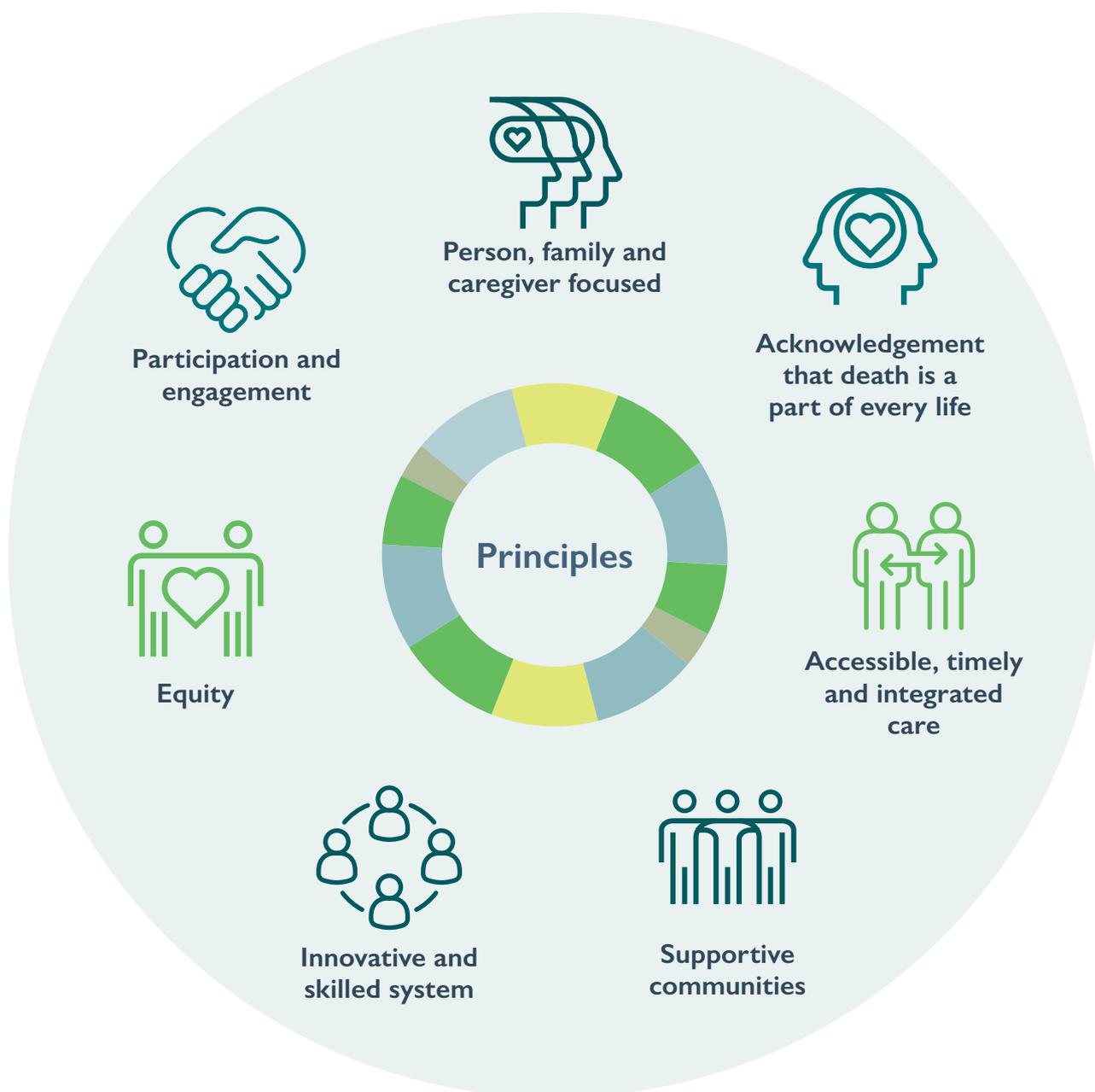
We recognise Aboriginal people are the knowledge holders and provide best practice in promoting health and wellbeing for Aboriginal people. We acknowledge and learn from the ongoing work of Aboriginal organisations in ensuring continued health and wellness. We commit to working in partnership with Tasmanian Aboriginal communities and health leaders now and into the future.



# Summary of framework

## Vision

A compassionate community that works together so that all Tasmanians have access to high quality, timely, coordinated, culturally appropriate, and responsive palliative and end of life care that delivers holistic person-centred care, supports families and caregivers and advocates for patient choice.



## Priority areas

### Priority 1:

Enhancing holistic person-centred and family inclusive palliative and end of life care

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### Priority 2:

Increasing community awareness and understanding of palliative and end of life care

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### Priority 3:

Enhancing psychosocial support and bereavement care for patients, families and caregivers

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### Priority 4:

Building the capacity of the workforce to provide equitable access to quality palliative and end of life care

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### Priority 5:

Building and delivering coordinated and integrated palliative care services to contemporary standards

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### Priority 6:

Conducting ongoing review and evaluation of the delivery and outcomes from the implementation of this Framework

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## Actions to support the implementation of the Framework

- Develop an intersectoral governance mechanism for the implementation of the Framework and its associated actions.
- Develop appropriate implementation plans, change management approaches, and monitoring, evaluation and reporting frameworks. The Implementation Plan will categorise actions as immediate (6–12 months), Medium term (1–3 years) or longer term (3–5 years) and will be included in the implementation plan. The implementation plan will be reviewed and updated over time, to ensure timeframes are current and reflect the availability of resources, including staffing.
- Ensure appropriate reporting as required (e.g. to the Minister and annual reports to the community).

