

END OF LIFE CARE:  
SUPPORTING TASMANIANS  
TO LIVE WELL AT END OF LIFE  
TASMANIAN POLICY STATEMENT



## PURPOSE

This End of Life Care Policy Statement provides a clear direction and describes what is needed to deliver high quality care into the future. The policy statement is about improving the experience of dying in Tasmania.

It is a priority action of *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017–21*, which sets the future directions for palliative care in Tasmania and describes the Tasmanian Government's vision for palliative care, which is:



# POLICY STATEMENT

The Tasmanian community, Government and service providers are committed to a consistent approach to end of life care. Safe and high-quality end of life care can be achieved by working together to ensure:

- All Tasmanians have access to information about death and dying.
- End of life care is inclusive and respectful of the unique needs of individuals and their family and carers.
- Early participation in end of life care planning, including care planning for people with life-limiting chronic disease.
- Bereavement care needs are identified early and are part of end of life care planning. Support is inclusive and provided according to need.
- All Tasmanians have the opportunity to participate in advance care planning and to complete an advance care directive.
- End of life care is informed by advance care planning and clinical information.
- End of life care is provided by a skilled, capable and confident community of care.
- Care delivered at end of life is consistent with the Australian Commission on Safety and Quality in Healthcare's (ACSQHC) National Consensus Statement: Elements for safe and high quality end of life care.
- Standardised, endorsed and accepted resources and training are available to support advance care planning.
- Systems facilitate end of life care planning and shared access to information across the community of care, supporting a coordinated and integrated approach to end of life care.

## BACKGROUND

Australians are living longer and more of us can expect to enjoy a reasonable quality of life as we age. However, living longer means that we are more likely to develop one or more chronic diseases and die following a period of progressive deterioration in our condition over months or years. This change in the way that we are dying has increased the demand for health and community care services.

While Australian end of life care services are well regarded internationally, there is a growing recognition that the quality of care provided at end of life is variable and not accessible to all. It is widely recognised that end of life care needs to be more responsive to the preferences of the dying person, in particular to their choices about how they are cared for and where they die and care for the bereaved.

In our communities, there is a reluctance to talk about death and dying and to acknowledge the dying process. This reluctance decreases the chances that a person at end of life and their family will receive palliative care. The focus of end of life care should be on ensuring comfort and wellbeing and achieving good quality of life right up until the moment of death.

Despite these challenges, there is a strong national commitment to improving end of life care. *The National Strategy for Palliative Care 2010; Supporting Australians to live Well at the End of Life* encourages all states and territories to develop consistent palliative care policies and services. This Strategy is further supported by the Australian Commission on Safety and Quality in Healthcare's (ACSQHC) *National Consensus Statement: Elements for safe and high quality end of life care (2015)*, which has been endorsed by the Australian states and territories. The updated *National Safety and Quality Health Service Standards* will also be implemented in 2019 and include new end of life care criteria and actions.



# END OF LIFE

End of life is the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma (ACSQHC 2015a, p.33).

# END OF LIFE CARE

End of life care is a broad concept that encompasses dying, death and bereavement. As defined by the ACSQHC (2015a, p.33), end of life care includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death.

Quality end of life care embraces a palliative approach to care, enabling the person and their family and carers to participate 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 when possible.

The palliative approach to care emphasises the need to develop supportive and responsive care for people at end of life and their families. This includes the importance of identifying bereavement care needs of family and carers early in the caring experience and providing support for those who need it. Evidence indicates most families and carers are adequately supported by family and friends, however, access to more specific bereavement care support and services may be required by some people (Australian Government Department of Health and Aging, 2011).



# TOWARDS A CONSISTENT APPROACH TO END OF LIFE CARE IN TASMANIA

Developing the required capacity within Tasmania to respond to the needs of the dying and their families requires a compassionate communities approach, a shared responsibility, and commitment to responsive and quality end of life care delivered across a range of settings. It requires an ongoing partnership and a commitment to change in our communities and health and community care systems.

There is a need also for sustained community and public engagement to develop awareness about the importance of preparation and planning for end of life, including advance care planning. This includes planning early for the unexpected such as an accident, or at the onset of a serious health condition.

Despite the ongoing work to promote advance care planning, less than 15% of Australians have an Advance Care Directive or Plan (*White et al, 2014*). Advance care planning is an important part of end of life care planning. It can involve completing an Advance Care Directive, but most importantly it is about having a conversation with family and friends about care preferences. It should also involve a discussion with the primary care provider or health care professional about treatment choices to inform clinical care planning. In Tasmania this includes the completion of a Medical Goals of Care plan.

If we are to have a comprehensive and consistent approach to end of life care in Tasmania, it is important that the individual at end of life, their families and carers, and other members of their community of care (e.g. General Practitioner, community nurse) are essential participants in discussions and decision making about care needs. This means we need to develop strategies to:

- encourage Tasmanians to talk about and plan for end of life and communicate their wishes with family and carers
- enable Tasmanians to talk about death and dying with health and community care providers
- develop the capacity of our communities of care to recognise dying and deliver quality end of life care
- increase awareness and understanding of bereavement, and access to bereavement support.

## POLICY SCOPE

We believe that providing supportive and compassionate end of life care for every Tasmanian is a shared responsibility, so this Policy Statement applies to everyone with a connection to a person at end of life. This includes all members of the community of care that surrounds and supports the person at end of life such as family, carers, hospitals, volunteers, primary care providers, home care providers, support workers and community groups.

This Policy Statement emphasises and supports personal choice about care at end of life, but it does not encompass or endorse euthanasia and assisted dying. In Tasmania, assisted suicide and euthanasia are crimes and are not endorsed by the Tasmanian Government and the Department of Health and Human Services (DHHS).

# ACHIEVING THE POLICY STATEMENT

A number of the priorities and actions in *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017–21* will contribute to achieving this Policy Statement, including through:

- the implementation of the *Tasmanian Palliative Care Community Charter*
- the implementation of *Strengthening Communities of Care: A strategy to build the capacity and capability of all Tasmanians in a palliative care 2017–20*
- the establishment of Bereavement Care Networks.

Resources and activities developed and implemented across these actions will contribute to a consistent approach to the delivery of high quality end of life care by:

- increasing community knowledge and awareness of death and dying
- promoting participation in advance care planning
- building the knowledge and skills of those involved in the delivery of end of life care
- producing a standardised suite of resources to support advance care planning
- increasing community awareness and understanding of bereavement as well as building the skills of existing services and support networks.

# MONITORING AND REPORTING PROGRESS AGAINST THIS POLICY STATEMENT

Progress against this Policy Statement will be monitored and reported by DHHS as part of the annual progress report on the implementation of *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017–21*.

# REFERENCES

Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC, 2015.

Australian Government Department of Health and Aging. *Guidelines for a Palliative Approach for Aged Care in the Community Setting- Best Practice guidelines for the Australian context*. Canberra: 2011.

White, B. Tilse, C., Wilson, J., Rosenman, L., Strub, T., Feeney, R., Silvester, W. Prevalence and predictors of advance directives in Australia, *Intern Med J.* 44 (10) 2014.



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