THE TASMANIAN PALLIATIVE CARE COMMUNITY CHARTER

The Tasmanian Department of Health and Human Services aims to ensure that all Tasmanians have access to the best possible palliative care when they are approaching the end of life, to help them die peacefully with dignity, compassionate care, and support for them and their carers.

The Tasmanian Palliative Care Community Charter is the result of extensive consultations across the state with Tasmanian community members, including Tasmanian Aborigines and people from a range of cultures and social groups, which enabled them to say what they want and expect from palliative care.

The Charter is underpinned by a Compassionate Communities approach which accepts that palliative care is everyone's business. At the end of life, we all need to know that services and resources are available to us, our carers and other people who are important to us, to support us at this time. This approach was strongly endorsed by the people of Tasmania during the consultations.

The following principles reflect the voices of Tasmanians about what matters most to them, and together form *The Tasmanian Palliative Care Community Charter.* The Charter demonstrates our commitment to advocate for compassionate and quality palliative care.

STATEMENT OF PRINCIPLES

⌖ Relief of Pain and Other Causes of Distress

The most important thing is being free from pain and other distress, whether that distress is physical, emotional or spiritual; unless we are comfortable we can't appreciate anything else.

We need the right amount of palliative care and other support, at the right time and in the right place, delivered by skilled, qualified professionals.

We want to keep life as normal as possible, so we can participate in our usual activities, eat and drink what and when we want, express our sexuality and have pets with us if that is what we want.

⌖ Respect, Dignity and Person-centred Care

We want to be respected for our individual values, beliefs, culture, sexual orientation and choices of who we want involved in our care.

We want our carers and other people who matter to us to be treated in the same way; respect the rights that our partners have to make decisions for us if we have lost capacity.

We want be at the centre of planning at all times, with support to manage our care and make our own decisions if we want to, without pressure from health care providers to take a particular path.

We want to be cared for by people who are experienced and culturally respectful of our rituals of death and dying, the roles of our family or other people in our community, however those are expressed in the community groups to which we belong.

⌖ Good Communication

Give us, and our carers if we agree, information in honest, simple language about our illness, what treatment is available and, if possible, when we are likely to die.

Tell us and our carers what to expect when death is coming.

Explain to us what palliative care is and how it will help us.

Give us all the information and access to care and support that we, or our family or carers, might need.

Coordination of Care

Everyone providing care should talk to each other and share information, so everyone knows what everyone else is doing and so we don't have to repeat information over and over. Keep a balance between sharing our personal information and respecting our confidentiality.

Make sure we know who you are, what organisation you are from and what support you have come to provide. Don't assume we'll remember you from last time.

Our GPs and home carers are an important part of our care team. Make sure they are included in all communication.

Place of Care and Place of Death

We want choice and control over where death occurs. If care at home isn't possible, we need a peaceful, home-like environment where people who are important to us feel welcome and, where appropriate, encouraged to assist with care.

When death is close, we and our family need privacy, even if care is being provided in a hospital.

Fair Access to Care that meets Individual needs

We need access to palliative and other care when and where it is needed, without us having to travel away from family and friends.

Affordable care and support needs to be provided to everyone who needs it, regardless of age, physical or mental capacity, cultural background, religion or sexual orientation.

We need a clear, understandable pathway to access care and support.

Support for People Important to Us

Our palliative care journey will be easier if our carers and other people who are important to us are respected and cared for as well. In particular, our carers need:

- to have their knowledge of us and what brings us comfort acknowledged and respected.
- education about reasons for providing or not providing treatment options.
- contact details for 24/7 emergencies.a check-list of what to do when we die, e.g., who to phone first, what needs to be done before the funeral home staff are called.
- support after our death, both immediately and in the weeks following the death. They should never feel abandoned.

Help with Planning End-of-life Care

Help us to plan ahead, as early as possible, for what treatment and care we want, or don't want, in case we can't tell you when we need the care and treatment. This includes assistance to complete an Advance Care Directive and to appoint an Enduring Guardian.

Give us information about who will have the legal authority to make decisions for us if we lose capacity and haven't appointed our own substitute decision-maker.

Support for Aboriginal People in Tasmania

Respect our wishes to go home or remain on country to die.

Take the time to understand and respect cultural considerations that affect us and our families, including the role of family and extended family in the dying process.

After the death, people may need the opportunity for 'sorry business'.

Give us a key contact person who we can go to if we are receiving mixed messages or don't understand something.