# Introduction



Death and dying is a part of every life. Palliative care aims to support people through the dying process in a way that meets their needs and wishes, and those of their family or caregiver. It is important that the palliative care system in Tasmania delivers palliative care services that meet the needs of these individuals, their families and caregivers so that they can access the right care, in the right place, at the right time.

## **Purpose of Tasmania's State-wide Palliative Care Policy Framework, 2022–27**

The Tasmanian population is ageing at a fast rate and experiences a higher number of persistent health issues compared to the general Australian population. These persistent health issues include higher rates of smoking, alcohol consumption, and obesity which contribute to higher rates of chronic and life limiting illness. Modelling using Tasmanian data forecasts that palliative care demand in Tasmania will grow by 33% over the next 10 years.

This Framework has been developed to create a path for improving and enhancing palliative and end of life care in Tasmania, and building shared understanding with communities about what they can do to support this objective by becoming compassionate communities.

Compassionate communities are communities that are informed about palliative care, end of life, 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.

## **What is palliative care?**

The World Health Organisation describes palliative care as an approach to improve the quality of life for patients, and their families and caregivers who face problems associated with life-threatening illnesses.<sup>1</sup> The palliative care system supports patients of all ages (including paediatric palliative care) where illnesses are incurable, such

as cancer, Alzheimer's disease, multiple sclerosis, cardiovascular diseases, and several others.<sup>2</sup>

The palliative care system aims to provide a "whole of person" care approach that meets the unique circumstances of each patient to prevent and relieve suffering through early identification, correct assessment, and treatment of pain and other issues, whether physical, psychosocial, or spiritual.<sup>3</sup> This care is provided until death, with some patients having more complex needs that benefit from palliative care intervention at the time of diagnosis, whereas others will require less support during their journey.<sup>4</sup> Palliative care is delivered across a number of settings, which are relevant or required will depend on the complexity of the patient's life limiting illness.

Settings may include at home, acute hospital care, hospice care, or other community settings such as residential aged care facilities. When relevant or appropriate, having flexibility in where care occurs means that patients are able to choose the care that suits them and their families/ caregivers. Holistic palliative care is delivered by a range of people including family, friends, carers, volunteers, community support groups, spiritual and cultural groups, medical staff, and other healthcare and allied health providers.<sup>5</sup>

## **What is end of life care?**

End of life care refers to the move from 'quantity of life' to 'quality of life' for patients in the final phase of their palliative journey.<sup>6</sup> This occurs when life-prolonging interventions are no longer effective or desirable, and care moves toward focusing on the comfort of the patient and



fulfilling their goals and wishes in the remainder of their life.<sup>7</sup> This journey is a normal process and does not quicken or postpone death.<sup>8</sup> It offers a support system to help people at end of life and their families and carers cope during an illness and includes care of the person's body after death.<sup>9</sup>

Typically, end of life care is provided when a person is likely to die within the next 12 months due to progressive, advanced, or incurable conditions or old age.<sup>10</sup> The care offered varies according to the individual's needs. End of life care also aims to assist families and caregivers with the support they require after the death of their loved one and may include bereavement and counselling services.<sup>11</sup>

## Who is this Framework for?

This Framework will shape the design and implementation of palliative care services and supports for everyone working directly and indirectly in all palliative and end of life care settings, and bereavement care regardless of profession, expertise, and employment (paid or unpaid). This includes the Tasmanian and Australian Governments, health and community sector organisations, community groups, the broader Tasmanian community and palliative care service consumers.

The Framework includes high level agreed actions under each of the priorities and will be supported further by the development of a detailed implementation plan (guiding future activities and investments made over the next five years) that is iteratively updated, and a monitoring and evaluation plan developed and managed by the Department of Health Tasmania (DoH).

## Policy context

### National policy context

National palliative care policy development is led by the Australian Government in partnership with States and Territories, the national peak body, Palliative Care Australia, and its state and territory affiliates (e.g. Palliative Care Tasmania). This includes the *National Palliative Care Strategy (2018)*.<sup>12</sup>

### The National Palliative Care Strategy (2018)

was developed after the completion of the previous Tasmanian Policy Framework *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017–21*. The 2018 National Strategy provides an overarching vision for palliative care in Australia, *that people affected by life limiting illnesses get the care they need to live well*. It stipulates that regardless of the circumstances that palliative care patients are affected by, they, their families and any other people or groups caring for them should receive the right level of support for them. Another important note mentioned in the National Strategy states that *“Helping people to live as well as possible for as long as possible is ultimately what palliative care is seeking to achieve”*. There are six guiding principles in the National Palliative Care Strategy (2018):

1. Palliative care is person-centred care
2. Death is a part of life
3. Carers are valued and receive the care they need
4. Care is accessible
5. Everyone has a role to play in palliative care
6. Care is high quality and evidence-based

This Framework is consistent with the objectives of the National Strategy and builds on the principles set out for palliative care nationally.

