

Townsville Area Palliative Care Plan: Situation Analysis 2020



Acknowledgements

Palliative Care Queensland (PCQ) acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pay our respects to Elders past, present and emerging.

This publication is an initiative of the PCQ's Connecting End of Life Care in Townsville project. PCQ would like to recognise the contribution of everyone who participated in this *Townsville Area Palliative Care Plan: Situation Analysis*, including consumers, community members, health, social and community care providers as well as Northern Queensland Primary Health Network, Townsville Hospital and Health Service, Townsville City Council, Health Consumers Queensland, Young Futures and the CELC-T project team and steering committee.

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About Palliative Care Queensland



Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. PCQ has been operating for over 30 years, has over 300 members and is a founding member of Palliative Care Australia. PCQ members include health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge and about the challenges the sector faces and the opportunities those challenges can bring.

Our organisational priorities are that all Queenslanders:

- are able to live every day until their last
- are able to have a dignified death, regardless of their illness, age, culture or location
- have access to a supportive social network at the end phase of life and have the choice of quality palliative care

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About the Connecting End of Life Care in Townsville (CELC-T) Project



The Connecting End of Life Care in Townsville (CELC-T) project is a partnership between PCQ and the Northern Queensland PHN.

The Connecting End of Life Care (CELC) program is an initiative of PCQ that aims to improve end of life care throughout Queensland by working with local Palliative Care services (both specialist palliative care and generalist palliative care), Primary Health Networks (PHNs), community groups, councils and community members to build culture, improve systems and develop clinical practices.

About Northern Queensland Primary Health Network (NQPHN)

Northern Queensland Primary Health Network (NQPHN) is an independent, not-for-profit organisation, funded by the Australian Government, to commission health care services to meet the needs and priorities for the population living in the north Queensland region.

The purpose of the NQPHN is to ensure that the population living in Northern Queensland access primary health care services that respond to their individual and community needs, and are relevant to their culture, informed by evidence, and delivered by an appropriately skilled, well-integrated workforce.

<https://www.nqphn.com.au/>

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Executive Summary

Since 2017, Palliative Care Queensland (PCQ) and the Northern Queensland Primary Health Network (NQPHN) have partnered to improve palliative care in the Townsville Hospital and Health Service (THHS) area. This partnership is called the Connecting End of Life Care in Townsville (CELC-T) project.

In 2019-2020, the CELC-T project identified the need to develop a palliative care plan for the Townsville Area, which, for the purposes of this document, is hereafter referred to as the 'THHS area'. The work is imperative as the total demand for specialist palliative care in Queensland is projected to grow by approximately 5,000 separations by 2026, and modelling suggests that the THHS area will experience one of the greatest absolute growths in the number of specialist palliative care separations and volume of bed days in Queensland [1].

To develop a palliative care plan that meets the needs of those living in the THHS area, the CELC-T project conducted a *Townsville Area Palliative Care Plan: Situation Analysis*, which aims to understand the current state of palliative care in the THHS area, and points towards opportunities to improve and transform palliative care in THHS area.

To identify the current state and the improvement opportunities, this palliative care plan's situation analysis is comprised of three main sections. The first section of the analysis provides an overview of the CELC-T project, the rationale for development of the THHS area Palliative Care Plan and methodology. This is followed by a 'snapshot' of the THHS area and overview of the policy context.

The second section reviews key findings from consultations with consumers, healthcare providers, and key decision makers and leaders. The full consultation report findings are included in a separate document, entitled, *"Supplementary Report to the Townsville Area Palliative Care Plan: Situation Analysis 2020 - Findings from the Roundtables, Kitchen Table Discussions and Community Consultations."*

The final section provides a series of directions that THHS area stakeholders could take as they develop a palliative care plan. The Townsville Area Palliative Care Plan will target the Northern Queensland Primary Health Network's reach in the Townsville Hospital and Health Service (THHS) area, including the eight local councils of Townsville, Charters Towers, Flinders, Burdekin, Hinchinbrook, Palm Island, Flinders and Richmond, together with THHS area palliative care service and support providers, aged care providers and the region's community members.

When complete, the Townsville Area Palliative Care Plan will inform strategy, priorities, funding, and policies to improve palliative care for all residents in the THHS area, including vulnerable populations where services must expand to meet the need.

“

We believe that the way we care for our dying is a significant indicator of the kind of society we are.

Palliative Care Queensland

A Summary: Directions To Consider When Creating A Palliative Care Plan

Direction 1: We can work together with communities in the THHS area to raise awareness about palliative care, and to activate people to help care for one another.

Direction 2: We will help patients and their loved ones navigate the palliative care system.

Direction 3: We can strengthen support to palliative care patients and families living in rural and remote areas in the THHS area.

Direction 4: We will aim to provide equitable and appropriate palliative care for all Indigenous residents.

Direction 5: We can initiate Advance Care Planning (ACP) conversations where they haven't yet begun, and continue ACP conversations where they have started.

Direction 6: We will connect palliative care services, improving continuity and integration so that patients and families can more easily access the care they need.

Direction 7: We can increase the capacity and capability of the THHS area workforce to provide safe, high quality, person-centered palliative care.

Direction 8: We can improve palliative care in the THHS area through data monitoring, evaluation and research.

Background

About the CELC-T Project

The Connecting End of Life Care in Townsville (CELC-T) project is an initiative of Palliative Care Queensland's (PCQ) Connecting End of Life Care (CELC) Program. The CELC Program is a collection of localised collaborative projects administered by PCQ to support local improvements in palliative and end of life care.

The CELC program primarily aims to improve end of life care throughout Queensland by working with local palliative care services (both specialist palliative care and primary palliative care), Primary Health Networks (PHNs), community groups, councils, and community members to build culture, improve systems and develop clinical practices.

Commencing in 2017, Connecting End of Life Care in Townsville (CELC-T) was the first CELC project, funded by the Australian Government through NQPHN. This *Townsville Area Palliative Care Plan: Situation Analysis* builds on previous phases of CELC-T (Figure 1), and lays the foundation for development of the four-year palliative care plan for the THHS area into 2024. Additional information on the CELC-T Project can be found at www.palliativecareqld.org.au/celc

Phase 1: Explore

City of Townsville 2017-18.

Improve the capacity and capability of RACF and General Practice's provision of primary palliative care and end of life care, with a focus on after-hours need.

Phase 2: Connect

City of Townsville 2018-19.

Connect systems to gain further understanding on key issues, interdisciplinary teams providing palliative care and organisations with education, support, and resources, and community to create awareness and understanding about palliative care services and support.

Phase 3: Expand

Townsville Area 2019-20.

Collaboration with Townsville University Hospital and the Queensland Centre for Palliative Care Research and Education. Wider support including Aboriginal and Torres Strait Island Health Services, allied health, acute care, and rural communities. Development of a Situation Analysis.

Phase 4: Build

Townsville Area 2020-24.

Develop a four-year palliative care plan, build partnerships and linkages with stakeholders, local, national, and federal projects and peak-bodies, deliver practice development and create networks of support and leadership opportunities with the palliative care workforce, and build community confidence to source information and services, and facilitate conversations about end of life.

Figure 1: CELC-T Project Phases

WHY A SITUATION ANALYSIS?

This *Townsville Area Palliative Care Plan: Situation Analysis* will review the current state of palliative care services in the Townsville Area, analysing both the services that are currently available and the ones that are needed to support people living in the region who have a life-limiting illness, their families, carers and the broader community in dealing with loss, ageing, dying and grief. The findings of the Townsville Area Palliative Care Plan: Situation Analysis result in a series of directions that will be used to develop a Townsville Area Palliative Care Plan in 2020. Hereafter, the region covered by this plan will be referred to as the THHS (Townsville Hospital and Health Service) area.

WHAT IS PALLIATIVE CARE & WHY FOCUS ON IT?

Palliative care is holistic healthcare that focuses on improving the quality of life and quality of care for people with a life-limiting illness and their families, and helps people live as actively as possible until death. Palliative care is about preventing and relieving suffering, communicating goals of care, and identifying, assessing, and treating physical, psychological, emotional, social and spiritual symptoms as early as possible [2, 3].

Palliative care can begin as soon as a person is diagnosed with a life-limiting condition, whereas care at the end of life or 'end of life care' represents a specific time frame. The timeframe identified by 'end of life care' is inconsistently used within the health sector – it can be defined as the last twelve months, six months or sometimes only the last few days of life. Unfortunately, when the health sector focuses on 'end of life' care alone, the focus of care is narrowed to the dying phase, meaning that earlier support for patients and their loved ones may be missed.

