



**PalliativeCare**  
QUEENSLAND

# Palliative Care Queensland submission to the 2019 Queensland Parliament Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

April 2019

This submission has been drafted by the Palliative Care Queensland Inquiry and Commonwealth Royal Commission Advisory Group and is endorsed by Palliative Care Queensland State Council

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## Executive Summary

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Palliative Care Queensland (PCQ) provides this submission to the Queensland Parliamentary Inquiry into aged care, end-of-life care, and palliative care and voluntary assisted dying (Inquiry). This submission is a response to the terms of reference and items in the Inquiry issues paper; it is also based on future priorities identified by the Queensland Palliative Care Sector in December 2018.

PCQ believes quality palliative care occurs when strong networks exist between specialist palliative care providers, generalist palliative care providers including general practitioners, and those working within aged care and disability care at all levels. We draw attention to the fact the World Health Assembly (WHA) has endorsed palliative care as a human right under article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), specifically stating that:

‘access to palliative care and to essential medicines... including opioid analgesics ... contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being’.<sup>1</sup>

PCQ believes there is a significant difference between the provision of palliative care and just care at the end of life. Palliative care is for people who have a serious illness that is unlikely to be cured. Care may be ongoing for many months or years, delivered concurrently with other treatments and is focused on helping people live their lives as fully and comfortably as possible until death and to help families cope throughout the illness and in their bereavement. Care at the end of life or ‘end-of-life care’ represents a specific time frame, which varies and is unclear within the health sector. End-of-life care is sometimes referred to as 12 months, sometimes 6 months and sometimes the last few days of life.

End-of-life care narrows the focus to the dying phase, often allowing opportunities for earlier support to be overlooked.

In 2018 PCQ held a Queensland Round Table Summit to listen to members and other stakeholders in palliative care. The Summit agreed on a set of five priorities for palliative care in Queensland for 2019<sup>1</sup>. These priorities have become the basis of our submission.

**Better funding**  
**Improved access**  
**Community activation**  
**Focus on advance care planning**  
**Workforce development**

This submission aims to describe the current state of palliative care in Queensland, considering relevant Queensland population demographics, services and workforce. In order to continue the progress made in palliative care in Queensland under the leadership of PCQ, we recommend:

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<sup>1</sup> World Health Assembly, *Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course*, WHA Res 67.19, 67<sup>th</sup> sess, 9<sup>th</sup> plen mtg, Agenda Item 15.5, A67/VR/9 (24 May 2014) 2.

## Recommendations regarding Palliative Care Queensland

1. Increase Palliative Care Queensland core funding to a minimum of \$500,000 per annum to enable greater outcomes for palliative care across the state, particularly providing increased support for the community, individuals and the health and social care sectors
2. Department of Health and Department of Communities to collaborate with Palliative Care Queensland as the industry peak body when developing policy, strategies and implementation plan with regards to care at the end of life and palliative care throughout Queensland
3. Support PCQ's Palliative Care in Queensland Annual Summit and Award Dinner to celebrate and promote leadership and innovation in the sector, highlight sector achievements and create annual priorities for the sector

**In addition, PCQ makes recommendations to address five priority areas identified through rigorous consultation with our members:**

## Recommendations related to palliative care funding

1. Develop and implement a Queensland Palliative Care Strategy based on the National Palliative Care Strategy which links to the Statewide Strategy for End-of Life Care but includes specialist palliative care, generalist palliative care and public health palliative care. This strategy should include services delivered outside of Queensland Health (including Private, NGO services and community organisations) and should highlight the value of Specialist Palliative Care as the providers of leadership, clinical expertise and strategic input
2. Review the administration of state-funded palliative care services, specifically the positioning of specialist palliative care services within subacute services and consider a stand-alone funded service line situated in acute care with requirement for networks to subacute and community
3. Support and advocate for a review of Medicare Item number remuneration for:
  - GPs doing home visits or RACF visits;
  - Specialist Palliative Care Nurse Practitioners undertaking home and RACF visits (currently under review); and
  - Outreach Palliative Care Services to support rural and remote areas with the greatest disadvantage, e.g. Palm Island and Charters Towers
4. Continue funding:
  - In hospital specialist palliative care services;
  - Existing consultative and integrated Palliative Care services; and

- Home-based services to continue to improve client outcomes and increase chance of clients dying at home
- 5. Develop a needs-based funding model for specialist palliative care which includes packages of care instead of time-limited funding models
- 6. Ensure funding is easier to access in a timely manner, particularly for home-based care and aged care
- 7. Ensure funding is equitable, particularly for people in rural and remote areas and for those under 65 years

### Recommendations to improve access to palliative care services

1. Increase number of specialist palliative care doctors to 2 per 100,000 population.
2. Increase the number of specialist palliative care nurse practitioners, specifically in regional and remote settings
3. Ensure, in conjunction with the Queensland Nurses and Midwives Union, specialist palliative care teams have an adequate number of registered nurses, who should at a minimum have completed professional development activities in palliative care
4. Each HHS requires a palliative care qualified clinical director overseeing the whole HHS
5. Ensure all Specialist Palliative Care Services (Level 3, 2 and 1) have a funded holistic team
6. Provide Queensland Health innovation funding for sustainable innovation, ie proof of concept, in service delivery that integrates services in state, federal and private sectors
7. Explore existing Queensland community based palliative care models (including the Hospice model) demonstrating emergent care, particularly in unsocial hours, to help families keep their loved one at home near end-of-life
8. To improve access to specialists in rural and remote areas, develop a 'Hub and Spoke' model with larger centres supporting more remote and rural areas, such as Townsville Hospital supporting Mackay, Mt Isa, Ingham, Ayr, Home Hill, Charters Towers, Richmond, Hughenden, and Palm Island areas, using existing Telehealth and other service delivery
9. Fund demonstration models of care that enhance specialist palliative care nurses to coordinate generalist (level 1) services in the community
10. Expand interdisciplinary specialist palliative care (Level 2 and 3) services to cover the community – decreasing the number of admissions to hospital and decreasing the number of avoidable or unwanted admissions to hospital (Abel J, Kingston H et al., 2018). Allow people to get care where they want. Build population's capacity to look after their own

11. Increase funding for community residential hospices for respite options and end-of-life care - supported by local GPs and with medical support provided to GPs via Specialist Palliative Care Physicians
12. Ensure sustainable funding is available for hospices, private and non-profit palliative care services throughout Queensland
13. Work collaboratively with specialist palliative care doctors to enhance consultant element of the role to increase collaboration with hospital-based specialists as well as general practitioners in the community
14. Create a statewide palliative care network which supports the linkages, innovation and supportive relationships across the state
15. Work with the Commonwealth to ensure better access to Commonwealth Home Care Services for end-of-life care at home and increased access to General Practitioner support (24 hours), including in the home
16. Ensure grants and scholarships for palliative care and end of life care are available for all specialist palliative care and palliative care service providers, not just Queensland Health Service providers

#### **Recommendations to activate the community to be more involved in palliative care**

1. Support Queensland Compassionate Communities (PCQ community arm) to act as an advocate, navigator and awareness raiser for community initiatives throughout Queensland
2. Develop and implement a state-wide public health palliative care strategy which incorporates health promotion, community awareness, health and community partnerships and compassionate communities (similar to the Age-Friendly Queensland strategy)
  - a. Implementation of this strategy should include grants for community groups similar to age-friendly grants which enable community development and engagement led by community groups
3. Conduct statewide community formal and informal service and groups asset mapping and share the results via platforms accessible to community members and service providers, based on tools within the La Trobe University Healthy End of Life Program
4. Encourage service providers to collaborate with the community to ensure carers have appropriate support networks around them
5. Provide statewide grants for palliative care services , peak bodies and community groups to promote Palliative Care during National Palliative Care Week

6. Support research grants to collect relevant data in relation to public health palliative care which adds to the literature in this area and shares Queensland's initiatives and leadership in this area on an international stage
7. Following the implementation of the *Compassionate Communities Conversation Series* across Queensland (a project administered by Palliative Care Queensland, in partnership with Health Consumers Queensland, Carers Queensland and Council on the Ageing Queensland, funded by Age-Friendly Queensland Grant) enable support to implement recommendations identified at both HHS and State level
8. Provide support and funding for PCQ's Good Life Good Death Expos. These events promote community engagement, education and promote service and supports. In addition, they education health professionals and promote health and social partnerships
9. Implement the La Trobe University Healthy End of Life Program (HELP) in Queensland
10. Create a Statewide Palliative Care Volunteer Training and Support Hub
11. Create a Compassionate Schools program
12. Implement the Last Aid courses throughout Queensland
13. Develop an online self-care and compassion training course for community members and health professions
14. Provide 3-year seed funding to develop a "Queensland Ambulance Wish" program

#### **Recommendations related to increasing focus on Advance Care Planning**

1. Continue funding for the Office of Advance Care Planning to support the advance care planning program across Queensland and provide oversight and build the evidence base
2. Ensure each HHS has ACP facilitators to promote and support Advance Care Planning in all settings
3. Provide statewide grants for palliative care services and community groups to promote Advance Care Planning during National Advance Care Planning Week
4. Establish an implementation funding program for evidence-informed decision-support tools for people to hold conversations about advance care planning in general practice
5. Standardise documents across Queensland and review issues related to Queensland Health documents/tools not being used or available for non- Queensland Health services (including Residential Aged Care and NGO community services)

## Recommendations regarding workforce development

1. Continue funding for the Centre for Palliative Care Research and Education to support sustainable and consistent education in palliative care
2. Encourage the Commonwealth Department of Health to increase the number of PEPA places on offer in Queensland by 20%
3. Explore educational partnership models between residential aged care and health services or hospices like the Teaching Nursing Home model
4. Provide funding for a scholarship program to increase Specialist Palliative Care Nurse Practitioners to work in RACF
5. Incentivise the inclusion of PCC4U into Queensland undergraduate health professional higher education programs
6. Create a mentorship and supervision program led by local specialist palliative care services to support the growth of the palliative care sector and develop local linkages between specialist and generalist services
7. Develop and implement a palliative care leadership program which includes a sector leadership needs analysis and leadership development program including training, resources, linkages, networking, communication and mentorship support
8. Explore the capacity for tertiary level health services to extend their new graduate nurse programs to include nurses in local residential aged care
9. Promote clinical learning and debriefing models by developing structures for debriefing and learning from usual clinical processes such as the morbidity and mortality meeting
10. Create palliative care research scholarships to ensure the sector has opportunities to lead research and showcase innovations

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## About Palliative Care Queensland

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Palliative Care Queensland (PCQ) is an independent not-for-profit peak body with charitable status representing the people who care for Queenslanders living with life limiting conditions. Queensland Compassionate Communities (QCC) is the community arm of Palliative Care.

