SUBMISSION

Legislative Council Sessional Committee
Government Administration A Sub-Committee

Rural Health Services Inquiry

Submitted on 11 March 2021

PalliativeCare
TASMANIA

Contents

Introduction

This submission is made by Palliative Care Tasmania Limited (PCT), the peak body for palliative care in Tasmania. PCT is a member organisation and represents medical practitioners, health professionals, and others with an interest in palliative and end of life care. PCT has both individual and organisational members.

PCT appreciates the opportunity to make this submission to the Legislative Council Sessional Committee Government Administration A Sub-Committee (the Committee) with respect to its Rural Health Services Inquiry (the Inquiry).

In this submission, we firstly provide background information on PCT, then comment on the Inquiry's terms of reference, in particular with respect to palliative and end-of-life care.

We are available to meet with the Committee to provide additional commentary if required.

Executive Summary

Palliative care provides a holistic approach to supporting people, and their loved ones, diagnosed with a life-limiting condition.

Tasmania does not have a "gold standard" palliative care system. This is even more pronounced in rural Tasmania, where a large proportion of older Tasmanians live.

Over the next 30 years we can expect a surge in palliative care demand of 135%. However, we do not have the capacity to meet the current demand, let alone future demand.

People living and dying in regional and rural Tasmania have difficulty accessing palliative care when and where they need it. These challenges are exacerbated by shortages of community GPs and nurses trained in palliative care, reduced specialist support, lack of physical infrastructure, inability to access professional development, lack of local services providing aspects of palliative care, and after-hours services usually reliant on local GPs.

These challenges are fixable though. We need to put our dying first. We need to increase investment in palliative and end of life care. This investment will result in cost savings to Government because lower numbers of our rural people will be leaving their communities to die in Launceston or Hobart, and their families will not suffer from complicated grief as a result of this.

About Palliative Care Tasmania Limited

Palliative Care Tasmania (PCT) is Tasmania's peak body for palliative care and one of eight member organisations of Palliative Care Australia. We have been lobbying for equitable access to best practice palliative care since 1989.

Our vision is that all Tasmanians with a life-limiting illness, together with those they value, are

supported to live, die and grieve well.

Our mission is to lead and influence policy and practice, advocate, educate and support people of all ages to access quality palliative care.

What we do:

- Provide support to Tasmanians with a life-limiting illness and their families.
- Educate service providers, carers, volunteers and the community about palliative care and best practice standards.
- Provide information about palliative care services across Tasmania.
- Support continuous development of best practice standards.
- Support workers involved in the care of people who are dying.
- Advocate for service provision and its future development.

Terms of Reference

To inquire into and report on health outcomes and access to community health and hospital services for Tasmanians living in rural and remote Tasmania, with particular regard to:
1. Health outcomes, including comparative health outcomes;
2. Availability and timeliness of health services including: rural and remote Tasmania, with particular regard to:
g. Palliative care services;
3. Barriers to access to:
g. Palliative care services;

Health Outcomes and Availability of Palliative Care

Palliative care provides relief of suffering through early identification, assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual needs for those who have been diagnosed with a life limiting illness. Currently in Tasmania, around 4,500 people will die each year. The great majority of these deaths (around 4,000) are what is described as 'expected' or 'predictable' deaths, that includes many people who have had life-limiting conditions or have been elderly and frail. It has been estimated that up to 90% of people with life-limiting conditions would benefit from, or need, palliative care. This need will increase by 135% over the next 30-40 years. [1]

The Productivity Commission describes this country as facing a tsunami of palliative care cases.[2] Tasmania can expect a greater proportion of people aged over 65, increasing rates of dementia and deaths from dementia, and multi-morbidities requiring much more complex care.

Regional and rural communities on Tasmania's East Coast have the highest proportion of older Tasmanians. Triabunna - Bicheno (29%), reflecting its popularity as a place to retire. This was

1 KPMG and Palliative Care Australia, Investing to Save: The economics of increased investment in palliative care in Australia
[2] Australian Government, Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services,* Productivity Commission Inquiry Report, No, 85, 27 October 2017.

followed by Forestier - Tasman (27%) and St Helens - Scamander (25%).[3]

Not all Tasmanians who need palliative care have access to services when they need it and where they need it, particularly at home and in community settings. These gaps are most pronounced in under-served and vulnerable communities, including rural communities.