While many assume that palliative care begins only once all treatment aimed at 'cure' has ended or when a person is dying, it is well accepted that there are benefits in providing palliative care in association with curative treatment, for longer periods, and earlier within a person's illness for non-malignant conditions such as respiratory disease, cardiovascular disease and dementia [4]. Palliative care is not 'one size fits all'. Rather, people who require palliative care may:

- Be at different stages, where differing illnesses (such as cardiovascular disease, dementia or renal disease) will have differing needs over various timeframes
- Be of all ages, where the needs of children and young people, and their parents and families are often quite different from those of people facing the end of life at an older age
- Have different cultural, social, emotional, relational and spiritual needs, and
- Need palliative care for a short period of time, intermittently, or consistently over months or years.

To care for their citizens, government and service providers have significant responsibilities to improve the availability of palliative care for all Queenslanders living with a life-limiting illness. Though estimates vary regarding the amount of people who could benefit from palliative care, it is estimated that between 80 000 and 140 000 Australians would benefit from palliative care each year [5, 4, 6].

WHY IS IT IMPORTANT TO PLAN FOR PALLIATIVE CARE?

Palliative care needs change over time

By optimising the quality of life for individuals, carers, family and friends, the THHS area promotes the vital role of palliative care at the end of life for many of its residents. However, planning for current and future palliative care needs is a complex task.

Palliative care and end of life care needs are changing as fewer people are dying suddenly or from illnesses with a predictable trajectory (such as cancer), and more Australians are experiencing a prolonged disability, frailty and illness before dying with varying illness trajectories from life-limiting chronic disease (such as heart disease, lung disease, neurodegenerative disease and dementia) [5, 4, 7, 1]. The types of palliative care and support that may be needed by an individual, their families and carers will vary and may include formal and informal supports.

As the THHS area plans for its future palliative care services, it must factor in the increase in chronic and non-malignant life-limiting illnesses that results in more people needing palliative care. The leading specific causes of death in Queensland in 2018 were coronary heart disease, stroke, lung cancer, dementia and COPD, noting the Indigenous death rate in Queensland is 49% higher than the non-Indigenous rate, with the main causes coronary heart disease, diabetes, lung cancer, COPD and suicide [12]. Within the THHS area, the leading causes of death were cancer (20.6%) and cardiovascular disease (15.5%) in 2017 [8].

There is a difference between where people want to die, and where they actually die

Inconsistencies between the preferred place of care, preferred place of death and the places where death most commonly occurs is an issue that needs exploring through research, policy and engagement, noting these can change overtime. Most people receiving palliative care prefer to be cared for, and to die, at home or in the community, however, many people do not achieve this [5, 9, 4, 7, 6, 10, 1].

People need different services – some need generalist palliative care, others need specialist palliative care and many need both

While PCQ believes that ‘palliative care is everyone’s business’, when creating a plan for palliative care services, it is important for a plan to include actions that focus on both generalist and specialist palliative care services.

- Some people living with a life-limiting illness will require only generalist palliative care, which is provided by a wide-range of providers including GPs, oncologists, community nurses, allied health, pharmacists, aged care, and other community service providers.
- There is a clear rationale for consideration of primary palliative care needs which includes specific support to earlier referrals and integration with chronic disease management programs, especially for people aged under 65 years.

Others who have more complex needs will require specialist palliative care which is provided by multidisciplinary teams with specialised skills, competences, experience and training in palliative care [4].

Ideally, the plan will include a focus on both specialist and generalist health services, as well as partnering with compassionate communities to provide care and support for residents. This focus is consistent with the Palliative Care New Essentials model:

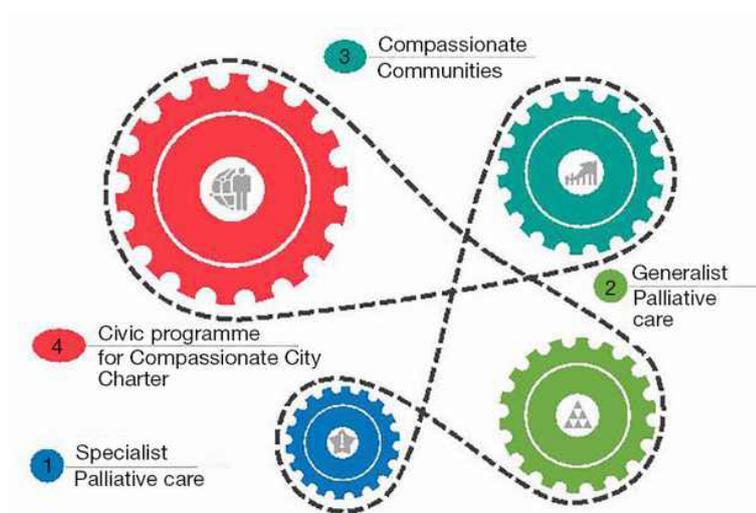


Figure 2: Palliative Care New Essentials Model [11]

Changes in demographics

The older population in Queensland is growing at a rate greater than Australia overall (38.2%). Where in the ten years previous to June 2016, this population grew by 47.1% (228,637 persons) to total more than 712,000 persons aged 65 and over or 14.7% of Queensland's population [12]. This is projected to rise to 1.01 million (17.7%) by 2026, 1.35 million (20%) by 2036 [12] and 2 million (2%) by 2046.

When creating a palliative care plan for the THHS area, future population projections must be considered. The population of the THHS area is projected to increase at a rate of 1.52% each year to 348,311 by 2036, noting:

- The population of two regions is anticipated to decline - Hinchinbrook region by 4% (-1,092) and Northern Highlands region (which includes Flinders Shire Council and Richmond Shire Council) by 9% (-322), and
- The area of greatest population growth will be in the Townsville North Local Planning Region, which will grow annually at a rate of 2.75% over the time period. [4]

As Queensland continues to grow with an ageing population, it is necessary for services and organisations to overcome challenges in the provision of palliative care and end of life care. The population increase will impact services substantially, requiring increases in all aspects of service delivery, including capacity, capability and workforce.

Methodology

To create the most appropriate plan possible, it is important to consider: the health status and demography of the THHS area and its placement within the context of Queensland and Australian health data and policies; best practices and findings from literature, and; the expressed palliative care needs of THHS area residents, health and care providers and key stakeholders.

To inform this analysis, three main activities were undertaken, as demonstrated by the following visual:



Figure 3: Situation Analysis Methodology

This *Townsville Area Palliative Care Plan: Situation Analysis* will provide the information needed to create a Townsville Area Palliative Care Plan, and was developed through a population-based approach, which recognises and responds to the growth of consumer or person-centred models that put individuals, their families and carers at the centre of planning, design and delivery of services [13]. Person-centred care models have shown that fully involving the individual with unique needs, concerns and preferences at all stages results in safe and high-quality care, and better outcomes for both the individual, the broader community and the health system [13]. This is underpinned by the Australian Charter of Healthcare Rights and National Safety and Quality Health Service Standards [13], and is also a key element of the National Palliative Care Strategy [6]. In Queensland, it is embedded in the work of the Queensland Clinical Senate on end of life care activities and the Patient Safety and Quality Improvement Service (PSQIS), the person-centred Healthy ageing: A strategy for older Queenslanders [12] and the THHS Clinician Engagement Strategy 2018-2022 [14].

The methodology also draws from the concept of public health palliative care, which aims to address the social determinants that impact on people's health and wellbeing at end of life and ensure equity of access to palliative care and other supports [15]. This happens through a focus on early intervention and a social approach to the issues and experiences of dying to respond to the 'medicalisation' of palliative care and end of life care and the loss of community skills and activities in supporting people at end of life [15].

INFORMATION

Over 100 documents were reviewed during the literature and policy review, which is reflected throughout the analysis. The core points of reference for this analysis include:

- THHS Services Plan 2018-2020 and Background Paper [8]
- Northern Queensland PHN Health Needs Assessment – Brief Update 2019-2022 [16]
- Queensland Health 'Statewide Strategy for End of Life Care 2015' [17]

- Queensland Health 'Palliative Care Services Review – Key Findings' [1] and
- Australian Government National Palliative Care Strategy [6].