**Our belief:** The way we care for our dying is a significant indicator of our society's values

**Our mission:** Quality care at the end of life for all

**Our vision:** to hear Queensland community members say:

*"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of loss, ageing, dying and grief, We are ready, willing and confident to have conversations about living, ageing, dying and grieving well, and to support each other in emotional and practical ways".*

PCQ has been operating for over 30 years, has over 400 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 wisdom about the challenges the sector faces and the opportunities those challenges can bring.

PCQ's mission includes advocacy for 'quality end-of-life care for all Queenslanders'. Since 1988 when PCQ began, the landscape of palliative care in Queensland has changed significantly. The acceptance of palliative care as a medical specialty, the growth in population (particularly the ageing population), the development of public, private and non-government services and the emergence of the public health approaches to palliative care have contributed to the current context of palliative and end-of-life care in Queensland. This is a dynamic space which needs to rapidly adjust to the exponentially increasing evidence base and new treatment therapies, as well as fluctuating community attitudes about death and dying.

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## *Increase support for the Queensland state-wide peak body for palliative care*

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PCQ facilitates state-wide discussion and action on important issues related to palliative care and end-of-life care. Our work spans a range of activities including, but not limited to:

- Community awareness and engagement
- Leadership, Education and Quality support for the palliative and end-of-life sector
- Providing information, navigation of the service systems and support
- Building collaborations and networks
- Providing policy advice to all levels of Government regarding palliative and end-of-life care in Queensland
- Engagement with Palliative Care Australia to ensure Queensland issues and priorities are represented nationally

***Adequate funding and funding certainty for Palliative Care Queensland is critical to ensure this important work is continued and enable strategic planning and program implementation in Queensland.***

The barriers to health care workers delivering high quality palliative/end of life care include difficulties communicating prognostic information to people with chronic diseases, and reluctance of the community to discuss death and dying. PCQ has established positive relationships with general community members, community groups, Local Government Authorities and the health and social care sectors. PCQ is ideally positioned to engage these groups in partnerships and lead initiatives which build awareness and promote compassion and death literacy. Several national resources have been developed by the sector to guide and plan palliative care in Australia with the involvement of PCQ. These include, but are not limited to:

- [Palliative Care 2030: Working Towards the Future of Quality Palliative Care for All \(2019\)](#)
- [National Palliative Care Strategy \(2018\)](#)
- [Palliative Care Service Development Guidelines \(2018\)](#)
- [National Palliative Care Standards \(2018\)](#)
- [Productivity Commission into Human Services Inquiry Report \(including End-of-life care\) \(2018\)](#)
- [Compassionate Communities: An implementation guide for community approaches to end-of-life care \(2018\)](#)
- [Barriers to accessing quality palliative care for under-served populations: workshop summary \(2018\)](#)

- *There were 31,555 deaths in Queensland in 2017, including 261 infant deaths and 897 deaths of Aboriginal and Torres Strait Islanders.*
- *Estimates which incorporate morbidity data to determine palliative care needs indicate that between 51,000 to 71,000 of the total population in Queensland require palliative care services. Among people over 65 years old, between 52,000 and 57,000 would require palliative care services.*
- *Similar to the lack of agreed approaches for the estimation of palliative care needs in the population, there is no specific information regarding unmet palliative care needs according to geographical locations in Queensland.*

**QUT (2019) Palliative care services review: Commissioned external literature review**

With a strong membership base and excellent relationships with all National Palliative Care Projects, Queensland Primary Health Networks and other Queensland peak bodies, PCQ is ideally placed to work with the Queensland Government across many departments, including the Department of Health and Department of Communities to develop state-wide strategies, advise on policies and lead round table priority discussions as well as support the implementation of any new Government initiatives in this space.

### Current PCQ funding

PCQ's funding is a major constraint to delivering the necessary outputs and outcomes in the context of a growing ageing population and need for palliative and end of life care in Queensland. In 2018-19 PCQ achieved significant outcomes through hard work, which resulted in a financial loss for the association. Table 1 shows income sources and amounts for the 2017-2018 financial year.

**Table 1: PCQ 2017-2018 financial summary**

Source	Income		Expenses
<b>Department of Health Service Agreement</b>	\$108,133	<b>Administration and General Expenses</b>	\$26,150
<b>Palliative Care Australia*</b>	\$5,000	<b>Employee Expenses</b>	\$242,711
<b>Membership Fees</b>	\$22,736	<b>Rent</b>	\$15,762
<b>Commonwealth of Australia</b>	\$0	<b>Resources, Marketing, Postage and Events</b>	\$152,683
<b>Donations</b>	\$4,526	<b>Staff and Volunteer Travel and Accommodation</b>	\$27,069
<b>Projects, event sponsorship and other income**</b>	\$333,124	<b>Other expenses (inc. Financial, legal, workcover, insurance expenses)</b>	\$11,897
<b>TOTAL</b>	<b>\$473,519</b>		<b>\$476,271</b>

\* This contribution is specifically to support resource dissemination during National Palliative Care Week

\*\*These are one-off project funding based on specific project deliverables and do not contribute to the core business of Palliative Care Queensland

Despite efforts to increase donations to the Association, PCQ has seen a steady decline in donations in recent years. PCQ believes this is due to the declining charity dollar generally as well as the marketing domination of charities focussing on “saving lives” and promoting “hope for cure”. Recently, PCQ has diversified its funding base by successfully tendering for project funding from two Primary Health Networks (PHN). However, this funding is time limited and is specifically targeted to project deliverables within the geographical boundaries of the funding PHN. Therefore, project funding provides limited opportunity to fund the core activities of a state-wide peak body. Through the Primary Health Network funded programs, PCQ has proven its’ strength in program development and the value of including PCQ in future program development. It is timely for local PHN programs to be scaled up, across Queensland and state government funding could support this type of advancement in care.

In the past 12 months PCQ has experienced a significant increase in sector and community need for support, and PCQ has increased its response significantly to meet this need with successful outcomes (see PCQ 2017-2018 Annual Report). PCQ expects the level of need to continue and the current level of PCQ response is not sustainable with the current funding. With PHN project funding expiring in April 2019, PCQ urgently seeks additional core funding support from the Department of Health.

In terms of its workload, PCQ has identified the following:

- 70% increase in inquiries to PCQ in the past 18 months
- Increased media enquiries
- Increase in requests to present at forums, conferences, reference groups and meetings
- Increase in requests to participate in steering committees, reference groups and advisory groups
- Increase in requests to participate in collaborative projects/activities with other peak bodies/projects/services
- Increase in requests to participate in activities in Queensland regional and remote areas

### **Benefit of PCQ to the Queensland Government**

PCQ holds a unique and special place in the ecosystem of palliative and end of life care in Queensland. PCQ has extensive engagement and involvement across all providers and settings of care. This includes public, private, non-government, acute care, primary care and aged care. This, coupled with PCQ’s proven track record in community engagement, enables PCQ to provide an authentic voice for all Queenslanders regardless of their disease, age, cultural background, socioeconomic status or geographical location. PCQ is the only organisation in Queensland that can provide this depth and breadth of understanding regarding palliative care to the Queensland Government.

### Proposed PCQ funding increase

PCQ is proposing a minimum increase of \$385,000 per year, to a total funding amount of \$500,000 per year. As well as maintaining the current activity, this funding would enable PCQ to continue to meet the growing demand for its services, specifically regarding:

1. policy and strategic advice to the Strategy, Planning and Legal Division, Department of Health;
2. promotion of the outcomes of the Queensland Government initiatives in Palliative and End-of-life Care;
3. community engagement and awareness of palliative care with community members and community groups;
4. support for palliative care and specialist palliative care services and health professionals;
5. building linkages between Commonwealth, state and local government initiatives;
6. establishing connections between Queensland Health services, private health services and non-government organisations (NGO);
7. state-wide engagement – particularly in regional/remote areas; and
8. timely response to community and media.



Figure 1. PCQ achievements in 2017-2018

### Recommendations regarding Palliative Care Queensland

1. Increase Palliative Care Queensland core funding to a minimum of \$500,000 per annum to enable greater outcomes for palliative care across the state, particularly providing increased support for the community, individuals and the health and social care sectors
2. Department of Health and Department of Communities to collaborate with Palliative Care Queensland as the industry peak body when developing policy, strategies and implementation plan with regards to care at the end of life and palliative care throughout Queensland
3. Support PCQ's Palliative Care in Queensland Annual Summit and Award Dinner to celebrate and promote leadership and innovation in the sector, highlight sector achievements and create annual priorities for the sector

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## *Palliative Care in Queensland Priority 1 – Increase funding for palliative care*

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### **Current Funding Models**

Public palliative care services are currently funded by the sub-acute care components of hospital activity-based funding which covers palliative care, rehabilitation, geriatric evaluation and psychogeriatric care. Ironically, this means that all the public specialist palliative care services in Queensland rely on hospital activity to deliver community services through the health service. This is contrary to the notion that most people would prefer to be cared for at home. The only additional source of funding for public palliative care services is through the Pharmaceutical Benefit Scheme (PBS) and Medical Benefits Scheme (MBS). These payments can be accessed for attendances in hospitals or in clients' homes. However, they are only relevant for medical services and complex allied health; it is anticipated Queensland Health nurse practitioner services will be reimbursed through the MBS in the near future.

A recent innovation by West Moreton Health has involved starting up a Hospital in the Home (HITH) model for palliative care patients. This enables the health service to access sub-acute activity-based funding for patients on the HITH palliative care program. However, the guidelines for HITH require substantial medical resources for this model of care and without significant further investment in palliative care services, this model may not be sustainable or attainable statewide.

