



**PalliativeCare**

TASMANIA

Tasmanian Association for Hospice  
and Palliative Care Inc.

22 June 2016

Mr Todd Buttsworth  
Secretary  
House of Assembly Standing Committee on Community Development






[Communitydevelopment@parliament.tas.gov.au](mailto:Communitydevelopment@parliament.tas.gov.au)

Dear Mr Buttsworth,

Thank you for the opportunity to provide a submission regarding the House of Assembly Standing Committee on Community Development Inquiry into Palliative Care. We welcome the opportunity to comment and believe the Inquiry will help create discussion within the Tasmanian community about issues relating to death and dying.

As you may be aware, Palliative Care Tasmania (PCT) is the peak non-government organisation in Tasmania committed to achieving quality palliative care for all Tasmanians. PCT is affiliated with the national peak body, Palliative Care Australia, and our vision is that all Tasmanians with a life-limiting illness and their families are supported to live, die and grieve well.

PCT is proactive in end of life education and information dissemination, community engagement and advocacy on behalf of the palliative care sector, the community and its members. It works to:

-  **Educate** service providers, carers, volunteers and the community about palliative care, death literacy (including advance care planning), grief and bereavement and best practice standards;
-  Provide **information** about services across Tasmania;
-  **Lead** in the continuous development of best practice standards;
-  **Support** workers and community sectors involved in the care of people who are dying; and
-  **Advocate** for service provision and its future development.

In July 2013, Palliative Care Tasmania received funding of \$2.66 million over 3 years for the project *Networking for End of Life Care across Tasmania: Integration, Innovation and*

*Inclusion*, under the Australian Government's Better Access to Palliative Care in Tasmania Program (BAPC).

Over the last 18 months we have provided and facilitated education and training to more than 13,000 Tasmanians in the areas of palliative care, death literacy (including advance care planning), and grief and bereavement

Evaluation of the education programs delivered during 2014-15 has shown that further education and training is needed for an overwhelming majority of the participants, the programs delivered to date are relevant to people's needs and that the skills and knowledge gained is being used in their workplaces and communities.

During 2014-15 PCT facilitated approximately \$750,000 in community projects through the provision of more than \$300,000 of direct funding to community organisations across the State, including King Island and Flinders Island. This has facilitated 61 projects specifically designed to help meet local community's need through the BAPC program.

As a result of our current success, momentum is building across the State. More people want to know about palliative care, grief and bereavement and death literacy (including Advance Care Planning). We are training more and more people to help support community members. With an aging population and rise in chronic progressive diseases this need will continue to grow.

All of this work has positive economic implications on the current health care system. Through effective end of life planning, encompassing education and community development, that PCT has been able to provide through the BAPC program, the capacity for people to gain a better understanding of their end of life options increases. They are more able to plan to die at home with the appropriate support structures around them, helping to relieve pressure on our acute system through fewer emergency department presentations, lower numbers of terminally ill people in intensive care, and a reduction in terminally ill people requiring ambulatory services, delaying the need to enter aged care facilities, if at all.

The fact that the BAPC program is Australian Government funded has provided the community with knowledge that palliative care, including palliative care education, is considered important by decision makers, and the process of dying is as important as the process of living.

PCT notes the Terms of Reference for the inquiry are to inquire into and report upon the matter of care of palliative patients generally, specifically the matters of:

- (i) advance care directives;
- (ii) administration of medical treatments to minors;
- (iii) the administration of emergency medical treatment; and
- (iv) other matters incidental thereto.

This submission will examine each of these matters.

## **Advance Care Directives**

Tasmania has perhaps Australia's most contemporary Advance Care Directive (ACD). It allows for people to plan ahead for diseases and illness that they don't currently have, addresses medical care, symptom management, spiritual and psycho-social care and life-style decisions. The document makes provision for naming of a preferred Person Responsible.

The Tasmanian ACD has not been legally tested in Tasmanian courts.

While not a legislatively binding document, the Tasmanian ACD for Care at the End of Life is based on the Common Law principle that individuals have the right to refuse consent to any unwanted medical treatment including treatment aimed at prolonging life. Naming of a preferred Person Responsible to act as substitute decision maker is also an expression of the common law principle of the right to autonomy.