**The National Framework for Advance Care Planning Documents (2021)**<sup>13</sup> provides for developing and enacting advance care planning documents in a nationally consistent way. Each jurisdiction is responsible for developing their own advance care planning documentation, having regard to these principles.

Palliative Care Australia sets out nine national standards for specialist services in the 5th (2018) edition of the **National Palliative Care Standards**.<sup>14</sup> These standards include assessment of needs; development of care plans; caring for carers; providing care; transitions between services; grief support; service culture; quality improvement; and staff qualifications and training.\*

**The National Palliative and End-of-Life Care Information Priorities (January 2022)**<sup>19</sup> outlines an aspirational vision for data development and collection, nationally and for all states and territories over the next 10 years. This will enable greater understanding of palliative care needs and inform service planning at all levels of government.

## State policy context

This Framework is part of a suite of reforms under the Tasmanian Government's Our Healthcare Future reforms, which seek to connect and rebalance care across acute, subacute, and primary care sectors with the overall objective to deliver more and better care in the community, and a more sustainable health system through a long-term health plan. This plan will be informed by regional and state-wide clinical service planning currently being undertaken by the Department of Health Tasmania.

This Framework also builds on Tasmania's previous state-wide palliative care policy framework, *Compassionate Communities 2017–2021*, which delivered a raft of reforms including a Tasmanian palliative care community charter, an end-of-life care policy statement, a bereavement care network, a model of care for specialist services and a workforce strategy: *Strengthening Communities of Care*.

Other current policy reforms relevant to this framework include changes to the *Guardianship and Administration Act 1995*. These amendments will establish a legislative framework for the making and implementation of advance care directives in Tasmania. The amendments will

- enable persons with decision making ability to give directions in relation to their future health care,
- ensure that health care is delivered in a manner consistent with those instructions,
- increase the confidence of those making advance care directives that their directions, values and preferences are respected at a time when they lack decision making ability,
- enables those health care and support providers to understand the values, wishes and preferences of a person at a time when they have lost the ability to make decisions and communicate those views,
- provide protection for health practitioners and other authorised decision makers who give effect to an advanced care directive,
- facilitate the resolution of disputes in relation to the advance care directive.

It is important that this Framework acknowledges recent changes in legislation relating to End-of-Life Choices (Voluntary Assisted Dying). While there is some discussion in the sector about the role of voluntary assisted dying (VAD) in palliation, the administration of the Act remains separate to this Framework. The Framework does, however, need to understand and align with any legislative changes.

The *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* laws were passed in Tasmania and commenced operation on the 23rd of October 2022. The introduction of the Act allows patients further options about their end of life care.

Voluntary assisted dying is a legislated process where a person who is competent, or has capacity, to decide to do so can voluntarily access assistance from a health practitioner to end their life, where the person meets the eligibility criteria and all parties follow the process within the legislation.

People ultimately should have options at end of life, and it is noted that both VAD and palliative care can operate in parallel. A person's choice

\* Additional standards include the Australian Commission on Safety and Quality in Health Care (ACSQHC) National Safety and Quality Health Service (NSQHS) Standards (Version 2),<sup>15</sup> the ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care,<sup>16</sup> the ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care,<sup>17</sup> the Accreditation Standards, as identified in the Quality of Care Principles 2014 and administered by the Australian Aged Care Quality Agency (AACQA)<sup>18</sup>



to access VAD should not affect the delivery of quality palliative care services up until the time they choose to take their substance and they should not have to choose between one option or the other.

For more information visit <https://www.health.tas.gov.au/health-topics/voluntary-assisted-dying>

Patients who meet all the requirements and follow specified processes as described in the legislation will be able to access VAD.

## Demand for palliative care in Tasmania – key insights

The need for palliative care in Tasmania is projected to grow over the next 10 years, as the population continues to grow, and the average age of the population continues to rise. The projected demand for palliative care is underpinned by the following key assumptions:

**Growth in palliative care demand:** Palliative care demand is expected to grow above and beyond the level of both population and deaths. This will likely lead to a greater requirement for palliative care services as the population's average age continues to increase.

**Projected decedent palliative care<sup>†</sup>:** Demand modelling using Tasmanian data indicates an additional 934 people requiring palliative care by FY2032. This is the equivalent of an increase in palliative care demand by almost 33% from FY2021.

Alternative modelling by KPMG, using national data, predicts that by 2060, the population will grow by 60% nationwide, and that total deaths nationally will increase from 160,000 in 2017 to 400,000 in 2060, with 214,000 of these 400,000 people requiring palliative care services. This means that the need for palliative care will grow faster than both the population, and total deaths.<sup>20</sup>

**Regional breakdown:** Palliative care referrals are expected to increase significantly within the North and North West regions of Tasmania. Further, based on historical palliative care admissions, the North will continue to grow in palliative care serviceability.