Since 2012 the years lost to disability due to non-communicable diseases have increased. The largest patient cohort are those with non-complex needs where care is provided by primary care and generalist palliative care personnel. Those patients with complex needs will require the care of a multi-disciplinary team and involve specialist palliative care services.[4]

This will only worsen as we see increases in demand in the coming years if we do not act now. Investment is needed in palliative care and advance care planning, particularly through increased availability of community-based palliative care.

Investment in palliative care makes economic sense. People living with a life-limiting illness who receive palliative care, compared with those who do not, have fewer hospitalisations, shorter hospital stays, reduced use of Intensive Care Units and fewer visits to Emergency Departments (EDs)[3]. They can remain in their communities and receive the care they need, rather than experiencing periods away to receive care, which can result in condition decline, particularly for those suffering with dementia.

It is important to note that delivery of palliative care services is not just a role for the health care system or palliative care specialist services – it also includes significant contribution from informal and community supports surrounding a person with a life limiting illness. That is why it is critical we focus on developing community-based care options into the future.

Barriers in Provision of Palliative Care

We know that people want to be supported and/or die at home, yet the current burden of palliative care provision rests heavily on the public health system. In the last weeks of life, preference for home care falls from 90% to 52%, mostly due to issues around symptom management and control. This indicates that while people want to die at home, they do not feel comfortable or supported to do so, resulting in the most common place of death for our dying Tasmanians still being hospitals. [5]

It is well documented that people living in rural Tasmania experience poorer health outcomes than non-rural Tasmanians. Rural Tasmanians generally have poorer access to local general practice services, with the majority of GPs per capita located in Hobart or Launceston.[6] This, coupled with lower access rates to specialists, means it is also more common for people from rural Tasmania to have more advanced stages of diseases before they access effective medical

[3] Available at https://www.abs.gov.au/ausstats/abs@.nsf/Previousproducts/3235.0Main%20Features402014?opendocument&tabname=Summary&prodno=3235.0&issue=2014&num=&view=

[4] KPMG and Palliative Care Australia, Investing to Save: The economics of increased investment in palliative care in Australia

5 KPMG and Palliative Care Australia, Investing to Save: The economics of increased investment in palliative care in Australia.

[6] *Provision of Primary Health Care Service Strategic Study*, Royal Flying Doctors Service Tasmania, 2015

care, including palliative care.

Communities in north west and north east Tasmania struggle to access GPs as the population ages and an increasing number of people are diagnosed with a chronic or mental illness. The GP workforce in rural Tasmania can also be transient. The result is a workforce that often lacks specific palliative care training or experience needed to support dying Tasmanians in rural communities. This is not a reflection on the dedication of this workforce. In fact, this workforce is often the most engaged when PCT provides professional development and recognise the important of palliative care for their professional development.

For dying Tasmanians in rural communities, it is important to have access to service providers (including GPs and nursing support) who are also part of that community. However, if GPs are at the forefront of a community-based model of palliative care, they need to be supported through professional development and they must have access to multidisciplinary teams.

Access to palliative care in aged care is also a critical and pressing issue. With an ageing population and the rise in chronic disease, it is essential that palliative care is recognised as core business for all aged care providers. Aged care staff must be supported by systems, funding and training to provide quality palliative care. At the same time, aged care must not be considered in isolation from the broader health system.

Community palliative care service provision should also provide direct support to Residential Aged Care Facilities (RACF) and an integration between hospital and aged care to improve community healthcare for older Tasmanians. Stronger linkages with clinical nurse coordinators for service coordination between hospital/aged care/ and generalist and specialist palliative care providers is required.

More work needs to be done to ensure older people do not fall between cracks created by interjurisdictional and intersectoral policy decisions, and fragmented and siloed funding models.[7] It is also critical that we acknowledge the strong role that some aged care services in rural Tasmania play, in partnership with Primary Health Tasmania, in providing primary care within their communities.

Currently there is not an after-hours palliative care service model that meets the needs of the Tasmanian communities, including rural communities. Many rely on local experienced GPs. However, levels of experience vary considerably across communities. On call nurses are also stretched. Palliative care and care of the dying is a substantial part of current community nursing practice. Additional investment is required to facilitate out of hours palliative care support.

There is a lower availability of grief, loss and bereavement support for rural Tasmanians. In an ideal situation, where best practice palliative care is provided, grief can be managed by existing social and community supports. However, for many rural Tasmanians their experience includes being separated from their loved ones and communities, resulting in complicated grief. This usually requires management from clinical providers.