There is strong national interest in ACDs and a need for a consistent approach across all jurisdictions.

In Tasmania the main issues in regard to ACD recognition are:

- Some medical practitioners are confused about the ACD's legal status because it rests in the Common Law rather than on statutory law.
- Community awareness is still not high regarding ACD. We have found a very high level of interest in ACDs and people generally understand that it is preferable to discuss wishes with family and significant others in advance, but are not sure about the next steps in the process. The burden also falls on the individual to provide their ACD to their GP and local hospital otherwise medical practitioners may be unaware of the care requested.
- Clarification of the role of the Substitute Decision Maker, (SDM). Health and aged care and community services continue to ask clients who their next of kin (NOK) is, even though NOK has no automatic legal status under Tasmanian Guardianship law.

Encouraging General Practitioners to have Advance Care Planning conversations with their patients, (especially those with life-limiting, chronic conditions, people newly diagnosed with dementia or other conditions which may impact on decision making capacity), along with discussion of Medical Goals of Care for those people who may wish to refuse life-prolonging treatments is an important step in increasing acceptance of ACDs across the community and the medical professions.

The critical step in improving end of life decision making is prompting people to talk with their family and friends about their preferences about end of life care and to name an agreed substitute decision maker. If others understand what a person's wishes are then they are able to speak for them in the event a person lacks capacity. The next step of completing an ACD form is helpful in supporting the Person Responsible in advocating for the Person Concerned.

The Tasmanian Guardianship Act hierarchy for determining a SDM is commendable in recognising that the quality of the relationship between the Person Concerned and their SDM is more important than blood/family relationship. Stronger recognition of the ACD and the naming of a preferred Person Responsible in the ACD would provide clarity for the public and for services providing care.

In our extensive education and public awareness activities over the past 5 years, PCT has been asked on almost every occasion what options there are for the many people who live alone and who have no-one in their lives who they could name as a Person Responsible, or nominate as Enduring Guardian.

The Tasmanian ACD is a way for these people to state their preferences for their care so that health and aged care teams are able to make informed decisions regarding likely treatment outcomes and place of care for the person who now lacks capacity, based on their preferences expressed in an ACD written when they had capacity.

In Tasmania ACDs are not centrally stored. In fact it is an individual's responsibility to provide copies to their GP and local public hospital. This lack of central storage poses problems when people are treated in facilities that do not have a copy, or ability to access a copy, of the ACD. In addition, it means there is no way of knowing how many Tasmanians current have an ACD.

#### *Death Literacy*

A large part of our education is around death literacy including advance care planning. There is confusion about Enduring Guardianship, Enduring Power of Attorney, Advance Care Directives, and Wills.

Improving Death Literacy can:

- Help prepare for difficult conversations;
- Increase knowledge;
- Build confidence;
- Enable others to be assisting in their advance care planning; and
- Give individuals more control over how they die.

It should be noted that at the moment a person must be 18 to complete an ACD. We would support the removal of an age and believe it should be related to the mental competence of a person no matter their stated age.

#### **Administration of medical treatments to minors**

In Tasmania there is currently no fixed age relating to consent to accept or refuse medical treatment. This tends to rely on the concept of maturity of understanding.

PCT does not support the setting of a mandatory age for informed decision making. All people, regardless of their age or assessed capacity, should have access to 'supported decision making' in an environment that is safe, respectful and timely, so they can participate in decision making about their care. This type of supported decision-making

would also be more sensitive to the cultural needs of people from diverse backgrounds. The ultimate decision regarding care may well fall to a SDM and the professional care providers, but everyone should be afforded the respect and dignity of participating in decisions about their welfare.

In Tasmania there are very few young people who receive palliative care. In many cases young people receive medical treatment in Melbourne. However, anecdotally it is reported that medical practitioners at Royal Children's Hospital in Melbourne have advised parents that there is no palliative care treatment options for young people in Tasmania, which is erroneous.

While there is no specialist paediatric palliative care unit in Tasmania, existing Specialist Palliative Care Services (SPCS) and Oncology Units at the Launceston General Hospital and Royal Hobart Hospital provide palliative care support to young people and their families. SPCS provide support to families in their homes and work in collaboration with local paediatric services to care for children with palliative care needs. Organisations such as Camp Quality, CanTeen, and various chronic disease associations and community groups offer social, emotional and practical support to children and families. Bears of Hope and The Compassionate Friends provide support to bereaved parents.