<sup>†</sup>Decedent Palliative Care: Health conditions that are a major cause of death usually generate a need for palliative care. We have estimated that a large proportion of palliative care need is identified within decedents with underlying health conditions that often result in serious health-related suffering. Non-Decedent Palliative Care: The broadening definition of palliative care encompasses the requirement for end-of-life care, but also the need for symptom management of life-limiting illnesses. We extend palliative care need to non-decedents with underlying health conditions that often result in serious health related suffering

# Palliative care in Tasmania at a glance

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## Key stakeholders in the system

### People with palliative care needs, their families, and caregivers

People with palliative care needs and their families and caregivers are crucial stakeholders in Tasmania's palliative care system. Individuals experiencing a life limiting condition understand what their needs are and should be given as much autonomy to make decisions about their care as possible. Families and caregivers support people with palliative care needs to live as well as possible to the very end of their lives. Families and caregivers also need support from the palliative care system including for grief, bereavement, stress, social isolation, or carer burden. Families and caregivers make a significant contribution to the wellbeing of Australians, including people with palliative care needs. It is acknowledged that many Australians provide a range of different types of informal care, including palliative care.

### Specialist palliative care services

Specialist palliative care services have a central role in the system through the management of the most complex cases, and in the provision of secondary consultation services to non-specialist palliative care service providers in hospital, hospice, or primary care settings, such as at general practice, community health centre or pharmacy. The Tasmanian Health Service (THS) provides palliative care across several care settings including acute care at major hospitals, sub-acute care at rural hospitals, in primary care settings, and at the patient's home (including aged care facilities). The THS also has dedicated Specialist Palliative Care Services (SPCS) in the North, North West, and Southern regions of the State, a dedicated palliative care inpatient unit in the South – the Whittle Ward, dedicated inpatient palliative care beds at the Mersey Community Hospital in the North West, and dedicated beds brokered from the private system at the Melwood Unit (St Luke's Hospital) in the North. Specialist palliative care teams can include doctors, nurses, allied health professionals and pastoral care practitioners.

## Primary care and private service providers

Most palliative care in the community is delivered by family and caregivers and mainstream primary health services. Primary health care providers such as general practitioners (GPs), general practice nurses and allied health professionals all have a key roles 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 make a significant contribution to the palliative care system by providing care for people at the end of life, as well as supporting their families and caregivers. The Tasmanian and Australian Governments also fund health and community sector organisations to provide a range of palliative care services, including home and community care to 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.

Other health professionals, such as paramedics and pharmacists, also play a significant role in providing palliative care support. Paramedics are often called to residential properties in times of crisis for people that are palliative or at the end of life, providing transport to health services and symptom management, including pain management where required. Paramedics also work with the families of the patient, if present, to help them understand the next steps that will be taken. Pharmacists are a central point of contact for people requiring palliative care as they support pain management, complete medication reviews, and build bonds with patients and families and caregivers of patients over time.

Private hospitals have 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.

## Peak bodies and professional organisations

Peak bodies such as Palliative Care Tasmania (PCT) and Palliative Care Australia have a major role in policy, and sector advocacy and development. As the peak body for palliative care in Tasmania, PCT plays a critical role in promoting palliative care education, Advance Care Planning and workforce development. PCT collaborates with other stakeholders including DoH, THS, private and primary care providers, volunteers and communities, to develop and implement palliative care initiatives state-wide.

The Australian Medical Association (AMA) and Royal Australian College of General Practitioners (RACGP) are strong advocates for quality and equitable palliative and end of life care and support the process of advance care planning, as does the Australian and New Zealand Society for Palliative Medicine (ANZSPM).

## Primary Health Tasmania

Primary Health Tasmania (PHT) is Tasmania's Primary Health Network and is funded by the Australian Government and supports primary care, aged care and commissioned services. The PHT plays a role in supporting palliative and end of life care provided across Tasmania including investment in digital infrastructure, after hours care and project-based funding, clinician and community education, advance care planning documents and toolkits, producing resources for clinicians to enhance their ability to support patients at end of life, and maintaining and updating the Tasmanian Health Pathways with palliative care information.

## Partners in Palliative Care Reference Group

The Partners in Palliative Care reference group was established by the Department of Health to provide advice and support in the implementation of Compassionate Communities 2017–21. It includes stakeholders from across the palliative, aged and community service sector with an interest in palliative care, for the purpose of information sharing, advice and input into policy making and service planning.

## Tasmania's Bereavement Care Network

The Bereavement Care Network aims to improve coordination and strengthen partnerships to support the delivery of bereavement care by connecting people, identifying services, and promoting education and support for people involved in bereavement care.

The specific functions of the Bereavement Care Network are to

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



## Volunteers

Volunteers in the palliative care sector provide a source of support and volunteer their time to care for others. They also help to provide personalised care, emotional and practical support. Tasmanian palliative care volunteers can help to provide short term respite, transport to and from appointments or outings, provide companionship and be someone to listen and can also provide bereavement support for families and caregivers, among multiple other roles. Palliative care volunteers are attached to each regional Specialist Palliative Care Service in Tasmania.

## End of life doulas

End of life care doulas are becoming more common within the palliative care service sector. A doula is a companion, advocate and educator for the dying and their family through the process of death. Doulas are generally found within the private sector, are unregulated and charge fees for their services.

## The Tasmanian 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 caregivers. Well-connected communities work together in partnership to enhance quality of life and help families and caregivers with grief, bereavement and loss. A connected community can also educate other members on the nature and benefits of palliative care and help to build trust in the system.