PCQ estimates that \$100 Million is allocated for Palliative Care Services in Queensland annually. This funding is provided to major tertiary hospitals through Hospital and Health Services. The inclusion of the funding within subacute services contributes to a lack of transparency in expenditure.

“In Townsville, apart from one additional funded position in 2014, there has not been any increase in funding. The Domiciliary nursing services cost per year has increased by \$100,000 each year up to \$500,000 until 1 year ago when there was a cap and investigation into why there was this increase. This service can only provide a maximum of 1 hour per client per day so 23 hours of the day rely on the carer to provide care. This should be increased to provide more care and support.

The quality of this service has dropped off with less support for clients in the community and with clients being asked to call an ambulance rather than being reviewed and assessed on site. The on-call service phone call support was put into an affiliated Residential Aged Care Facility where the busy staff member would not have any knowledge about the client to be able to give advice.”

*Regional Palliative Care Service Provider (2019)*

"One of the worst conversations to have is when a client has been put on Palliative Care funding and they have rallied and stabilised and to allow equity of access then we have to withdraw our funding and transfer them on to other funding for services."

*PCQ Member*

Further, the provision of funding to subacute services, without specific activity outcomes related to community-based investment, **reduces** incentive for funding to flow to remote and rural areas.

The funding does not always filter down to on the ground community based palliative care services. Instead funding goes into subacute services, such as rehabilitation. This disadvantages people with life limiting illnesses who are not able to receive services because of such funding decisions.

There is little financial incentive for General Practice engagement in home-based palliative care. GP Home visits or visits to RACFs do not

attract higher fees than standard consultations, despite taking the GP out of the office for long periods, reducing opportunities for multiple patient transactions. The current funding is insufficient to encourage GPs or Specialist Palliative Care teams to visit RACFs where they are needed.

Palliative care interventions have demonstrated savings to clients, families and health services. Specialist palliative care interventions are less expensive compared to acute interventions including Intensive Care Unit (ICU) admissions. Further, palliative care can reduce emergency department presentations (Abel, Kingston et al. 2018; McNamara et al., 2013).

In addition to public funding through the hospitals, the Queensland Government provides block funding to the seven non-government hospice services in Queensland. Historically, this funding has been inequitable across the services and has not increased (beyond CPI) for at least a decade. However, a recent review of this funding by the Department of Health has resulted in an increase across all the services, to achieve sustainability and equity for service provision. These non-government hospice services operate in a primary care model so medical services are largely funded through MBS and PBS sources.

## The Evidence

### **Queensland University of Technology Palliative Care Services Review: Queensland Health Commissioned external literature review January 2019.**

There is no national model for funding inpatient or community palliative care services, which are a State/Territory responsibility (Gordon et al., 2009). Funding models influence the provision and development of palliative care services (Greneveld 2017). A recent review of international funding models for palliative care sought to inform optimal payment arrangements for the sector.

Recommendations are that payment models move towards activity-based funding using an agreed classification, be uncapped funding with performance monitoring and make explicit use of performance metrics and reporting (Duckett 2018).

Duckett also recommends specialist palliative care services are paid on the basis of the population served and the expected number of deaths in that population. Hospital-based palliative care, funded under activity-based funding arrangements, attracts funding for hospital admissions, which incentivises emergent hospital usage rather than community-based services. In contrast, community or home-based care is funded on a population basis, so additional clients do not attract additional funding (Duckett 2018). The different funding mechanisms thus create a greater incentive for admissions to hospitals than for community-based treatment.

For Queensland, it is critical that equally flexible funding models are developed that promote a seamless interface between hospital and community-based care.

Funding models influence the provision and development of Palliative Care services

### Increasing demand for palliative care

There is a community expectation of equity of access to palliative care services. However, not all people who have life-limiting diseases require specialist palliative care.

Palliative care services have increased over the last 20 years. While the palliative care movement stemmed from caring for adults living with cancer near the end-of-life, palliative care providers now see clients of all ages, including children and those with a range of life-limiting conditions. Recognising that early referral to specialist palliative care can improve outcomes for the client, family and health service (Temel et al., 2010), the demand for specialist consultations is rising. These demands are only likely to increase substantially over the coming decades.



The Townsville Hospital Specialist Palliative Care Service has had a limited budget of funds to help with equipment and domiciliary nursing services. With 7 Motor Neurone Clients on the books, the budget was wiped out due to the on-going expenses for equipment and nursing care. The funding should therefore be allocated by complexity too

Queensland Health's State-wide strategy for End-of-Life Care 2015 has provided SEED Funding to support health services to explore the capacity of their services to respond to the needs of those with progressive life-limiting illnesses. The findings from these projects have illuminated a range of notable service gaps. While some projects have attempted to address local problems or concerns, the funding model does not produce outcomes that can be scaled up or sustained within the current health service context. Sustained investment is required into new models of care that integrate state palliative care services with community-based health services and private hospice services.

Palliative Care Australia (2018a) recommends that level 1 palliative care, also known as generalist palliative care, be available to everyone. This means that General Practitioners, nurse practitioners, medical officers, allied health officers, Residential Aged Care Facilities staff and staff in community-based services should be familiar with the principles of palliative and end of life care. Moreover, there is an expectation that level 1 palliative care is safe and of high quality.

To meet increasing demand, funding is necessary for high quality innovations in care delivery to ensure access to high quality level 1 palliative care across Queensland. Innovations that are cross-sectoral, integrating existing services in the state, federal and privately funded systems are urgently required. Palliative Care Queensland's high-level client advocacy and experience in collaboration with state, federal and private providers, positions the organisation well to co-lead innovation in service design with the state government.

### Recommendations related to palliative care funding

1. Develop and implement a Queensland Palliative Care Strategy based on the National Palliative Care Strategy which links to the Statewide Strategy for End-of Life Care but includes specialist palliative care, generalist palliative care and public health palliative care. This strategy should include services delivered outside of Queensland Health (including Private, NGO services and community organisations) and should highlight the value of Specialist Palliative Care as the providers of leadership, clinical expertise and strategic input
2. Review the administration of state-funded palliative care services, specifically the positioning of specialist palliative care services within subacute services and consider a stand-alone funded service line situated in acute care with requirement for networks to subacute and community
3. Support and advocate for a review of Medicare Item number remuneration for:
  - GPs doing home visits or RACF visits;
  - Specialist Palliative Care Nurse Practitioners undertaking home and RACF visits (currently under review); and
  - Outreach Palliative Care Services to support rural and remote areas with the greatest disadvantage, e.g. Palm Island and Charters Towers
4. Continue funding:
  - In hospital specialist palliative care services;
  - Existing consultative and integrated Palliative Care services; and
  - Home-based services to continue to improve client outcomes and increase chance of clients dying at home
5. Develop a needs-based funding model for specialist palliative care which includes packages of care instead of time-limited funding models
6. Ensure funding is easier to access in a timely manner, particularly for home-based care and aged care
7. Ensure funding is equitable, particularly for people in rural and remote areas and for those under 65 years

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## ***Palliative Care in Queensland Priority 2 – Increase access to palliative care services***

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### **Background**

Access to palliative care services requires understanding of what is available. General information on palliative care services is available on My Aged Care and Queensland Health websites, however accessing services available in one's own area is difficult.

In one Australian jurisdiction, Hollingworth and colleagues (2016) found that an innovative approach to case conferencing, whereby the General Practitioner, the specialist service provider (heart failure or lung disease), and a palliative care consultant physician, can significantly reduce hospitalisation and emergency department visits. Queensland leads the way with the development hospice models in Australia – including hospice in the home and hospice bed-based models. These models demonstrate findings in the United Kingdom suggest that this model of care supports families to continue coping, have rapid access to services and feel able to stay at home (Jack et al., 2013).

### **What is currently working to improve access?**

There are numerous programs to support generalist palliative care e.g. GPs, RACF staff, acute hospitals, community nursing and allied health, and pharmacists. These programs demonstrate improved outcomes for clients and health care clinicians. Current initiatives that are making a difference and should continue include:

- Tools such as the very detailed Care Plan for the Dying Person initiative for acute hospitals and RACFs, and associated guidelines (Queensland Health, 2019);
- Queensland Health Hospital and Health Services – End-of-life Care Committees, and End-of-life care Ward Staff Champions;
- Online education modules and resources e.g.
  - PCC4U curriculum ([www.pcc4u.org](http://www.pcc4u.org)),
  - Caring@home project ([www.caringathomeproject.com.au](http://www.caringathomeproject.com.au))
  - CareSearch, the palliative care knowledge network ([www.caresearch.com.au](http://www.caresearch.com.au))
  - ELDAC - End of Life Directions for Aged Care ([www.eldac.com.au](http://www.eldac.com.au))
- Queensland Health End-of-life Care project working on Advanced Care Planning;
- Face to face training and education provided by Specialist Palliative Care Services around the State;
- PEPA placements; and
- Work done by some PHNs with community based services.

## What are the barriers to equity in access?

### Geography

Between 41% -76% of people with life limiting illnesses will require specialist palliative care services. A recent review undertaken by Queensland University of Technology found there are not enough specialist palliative care physicians to meet the needs of Queensland. There are ‘blackspots’ in care provision, particularly evident through the Western Central corridor where there is an ageing population and limited services (QUT report 2019). Services are inequitable because of geography. Specific examples include:

- Townsville has a population of 250,000 and 3 specialist palliative care physicians whereas Mackay has a population of 125,000 and no specialist palliative care physician;
- Mt Isa has a visiting locum only; and
- Palliative care medical specialist Dr Peter Whan has been providing palliative care services to rural and remote areas and will be retiring soon, with no certainty that his position will continue.

### Demographics

Australian Bureau of Statistics (ABS) data indicate that 55% of all deaths in Queensland in 2017 were caused by life-limiting chronic diseases and 30% were caused by cancer (see Figure 2 below).