The literature and policy review was supplemented by desktop mapping to identify what services and supports could be found online by residents in regional and rural areas of Queensland. The mapping identified who was providing the service as well the type of service being provided, across both specialist and primary palliative care. The scope of this exercise was limited to:

- Common online directories of PalAssist, National Palliative Care Service Directory, HealthDirect, My Community Directory and Queensland Health's 'Find a health service'
- Queensland HHS websites for regional and remote locations
- Queensland Health state-wide palliative care project websites, and
- National Palliative Care Project websites.

A total of 312 support services including helplines and websites were included in the desktop mapping, the results of which were compiled to inform a community directory for THHS AREA residents.

COMMUNITY ENGAGEMENT

To view the community as an equal partner in providing quality care at the end of life is essential to public health palliative care [9, 14]. This builds on work previously undertaken by PCQ during the Compassionate Communities Conversation Series conducted in 2019 across Queensland.

PCQ engaged Health Consumers Queensland to undertake the Kitchen Table Discussion method, as this process enables community members who may not normally have a say to have their voice heard in an informal, friendly and safe setting. Four Kitchen Table Discussions were held in the THHS area in 2020, and each host led consumers in a discussion by asking five questions:

1. What palliative care services and supports do you know that are available in our local region?
2. Of the Palliative Care services you know about, which ones do you think are working well and which are not?
3. What additional palliative care services and supports do you believe are needed in our region?
4. What do you think are opportunities for improvements in palliative care services and supports in our local region?
5. Based on everything we have discussed - what do you believe are the biggest priorities to improve palliative care in our region?

These same questions were asked in another community consultation held in February 2020 at the Notch Community Hub.

Full reports of the community engagement consultations can be found in the Supplementary Report to the Townsville Area Palliative Care Plan: Situation Analysis 2020 - Findings from the Roundtables, Kitchen Table Discussions, and Community Consultations.

SERVICE ENGAGEMENT

To gain the perspectives of healthcare providers, a series of roundtables and interviews were held from February – May 2020. These were undertaken with healthcare leaders, palliative care providers, allied health, and community representatives with a lived experience of palliative care in the THHS area. Consultations included:

- Two roundtables held with 37 key decision makers and leaders;
- Numerous roundtables held with a total of 73 frontline staff;
- One diversional therapist and pastoral carers roundtable discussion with 12 participants; and
- Four Key Informant interviews with six stakeholders representing perspectives of consumers, the Townsville Hospital and Health Services, the Northern Queensland Primary Health Network, and the Townsville City Council.

All service engagement activities followed the same question guide:

1. What palliative care services and supports are available in the THHS area?
2. Of these, which services and supports are working well and which are not?
3. What additional palliative care services and support are needed in the THHS area?
4. What are some opportunities for improvements in palliative care supports and services?
5. What are the recommended priorities to improve palliative care in the THHS area?

A common journey pathway mapping exercise was also held with the CELC-T Steering Committee, using these same five questions.

Full reports of the service engagement consultations can be found in the Supplementary Report to the Townsville Area Palliative Care Plan: Situation Analysis 2020 - Findings from the Roundtables, Kitchen Table Discussions, and Community Consultations.

Information Key Findings

The THHS area - Snapshot

The THHS area is home to over 241,000 people or approximately 4.7% of Queensland's population, and covers 149,500 square kilometers (Figure 1) [8]. This area consists of the seven local planning regions and seven local councils:

- Townsville City (including Magnetic Island), Townsville North and Townsville South which are all within the City of Townsville Council,
- Charters Towers (Charters Towers Regional Council),
- Burdekin (Burdekin Shire Council)
- Hinchinbrook, including Palm Island (Hinchinbrook Shire Council and Palm Island Aboriginal Shire Council), and
- Northern Highlands (Flinders Shire Council and Richmond Shire Council)



Figure 4. Townsville region and geographic boundary: Townsville Hospital and Health Service with inpatient facilities [8]

The region has a rich diversity of traditional owners and custodians. This includes the Bindal and Wulgurukaba People in the THHS area [18], the Gudjal people around Charters Tower, the Nywaigi People at Mungalla Station, and the history of forced removal of Aboriginal people and Torres Strait Islanders from across Queensland to Palm Island between 1918 and 1972, where many of the community members being descendants of this process [19].

Considered the unofficial “Capital of North Queensland” by locals, the city of Townsville has 80% of the resident population of the region with around 12.5% of the population aged 65 years or older [8]. The city of Townsville is located on the north-east coast of Queensland, about 350 kilometers south of the Cairns and about 1,300 kilometers north of Brisbane. It is the largest city in regional Queensland, outside the southeast corner [8]. Townsville's economy is primarily reliant upon retail trade, health and education services, government administration, defence, construction, mining, manufacturing as well as property and business services [18]. This includes the Port of Townsville which provides a transportation hub for Northern Queensland's mining and agricultural industries, a Copper Refinery, Zinc Refinery, Queensland Sugar Corporation Distribution Centre, James Cook University, Lavarack Barracks, Townsville RAAF and is home to the Townsville Fire which compete in the Women's National Basketball League and the North Queensland

Cowboys National Rugby League team [18]. Further, the region adjoins the Great Barrier Reef World Heritage Area and the Great Barrier Reef Marine Park [18]. More broadly, the region's main economy is agriculture, transport, and tourism.

The region is covered by the THHS, which is one of the most geographically dispersed hospital and health service catchments in the state of Queensland (figure 1 and 3). The THHS comprises 21 facilities across its catchment, including 19 hospitals and community health campuses, where 15% of total separations from THHS in 2014/15 were residents of other HHS's [8].

Townsville University Hospital (TUH), located in the city of Townsville, is the tertiary referral hospital for the THHS area, and the only tertiary referral centre in North Queensland, supporting a referral catchment of almost 700,000 people from remote communities – located as far as the Cape York Peninsula and the Torres Strait Islands in the north, and Mount Isa and the Gulf of Carpentaria in the west [8]. Aboriginal and Torres Strait Islander health services include the Townsville Aboriginal and Torres Strait Islander Corporation for Health Services, Indigenous Hospital Liaison Officers within THHS, and on Palm Island, the Joyce Palmer Health Service and Palm Island Primary Health Care Centre.

During development of the Townsville Area Palliative Care Plan, there is a need to consider social determinants and community development, as, within the region, there is variation between the health determinants and health status of residents, including:

- 10,738 (8%) of the population identify as Aboriginal or Torres Strait Islander, where the local region of Hinchinbrook has the highest number of Indigenous Australians (21%) [8, 20]
- 48.0% of dependent children in families with Aboriginal and/or Torres Strait Islander persons were from jobless families compared with 11.4% of dependent children in non-Indigenous families [20]
- 24.4% of people residing in THHS are considered most disadvantage on the index of relative socio-economic disadvantage quintiles, compared with 20% for Queensland [16]
- The region has an unemployment rate of 9% compared with 6% for Queensland and for those in employment, 27.9% earn an income of less than \$20,800 annually [16]
- Flinders and Richmond Local Government Area (LGA) have been drought declared since 2017, in addition to a large proportion (46%) of Charters Towers LGA [16], and
- Richmond and Hughenden inpatient facilities are located within areas classified according to the Australian Standard Geographical Classification (ASGC) as Remoteness Area (RA) 5 (very remote) [8].

The region also has higher rates of chronic diseases, such as diabetes, chronic obstructive pulmonary disease, coronary heart disease and stroke, than the rest of Queensland and Australia, with diabetes, cardiovascular, mental health and chronic kidney disease responsible for higher hospitalisation rates among the Aboriginal and Torres Strait Islander population, which make up approximately 8% of the population living in Townsville.⁶ The appendix provides further detail with its inclusion of the 2018 THHS Area Health Snapshot, developed by the NQPHN.

Approximately 9% of the population is aged 70 years and over, which is predicted to increase at an annual growth rate of 4.1%, compared to total population growth of 1.5% [8]. The THHS area falls within the Northern Aged Care Planning Region (ACPR), noting this also includes locations outside of the THHS boundary [21]. With respect to aged care, the Northern ACPR:

- Had 3.8% of the Indigenous population aged over 50 years and 20.5% of those aged over 65 years were born outside of Australia (2016) [21]
- 25.9% of older people live alone, higher than Queensland and Australia overall (2016) [21]

- There were a total of 1,376 people on a Commonwealth Home Care Package¹ or 5.4% of packages in Queensland (at 30 December 2019), including 564 Level 4 'high-level care needs' packages (7.6% of Queensland) [22]
- 668 people in the region (7.6% of Queensland) were waiting on a package at their approved level at 31 December 2019, who had yet to be offered a lower level package, noting estimated wait times of 3-6 month up to 12+ months [22]
- Of those people using home support, 80.8% did not have a carer in 2017-18 [21]
- There were 74 places in residential care per 1,000 people aged over 70, compared with 74.4 in Queensland and 75.9 in Australia, where there was a 91.3% occupancy rate for residential aged care at 30 June 2018 [21]
- 56.2% of people within residential care had a diagnosis of dementia (2018) [21], and
- The average length of stay in residential care was 31 months before their death in 2017-18 [21]

Despite the crucial role of GPs in primary palliative care there is not nationally consistent, routinely collected data enables reporting on this [23].