# Building for the future



While palliative care is traditionally associated with illnesses such as cancer, healthcare professionals in Tasmania and nationally note that there is increasing palliative care presentation for patients with other life limiting illnesses such as neurodegenerative diseases (e.g. dementia, Parkinson's Disease), cardiovascular, and respiratory diseases. This diversity in life limiting illness presentation has broadened the scope of palliative and end of life care in Tasmania and has further been adopted as the current best practice definition of palliative care, as identified by the World Health Organisation<sup>21</sup> and the Lancet Commission<sup>22</sup> through their recent publications on access to palliative care services and pain relief.

With increasing demands for palliative care come opportunities to strengthen Tasmania's palliative care service system, particularly in the areas of improving awareness, providing enhanced services, supporting vulnerable populations, embracing new and or improving technologies and introducing workforce reforms.

## Increasing awareness

Helping the wider community to understand what palliative care services are, and the assistance they provide is important to ensure people are aware of their options. It is also important to up-skill the palliative care workforce in building broader community awareness, to support earlier referrals into the palliative care system.

## Delivering person-centred services when and where they are needed

Opportunities to strengthen palliative care services include better access to palliative care after hours and improving the access to digital care.

A recurring theme in the provision of palliative care in Tasmania is the need to broaden the availability of 24-hour seven day a week support, both within a hospice and community care

context. While satisfaction levels with current arrangements are high,<sup>23</sup> there is a view that for the service system to be comprehensive, access to care in the after hours period is needed.

## Improving workforce education and training

As the demand for palliative care in Tasmania increases, an appropriately skilled and trained workforce needs to be supported to grow. There is a need for more opportunities for nurses, allied health professionals and medical professionals to increase their clinical knowledge and skills in palliative care beyond what is traditionally offered through programs such as Programs of Experience in the Palliative Approach (PEPA) and professional body continuous professional development activities.

## Supporting vulnerable populations

Tasmania is a diverse State, and its palliative care system must meet the needs of all groups within its population. Specific considerations for vulnerable populations in our community including children, people with disability, Aboriginal peoples, members of culturally and linguistically diverse (CALD) communities, and those experiencing homelessness must be a focus for the future to ensure that care is accessible, and appropriate to their needs.

## Improving system and service navigation

Entry into the palliative care system and navigation between different services can be a daunting experience. As the patient's palliative care journey progresses, transition from care setting and care provider should be made as seamless as possible to reduce anxiety and promote integration, leading to better experiences for patients and their families and caregivers.

## Enhancing choices and developing ‘communities of care’

Giving Tasmanians a choice regarding their preferred place of treatment and death is an important consideration in the delivery of palliative care. That choice is only possible when the service system is able to support care across different settings, including in people’s homes. This means that system capability must be extended beyond emergency department and inpatient settings and into the community.

In this sense, palliative care becomes not just the responsibility of health services, but a shared responsibility. Contemporary approaches to palliative care emphasise ‘communities of care’ that includes health services, volunteers, social networks, clubs, neighbours, local organisations, faith groups, local businesses, people living in a particular geographical area and, most importantly, families and caregivers. It is a shared responsibility, that communities, both informal and formal, work together in partnership to enhance quality of life and help families and caregivers with grief, bereavement and loss.

## Increasing use of telehealth and technology in palliative care

While telehealth has been used in Tasmania for palliative care for over five years it has become increasingly evident the need for advanced technological services to support patients, their families and caregivers. It is often difficult for those living in rural and remote communities to access the services they need, and the use of telehealth and other digital technologies offer ever increasing opportunities for ‘virtual’ healthcare. Telehealth has been found to be an effective way to manage and prioritise care for patients in the community<sup>24</sup> and there is mounting evidence for the efficacy of technology-enabled models of care for people with palliative and end of life care needs (e.g. remote monitoring, wearables and other smart technology). Advancing technology can also support provision of secondary supervision to a rural and remote workforce where there may be limitations on the availability of skilled staff or access to appropriate clinical support.

While there are many opportunities in the digital health space, there are also challenges and limitations. Infrastructure (e.g. limited internet

and phone connectivity in some areas), digital literacy (both of patients, their families and the healthcare workforce), and the workforce needed to support the design, implementation and maintenance of this technology.

## Investing in palliative care in Tasmania

State and Territory governments are responsible for palliative care service provision. The Australian Government does not directly fund palliative care services but provides financial support to State and Territory governments as part of National Partnership or National Project Agreements, bilateral agreements, activity based or block funding. The use of this funding and the delivery of palliative care services in each jurisdiction is the responsibility of the individual State and Territory governments, their Agencies and health services.

The Tasmanian Health Service (THS) provides palliative care across several care settings including at major hospitals, at rural hospitals, in primary care settings, and patients own homes (including aged care facilities). Most palliative care in the community is delivered by family and caregivers and mainstream primary health services, including general practitioners and community nursing.

The Australian Government confirmed \$20 million in funding in its October 2022 Federal Budget to establish a dedicated public palliative care inpatient facility in northern Tasmania. It is expected that this will happen during the life of this Framework, and will substantially affect service delivery in the north by the State, providing more dedicated palliative care beds.

In the 2021–22 Tasmanian State budget, ongoing funding of \$21 million over four years has been dedicated to strengthening home and community based palliative care and palliative care partnerships, including after hour services from 2021 onwards. This Framework will help guide investment into palliative care services over the life of the document.