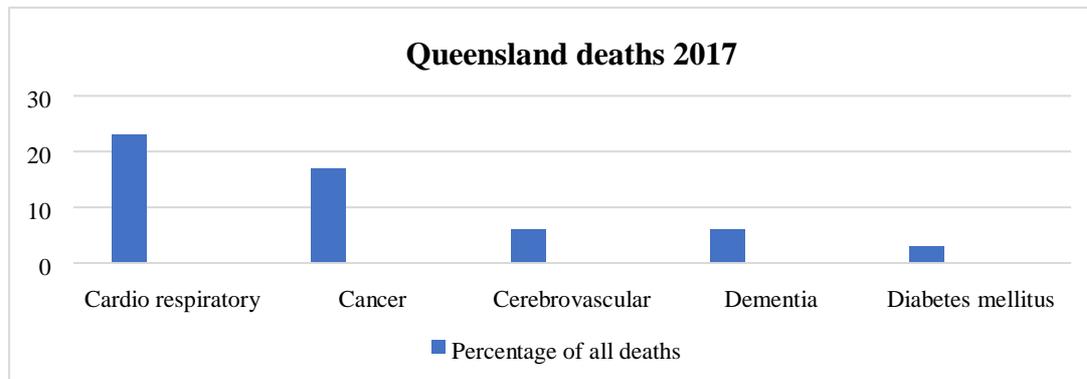


Figure 2: Causes of Death in Queensland in 2017 (ABS 2019)

Despite these statistics, the most recent Palliative Care Outcomes Collaboration (PCOC) report for Queensland shows that 78.3% of people who have access to secondary and tertiary levels of palliative care have a malignant (cancer) diagnosis (Connolly et al., 2018). This suggests that people living with life-limiting, chronic (non-cancer) conditions have limited access to palliative care services near the end-of-life. The impact of this is significant and may include multiple presentations by such persons to the Emergency Department in the last year of life, followed by death in the acute hospital.

## What the evidence says

The benefits of early access to palliative care for clients and families include reduction in aggressive or futile (non-beneficial) therapies at end-of-life, prolonged life in some client populations (Temel et al., 2010) and reduction in the number of transitions between care settings in the last months of life, which represent a source of stress for clients and their families (Casotto et al., 2017). There are also benefits to the health system, with evidence suggesting early access to palliative care can significantly reduce hospital costs (Morrison et al., 2008).

Whilst there is a clear disparity between access to palliative care by people with a cancer diagnosis and those with a chronic condition, it is evident that not all people with an advanced disease (of any diagnosis) require specialist palliative care. This point is made in the Background Report to the Palliative Care Service Development Guidelines (PCA 2018b).

*‘Some people have needs that can be effectively met through their existing relationship with the health professional or team of health professionals involved in managing and providing their care.*

*The medical management and coordination of care for people who are living with a life-limiting illness may be undertaken by a wide range of health professionals including GPs, geriatricians, physicians, oncologists, paediatricians, renal specialists, cardiologists, endocrinologists and other specialists caring for people with advanced disease. Other essential team members will include nurses and allied health personnel.’*

*Background Report to the Palliative Care Service Development Guidelines, 2018b*

However, PCOC data demonstrate that those receiving care in a hospital with designated palliative care services have better pain and symptom control than those receiving palliative care at home (Eagar et al., 2018). Whilst there are no definitive reasons from the data explaining better outcomes in hospital than in the home, PCQ contends that resources and access to specialist services in the hospital are far superior to those in the community.

Palliative Care Australia published Service Development Guidelines in 2018, outlining workforce requirements for the future. A benchmark is set at 2.0 specialist palliative medicine physicians per 100,000 population. This is a rise in the 2003 benchmark of 1.5 per 100,000 on the grounds that access to palliative care services should include people with life-limiting conditions other than cancer (PCA, 2018a). **For the population of 5 million Queenslanders, this equates to 100 specialist palliative medicine physicians.** The report also recommends further exploration of the efficacy and feasibility of nurse-led models of palliative care, particularly in regional and remote centres.

Specialist palliative care services are developing integrated models in the cancer space (Cassotto et al., 2017), which may be useful models for developing the palliative care workforce in the noncancer areas.

### **International models of care**

In the United Kingdom, the Marie Curie Organisation provides nurses for people living with a terminal illness and who want to be cared for in their own home. This care principally involves overnight care in the home to enable the family caregivers to rest. In 2012, a comprehensive evaluation of the impact of Marie Curie Nursing Service (MCNS) on hospital use was completed and the main findings include (Chitnis et al., 2012):

- 76.7% of those who received MCNS died at home, compared to 35% of those who did not receive MCNS;
- 7.7% of those who had MCNS died in the acute hospital, compared to 41.6% of those that did not receive MCNS care;
- Those with access to MCNS were less likely to use all forms of hospital care (including emergency department and outpatients); and
- The overall costs of care for people with access to MCNS were less than those who did not have access.

A key goal of palliative care is to provide support for clients in their preferred place of care; 70% of Australians state they would prefer to receive care and to die in their own homes. Unfortunately, across Australia, only 17% achieve these goals, and some services report only 14% of clients are able die at home. The reasons for this are complex and multifaceted, but it is widely understood and accepted that palliative care support can make a pivotal difference. The limited access to specialist palliative care services creates a need to triage clients for palliative care, with lower ranked people missing out on essential support (Philip et al., 2019).

### **Barriers and enablers to specialist (Level 2 and 3) services**

There is an urgent need to increase the number of specialist palliative care physicians. There are vast areas and regions of Queensland that do not have access to a specialist palliative care physician (for example, Mackay). There is also inequity across the regions. For example, the Darling Downs Hospital and Health Service (HHS) has a population of 280,000 people and has one palliative care physician; whereas Metro North HHS has a population of 900,000 and has eight palliative care physicians. It is important to note that the vast majority of these palliative care physicians are hospital based, and do not work in the community, leaving a significant gap in home based palliative care.

The limited number of palliative care physicians in some areas of Queensland potentially creates health and wellbeing issues for this group of health professionals. For example, in the Sunshine Coast HHS there is one specialist palliative care physician on 24 hour call every second or third night 365 days of the year, year in and year out. These specialist physicians are clinically responsible for the specialist level palliative care management for an increasingly high volume of clients in the acute and community sector.

### Barriers and enablers to generalist (Level 1) services

There are barriers to people with chronic conditions accessing palliative care at every level.

At the system level, the lack of resources in the community limits family capacity to provide end-of-life care for a loved one at home. Findings from research suggest:

- Additional services, such as a discharge nurse are necessary to enhance rapid discharge in the last days of life (Jones et al., 2015);
- Transition home from hospital in last days of life is resource intensive and unsustainable within current structures (Moback et al., 2011); and
- Families carry direct and indirect costs for end-of-life care including transportation to services, medications, continence products, laundry, as well as emotional and spiritual burden with little support (Rocio et al., 2017).

Clients and families themselves may also create barriers to accessing palliative care. For example, community perceptions of palliative care being closely associated with death are a significant barrier to use of supportive services (Mason et al., 2016).

Caring for a person at end of life at home involves significant commitment from family caregivers. Evidence suggests that supporting family caregivers at home, with health professionals specifically trained in end of life care is paramount to enabling a person to die at home (Jack et al., 2014). Furthermore, health professionals who support family caregivers identify that crisis interventions or emergent care at home must be included in any community-based palliative care model (Jack et al., 2013). A clear referral letter, that outlines present and emerging symptoms and plan of care is required and should be prepared by experienced staff (Lowey & Liebel, 2016).

The literature identifies staff concerns as potential barriers to transitioning people with chronic conditions at end of life from hospital to home. For example, staff are often concerned about client safety and risk (Coombs, Parker & DeVries, 2017) as well as possible litigation (Willmott et al., 2019).

Home-based hospice services may reduce barriers to discharging clients from hospital including health professionals' fear of litigation related to perceived accountability for managing potential risks. While the fear of legal repercussions is contested (Willmott et al., 2018), our experience in one southeast Queensland jurisdiction indicates widespread

concern from health professionals about the process of discharging clients home to die. These concerns are derived from limited resources, including access to general practitioner and community nursing care.

In a New Zealand study of the decision-making processes that influence transition in care when approaching end of life, managing risk emerged as an important factor that influenced transitions (Coombs et al., 2017). Coombs' team (2017) notes that risk is perceived quite differently by health professionals and clients/families. Further to this, in a study of older people with advanced multimorbidity, clients indicated that they would limit their interactions with care providers in an effort to preserve their autonomy (Mason et al., 2016). While there is emerging evidence that home-based care near end-of-life is valued, education of health professionals about the balance between person focused care and risk management is required.

Other community-based models that require further investigation include the use of a community case conference worker. This model was found to improve the quality of experience at home near end-of-life (Austrom et al., 2016). This model could be incorporated into the emerging Nurse Navigator role, where Nurse Navigators assist families to negotiate access to palliative and end-of-life care services.

Whatever model is employed, health service providers will need to be available 24 hours per day to manage emergent care needs as they arise (Jack et al., 2013) and respite services need to be available to support carers who may be tiring under the pressure of responsibility associated with end-of-life care (Rocio et al., 2017).

### **Current government subsidised programs**

Currently multiple barriers exist which prevent access to appropriate services. Figure 3 provides examples from a project undertaken at the Gold Coast which aimed to identify barriers to their palliative care service. Figure 4 summarises the current Government subsidised programs with the limitations for palliative care. All programs have multiple barriers that prevent seamless transition to palliative care services in the home.

Clients and their families cannot rely on the Commonwealth Home Support Program with its time limited reablement focus; the NDIS and Home Care Packages have complex and lengthy approval criteria and prioritization; and the Queensland Community Care program has significantly reduced funding with a reablement focus.

Even the Palliative Care Program (PCP) funding via the State Queensland Health budget is very limited and considered a way to add home based palliative care nursing support, and some limited equipment in the last 3 months of a person's life – when client and caregivers

hope supports from other subsidised programs are already in place. Additionally, as clients get less access to, and service support from these programs, there is greater reliance on PCP funding. The current PCP funding cannot cope with this increased demand.