The region experiences a relatively high number of palliative care separations and bed days (Figure 5) [7], where the THHS demand for specialist palliative care as measured by separations is anticipated to grow by 42% between 2016-17 and 2026-27 [1]. The region has one of the highest number of specialist palliative care physicians in Queensland, after Metro North HHS, Metro South HHS and Gold Coast HHS [1].

Place of residence	Separations 2017-18	Bed days 2017-18
Cairns and Hinterland	644	6,274
Central Queensland	364	2,565
Central West	16	72
Darling Downs	862	7,597
Gold Coast	1,014	8,822
Mackay	162	1,209
Metro North	2,175	22,131
Metro South	3,008	28,742
North West	58	820
South West	54	516
Sunshine Coast	1,020	5,562
Torres and Cape	30	479
Townsville	595	5,560
West Moreton	708	6,062
Wide Bay	662	4,978
Interstate/overseas/Unknown	52	378
Not stated	8	65
Total in public and private facilities	11,438	101,832
Total in public facilities (includes public and privately funded care)	8,897 or 78% of all separations	65,293 or 64% of bed days

Figure 5: Specialist palliative care separations for all ages, all facilities, all funding types by residence, 2017-18 [1]

¹ Home Care Packages provides different levels of aged care services for people in their own homes

The Policy and Fiscal Context

It is widely acknowledged that the policy, funding and service delivery of palliative care, end of life care and aged care is complex in Australia [5, 24, 7, 1]; however, the Queensland Health Palliative Care Service Review and outcomes of the Queensland Parliamentary *Inquiry into aged care, end of life and palliative care and voluntary assisted dying* provide a unique opportunity for both specialist palliative care and primary palliative care in Queensland. The provision of palliative care services in Queensland is guided by the *Statewide Strategy for End of Life Care 2015* [17], the *Queensland charter for care of adult patients at the end of life* [25], the *Clinical Services Capability Framework – Palliative Care* [26] and the *Care Plan for the Dying Person – Health Professional Guidelines* [27].

While Governments have recognised community concern about palliative care and end of life care, progress is being hindered by conflict over responsibilities and how service provision is coordinated across different settings, with the 2018 Productivity Commission Report highlighting reforms are needed to put consumers' needs and choices at the heart of palliative care and end of life care services and to ensure capacity to meet needs [5]. The states and territories have different approaches to planning and delivering publicly funded services, different local service delivery practices and differently structured health-care systems [23]. For palliative care, in crude terms:

- The Australian Government has funding and program responsibility for aged care (including RACFs and Home Care Packages), the National Disability Insurance Scheme (NDIS) and in-part general practice and community pharmacy through the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS) [5, 1, 24, 28].
- States are responsible for the public hospital system, paramedic services and community health services (including community palliative care), which is jointly funded by the Australian Government.
- In Queensland, Hospital and Health Services (HHSs) provide specialist palliative care services, including in-patient care in a designated bed, consultation liaison and outpatient services in the acute hospital setting, and specialist palliative care advice and support to home and community-based care [1].
- Further, The Queensland Health Community Funding Branch provides funding for hospices and some private palliative care services in Queensland [1], none of which are located in the THHS area.

In 2017-18, the total amount spent across Queensland HHSs for palliative care services², was approximately \$101,046 million [28]. The 2019-20 there was a state budget announcement of an additional \$17 million for community-based palliative care services, with a focus on rural and remote areas of Queensland [28]. Agreements made by Queensland Health with each individual HHS leads to a different model for funding, levels of care and service delivery, where each HHS determines how it distributes funding to each of the sub-acute specialised care types, including palliative care, and there are no specific activity outcomes or measurements tied to this funding [28]. The Service Agreement 2019/20 – 2021/22 for THHS includes funding for 'Palliative, Maintenance & Frail Elderly' of \$47,850,103 under the National Health Reform Agreement, and \$445,811 for a Specialist Palliative Care Telehealth Service under Care in the Right Setting (CaRS) funding for 2019-20 [29].

² Include admitted patient allocation, non-admitted patients and community palliative care services to admitted patients.

There were a number of recent key policy documents and activities to consider in this *Townsville Area Palliative Care Plan: Situation Analysis*, however given the complexity of palliative care provision across setting and sectors, many more could be added at varying levels:

AUSTRALIAN GOVERNMENT

- National Palliative Care Strategy
- Royal Commission into Aged Care Quality and Safety
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability
- Exploratory Analysis of Barriers to Palliative Care Policy Papers
- National Safety and Quality Health Care Standards (2nd ed)
- National Aboriginal and Torres Strait Islander Health Plan 2013-2023
- National Strategic Framework for Chronic Conditions
- National Consensus Statement: Essential Elements for Safe and High Quality End of Life Care
- The National Framework for Rural and Remote Health
- Review of National Advance Care Directive Framework
- Introducing Competition and Informed User Choice into Human Services Report 2018
- National Carer Strategy
- Cancer Australia Strategic Plan 2014-2019
- Australian National Diabetes Strategy 2016-2020
- National Strategic Action Plan for Lung Conditions
- National Dementia Framework for Action 2015-2019

QUEENSLAND GOVERNMENT

- Queensland Statewide Strategy for End of Life Care
- Inquiry into aged care, palliative care, end of life care and voluntary assisted dying
- Healthy Ageing: A strategy for older Queenslanders
- Queensland Health Palliative Care Services Review
- Queensland Health Palliative Care Clinical Services Capability Framework
- My health, Queensland's future: Advancing health 2026
- Queensland Health System Outlook to 2026
- Advancing Kidney Care 2026
- Queensland Charter for Care of Adults at the End of Life

TOWNSVILLE HOSPITAL AND HEALTH SERVICE

- Strategic Plan 2018-2028
- Services Plan 2018-2020
- Palm Island Health Action Plan 2019-2020
- Reconciliation Action Plan 2019-2021
- Clinician Engagement Strategy 2018-2022

In addition, many of the local Councils have Community Plans which recognise that the greatest resource is their people, outlining strategies to 'build, preserve and enhance this asset' [30].

Desktop Mapping

The key findings from the desktop mapping revealed a lack of consistency in mapping and inaccurate information on the internet and highlighted that there are no Australian standardised palliative care service navigation tools or directories available. This is likely to increase problems in accessing palliative care, due to consumer and clinician confusion. The key findings and opportunities of the desktop mapping were:

- Need for a directory of services online for THHS area users to find the correct type of service, structured in such a way to increase the likelihood of sourcing a service complementary for the THHS area user's need
- A telephone navigation system to be available 24/7 to enable THHS residents with limited computer literacy to access the right services at the right time
- The National Palliative Care Service Directory and PalAssist should be included in a statewide palliative care directory, e.g. My Community Directory
- Regular user testing of the directories should be reviewed by an organisation external to the provider to ensure user needs are being met
- Nurse navigators and social workers should be involved in a palliative care mapping steering committee/focus group to utilise expertise and experience in providing patient support

In addition, a services profile of the Palliative Care Centre at the Townsville University Hospital was compiled (Table 1) as a baseline for service development and the Townsville Area palliative care plan.