7 *Palliative Care it is more than you think* – Palliative Care Australia

We need to recognise that our rural medical professionals are often providing palliative care for their friends, or people well known to them in their communities.[8] This results in additional mental health impacts.

Physical palliative care infrastructure is not consistent across regional and rural Tasmania. For example, in the North and North East there are palliative care suites in most of the regional hospitals, this is similar in Southern Tasmania (noting there are fewer regional hospitals). Unfortunately, there are no designated palliative care beds in North West Tasmania. The Tasmanian Government has announced that 4 beds at Mersey Hospital will be imminently opened. However, this is 2 below the national standard based on population. Mersey is not an optimal site for people living on the West Coast of Tasmania. PCT has consistently lobbied for beds at North West Regional Hospital to help meet community need.

In order for these regional and rural palliative care beds to be effective, the workforce supporting them must be skilled and experienced delivering palliative care. Levels of expertise on palliative care can vary widely, resulting in inconsistency in care.

Limited time and access to professional development and to best practice resources restricts health professionals' effectiveness in providing palliative care. There is also the challenge of providing professional development to an understaffed workforce, which is time poor. As a result, patients can "fall through the gaps", leading to development of significant health issues, psychological distress, and potential increased cost to the health system.

Essential health professionals, clinicians and health services alone are insufficient to address the needs of people with life limiting conditions and their families. Communities of Care must be developed and supported as part of an effective community palliative care model. PCT believes this is a reason why rural Tasmanian women, in particular have reported that people with life-limiting conditions have been transferred out of small communities to larger centres, causing significant stress for them and their families.[9]

There is a shortfall in the supply of palliative care practitioners due to an ageing palliative care workforce. However, while feedback from PCT consultations affirmed that the workforce is older, it also indicated that the typical entry point to palliative care work is at a later career stage. It was also indicated that there is a demand for more male workers in order to provide options for clients who would prefer services to be provided by a male.

Tasmania's rural areas do not have consistent coordination of care. We do not have palliative care clinical nurse coordinators or a consistent multi-disciplinary approach to care, which is critical to ensure that rural Tasmanians are supported to die well. We talk about "person centred care" but we try and make the person fit an unsustainable system, rather than mobilising the system around the person and family. As a result, we waste money by ensuring our system continues to force dying Tasmanians away from their communities and into hospital where unnecessary interventions are provided.

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8 *Rural community nurses: Insights into health workforce and health service needs in Tasmania*, Centre for Rural Health University of Tasmania, 2013

9 *Talking to Women in Rural and Remote Tasmania 2019*, Women's Health Tasmania, 2019

Fragmentation of care is a major issue, with families often left to navigate the complex system. Coordination of specialties and providers involved in end-of-life care, such as GP, Geriatrics, Palliative Care, Psychiatry, NGO support agencies, is required. However, for this to happen there needs to be consistency in the training and knowledge across the workforce to be able to deliver this effectively.

Quality coordination, liaison and collaborative partnerships between palliative care specialist teams, aged care teams and general practitioners in an integrative model of care in the community are needed.

High quality, person-centred palliative care also requires a more inclusive definition of 'workforce' which recognises and values the roles of both the paid workforce as well as the informal and community supports that make up our communities of care[10].

Conclusion

Tasmania's regional and rural palliative care workforce provides the absolute best support they can in challenging circumstances. They are faced with issues including:

- Staff shortages;
- No consistent after hours palliative care services;
- Transient workers within their workforce;
- Lack of coordination of care and multi-disciplinary approaches to care;
- Lack of key trained people in palliative care in their workforce;
- Difficulty accessing professional development;
- Increased trauma and mental health issues as a result of consistently caring for community "friends";
- Lack of physical infrastructure to offer respite, pain management and other symptom control methods.

The impact on dying Tasmania's include;

- Lack of choice of place of care and place of death;
- Accessing care in later stages of diseases, leading to increased complexity in management;
- Increased complexity resulting in removal from community to a larger "metro" hospital; and
- Families being separated resulting in exacerbated mental health and social impacts for the dying and their loved ones.

In order to overcome these issues and plan effectively for larges increases in demand, it is critical that the Government investment in community palliative care that is consistent across Tasmania.

[10] *Strengthening Communities of Care Strategy 2018-2021*