***The Experience of the End of Life Care Discharge Project, Gold Coast (Griffith University):***

This project aims to standardise discharge practices to enhance the transition of older people with chronic conditions from hospital to die at home. The project has experienced several barriers to discharging (non-cancer) patients requiring significant effort to work around:

**Families and Caregivers**

Families do not always know how to provide physical care and require training in basic care skills. This can be provided in hospital by Registered Nurses (RNs). RNs are not necessarily skilled in family education and may need training in this skill.



Families do not always understand what is involved in 24 hour care and require an opportunity to see what overnight care looks like before agreeing to take the person home. The overnight accommodation policy was reviewed and updated. Sofa beds were purchased for the two participating wards, so families could experience what care they would need to provide at home.

**Costs**

Currently, the Commonwealth Home Support Program only funds four hours per week of palliative care nursing services. This is woefully inadequate and families may have to pay the shortfall for additional hours.



The cost of non-PBS medications and equipment can be prohibitive to a family caring for a person at home.

The current fee schedule for GPs does not provide adequate remuneration for home visits.

**Planning and Preparation**

A meeting between the family and hospital staff is considered critical to ensure adequate support set up at home, including access to non-government organisations offering home based nursing services and notification to GP.



Set up support includes drawing up a resuscitation plan that is considered acceptable to the QAS. Medications need to be arranged, with prescriptions for expected emergent medications. Equipment may need to be arranged including hospital bed, urinary or commode equipment, oxygen, etc.).

Discharge letters are usually prepared by junior medical staff. The specialist may try to call the GP but it is rare for a handover conversation to happen. The discharge letter must be written in an informative way as it is used to guide non-government organisations in nursing care requirements and the GP in monitoring requirements.



**Governance**

There is little clinical governance over transitions between health services in the integrated space. This provides few opportunities for feedback and continuous improvement.

Figure 3. Gold Coast Health Experience

Figure 4: Government Subsidised Programs

Program features		Barriers for palliative care
<b>The Commonwealth Home Support Program</b>		
	Target population over 65 years of age	Does not cater for people under 65 years of age
	Need to be assessed by My Aged Care through a Regional Assessment Service	Assessment based upon current function- does not anticipate the expected deterioration with life-limiting conditions
	Program focused on reablement	Not designed to specifically consider a person's care needs as they progress to end-of-life care
	Process is complex for communicating and requesting services	Clients are overwhelmed and may die before they are assessed
<b>The NDIS</b>		
	Target population - people under 65 years with a permanent disability	Well-resourced for people with palliative conditions such as MND, multiple sclerosis, but people with advanced cancers are not likely to be eligible
	Focus is on support services including education, employment, social participation, independence, living arrangements and health and wellbeing	Nursing services for symptom management not considered NDIS responsibility.
<b>Queensland Community Care program</b>		
	Target population - people under 65 years	Does not cater for people over 65 years of age
	QCC funding to be greatly reduced by July 2019, with funding being redirected to the NDIS	People may have to test their eligibility for the NDIS first resulting in significant time delays and likely rejection, before going back to the QCC program
	Focus is on reablement (not progression to end-of-life care)	Does not focus on disease progression and end-of-life care
	Service provision is extremely limited	Not likely to meet the needs of a palliative care client
<b>DVA Gold Care Entitlements</b>		
	A well-resourced program that effectively meets the needs of its very specific client group	Only caters for a small proportion of the population
<b>Home Care Packages (HCP)</b>		

	Target population people over 65 years (or those people not eligible for NDIS)	
	Need to be assessed by My Aged Care through a Regional Assessment Service	Advocacy required to obtain assessment through ACAT process rather than RAS
	Assessors are not aware of life-limiting illness trajectories, future planning needs not encouraged	
	<p>Medium and High level priorities have very strict guidelines – High priority requires:</p> <ol style="list-style-type: none"> <li>1. Carer arrangements are unsustainable or carer at crisis point or</li> <li>2. Client at immediate risk due to personal safety or immediate risk of admission into residential care</li> </ol>	<p>Short prognosis is no guarantee for high priority</p> <p>Caregiver stress not recognised as a need</p>
	<p>Current wait time for medium priority 12-18 months</p> <p>Wait time for high priority 6-8 months</p>	Many people with a life limiting illness, even if they have been given approval for a HCP will die before their HCP funding allocation.
	Assessed at different levels according to need at time of assessment	Does not account for disease progression and end-of-life care. Majority of people with a life limiting illness and short prognosis will not have access to the support of a HCP under the current HCP design and allocation arrangements.
<b>Transition Care Program</b>		
	Time limited (12 week) home or residential care based rehabilitation program with the focus of specific reablement goals	Limited benefit to people experiencing a life limiting illness and progressive deterioration
<b>Palliative Care Program (scripting) QH State Government funding</b>		
	Utilized for the hire of certain pieces of equipment such as a hospital bed and mattress, and to fund hours of palliative care nursing in the home, plus a very limited amount of funding for consumables	No funding available for other areas of practical assistance such as personal hygiene support before the person gets to the terminal stage, in-home respite for the carer, domestic help etc..

	Funds can be greatly reduced towards the end of the financial year	Distribution of funding support for clients may not be fully equitable throughout the year.
<b>Integrated Carer Support Program – (commences Sept 2019)</b>		
	New national model of service delivery for carer support to be commenced in Sept 2019	There is the potential for further confusion on processes to seek support for carers (MAC service pathways or Carers Gateway service pathways, or both – with the potential for multiple assessment teams, and multiple service providers from MAC and the Carer Gateway referral streams).
	Similar system to My Aged Care for Carer’s to seek support – via the national Carer Gateway.	
		Multiple referral and assessment processes can result in confusion, disempowerment for carers and time delays for them to access needed support.
	There is no indication that there will be any increase in availability for planned residential respite care.	This is a major gap in service support for carers. Increasingly RACFs are only offering unplanned ‘respite’ availability when they are unable to fill a permanent bed.

## Recommendations to improve access to palliative care

1. Increase number of specialist palliative care doctors to 2 per 100,000 population.
2. Increase the number of specialist palliative care nurse practitioners, specifically in regional and remote settings
3. Ensure, in conjunction with the Queensland Nurses and Midwives Union, specialist palliative care teams have an adequate number of registered nurses, who should at a minimum have completed professional development activities in palliative care
4. Each HHS requires a palliative care qualified clinical director overseeing the whole HHS
5. Ensure all Specialist Palliative Care Services (Level 3, 2 and 1) have a funded holistic team
6. Provide Queensland Health innovation funding for sustainable innovation, ie proof of concept, in service delivery that integrates services in state, federal and private sectors
7. Explore existing Queensland community based palliative care models (including the Hospice model) demonstrating emergent care, particularly in unsocial hours, to help families keep their loved one at home near end-of-life
8. To improve access to specialists in rural and remote areas, develop a 'Hub and Spoke' model with larger centres supporting more remote and rural areas, such as Townsville Hospital supporting Mackay, Mt Isa, Ingham, Ayr, Home Hill, Charters Towers, Richmond, Hughenden, and Palm Island areas, using existing Telehealth and other service delivery
9. Fund demonstration models of care that enhance specialist palliative care nurses to coordinate generalist (level 1) services in the community
10. Expand interdisciplinary specialist palliative care (Level 2 and 3) services to cover the community – decreasing the number of admissions to hospital and decreasing the number of avoidable or unwanted admissions to hospital (Abel J, Kingston H et al., 2018). Allow people to get care where they want. Build population's capacity to look after their own
11. Increase funding for community residential hospices for respite options and end-of-life care - supported by local GPs and with medical support provided to GPs via Specialist Palliative Care Physicians
12. Ensure sustainable funding is available for hospices, private and non-profit palliative care services throughout Queensland
13. Work collaboratively with specialist palliative care doctors to enhance consultant element of the role to increase collaboration with hospital-based specialists as well as general practitioners in the community
14. Create a statewide palliative care network which supports the linkages, innovation and supportive relationships across the state

15. Work with the Commonwealth to ensure better access to Commonwealth Home Care Services for end-of-life care at home and increased access to General Practitioner support (24 hours), including in the home
16. Ensure grants and scholarships for palliative care and end of life care are available for all specialist palliative care and palliative care service providers, not just Queensland Health Service providers

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## ***Palliative Care in Queensland Priority 3 – Activate the community to be more involved in palliative care***

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### **Public health palliative care**

Public health approaches aim to be inclusive for all people and for all ages. These approaches include community development to support the dying, those important to them, and those who are bereaved. Professional care is struggling to meet current demands. Using a public health approach to end of life care is a way of enhancing supportive networks other than the professional ones. Adding this to the overall picture of end of life, and bereavement, will hopefully make significant further improvements by building on the work and infrastructure that has already been done.

There are increasing movements to mobilise local community networks to support families caring for a person dying at home (Abel et al., 2011). In Queensland the Compassionate Communities network is growing. The aim of Compassionate Communities is to promote and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities.

The proliferation of professionals in end of life care over recent years has led to many achievements and improvements in symptom control or aspects of quality of life. However, increasing the numbers of professionals is simply not the answer to many of the social issues people face. There is increasing awareness that with the growing numbers of people dying and increasing demand for all aspects of health and care services, we need a different discussion from simply asking for more resources and more staff.<sup>2</sup>

Recognition of the impact of loneliness on mental and physical wellbeing, the use of health services, and mortality (Holt-Lunstad et al., 2010; Reeves, Blickem et al., 2014), has led many across health and social care to reconsider which interventions may be appropriate to support people near the end of life and those caring for them.

Compassionate Communities Initiatives are part of the public health palliative care conversation. They also normalise death and dying, and empower local communities to care for and support people at end-of-life, and into bereavement for family and carers

### **Nurturing Compassionate Communities**

*“A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other’s company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city’s influence, even to the end of our days”.*

Compassionate City Charter, A Kellehear.

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<sup>2</sup> The National Council for Palliative Care UK (2016) Each community is prepared to help: Community development in end of life care – guidance on ambition six

Compassionate Communities are communities where everybody recognises we all have a role to play in supporting each other in times of loss, ageing, dying and grief. Compassionate Communities are a core part of public health approaches to palliative care, end of life care and bereavement. Compassionate Communities are derived from the World Health Organisation concept of ‘Healthy Cities’ or ‘Healthy Communities’ and are based on the ‘New’ public health idea that health is more than mere absence of illness and that it is everyone’s responsibility—not just their doctor’s and their health services’ (Kellehear, 2013).