Table 1: Service Profile of the Townsville Specialist Palliative Care Centre

Townsville Palliative Care Centre (Townsville University Hospital)		
<p><i>TUH provides generalist and specialist inpatient and outpatient palliative care services for patients across Northern Queensland and also supports a referral catchment of almost 700,000 people from remote communities – located as far as the Cape York Peninsula and the Torres Strait Islands in the north, and Mount Isa and the Gulf of Carpentaria in the west.</i></p> <p><i>Capacity and capability: It is a level five (5) specialist service, training medical and nursing staff and also providing inpatient care for management of complex symptoms and provision of end of life care.</i></p>		
Current Resources Profile (as of June 2020)		Description / Further Comment
Ward	18 Beds	
Nursing	<ul style="list-style-type: none"> • Funded to 18 patients • 1.0 Nursing Unit Manager (overseeing both ward and outreach) • 1.0 Clinical Nurse Consultant • 3.0 FTE nursing for the outreach service 	Hours per Patient Day (HPPD) is 7.127 – 1/3.2 ratios on an early; 1/3 on a Late shift; and 1/6 on a night shift. At full capacity there are 56 hours AM; 48 hours PM and 24 hours Night shift.
Medical Officers	<ul style="list-style-type: none"> • 3.0 FTE Consultants • 2.0 FTE Registrars • 1.0 FTE Resident • 1.0 FTE intern • Staff Specialist (≈ 0.4 to 0.5 FTE) 	Split across the whole service. Registrars include an advanced palliative care trainee.
Allied Health	<ul style="list-style-type: none"> • 2 x Social Workers • 1.0 FTE Senior Occupational Therapist • 1.0 FTE Junior Occupational Therapist • 1.0 Physiotherapist • 1.0 ILO (Indigenous Liaison Officer) 	<i>Indigenous Liaison Officers:</i> Respondents indicated that around 7% of Aboriginal and Torres Strait Islander peoples are referred to the Townsville Palliative Care Unit or Outreach Services, from Townsville Aboriginal and Island Health Services (TAIHS) alone. ILOs are instrumental in end of life care decision making and providing key assistance to

		keep First Nations people on country. ILOs link up appropriate Queensland Health inpatient and community services for First Nations people across Northern Queensland
Administration	<ul style="list-style-type: none"> • 1 for Ward • 1 for Outreach • 1 Volunteer coordinator 	
Palliative Care Outreach Services	Services provide coordinated care (from Townsville) for patients, carers and families - as well as health care professionals - who are located in Townsville, Ingham, Ayr and Charters Towers. The Outreach team consists of medical, nursing, contracted domiciliary nursing services and allied health staff who are available for inpatient as well as in home visitations, where possible. Respondents stated that the Outreach team oversee contracted Non-Government Organisations (NGO) i.e. Anglicare, however they are not funded to provide direct service into the community.	
Other Supporting Services	<ul style="list-style-type: none"> • Bereavement and counselling service (offered by social workers) are available as consultancy service for generalist palliative care/end of life patients in any department/ward at the Townsville University Hospital (TUH). This service is available 24/7 to all TUH hospital staff and also GPs and medical officers in rural and remote locations. • Consultation services with patients (as an inpatient or in outpatient clinics); as well as primary palliative care providers across the THHS area • Telehealth services for medical appointments, multidisciplinary team meetings and case conferencing particularly for patients that are unable to travel to Townsville. • Volunteers are specifically trained in the principles of palliative care and are available to support the Specialist Palliative Care Unit 	

Notes: FTE – Full Time Equivalent



KEY INFORMATION SOURCES FOR FURTHER READING:

- Queensland Health *Palliative Care Services Review – Key Findings* [1].
- Queensland Parliament *Inquiry into Aged care, end of life and palliative care Report (no. 33)* [28]
- Queensland Health *Healthy ageing: A strategy for older Queenslanders* [12].
- Queensland Health *Statewide Strategy for end of life care 2015* [17].
- Queensland Health *Care Plan for the Dying Person Health Professional Guidelines* [27].
- Townsville HHS *Health Service Plan Background Paper* [8]
- Northern Queensland PHN *Health Needs Assessment Brief Update 2019-2022* [16]
- ACSQHC *National Consensus Statement: essential elements for safe and high-quality end of life care*
- PCA *Palliative Care Service Development Guidelines* [24, 4].
- WHPA *Global Atlas of Palliative Care at the End of Life* [3].
- AIHW *Palliative care services in Australia - Web Report* [23].
- AIHW *Gen: Aged Care Data website* [21].
- Palliative Care Queensland website [46].
- CareSearch Project [42].

Consultation Key Findings

Findings: Community Engagement

THHS area Consumer Kitchen Table Discussions

In February 2020, four Kitchen Table Discussions were conducted in Townsville, Charters Towers and Palm Island. Thirty-two consumers, including four hosts, were consulted.

For a full review of the consultation findings, please refer to the Supplementary Report for the *Townsville Area Palliative Care Plan: Situation Analysis*. The key findings under knowledge of palliative care services in the THHS area included:

- Varied knowledge of available palliative care services in the Townsville area outside of the Townsville Hospital Palliative Care Service, which appears to be highly regarded
- The Mater Hospital and three aged care facilities were also discussed, but it was not known if these facilities provided palliative care services
- Knowledge of palliative care services available in the home seems limited with many consumers indicating a non-awareness of available services in the home

Consumers considered that the most important element of care at the end of life is communication. Related to the question of what is not working well in palliative care support and services was that communication between care providers, patients and patients' family and friends was not always adequate or appropriate to the situation, leading to angst and longer-term impacts on family members. Frustration was voiced at not being kept informed by health clinicians of patients' conditions and choices at end of life.

Feedback from Aboriginal and Torres Strait Islander participants spoke of the need for health staff to have a better understanding of cultural needs and empathy towards indigenous patients and their family members. Other comments included the need for health staff to understand cultural ways, including wailing for their loved ones, why families bring in food, and having enough space for large family groups.

With regards to additional services and supports in palliative care, consumers raised the need for:

- Access to transport for elderly family members
- Reasoning for medication or food stoppage to patients
- Access and direction to financial and legal advice
- Provision of counselling
- Where and how palliative care is provided
- Introduction of a case manager for families
- Access to cultural liaison officers
- Awareness by health professionals on the spiritual needs of palliative patients

Improvements to services included more support for carers, availability of palliative care information (via brochures) in general practice clinics, health professionals supporting the upload of advanced care directives to health systems, recognise advanced care directives to support the end of life journey, and cultural competence training for all palliative care staff.

Priority areas were identified as:

- Increasing community awareness and education about palliative care, what it is, what it involves and what services and supports are available
- More conversations about dying and what is involved in end of life care
- Assessment officers and case managers for patients' families
- Less clinical palliative care service environment, e.g. more peaceful and calming areas
- Understanding culture and culturally sensitive staff in palliative care

- Person-centred care that is accommodating to the individual's need

Community aged care family and friends

In this community café, held at the Notch Community Hub, family and friends of those in aged care residences and in the community shared their experiences of palliative care in the THHS area.

The key findings from this activity included:

- Most community members identified the Specialist Palliative Care Unit at the Townsville University Hospital as a place to receive palliative care or the Emergency Department after hours
- Other palliative care services were listed as General Practitioners (GPs), community nurses, community providers in the home, and nursing homes/residential aged care facilities
- Difficulty understanding what constitutes palliative care, respite and end of life – community members find the terms used by health professionals confusing
- Greater education is required to enable families to discuss dying wishes – community members felt that GPs and health providers do not prompt these issues and it was seen as important to make appointments with GPs to undertake such conversations
- Terminology used by health professionals is not considered easy to understand, with community members feeling that the use of simple terms would reduce angst and negative longer-term impacts on families

Opportunities for improvements in palliative care services and supports within the THHS area were highlighted as:

- Needing more conversations similar to this exercise being conducted, with targeted consideration of Torres Strait Islander people
- Hospital bedding arrangements for a family member to be with the palliative patient
- Greater opportunities for community volunteers with adequate support
- Policy changes to enable greater cultural understandings and support mechanism to be delivered by competent people
- Proper funding of programmes and services to enable continuance of trust

Recommendations for additional support and services included:

- Clear pathways (navigation tools) on how to negotiate palliative care available in the community and in aged care
- More aged care staff, social workers and community nurses
- Greater support for carers, with more community conversations and engagement
- Provision of greater support for those who are isolated, older, alone, have limited assistance, and reduced access to information and/or the means to seek assistance.

The largest priorities identified to improve palliative care in the THHS area included:

- Greater number of community conversations and education programmes
- Assistance to upload advance care documents online to the appropriate areas
- Sufficient funding to ensure all community members receive quality of care at the end of life

Comments from Townsville Area Consumers

"Nurses were lovely with patient and family. They explained why food was being withheld and why they were no longer taking his blood pressure. Nurses were upset when family member died as well."

"What happens in palliative care? Where is it? Who do I contact if I need to go there? This knowledge all needs to be made available to people because we don't want to find out when we're dying and stressed."

"We need help with Advanced Care Directives. People are too scared to complete one. I tried to complete one and could not answer the questions now for what I would want."