# The framework

## Vision statement

A compassionate community that works together so that all Tasmanians have access to high quality, timely, coordinated, culturally appropriate, and responsive palliative and end of life care, that delivers holistic person centred care, supports families and caregivers, and advocates for patient choice.

## Principles



### Person, family and caregiver focused

- Palliative and end of life care are provided based on the wishes and preferences expressed by the person, or their substitute decision maker where they do not have capacity to decide for themselves.
- All planning, thinking, and action in relation to palliative care is built on a holistic understanding of the needs of patients, and their families and caregivers, and occurs in partnership with these people wherever possible.



### Acknowledgment that death is a part of every life

- Members of the Tasmanian public understand the crucial role palliative care plays supporting a good death, and that palliative care aims to optimise quality of life and mitigate suffering.
- Palliative care professionals provide safe, high quality and culturally appropriate information, language and support on death and dying.
- Talking about death should be normalised in the community, where culturally appropriate.



### Participation and engagement

- All members of the Tasmanian community but, in particular people at the end of life and their families and caregivers, should be empowered to participate as fully as possible in decision making about their own 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

- The community recognises that social connectedness, personal relationships, and networks play an important role in helping the individual and their family and caregivers during the caring phase and bereavement.
- Supportive communities have a meaningful contribution to make, caring for one another, reducing fears of death and dying associated with the phrase “palliative care”, and promoting respect and choice.



### **Accessible, timely and integrated care**

- Appropriate care is provided when and where it is needed, and the community knows how to access it.
- Care is delivered seamlessly across care settings so the person at the end of life, and their families and caregivers, can easily gain access to the care and information they need wherever their care is being delivered.



### **Equity**

- People with palliative care needs and their families and caregivers receive the care that they need, regardless of their age, gender, culture, sexual or gender identity, spirituality, or where they live.



### **Innovative and skilled system**

- 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.
- Appropriately skilled staff are recruited and retained in the Tasmanian palliative care sector.
- The leadership of professions and health services supports the ongoing development of evidence based palliative care services across the education continuum and in all aspects of health service management and planning.
- A commitment to monitoring, evaluation and reflection to ensure that the palliative care system in Tasmania continues to grow and improve.



### **Accountable, value based 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 in the most cost-effective way for people receiving palliative care.

# Priority 1: Enhancing holistic person-centred and family inclusive palliative and end of life care

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## Why has this been prioritised?

Diversity in the Tasmanian population accessing palliative care means that there is a significant need for culturally appropriate and equitable care. There is an emerging need for increased palliative care awareness and education to ensure appropriate high quality information and care are provided to priority groups such as Aboriginal peoples, members of the LGBTQIA+ community, children, people with disability, members of the CALD community and those experiencing homelessness.

While demand for palliative care services for children are disproportionately lower than those for older adults in Tasmania, part of enhancing holistic person and family inclusive palliative care includes ensuring the workforce is equipped with the skills to provide care for children and their families.

Increasing an individual's ability to choose where and how they die, whenever possible, will increase patient and family satisfaction with the system and increase the positive image of palliative care services. To do this, an increased emphasis is needed on how patients are cared for in their own homes and across other settings.

## What we will do

- Refresh, update and disseminate the Tasmanian Community Charter (including appropriate governance, monitoring and evaluation, reporting and change management mechanisms) which includes recognition of holistic care needs.
- Support people who are accessing palliative care and their families and caregivers to better understand what palliative care is, what options they have, and how best to navigate the system and how to source wider supports (e.g. such as estate planning).
- Support those who provide palliative care to build and maintain patient, family and caregiver agency in decision making across the entire palliative care journey, including into bereavement.
- Build the capacity of the workforce to provide care which addresses the mental, social, emotional, and spiritual needs of their patient, their families and caregivers, including a focus on care for under-served groups that access palliative care (e.g. such as people with disabilities, children, Aboriginal and/or Torres Strait Islanders, homeless peoples, rural and remote and CALD peoples).

## Priority 2: Increasing community awareness and understanding of palliative and end of life care

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### Why has this been prioritised?

Stakeholders noted that, in their view, there is low understanding within the Tasmanian community of the aims and purpose of the palliative care system, resulting in general hesitancy for patients and their families and caregivers to access care when they need it, leading to a reduced quality of life before death.

As part of a 'communities of care' approach, this priority aims to reduce the stigma of talking about death and dying and increase the number of early referrals into palliative and end of life care services, to ensure the best death possible.

Through this priority, we will improve the palliative care knowledge of the Tasmanian community and continue to build on the work that has been done to date.

### What we will do

- Continue to disseminate and promote the end-of-life care policy developed in 2018 and work with relevant teams and organisations within and external to DoH, as required, to clarify and communicate differences between palliative and end of life care, and Voluntary Assisted Dying.
- Renew and refresh the Strengthening Communities of Care Strategy<sup>25</sup> (with appropriate governance, monitoring and evaluation, reporting, and change management mechanisms), including a continued commitment to:
  - Building the Tasmanian community's health literacy related to palliative care and end of life care.
  - Building of knowledge about palliative care and care at the end of life so that the communities can talk about death, dying and bereavement.

## Priority 3: Enhancing psychosocial support and bereavement care for patients, families and caregivers

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### Why has this been prioritised?