Compassionate Communities “publicly encourage, facilitate, support and celebrate care for one another during life’s most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care.” (Kellehear, 2015). Key priority areas in relation to this are:

- a. Promote community engagement strategies, including schools, churches and community groups
- b. Queensland Compassionate Communities (PCQ community arm) should act as an advocate, navigator and awareness raiser for community initiatives
- c. Promote ‘community hubs’ for sharing ideas, resources and information
- d. Map community assets and make results accessible
- e. Collaborate with General Practitioners to ensure they understand compassionate communities models and the value of palliative care as part of their role

### Current initiatives making a difference

Palliative Care Queensland is the leader in end of life community engagement and development activities throughout Queensland. PCQ partnered with Health Consumers Queensland, Carers Queensland and Council on the Ageing Queensland to conduct kitchen table conversations and the statewide compassionate community’s conversation series.

La Trobe University is the only university in Australia with a palliative care team within their school of public health. They have developed a Healthy End of Life Program (HELP) which uses an asset based approach in partnership with local government and collects evidence as part of the methodology. This program also supports disability and palliative care models.

### Recommended initiatives

INITIATIVE	BENEFITS
<b>Implement the La Trobe University Healthy End of Life Program (HELP) in Queensland</b>	This strengths-based sustainable community development program will create a collaborative community culture that attends to local end-of-life care needs. Communities will be guided through a practical suite of resources on how to work cooperatively with carers, family, friends and neighbours, to support residents who wish to receive end-of-life care in their home, or community setting.
<b>Create a State-wide Palliative Care</b>	Effective training is critical to the recruitment, activity and retention of volunteers in palliative care. A state-wide training hub would promote

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**Volunteer Training and Support Hub**

consistency and connectedness for volunteers, based on a similar approach in New South Wales.

Consistent, evidence-based volunteer training builds confidence and competence, enabling a broader role in their local communities and with service providers.

Ongoing support and networking for volunteers values them and connects them into a more integrated effort to help support people, their families and communities.

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**Create a compassionate Schools program**

Compassionate Schools are primary and senior schools which embed compassionate communities' models within their school systems. Using a similar model to SunSmart schools, the program would provide high quality information and support for schools to understand the principles of compassionate communities. It would create an opportunity for schools to join a program to embed the compassionate community approach into their systems, policies, staff training, parent networks and curriculum to enable the school to provide a network of support around people experiencing loss, ageing, dying and grief within their school community.

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**Implement the Last Aid courses throughout Queensland**

Based on a successful international initiative, Last Aid courses are a simple and effective concept to teach the public about palliative care to enhance public discussion about death and dying (Bollig & Heller, 2016). The current course consists of four modules:

1. Care at the End of Life
2. Advance Care Planning and decision making
3. Symptom Management
4. Cultural aspects of death and bereavement.

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**Develop an online self-care and compassion training course for community members and health professions**

With an ageing population our community members and health professionals are becoming increasingly exposed to dying and death. Compassion and self-compassion as positive emotions associated with wellbeing (Mills et al 2017a) and essential component of palliative care. The development of a free online course that allows individuals, community groups and health professionals to understand compassion and self-care, particularly in relation to end of life, plus information to develop strategies and self-care plans, would promote community wellbeing.

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**Provide 3-year seed funding to develop a "Queensland Ambulance Wish" program**

Based on international models, Ambulance Wish has been fulfilling last wishes for terminally ill people for many years. This unique and heart-warming program has medically trained volunteers and adapted ambulances which fulfil the desires of those who have one final wish but need assistance to realise it. Wishes can range from fish and chips at the ocean, to visiting family members, to watching their favourite sporting team and more.

This program enables community members to focus on making moments matter and leaving legacies when people are palliative, rather than focusing on symptom management and loss.

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## Recommendations to activate the community to be more involved in palliative care

1. Support Queensland Compassionate Communities (PCQ community arm) to act as an advocate, navigator and awareness raiser for community initiatives throughout Queensland
2. Develop and implement a state-wide public health palliative care strategy which incorporates health promotion, community awareness, health and community partnerships and compassionate communities (similar to the Age-Friendly Queensland strategy)
  - a. Implementation of this strategy should include grants for community groups similar to age-friendly grants which enable community development and engagement led by community groups
3. Conduct statewide community formal and informal service and groups asset mapping and share the results via platforms accessible to community members and service providers, based on tools within the La Trobe University Healthy End of Life Program
4. Encourage service providers to collaborate with the community to ensure carers have appropriate support networks around them
5. Provide statewide grants for palliative care services , peak bodies and community groups to promote Palliative Care during National Palliative Care Week
6. Support research grants to collect relevant data in relation to public health palliative care which adds to the literature in this area and shares Queensland's initiatives and leadership in this area on an international stage
7. Following the implementation of the *Compassionate Communities Conversation Series* across Queensland (a project administered by Palliative Care Queensland, in partnership with Health Consumers Queensland, Carers Queensland and Council on the Ageing Queensland, funded by Age-Friendly Queensland Grant) enable support to implement recommendations identified at both HHS and State level
8. Provide support and funding for PCQ's Good Life Good Death Expos. These events promote community engagement, education and promote service and supports. In addition, they education health professionals and promote health and social partnerships
9. Implement the La Trobe University Healthy End of Life Program (HELP) in Queensland
10. Create a Statewide Palliative Care Volunteer Training and Support Hub
11. Create a Compassionate Schools program
12. Implement the Last Aid courses throughout Queensland

13. Develop an online self-care and compassion training course for community members and health professions
14. Provide 3-year seed funding to develop a “Queensland Ambulance Wish” program

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## ***Palliative Care in Queensland Priority 4 – Focus on advance care planning***

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### **Background**

#### **“Let us understand your wishes”**

Advance Care Planning (ACP) is an essential component of quality palliative care and needs to be incorporated into all models of care to ensure client-centred care and high-value outcomes for Queensland.

The end of life can be a difficult, confusing, painful and emotional journey for the person and their significant others as well as for the treating practitioners. Unwanted outcomes can result from a lack of shared understanding and documentation of the personal choices and wishes of the person. The absence of a clear end-of-life decision and treatment pathway for the client can also lead to futile care and inappropriate use of health care resources. Consensus-based best practice recommends the preparation of advance care plans which document end-of-life preferred processes and that empower treatment decision making to be shared between clients and clinicians as per the client's expressed wishes and in accordance with medical and jurisdictional legislation. Such plans also allow clients' choices to be known by substitute decision makers, families, and carers who can help to ensure the end-of-life plan is met when the client can no longer directly communicate their wishes, and so inform treatment decisions. Early advance care planning discussions provide sensitive, honest information to clients and their families and carers to minimise unexpected outcomes and increased bereavement burdens.

The value of dedicated ACP facilitators has been demonstrated recently across Queensland with a project funded through a time-limited Quality Improvement Payment. Findings were significant. Compared with people who did not complete an ACP, those who did complete an ACP, with the assistance of an ACP facilitator, in accordance with their wishes:

- were significantly more likely to die out of hospital;
- spent significantly fewer days in hospital in their last 6 months of life; and
- were less likely to be admitted to ICU in their terminal admission.

Findings also showed that the earlier in a person's illness trajectory that an advance care plan was completed, the less time they spent in a hospital.

**Completion of an advance care plan translates to more people being cared for in their environment of choice, avoiding potentially non-beneficial care and less unwanted transfers from community settings to hospital setting.**

Coupled to this is the clear need for a systematised approach to information sharing and to create quick, easy visibility of ACP documents to frontline clinicians with added reassurance about document validity. The establishment of the Queensland Office of Advance Care Planning, supported by infrastructure such as the Queensland Health information technology portal ‘The Viewer’, creates visibility of ACP documents across primary and tertiary care agnostic of geography. General

Practitioners are able to access documents relevant to their patients, once they are registered on the system.

**The ongoing success of this model of ACP has already demonstrated benefits to the Queensland community and meets the requirements of frontline clinicians but is dependent on an ongoing committed investment of recurrent funding**

#### Recommendations related to increasing focus on Advance Care Planning

1. Continue funding for the Office of Advance Care Planning to support the advance care planning program across Queensland and provide oversight and build the evidence base
2. Ensure each HHS has ACP facilitators to promote and support Advance Care Planning in all settings
3. Provide statewide grants for palliative care services and community groups to promote Advance Care Planning during National Advance Care Planning Week
4. Establish an implementation funding program for evidence-informed decision-support tools for people to hold conversations about advance care planning in general practice
5. Standardise documents across Queensland and review issues related to Queensland Health documents/tools not being used or available for non- Queensland Health services (including Residential Aged Care and NGO community services)

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## ***Palliative Care in Queensland Priority 5 – Develop the healthcare workforce***

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### **Background**

The need for palliative and end-of-life care services has risen rapidly in the last 20 years due to an ageing population and rising chronic disease burden. Palliative care emerged as a specialist health service in the mid-1970s and is well established across Australia. Specialist palliative care services exist in health services across Queensland, however the issue of access to specialist palliative care services remains contentious.

Many hospital staff recognise that dying in hospital is not preferred but lack the capacity or understanding of community services to arrange transfer of care to the community. This is particularly salient when rapid discharge is required to support imminently dying clients (Jones et al., 2015; Tan & Blackford, 2015). To prepare families to manage care at home, nurses carry responsibility for family education. However, many nurses have limited understanding of palliative care and community care, making this task very challenging to complete.

This section of the submission addresses the educational requirements to sustain a workforce that can deliver palliative and end-of-life care to a wide range of Queenslanders living with life-limiting disease. The approach is to focus on four sites of palliative and end-of-life care including the community, the residential aged care facility, the hospital, and specialist palliative care units/hospices.

### **Professional competencies in palliative care**

In the Gold Coast HHS, five key competencies have been identified for palliative or end of life care:

1. Communicate with compassion
2. Recognise the dying trajectory
3. Refer, escalate and coordinate care
4. Provide supportive care i.e. manage symptoms and promote psychosocial well-being
5. Act within legal and ethical frameworks

These were then aligned with End-of-life Essentials and other Australian education modules to support staff to become competent in generalist palliative care (see attachment 1).