"Focus on the living, not just the dying. The family need support and don't know where or how to get it."

"Why is death and dying still a "taboo" subject in society? How can we change this?"

"I just found out that palliative care isn't just about the last few days. It is mostly monitoring patients from diagnosis to death, it can be long term or short term."

"One Indigenous family in Townsville was told off about taking a chair from a different room to sit near the bedside of their dying relative; this was traumatic for the extended family; the dying relative passed away in 2019 and since then one of the family members (the eldest son) who was traumatised by palliative care hospital staff present during their mother's illness has since suicided in early 2020."

"We are all going to die. We'd like to know where palliative care begins and ends."

"Educate families on discussing and talking about what the wishes are for the dying person. Families must often do this themselves as health care providers don't seem to prompt."

Findings: Service Engagement

Roundtable on common journey pathway mapping

In November 2019, a round table was held with the CELC Townsville Steering Committee to gain insight into committee members' views on the palliative care services and supports availability, usefulness, requirements, opportunities for improvement, and targeting areas of priority.

This group included both consumers and healthcare providers.

The key findings under current palliative care support and services included:

- Health clinicians could readily identify community-based support and services and special care, including community outreach nurses with THHS
- Community members remain unsure what palliative care is, and the issues surrounding voluntary assisted dying is further confusing people
- Some community palliative care services are classifying themselves incorrectly as specialist care
- Within the community, services offering palliative care have 50% of staff with no palliative care training
- Primary palliative care providers cannot recognise suffering and/or lack the confidence to address the knowledge and practice gap

Within palliative care services and supports, the following were viewed as opportunities for improvement:

- Rebranding of palliative care services to “Supportive and Palliative Care Services” to better recognise that palliative care services should be considered at the diagnosis of a life-limiting illness
- Create a continuum of supportive services to end of life palliative care, and creating a pathway of care required, [28] recognizing deterioration and changes to individual health plans
- Strengthening general practitioners in palliative care skills
- Suitable training for assistants-in-nursing (AIN) and personal care workers in dementia and palliative care
- Training in multiculturally appropriate palliative care
- Advance learnings and change in organisations through the use of e.g. Reverse Program for Experience in the Palliative Approach (PEPA) - senior palliative care nurse from PEPA made available to RACFs to provide shadowing and training opportunities
- Use of champions to facilitate change in organisations, using a no-blame culture to maintain a learning culture
- Use of horizontal care from AINs to Registered Nurses in RACFs.

Cultural change is not achieved through education – it requires champions to lead cultural change whereby primary health palliative care workers are able to recognise when patients or residents require specialist palliative care and alert the appropriate persons to initiate the change.

Priority was given to those opportunities for improvement with relations to cultural change, recognition of suffering, capacity building in RACFs, and the provision of palliative care greater than in the community.

Findings: Roundtable Discussions with Services and Key Informant Interviews

From February – May 2020, a series of roundtables and interviews were held with 128 healthcare leaders, palliative care providers, allied health professionals and civic leaders (including a few community representatives with a lived experience) in the THHS area to gain their insights on the current state of palliative care in the THHS area, and the opportunities for improvement.

Palliative Care Services and Supports: What is available?

In addition to the specialist services provided by the THHS Palliative Care Centre, roundtable participants identified palliative care services and supports available across the THHS, including:

THHS Services that were identified as providing palliative care or help at end of life:		
Aged Care/Older Persons Services including community and acute/hospital services and supports i.e. advance care planning, dementia services, sub-acute units at TUH	Community care nurses and core 'in home' providers across THHS i.e. Anglicare, Blue Care, Salvation Army, Hospital In Your Home, Right at Home – where services include medication monitoring, nursing care, education, symptom assessment and management	Palliative Care Queensland and its CELC-T project, which offers resources, education, upskilling opportunities, and palliative care awareness to both the community and professionals
Aged Care Assessment Team (ACAT)	Care at Home Kit – offers education and resources for subcutaneous administration of common palliative/end of life medications	Funeral directors – promote end of life preplanning especially for palliative care patients. Respondents identified that funeral homes in Townville completed this service in private homes, on site, and in Palliative Care Unit
GPs and practice nurses – multiple practices and personnel identified	Canteen – providers of supportive service for palliative care children, adolescence and young adults	Mater Hospital – private hospital – provide inpatient care for palliative patients
TUH emergency medicine staff i.e. doctors, nurses, social workers	Community allied health i.e. physiotherapy	Cancer Council Queensland – offers financial assistance, telephone counselling services, transportation to treatment service, accommodation
Queensland Ambulance Services i.e. ambulance officers, paramedics, LARU (Lower Acuity Ambulance Unit) officers	Queensland Health Nurse Navigators/Discharge Planners	RACF staff i.e. nurses, personal care workers, diversional therapists

Roundtable participants also mentioned state and national palliative care resources that were available:

- End of Life Direction for Aged Care (ELDAC)
- Program of Experience in the Palliative Approach (PEPA)
- End of Life Care, Australian Commission on Safety and Quality in Health Care
- PalAssist (A Queensland-based online and telephone support that provides palliative care service and advice to palliative care patients and health professionals using a call back service)
- My Health Record, GP Portal – “the viewer”

Palliative Care Services and Supports: What is working well in the THHS area?

In this section we look at palliative care through the Palliative Care New Essentials framework [11], considering three of the four elements: specialist palliative care services, generalist palliative care services, and compassionate communities.

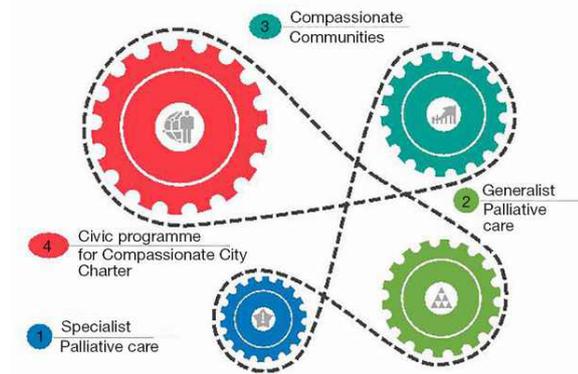


Figure 6: Palliative Care New Essentials Model [11]

Specialist Palliative Care Services in the THHS area

The THHS Specialist Palliative Care Service has a multidisciplinary team which provides specialist palliative care for patients in the TUH Palliative Care Unit, consultancy service throughout the Hospital and community based care through outreach an outreach specialist team based in the hospital and fund a domiciliary service to provide care to people in their home. This team has a group of trained volunteers to provide additional support to patients and their families.

In addition to providing care for patients with complex and persistent issues, THHS Specialist Palliative Care Service provides education and support to generalist services, including clinical placements, education and advice.

During the consultations, participants noted the following:

- Outreach Service: The supports and services provided by the Palliative Care Outreach Team were described by the community as 'exceptional', especially for patients with complex needs
- They have a roster of skilled medical and multidisciplinary team members who provide excellent care, consultation and outreach services. This includes allied health referrals, equipment aid loans, patient education and support and also nursing and medical care and support.
- Bereavement Care: The bereavement and counselling services provided by the specialist palliative care service were also described as excellent.
- Training: During consultation we noted that the THHS Specialist Palliative Care Service has also been a significant influencer to increase in palliative care content in undergraduate medical training.
- Volunteers: The palliative care volunteers were described as an invaluable supportive service for palliative care patients, carers and families
- Telehealth: The services expansion into telehealth was noted as a great initiative.

Generalist Palliative Care Services in the THHS area

Generalist palliative care is provided by health services in hospital, clinics or at home (including Aged and Disability Care).

During the consultations, participants noted the following:

- A number of GPs in the region go above and beyond to provide high quality generalist palliative care that is person-centered and comprehensive in community (RACFs and in-home)
- Many nurses and allied health teams are highly skilled in providing compassionate palliative care
- Many community care service providers provide excellent generalist palliative care
- 24/7 capacity and capabilities of pastoral care outreach services available to and or associated with RACFs across the THHS area
- GPs and other health professionals are using Telehealth in regional and rural areas and it is proving beneficial for people requiring generalist palliative care management
- Queensland Ambulance Service (QAS): Lower Acuity Ambulance Unit (LARU) officers play a helpful role in the provision of palliative/end of life care services and supports:
 - LARU officers have the scope to spend more time in the community with the patient and can also be used as an interim measure to triage a patient before full ambulance arrives.
 - Capability and capacity to provide end of life care, including administration of prescribed medications (if relevant paperwork is available in the home) which means patients can remain at home to die and not present to hospital
- Residential Aged Care Facilities:
 - Many are providing excellent end of life care, providing residents with compassion a more peaceful death than they might experience if they were moved out of facility
 - The Frailty Intervention Team (FIT) has been helpful for RACFs that have used this service, as RACFs value the education and support offered by nursing and medical staff within the FIT
 - This service has been useful in the emergency department

Compassionate communities and civic programs in the THHS area

Compassionate Communities are networks of support around people experiencing loss, ageing, dying and grief. Significant work has occurred Townsville to build a death literate community and build community capacity in relation to this area. Local Councils play a important role in the civic programs which promote positive ageing and dying messaging and build compassionate neighborhoods.