A number of stakeholders in the palliative care sector (including consumers and the community) were not aware of the Bereavement Care Network or the service/information they provide. A greater emphasis should be placed on improving community understanding of the bereavement care options available to all Tasmanians.

Bereavement care should begin prior to death and appropriate measures need to be taken to ensure bereavement care is offered earlier in the palliative process.

Community members noted that further work could be done to enhance care at the end of life by including families and caregivers in decision making and by improving access to psychosocial support during and after a loved one's death.

### What we will do

- Support health care providers to better understand the role of families and caregivers in palliative and end of life care, and provide psychosocial support to them across the palliative care journey.
- Support families and caregivers across the palliative care journey including the bereavement period by:
  - Continuing to support and promote the Bereavement Care Network (BCN) to increase knowledge of and access to bereavement care for patients, families and caregivers prior to death.
  - Reviewing, and where necessary, implementing outstanding recommendations in *Bereavement Care in Tasmania: Current Status and Future Directions for Palliative Care* (internal document).

# Priority 4:

## Building the capacity and capability of the workforce to provide equitable access to quality palliative and end of life care

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### Why has this been prioritised?

Building the capability of the generalist health workforce and increasing the capacity of generalist health workers is essential, so that they have the skills and confidence to provide palliative and end of life care. This will reduce the impact of workforce shortages in specialist palliative care services, but also support equity in access for palliative care support, including for people who do not require the support of specialist services. Education and training for all employees who provide some palliative care will ensure all patients have access to a uniformly high standard of care.

Generalist professions that care for palliative patients should understand what type of care needs to be provided and what avenues patients can take to ensure they have a good death, where and how they choose. Generalists should have the capacity to link patients into required services as needed and be involved in specialist conversations if it will enhance their ability to care for a patient at the end of life. This includes having the knowledge about working with diverse patient groups that are often under-served such as members of the LGBTQIA+ community, members of the Aboriginal and/or Torres Strait Islander community, children, those experiencing homelessness, people with a disability, and members of CALD communities, including safe, high quality, culturally appropriate information and service provision.

Upskilling palliative care professionals in telehealth and the use of technology may help to include patients' families and caregivers more effectively in all major decisions that are made, especially if these decisions are made in an acute setting and any pandemic like situations prevent family member from being present. Creating a greater understanding of the roles and workforce requirements each member should play in palliative care will help to grow the sector and remove misunderstanding about who has what responsibility within the palliative care journey. Contemporary workforce solutions will need to be investigated to improve the access to quality care, especially for those in regional areas.

### What we will do

- Develop strong connections with the training and education sector to produce the specialist palliative care workforce required to meet current and future need for palliative care services, and identify who will train, educate and provide specialist advice to the general healthcare workforce necessary to support the level of need for palliative and end of life care.
- Investigate, design, and implement workforce models that aim to maximise the scope of practice of nursing, pharmacy, and paramedic professionals (e.g. as appropriate: medication reviews, prescribing, inserting syringe drivers etc.) to improve access for under-served communities, including those living in rural and remote regions, or provision of after hours care.
- Facilitate opportunities for professional development and training of the palliative care workforce to:
  - Support the delivery of culturally safe palliative and end of life care.
  - Support equity of access to palliative and end of life care for traditionally under-served populations, including LGBTQIA+ people, Aboriginal and/or Torres Strait Islanders, children, people with disability, those experiencing homelessness, people from CALD communities, and those living in rural and remote areas.
  - Identify the need for interstate service provision in areas where access is poor or waiting times are extended (e.g. access to psychosocial care from mainland providers of psychology, psychiatry and dementia care), and facilitate this interstate care where required.

- Develop a state-wide, cross-sector workforce strategy (including workforce modelling) for palliative and end of life care that identifies the necessary actions to improve the recruitment, retention and support of both a specialist palliative care workforce, and the improved capability and capacity of the general health and social care workforce to provide palliative and end of life care. This work will build on the PCT State of Palliative Care Report 2021<sup>26</sup> developed as part of the Strengthening Communities of Care project commissioned by the Department of Health Tasmania.
- Continue to work with Residential Aged Care Facilities (RACFs) under the Comprehensive Palliative Care in Aged Care (CPCiAC) program to provide inreach specialist palliative care services and enhance the capacity of the RACF workforce to provide palliative care *in situ*.

# Priority 5: Building and delivering coordinated and integrated palliative care services to contemporary standards

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## Why has this been prioritised?

Quality care that aligns to contemporary standards requires coordination and integration across the range of services and health professions that will support holistic palliative care for patients and their families and caregivers. Integrated and coordinated care includes supporting care teams to work collectively wherever possible, and the appropriate and relevant sharing of information between different services (e.g. a specialist made aware of their patient's occupational therapy and physiotherapy needs and vice versa).

Updating the referral process into the specialist palliative care system will make it more user friendly for health professionals to navigate, and support the service, encouraging more health professionals to reach out to the SPCS to support their patients at the end of life, either directly or through specialist consultation and liaison. Increasing the equity of palliative care across all three major regions of Tasmania will help build sustainability in the sector, with the proposed establishment of a public inpatient facility in northern Tasmania a central feature in increasing equity of access.