While the use of volunteers in palliative care is advocated, the programs require strong leadership, supervision and educational support. Further, there is limited robust evidence regarding the efficacy and feasibility of these services in combination with specialist and non-specialist palliative care (PCA, 2018b). While volunteers offer a potential workforce, their ability to provide high quality, safe care must be addressed by appropriate education.

It is possible that volunteer programs may emerge from the Compassionate Communities work. This type of development would require external, targeted, funding.

## The Residential Aged Care Facility setting

Reconfiguration of the aged care sector occurred in the national 1997 reforms, where the term for aged care facilities shifted from nursing homes to residential care. While autonomy for older people was enhanced, access to nursing and other health services was reduced. Access to general practice services is limited in residential care, as is access to specialist palliative care services unless residents are transferred to hospital.

The knowledge of palliative care among residential aged care staff is low, with Personal Care Assistant knowledge found to be no different to ancillary staff i.e. laundry, food services, and maintenance staff (Ford & McInerney, 2011). This is particularly alarming when most of the care providers in the residential care sector are Personal Care Assistants. While information is much easier to access than before, and high quality on-line services are available such as palliAGED (<https://www.palliaged.com.au/>), educational barriers in residential aged care services continue. These barriers were described over 15 years ago and include high staff turnover, time constraints, and lack of institutional commitment (Braun & Zir, 2005). For those staff who do participate in training, the capacity to translate that learning into practice on return to work is limited (Latta & Ross, 2010). Further work on translating evidence on end-of-life care into practice in the residential aged care sector is required. In the federal government's Teaching and Research in Aged Care (TRACs) program, the value of partnerships between residential aged care and universities to improve education and research in aged care facilities was found to be successful (Barnett et al., 2016). This model could be developed with partnerships between local hospices and health services, as well as the higher education sector.

Another suggested educational model for residential care might include partnership arrangements with hospice services, whereby hospice staff can provide consultancy services much like they do with families in home-based care. This would provide opportunities for residential care staff to learn by doing, much the same way that families learn about end-of-life care (Stajduhar et al., 2013).

## Hospital services

Many tertiary hospitals in Queensland offer hospital-based specialist palliative care services. As noted earlier, access to these services is limited due to limited numbers of specialist physicians and limited beds; therefore, clients are triaged. Often clients with non-malignant disease do not meet the triage requirements and their end-of-life care will be provided by generalist, often general medicine, clinicians. The End-of-life Care Pathway, instituted in Queensland in the last five years, provides a strong framework of support for generalist clinicians to deliver the care required near end-of-life.

Other resources for general clinicians that have value and should continue include the Program of Experience in the Palliative Approach (<https://pepaeducation.com/>), where clinicians can complete an observational placement with a specialist palliative care team for 2-4 days to learn on-the-job. Challenges in the hospital setting include inability of many clinicians to recognise when clients are near end-of-life, concerns about legal liability when withdrawing non-beneficial treatment, and lack of knowledge regarding symptom management.

Many clinicians today have had some palliative care content in their undergraduate education, through PCC4U (<http://www.pcc4u.org/>), a national evidence-based curriculum for palliative care. General clinicians also have access to on-line courses such as End-of-life Essentials (<https://www.endoflifeessentials.com.au/>). However, despite these resources, up to 50% of current Australian healthcare clinicians have little or no undergraduate training in end-of-life care or palliative care.

### Specialist palliative care

Australia has high-quality specialist palliative care services. It is supported by a strong national association, Palliative Care Australia, and state-based affiliates such as Palliative Care Queensland. There are opportunities for ongoing learning through national and international conferences, short courses, and local activities. However, specialist palliative care clinicians are at high risk of reduced well-being (Back et al., 2016), often related to inconsistent self-care practices (Mills et al., 2017b).

These feelings can be exacerbated by confrontation with unmet demand for services and the continual need to undertake triage work (Philip et al., 2019).

### Recommendations regarding workforce development

1. Continue funding for the Centre for Palliative Care Research and Education to support sustainable and consistent education in palliative care
2. Encourage the Commonwealth Department of Health to increase the number of PEPA places on offer in Queensland by 20%
3. Explore educational partnership models between residential aged care and health services or hospices like the Teaching Nursing Home model
4. Provide funding for a scholarship program to increase Specialist Palliative Care Nurse Practitioners to work in RACF
5. Incentivise the inclusion of PCC4U into Queensland undergraduate health professional higher education programs
6. Create a mentorship and supervision program led by local specialist palliative care services to support the growth of the palliative care sector and develop local linkages between specialist and generalist services
7. Develop and implement a palliative care leadership program which includes a sector leadership needs analysis and leadership development program including training, resources, linkages, networking, communication and mentorship support
8. Explore the capacity for tertiary level health services to extend their new graduate nurse programs to include nurses in local residential aged care
9. Promote clinical learning and debriefing models by developing structures for debriefing and learning from usual clinical processes such as the morbidity and mortality meeting
10. Create palliative care research scholarships to ensure the sector has opportunities to lead research and showcase innovations

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## ***Response to issues identified by the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee***

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### **Aged Care**

#### **1. *Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?***

No. Despite the *Aged Care Act 1997* stipulating<sup>3</sup> that providers are responsible for providing access to a qualified practitioner from a palliative care team and for the establishment of a palliative care program for any resident that needs it, palliative care is not seen as or supported systematically to be core business within aged care.

Fundamentally it is important to understand the definition of palliative care - person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

To emphasise this point, palliative care is not mentioned within the new Aged Care Quality Standards. The Standards make reference to 'end of life'<sup>4</sup> on two occasions, however there is a major difference between the provision of palliative care and just care at the end of life. Palliative care is for people who have a serious illness that cannot be cured. Care may be ongoing for many months or years, delivered concurrently with other treatments and is focused on helping people live their lives as fully and comfortably as possible until death and to help families cope during the time of illness and in their bereavement. Care at the end of life or 'end-of-life care' represents a specific time frame<sup>5</sup> and narrows the focus to the dying phase allowing opportunities for earlier support to be overlooked, particularly within aged care.

This lack of prominence of palliative care within aged care at all levels including policy, systems, education and training, is impacting on individuals, families, aged care staff and the broader community's experiences and perceptions of aged care (particularly residential aged care), death and dying, as well as the rates of avoidable or unnecessary hospital admissions, increased costs across systems and sectors, and grief and bereavement support.

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<sup>3</sup> Aged Care Act 1997 (Schedule of Specified Care and Services) stipulating that approved residential aged care providers are responsible for providing access to a qualified practitioner from a palliative care team and for the establishment of a palliative care program, including monitoring and managing any side effects for any resident that needs it.

<sup>4</sup> The Aged Care Quality Standards make reference to 'end of life planning' within Standard 2 and 'the needs, goals and preferences of consumers nearing the end of life are recognised and addressed, their comfort maximised and their dignity preserved' under Standard 3.

<sup>5</sup> ASSQHC (2015) National Consensus Statement Essential Elements for Safe High Quality End of Life Care. ACSQHC, Sydney

Too often, people are transferred back and forth between hospitals and aged care facilities, as aged care facilities lack palliative care expertise and qualified staff to administer pain relief<sup>6</sup>.

PCQ has consulted widely and has identified the following gaps in the aged care system:

- My Aged Care (MAC) is the portal via which older people and their families must access assessment for care and care provision. Consumers report that MAC is complex and difficult to navigate.
- When an older person is assessed as eligible for a Home Care Package, they often have to wait until a package becomes available. This can take up to **two years**. The person often deteriorates significantly, requiring a higher level of care, admission to acute care or admission to a residential facility. This situation places an increasing burden on families who are filling the 'care' gap in the meantime.
- Residential Aged Care in Queensland is woefully under-resourced, resulting in poor outcomes for residents and unnecessary transfers to acute hospitals. Staffing and skill levels in residential aged care prohibit the early recognition of resident deterioration, where, if identified early, a plan could be implemented to prevent further deterioration that inevitably ends in presentation to an Emergency Department.
- The primary care model of medical care in aged care is problematic. Medical governance of older people in the community or living in residential aged care is provided by General Practitioners (GPs). GPs largely work business hours and rarely provide medical support after-hours. GPs report they are not adequately remunerated for visits to residents in residential aged care, or for after-hours visits. Furthermore, their busy practice commitments prohibit emergency visits, which inevitably result in residents being transferred to hospital.

## ***2. Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?***

No. As has been represented to the Royal Commission into Aged Care Quality and Safety through the hearings to-date, waiting times for CHSP or HCP, or residential beds are unacceptable, particularly within the context of palliative care need. Dr McEvoy in his closing remarks told the Royal Commission 'the waiting times to which older Australians have been subjected in between being assessed as needing home care packages and actually receiving funding for care are severe and unacceptable. This has caused great suffering and continues to do so. The long waiting lists are cruel, unfair, disrespectful and discriminatory against older Australians'<sup>7</sup>.

For older Australians living with a life limiting illness, particularly when prognosis is difficult or already assessed as short, the wait times to receive a home care packages usually means that:

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<sup>6</sup> Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra. page 109

<sup>7</sup> Transcript of Proceedings, Royal Commission into Aged Care Quality and Safety 22 March 2019 P-1097

- the person has passed away prior to receiving the care they were assessed as requiring;
- periods of hospitalisation are extended due to the lack of support for them to return home;
- people move to residential aged care against their and their families wishes, who could otherwise be supported in the community.

Length of time to access a HCP is now being factored into deliberations of Guardianship and Administration Tribunals around the country. Estimated wait times at 28 February 2019, for a person with a medium priority approval joining the system for a package for levels 2, 3 and 4 all sit as 12+ months.<sup>8</sup> However how much longer than 12 months is not clear. A comment posted on an Australian Ageing Agenda article on HCPs said ‘as of today, (my brother) has been in the queue 950 days. That’s about two years and eight months’<sup>9</sup>.