During the consultations, participants noted the following:

- Initiatives of the Townsville City Council highlighted including: Death Cafes; contributing to Seniors Expos, the Good Life Good Death Expo, and events at retirement villages; delivering a Cultural Artwork Space within the Belgian Gardens Cemetery; and facilitating a Father's Day Memorial at Belgian Gardens Cemetery.
- Initiatives from the Connecting End of Life Care in Townsville (CELC-T) project included: information booths at shopping centres, university open days and retirement villages; community survey; Good Life Good death expo; and Compassionate Communities Conversation Series

Directions: Opportunities for Action

Directions: Opportunities for Action

These opportunities for action are based on the findings from the information reviewed, as well as the many consultations that were held as a part of the *Townsville Area Palliative Care Plan: Situation Analysis*.

They are necessarily detailed so as to aid the development of the Townsville Area Palliative Care Plan.

Direction 1: We can work together with communities in the THHS area to raise awareness about palliative care, and to activate people to help care for one another

As we plan, we can consider:

1. Building relationships between organisations and community members to advance palliative care initiatives at all levels – including local council/s, the community, the healthcare system and its leadership
2. Developing a culturally sensitive awareness raising strategy aimed at community members by:
 - a. Providing a plain language explanation of concepts and terms in palliative care and end of life care
 - i. To further the community’s understanding of the breadth of palliative care as relevant to anyone with a life-limiting illness, rather than primarily focusing on the last days and weeks of life
 - b. Holding public education on palliative care
 - i. To raise awareness regarding: what to expect in palliative care and what end of life care can look like; continuum of cares, with the difference between specialist palliative care vs generalist palliative care vs end of life care and also on symptom management
3. Continuing to advance Townsville’s participation in the Compassionate Communities’ movement, harnessing the goodwill demonstrated by the community through the COVID-19 pandemic, to advance the movement, including:
 - a. Partnering with the community to develop knowledge, skills and experience that allows them to advocate for health and social care for themselves and for others
 - b. Activating the role of volunteers to support patients, informal carers in palliative care and bereavement care
 - c. Creating opportunities to network with other organisations, consumers or peer networks and social supports
 - d. Bringing together generalist and specialist palliative care providers, policy makers and other key stakeholders to work together and improve the connectedness of services
 - e. Initiate discussions with local councils to consider the adoption of a Compassionate City Charter
 - f. Review models from other locations and consider implementing in the THHS area
4. Building community capacity and comfort with discussing dying, death grief and loss through:
 - a. Community awareness and education (knowledge and understanding) campaigns that aim to reduce stigma about discussing death and dying across all age groups
 - b. Death literacy initiatives
 - c. Community asset-based development activities

- d. Annual events – particularly during National Palliative Care Week, Seniors Week, Good Life Good Death expos and Compassionate Community Conversation Series

Direction 2: We will help patients and their loved ones navigate the palliative care system

As we plan, we can consider:

1. How to ensure equitable and appropriate palliative care for all residents in the THHS area, including Aboriginal and Torres Strait Islanders, those from Culturally and Linguistically Diverse backgrounds, new arrivals, including refugees, Children, and young Adults, including a transition to adult services, people living with a disability, and people who are LGBTIQ+
2. Developing a Northern Queensland directory on 'how to access palliative care services, supports and resources guide' that includes local, state and national literature and resources available across all organisations who provide care for people experiencing loss, dying and grief.

health professionals and patients (including carers and families) may not know where to start, information needs to be combined into a single document (online and hardcopy) for patients, carers and families in living in the THHS area.

- a. Include a primer on what palliative care is so that patients and carers can ask about different services
 - b. Ensure that supports list palliative care services and supports including hospital services, community care services, GPs and pharmacy services, allied health, RACFs as well as pastoral care, chaplaincy and other support services.
 - c. Ensure that this directory includes practical supports like accommodation for those coming to Townsville from other areas, access to transport, financial and legal advice
3. Enhancing the role of nurse navigators and case managers for palliative care patients and families
 4. Reviewing supports and services available for carers along the palliative care continuum
 5. Developing or identify existing education resources to improve communication between providers and patients, families and carers – including question and answer guides and handover resources for both specialist and generalist palliative care providers

Direction 3: We can strengthen support to palliative care patients and families living in rural and remote areas

As we plan, we can consider:

1. Increasing health services and improving access to primary palliative care particularly on Magnetic Island and Palm Island
 - a. Begin by increase access to health providers including nursing and medical staff to these areas
2. Improving palliative care support/services to Burdekin, Richmond, Hughenden, Charter Towers, Ingham and Cardwell

3. Funding an additional specialist palliative care provider position allocated to regular rural and remote outreach to be a 'face on the ground' to those who are not able to regularly travel to Townsville and/or who elect to die at home in a rural/remote community.
4. Developing accommodation options for clients from rural and remote areas coming to Townsville for palliative treatments
5. Promoting and/or facilitating the use of Palliative Care telehealth care to rural and regional sites between medical officers and/or GPs and or Palliative Care Outreach Team
6. Facilitating half yearly Palliative Care Roadshows visits to rural and regional areas namely Burdekin, Charters Towers and Ingham
7. Continue to promote and engage the Program for Experience in the Palliative Approach program (PEPA) for rural and regional clinicians with a special interest in palliative care.

Direction 4: We will aim to provide equitable and appropriate palliative care for Indigenous residents

As we plan, we can consider:

The specific needs of Aboriginal & Torres Strait Islanders:

- a. Developing services that enable Aboriginal and Torres Strait Islander people to die on Country.
- b. Helping develop an Aboriginal and Torres Strait Islander palliative care workforce
- c. Locating interpreters both male and female
- d. Work with Indigenous Liaison Officers to understand the palliative care for the indigenous population in the region
- e. Examining how to create services that allow for family accommodation and extended family cultural protocols where services cannot be provided on Country

Direction 5: We can initiate Advance Care Planning (ACP) conversations where they haven't yet begun, and continue ACP conversations where they have started

As we plan, we can consider:

1. Targeting the wider community as well as those in hospitals and RACFs, we can create ACP initiatives for all ages along the entire spectrum, from when people are healthy, when they are diagnosed with a life-limiting condition, and along the trajectory of their condition. Include carers and families, and educate the community to plan for all stages of life.
 - a. Providing public education courses on Enduring Power of Attorney (EPOA), Advance Health Directives (AHD), Statement of Choices, Acute Resuscitation Plans (ARPs) and advance care planning
 - i. Communicate the purpose of the conversations and documents, provide instruction on how to fill them out, and help the community understand the utility of having their documents uploaded to the 'My Health Record' and/or the viewer so that they can be used in an emergency to guide care that respects a patient's wishes
 - b. Promoting community awareness that GPs can help community members complete early advance care planning, community Acute Resuscitation Plans and chronic care plan management

- c. Creating an ACP initiative for people with dementia as part of their care pathway
2. Ways to increase the knowledge, tools and confidence of healthcare providers in the region as they initiate and continue ACP discussions by:
 - a. Using the GP training program to provide GP targeted palliative/end of life care education – on end of life matters, Advance Care Planning, Enduring Power of Attorney, ARP, Statement of Choices and facilitating difficult conversations
 - b. Improving GP and other non-hospital services' access to 'the viewer'
 - c. Providing education for all healthcare providers on goals of care, and how to initiate discussions on implementing goals of care and managing when there are significant differences in the views of patients, carer/families, and care teams
 - d. host special interest groups to maintain interest in the support, grow networks and increase knowledge

Direction 6: We will aim to connect palliative care services, improving continuity and integration so that patients and families can more easily access the care they need

As we plan, we can consider:

