THE TASMANIAN PALLIATIVE CARE Community CHARTER

A shared commitment to compassionate and quality palliative care

Palliative care can improve the quality of life for people facing life-limiting illness. It aims to help the person to live as well as possible and to provide care that addresses the physical, emotional, social, cultural and spiritual needs of the person, their families and carers*.

The Charter is an agreement between the Tasmanian community and service providers.

The Tasmanian Palliative Care Community Charter is the result of extensive consultations with Tasmanian service providers and community members, including Tasmanian Aboriginals and people from a range of cultures and social groups. The following principles reflect the voices of Tasmanians about what matters most to them.

The Charter is built on a Compassionate Communities approach, which recognises that palliative care is an important, shared responsibility for all Tasmanians. 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.

The Charter demonstrates our shared commitment to advocate for compassionate and quality palliative care.

www.dhhs.tas.gov.au/palliativecare

Department of Health and Human Services

Tasmanian Government

The Tasmanian community and service providers are committed to the following principles:

Relief from Pain and Other Causes of Distress

The most important thing is relief from pain and other distress, whether that distress is physical, emotional or spiritual. If we are comfortable we can enjoy the things that are important to us.

We need palliative care and other support at the right times 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 and have our pets with us, if we wish.

Respect, Dignity and Person-Centred Care

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

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

We want to be at the centre of planning at all times, with support to manage our own care and decisions if we want to, without pressure from others 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 as well as the roles of our family or other people in our community.

Good communication

Listen to us so that you clearly understand our wishes and needs.

Give us – and our chosen carers – honest, clear information about our illness, what treatment is available and – if possible – when we are likely to die.

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

Explain to us what palliative care is and how it can help us. Give us all the information and access to care and support that we, or our family and carers, might need.

Coordination of Care

Those providing care should talk to each other so everyone knows what each care provider is doing and we don't have to repeat information over and over.

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 involved in all communication.

Place of Care and Place of Death

We want as much choice and control as possible over where death occurs. If care at home isn't possible, we need a peaceful environment where people who are important to us feel welcome and are encouraged to assist with our care however they can.

When death is close, we need privacy, even if care is being provided in a hospital or other facility.

Fair Access to Care

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

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

We need clear, understandable pathways to access care and support, and the option to choose which pathway is best for us.

Help with Planning End-of-Life Care

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

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 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. Our carers need:

- their knowledge of us and what brings us comfort acknowledged and respected
- education and information about reasons for providing or not providing treatment options
- contact details for 24/7 urgent care; a checklist of what to do when we die, e.g. who to phone first, and what needs to be done before the funeral home is called
- support after our death, both immediately and in the weeks and months to follow. Our carers should never feel abandoned.

Support for the Unique Needs of Children, Young People and our Families

Remember that every child and young person is an individual; make sure we receive care and support that meets our unique needs and the needs of our family.

We need care and communication that is appropriate for our age and development. Listen to us and encourage us to talk through our wishes and care choices.

We are part of a family unit. It is important that our family, friends and people close to us are supported and included in our care.

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

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

**The term carer is inclusive of both paid and unpaid support people; this might include family members, volunteers, partners and/or paid support workers. Carers are people who are nominated by the person to be involved in their care.*