Feedback from some parents indicate that the quality of care received by young people is outstanding. However, issues seem to arise after the young person dies. At an education event held for parents of deceased young people, parents indicated that they felt cut off following the death of their child. They were given brochures but could not recall any follow up occurring from the SPCS. Discussions with SPCS indicate when a SPCS patient dies (whether a young person or older person) their loved ones can be supported by SPCS if their bereavement is to extent that they need assistance. However, in practice there may be issues providing this service, primarily due to a lack of understanding that the service is available and in some cases resourcing constraints.

### **The Administration of Emergency Medical Treatment**

Emergency medical treatment for palliative care patients is complex. In Tasmania there is no central repository for ACDs meaning emergency services do not have fast access to understand a person's end of life wishes. Therefore at this present time it is appropriate that emergency services respond in a way aimed at preserving life.

In cases where a person is dying at home and emergency medical treatment is required to ensure they are comfortable, it is recommended that the treating doctor completes a Medical Goals of Care stating that the person is not to receive life prolonging treatment, including resuscitation. This can then be provided to paramedics on arrival.

In practice it is very unlikely that a palliative patient would suffer an emergency event requiring resuscitation.

## Other Matters

It should be recognised that Tasmania has exceptional palliative care services. However, it is important to understand that a large amount of palliative care is provided by the community, palliative care is not the sole domain of the SPCS. The main issues impacting effective delivery include:

- Lack of community understanding about palliative care and service options;
- Lack of community understanding about death literacy, including advance care planning;
- Lack of communication between service providers;
- Insufficient grief and bereavement services, particularly for bereaved parents;
- Southern Tasmania lacks scope of regional palliative care suites, limiting the ability of people to die within their communities;
- Aging palliative care workforce and a workforce that will need higher skills to effectively care for the larger number of patients with chronic illness; and
- Support for carers.

Another key issue is appropriate training of medical professionals. Medicine is geared towards cure and many professionals are not appropriately trained in diagnosing death. Many GP's in particular also express their lack of confidence in talking to patients about advance care planning and delivering bad news. PCT has developed two short films to help educate in these areas and is also in the process of developing a Medical Goals of Care app.

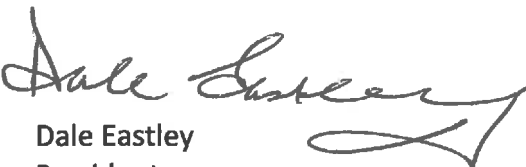
It should also be noted that palliative care is not an either/or choice. We need to ensure there is effective interaction between chronic illness and palliative care. It is noted that SPCS already provide good quality care to people suffering with a chronic illness. However, the impact of chronic illness on the palliative care system is great. As a result it is critical to ensure that services are resourced effectively to ensure high levels of care are achieved.

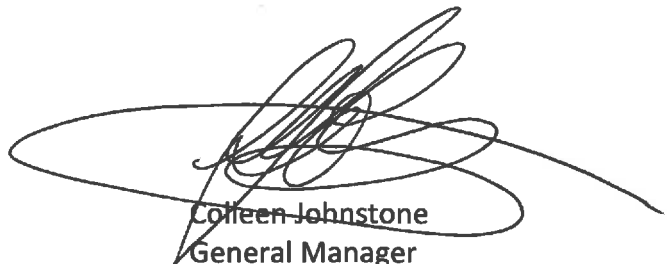
PCT has been working hard across Tasmania, educating approximately 13,000 Tasmanians in the past 18 months in the areas of palliative care, death literacy and grief and bereavement. PCT funding under the Better Access to Palliative Care in Tasmania Program ends on 30 September 2016 and there are no other organisations in the State with the skills or expertise to provide this education and increase community awareness. This will create a gap in this area resulting in unmet demand across the State.

PCT is more than happy to discuss any of these issues with the Standing Committee if required.

Thank you for the opportunity to provide a submission.

Yours sincerely

  
Dale Eastley  
President

  
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General Manager