1. Advocating for systematic consideration of generalist and specialist palliative care when relevant new HHS & PHN initiatives are introduced (e.g. NQPHN initiatives such as Integrated Team Care, GP Support, Afterhours Support, and Primary Mental Health)
2. How to establish models of shared care, which includes the who palliative care pathway from diagnosis to bereavement
3. Initiatives to increase early referrals to specialist palliative care
4. Improving access and referral through Townsville HealthPathways to assist in the management of palliative care/end of life symptoms. Review relevant disease and chronic condition pathways to ensure palliative care referrals are appropriately identified
5. Reviewing locally effective models of shared care and consider how they could be adapted to palliative care (i.e. THHS pain clinic: where the pain team attends local general practice to provide clinics, and provision of in-reach to residential aged care facilities by gerontology services)
6. Creating a continuum of supportive services for palliative care, and creating a pathway of care which recognises deterioration and changes to individual health plans
 - a. Include input from RACFs, older persons/gerontology, chronic care coordinators, nurse navigators, medical and nursing palliative care specialists, QAS, emergency medicine, TUH inpatient and outpatient palliative care, and community care agencies to avoid unnecessary hospital admissions.
7. Strengthening the linkages between curative services and palliative care
 - a. Make it clear that health providers and patients will be supported to access both curative services and palliative care simultaneously
 - i. Ensure the pathway lays out guidance for deterioration and changes to individual health plan

8. Consider a step-down palliative care unit, with an aim to reduce inappropriate use of interim beds and addressing the problem of hospital readmission for the patient and/or inappropriate transfer back to RACFs
9. Increasing referrals to multidisciplinary care
 - a. Promote referrals to social workers, through GP initiated Chronic Care Planning, for residents in RACF's
 - i. Utilise social workers in helping families in community/RACF to help with conversations on Advance Care Planning, Goals of Care, and holding family consultations
 - b. Engage nurse navigators and various allied health providers
10. Handover between services: Investigate and pilot models to assist in the documentation and communication of palliative management plan between service providers.
 - a. For example: the aged care yellow envelope project

We can redesign how we support palliative care patients and carers in the community and RACFs by:

1. Identifying mechanisms for resolving challenges experienced at the interface between different parts of the health system
 - a. For example: Building on the successes of locally used models, such as the Queensland Health Frailty Intervention Team that has been warmly received by THHS RACFs and TUH ED
2. Undertaking a mapping exercise of current programs that connect with palliative care. Map the patient journey, and then conduct systematic mapping of both the capacity and capability requirements to fulfill plans the plans of care created.
3. Improving MBS rebates for GPs providing palliative care services
4. Advocating for the development of flexible packages of care administered by specialist palliative care teams
5. Increasing the number of specialist and generalist palliative care services in the community such as:
 - a. Specialist palliative care medical providers
 - b. Nursing and Nurse Practitioners
 - c. Chaplaincy and pastoral care
 - d. Carer-focused support
 - e. Bereavement Support
 - f. Create a mobile palliative care multidisciplinary health team that is linked to specialist services to support those patients who wish to die at home or in their community
6. Developing a palliative care service that can support home-based care options where families have capacity:
 - a. Review the Hospital in the Home program
 - b. Improve systems to facilitate preferred place of death for all patients, especially First Nations people

- c. Inform the community about the services provided by the Specialist Palliative Care Outreach Team, including allied health referrals, equipment aid loans, patient education and support, as well as nursing and medical care and support
7. Improving the support and advice to RACF healthcare and staff when residents are:
 - a. Experiencing complex palliative care needs but are unlikely to benefit from admission to Emergency Department or Hospital
 - b. Flagging all RACF residents who are admitted to hospital for a review of the ACP, to ensure discussions can be initiated, if relevant
 8. Improving the support to those living with dementia, as well as those who are caring for them, both in the community and in RACFs.
 - a. Create a pathway for advanced dementia patients from home to RACF, ensuring appropriate care and documentation is in place including an advance care plan, and also create a carer pathway to help their families navigate the systems and supports
 - b. Liaise with GPs, geriatricians, older persons community health, Frailty Intervention Team to ensure palliative care patients living with dementia and their carers are supported in regard to end of life care
 9. Creating formalised linkages with relevant services, particularly new services are being developed in the region
 - a. For example: Mater Cancer Centre and Icon Care
 10. Ensure formalised links and positive relationships between public and private palliative care services across the THHS area

Direction 7: We can increase the capacity and capability of the THHS area workforce to provide safe, high quality, person-centered palliative care

As we plan, we can consider:

1. Conducting regular palliative care training analysis of healthcare providers to ensure identify needs and track improvements
2. Creating education and training sessions to THHS area healthcare providers that:
 - a. Make clear the difference between specialist and generalist palliative care
 - b. Particularly focus on pain management in palliative care, including:
 - assessment, medications, dosages, administration methods, documentation, and communicating continued pain management education plans between service providers and families
 - c. Implement palliative care education and resources targeted towards primary palliative care service providers, particularly RACFs and GPs
 - d. Continue to promote local, state and national palliative initiatives, resources, education material and funding opportunities
 - e. Involve people with a lived experience of palliative care in training including young adults
 - f. Increase cultural competence and awareness of cultural practices associated with death, dying, grief and loss for people who are Aboriginal, Torres Strait Islander, CALD (including refugees) and LGBTIQ+ individuals
 - g. Provide training and opportunities for reflective practice including self-compassion and self-care

3. Supporting initiatives that review certificate, undergraduate and postgraduate education programs to ensure core content (not elective content) includes palliative care by:
 - a. Establishing formal relationships with James Cook University, College of Medicine and Dentistry, College of Nursing and Health Sciences, TAFE QLD and other RTOs who provide Certificate III in Aged Care education
4. Creating palliative care learning exchanges with:
 - a. Ongoing clinical placements/exchanges for THHS staff
 - b. Promote PEPA placements and Reverse PEPA
5. Encouraging collaboration and networking by:
 - a. Participate in statewide palliative care networks
 - b. Joining and working with local collaborative projects to enhance QAS, ED, RACF and Older Person/Geriatric initiatives – i.e. Frailty and GEDI projects, LARU

We can also encourage specialist consultation services to generalist palliative care providers by:

1. Increasing the use of Telehealth and digital technologies where possible (and enhance the Telehealth gains made during COVID-19)
 - a. Promote the effective use of telehealth to facilitate delivery of care close to home or at home (RACFs, communities, GP settings and HHS)
 - i. Examples include providing mechanisms for: professionals to seek and share clinical advice, for clients to access clinical consultations from home, for vital signs to be relayed in real time, and to share other relevant clinical information
2. Encouraging the use of relevant existing services, such as PallConsult and Care in the Right Setting project (CaRS) models
3. Establish a THHS area 24-hour nurse palliative care triage line

Direction 8: We can improve palliative care in the THHS area through data monitoring, evaluation and research

As we plan, we can consider:

1. Reviewing our systems for capturing generalist and specialist palliative care data, ensuring that we are consistently tracking the data necessary to improve quality of care and to advocate for system improvements where service supply and structures do not meet the needs, working with state and national palliative care data collaboratives where possible. We can monitor the data and conduct evaluations to see which of our services are working well and which services need improvement.
2. Reviewing our research activities to continue advocating for the needs of Queenslanders living in the THHS area and Australians living in rural and remote regions who will need palliative care

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Appendix

Townsville Hospital and Health Service (THHS) Area

» HEALTH SNAPSHOT



NORTHERN QUEENSLAND
An Australian Government Initiative







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POPULATION



AGE



ETHNICITY



SOCIO-ECONOMIC DETERMINANTS OF HEALTH



UNEMPLOYMENT



EDUCATION



LOW INCOME EARNERS



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Health risk factors » THHS AREA

DAILY SMOKERS



OVERWEIGHT AND OBESE



ALCOHOL CONSUMPTION

Aged 18+, life time risky drinking.



PHYSICAL ACTIVITY

Those who do sufficient physical activity at least five days a week.



HEALTHY EATING

People eating sufficient fruits.



People eating sufficient vegetables.



MENTAL HEALTH AND SUICIDE - TOWNSVILLE HHS AREA 2016-17

3,100 / 100,000
persons report mental and behavioural disorders in 2016

Suicide rates (per 100,000):



TOP 10 POTENTIALLY PREVENTABLE HOSPITALISATION (PPH) - THHS AREA 2016-17



Total PPH: 9,297

CHILD IMMUNISATION*



PERSONS WITH SEVERE DISABILITY



Notes