This Framework prioritises reviewing the current state of the Tasmanian palliative care system to ensure services are delivered to contemporary standards, to ensure the future demand for palliative care can be met and all patients have access to appropriate care at the right level, from the right service, in the right place, at the right time.

## What we will do

- Undertake discussions and planning for the proposed establishment of a public palliative care inpatient facility in northern Tasmania, to be delivered in 3–5 years.
- Review access to after hours palliative care in Tasmania, with a focus on the availability of support in the after hours period (11pm–8am weekdays, outside 8am–12pm Saturdays, and on Sundays and public holidays).
- Establish a palliative care clinical network to drive improvements in quality, safety, and equitable access to palliative care across the State.
- Review the current landscape of palliative care services across primary, acute, sub-acute, and community sectors to determine how to improve:
  - Availability of and access to care in the place and setting that best suits each person (including investment in community and home-based care).
  - Involvement of telehealth and virtual care to support better access to care in general, and especially after hours.
  - Support for Tasmania's digital health transformation to future ensure interoperability of digital health records across sectors (including resourcing to support uptake of digital records and development of appropriate information sharing processes and documentation across sectors).
- Design, develop and implement innovative and contemporary solutions, as appropriate to address the findings of the review of palliative care services across primary care, acute, sub-acute, and community sectors.
- Monitor and evaluate the impact of implemented solutions on the equitable access, quality and safety of a joined-up palliative care and end of life care service system.

- Continue support for the SPCS Model of Care and evaluation across the six domains of the Reporting and Performance Framework, and continued development to ensure that the Model of Care (MOC) is:
  - Evidence based and aligned with contemporary standards and best practice.
  - Able to provide feedback into wider workforce planning and strategy to ensure appropriate workforce availability and distribution to deliver the MOC.
- Review the current referral processes into SPCS to make it easier for health providers to refer into services and to move people between levels of care as their needs change.
- Where required, develop patient facing care pathways to improve health system literacy and ease of navigation by patients, their families and caregivers.
- Contextualise and promote available evidence-based pathways to the workforce providing palliative and end of life care.
- Complete evaluation of the Tasmanian CPCiAC project. Subject to evaluation outcomes and recommendations, consider development of a budget submission to extend the program beyond the period funded by the National Project Agreement between Tasmania and the Australian Government.

# Priority 6: Conducting ongoing review and evaluation of the delivery and outcomes from the implementation of this Framework

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## Why has this been prioritised?

Continually reviewing and evaluating the activity toward outcomes is important to ensure that priorities are iteratively updated, and that progress can be communicated back to stakeholders, including the Government, palliative and end of life care sector, and wider Tasmanian community. Evaluation and monitoring will support progress to meet projected increases in demand and ensure that the activities under the Framework meet any changing needs.

Users of the system are the most reliable indicator of success and therefore the patient, family and caregiver experience of services, the service system, and views on the progress of the priorities and actions of the Framework are a valuable way to evaluate the implementation of this framework.

## What we will do

- Develop a monitoring and evaluation framework to assess the quality and experiences of palliative care by individuals, families and caregivers to support continuous quality improvement (including where appropriate and possible, inputs from those accessing palliative care).
- Continue to develop datasets and analytic capacity to increase understanding of service uptake, outcomes, and demand at national, state and local levels which can inform resource allocation.
- Use system-wide monitoring and evaluation findings, including datasets mentioned above, to support Tasmania's input into local, cross sectoral and national level discussions about legislation, standards policies and guidelines.

# Implementation, monitoring and evaluation



Ongoing monitoring of progress on the implementation of the Framework will be achieved through the following methods and processes.

## Implementing the Framework

The Department of Health (DoH) Tasmania will lead implementation of the Framework, in collaboration with the Partners in Palliative Care (PIPC) Reference Group. The PIPC Reference Group has broad state and sector-wide representation and influence within the palliative care service provider sector.

Implementation will occur in partnership with consumers, their families and caregivers, the THS, health and community service providers, peak bodies, and the Tasmanian community through the PIPC Group.

Annual implementation plans will follow State and Federal Budget resource allocations for each year the Framework is operational.

## Governance

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

## Monitoring, evaluation and reporting

As leader of the implementation, the DoH will also be responsible for monitoring and evaluating the progress of implementation.

A monitoring and evaluation strategy will be developed by the DoH, and recommendations made regarding the reporting structure of the evaluations.

# Glossary

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<b>Acronym</b>	<b>Full name</b>
ACP	Advanced Care Planning
AMA	Australian Medical Association
BCN	Bereavement Care Network
CALD	Culturally and Linguistically Diverse
CPCiAC	Comprehensive Palliative Care in Aged Care
CPD	Continuing Professional Development
CSP	Clinical Services Plan
DoH	Department of Health Tasmania
GP	General Practitioner
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual +
MOC	Model of Care
PCT	Palliative Care Tasmania
PHT	Primary Health Tasmania
PIPC	Partners in Palliative Care
RACF	Residential Aged Care Facility
SPCS	Specialist Palliative Care Services
THS	Tasmanian Health Service
WHO	World Health Organisation
VAD	Voluntary Assisted Dying

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[palliativecareservicedevelopment@health.tas.gov.au](mailto:palliativecareservicedevelopment@health.tas.gov.au)