At 31 December 2018, there were 73,978 people who were awaiting their approved level package who had not yet been offered a lower level home care package. Of these people, 93.9 per cent (69,476) had been provided with an approval to access CHSP<sup>10</sup>. However, CHSP is only designed to provide entry level support, which is well below the support most people with a life limiting illness and a short prognosis require. Yet, even when the services provided by CHSP would not be considered suitable, the Guidance on Priority for Home Care Services says ‘if the client does not want to accept other interim services or informal / formal supports they should not be considered high priority’ for a Home Care Package<sup>11</sup>.

Lack of clarity about eligibility for Commonwealth Home Support Program (CHSP), delayed access to home care packages (HCP) and limited funding available represent significant barriers for people with a life limiting illness in being able to access necessary services and choose where they received care as they near the end of their life.

Accessing aged care services is a complex, multi-step process which requires good English language skills, high levels of literacy and patience to navigate. The My Aged Care website is not user friendly and contact with the call centre can leave consumers frustrated.

‘The CHSP provides funding for a broad range of entry-level support services to assist frail older people aged 65 years and over (50 years and over for Aboriginal and Torres Strait Islander people) and who have functional limitations (including cognitive), to remain living independently at home and in their

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<sup>8</sup> Home Care Packages Program Data Report 2nd Quarter 2018-19 1 October – 31 December 2018 March 2019  
[https://www.gen-agedcaredata.gov.au/www\\_ahwgen/media/Home\\_care\\_report/HCP-Data-Report-2018-19-2nd-Qtr.pdf](https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/HCP-Data-Report-2018-19-2nd-Qtr.pdf) pg 14

<sup>9</sup> Response posted 13/4/2019 to Australian Ageing Agenda article Government announces \$280m for new home care packages by W Sullivan.

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<sup>10</sup> Home Care Packages Program Data Report 2nd Quarter 2018-19 1 October – 31 December 2018 March 2019  
[https://www.gen-agedcaredata.gov.au/www\\_ahwgen/media/Home\\_care\\_report/HCP-Data-Report-2018-19-2nd-Qtr.pdf](https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/HCP-Data-Report-2018-19-2nd-Qtr.pdf) pg 15

<sup>11</sup> Department of Health, My Aged Care *Guidance on Priority for Home Care Services* Version 1.0  
[https://agedcare.health.gov.au/sites/default/files/documents/06\\_2018/guidance\\_on\\_priority\\_for\\_home\\_care\\_services\\_v1.0.pdf](https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.0.pdf) viewed 4 April 2019

community. CHSP services are delivered on a short-term, episodic or ongoing basis, with a strong focus on activities that support independence and social connectedness and taking into account each person's individual goals, preferences and choices'<sup>12</sup>.

Whilst the CHSP Manual states that 'State and Territory governments are responsible for the provision and delivery of palliative care and hospice services as part of state health and community service provision responsibilities', it says 'CHSP clients are able to receive palliative care services from their local health system in addition to their home support services'<sup>13</sup>. However, My Aged Care staff undertaking screening, Regional Assessment Service (RAS) and Aged Care Assessment Team (ACAT) assessors often dispute whether a CHSP personal care service should be provided when a specialist palliative care service is involved. Lack of consistency about service provision responsibilities at the State/ Territory and Commonwealth levels lead to lack of clarity about eligibility, all resulting in delayed or limited services being provided to older people with a life limiting illness. Often this results in transfer of the person to a residential facility or hospital against their wishes, when adequate support could and should have been provided in the home, at a lesser cost.

People are prioritised for a HCP based on their assessed need. However, care level and priority for home care service are not necessarily linked – a level 4 client will not always have a 'high' priority for home care service – they may need a high level of care, but not be considered to be at immediate risk for a range of reasons<sup>14</sup>.

PCQ appreciates the competing priorities for people requiring a home care package and supports a single package assignment process which ensures equity of access. However, the time critical nature of the need for care for people with a life limiting illness with a short prognosis needs to be considered when assessing priority for access to a home care package.

The *Guidance on Priority for Home Care Services* says 'an assessor's recommendation regarding a client's priority for home care service should be based on their clinical judgement, information they have gathered during the comprehensive assessment and knowledge of the relative urgency of the client's need for a Home Care Package'. It goes on to say:

- high priority should only apply to a small number of clients approved for home care;
- 'high' priority is defined as: Client is considered at urgent and immediate risk in terms of their personal safety or at immediate risk of entry to residential care. The client may have a carer and the carer arrangements are unsustainable or at crisis point;
- clients with special needs should not automatically be considered to have a 'high' priority, as they may not have an urgent need to access a package quickly;
- there is immediate risk of the client entering residential care due to:
  - carer in crisis and / or inability of carer to offer required support; or
  - lack of interim services to meet the client needs; and
  - if the client had access to these services (as soon as possible), they could be managed at home<sup>15</sup>.

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<sup>12</sup> Commonwealth Home Support Programme Program Manual 2018 pg 1

<sup>13</sup> Commonwealth Home Support Programme Program Manual 2018 pg 72

<sup>14</sup> Department of Health, My Aged Care *Guidance on Priority for Home Care Services* Version 1.0

[https://agedcare.health.gov.au/sites/default/files/documents/06\\_2018/guidance\\_on\\_priority\\_for\\_home\\_care\\_services\\_v1.pdf](https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf) viewed 4 April 2019

<sup>15</sup> Department of Health, My Aged Care *Guidance on Priority for Home Care Services* Version 1.0

[https://agedcare.health.gov.au/sites/default/files/documents/06\\_2018/guidance\\_on\\_priority\\_for\\_home\\_care\\_services\\_v1.pdf](https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf) viewed 4 April 2019

Despite this Guidance there is a lack of transparency in how the waiting list and priority allocation works in reality making it difficult for consumers and those making referrals to know if, when or whom may be allocated high priority. Anecdotal feedback indicates the 'likelihood of being assessed as being high priority relates more to the availability / ongoing support of a carer than the other criteria'<sup>16</sup>. Consumers receive confusing communication which gives the impression a HCP may be assigned to them in three months when it ends up being much longer.

Ease of access and waiting times vary across the state and for various reasons. The waiting times generally depend on location. For example, in remote and very remote areas, there are fewer options but the population needs for care are growing. It can be a considerable wait for residential aged care in these areas, or a shorter wait for a place in a facility a long way from home. Waiting times in the major cities and inner regional areas are generally short and manageable for families.

**3. *Do the standards of residential aged care, home care and other aged care services provided in Queensland meet clients' and the community's expectations? Can you give examples?***

PCQ has received conflicting opinions to this question. Some argue the new standards are reflective of community expectations, while others dispute that.

**4. *How will demand for aged care services change in Queensland as the population increases and ages, and what changes to the aged care system will be needed to meet future demands for aged care?***

PCQ contends that there will be greater need and demand for aged care services across all settings of care as the population ages. The increase in demand is likely to increase the burden of care in the already burgeoning acute hospitals, as well as community and residential aged care. PCQ would like to see the following explored to meet the growing demand:

- Increased and improved integrated care models between primary and secondary care services/settings.
- More support from the acute sector for outward facing services. For example, Nurse Practitioner support in RACFs and general practice.
- Increased funding to support quality palliative care in the community and residential aged care.

As our population ages, there will need to be more HCP's available to meet the growing demand for at home services, as this is the preferred place of choice for senior Queenslanders to stay while they age, and if they choose, die.

**5. *Are there enough residential aged care places (beds) available in aged care facilities, in areas and at the levels of care that are required?***

Again, the adequacy of access to RACF places varies throughout the state. Some areas report having a surplus of beds, whereas others do not have enough supply to meet demand. An example of surplus is

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<sup>16</sup> PCA consultations 13/3/19, 19/3/19, 25/3/19, 26/3/19, 27/3/19, 28/3/19.

in the Federal electorate of Petrie in Brisbane North where there are reportedly 600 vacant RACF beds, though PCQ has seen no evidence to support this statement.

It is not necessarily a matter of physical beds or places, rather the business models of individual providers and the funding requirements they need to respond to.

**6. Are adequate numbers of home care packages available in areas at the levels required?**

The predominant feedback to PCQ is that there are inadequate numbers of Home Care Packages across Queensland. Whilst demand varies in different regions, the general consensus is that (even with the recent increase in funded packages) demand far outstrips supply and people are waiting for long periods for a package.

**7. Are there sufficient staff in the aged care sector to meet current and future workloads?**

PCQ's response is in the context of meeting palliative care provision needs - 35% of all Australians who die do so in residential aged care, equating to approximately 60,000 people each year<sup>17</sup>. Aged care requires the right skill mix and number of staff, available 24 hours a day to be able to respond to the palliative care needs of residents and consumers so they can be supported to have a high quality of life right to the end of life. Staff need time for clinical assessments and monitoring as well as adequate time to spend with residents which is not task oriented<sup>18</sup>.

There has been much debate about whether or not staff to resident ratios should be mandated for residential aged care, yet there is little consensus on the issue<sup>19</sup>. When discussing staff ratios the focus tends to be on registered nurses, rather than other staff. PCA is on the record as stating that the benefit of having ratios means predictability for staff in terms of rosters and a growing body of evidence that adequate nurse to resident ratios lead to better outcomes. The outcome PCA and PCQ seeks when discussing staff numbers, skill and mix is to ensure that a predictable standard of care is provided<sup>20</sup>.

A key concern is the quality and availability of after-hours care including weekend care for residents. Residents and their families need assurance that appropriate care will be provided in any 24 hour period including on weekends. This needs to include the staffing sufficient to ensure residents are able to receive palliative pain medication and symptom management at any time of the day or night. PCQ supports the notion of transparency for staffing, allowing prospective residents and their families to determine if a facility provides staffing levels that they believe will meet their needs and to help manage expectations.

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<sup>17</sup> Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra. page 109

<sup>18</sup> Palliative Care Victoria, *Palliative Care Consortia Aged Care Projects Survey results*, 2018

<sup>19</sup> Royal Commission into Aged Care Quality and Safety, *Navigating the Maze: An Overview of Australia's Current Aged Care System – Background Paper 1*, 2019 pg 40

<sup>20</sup> PCA Submission to the Senate Standing Committees on Community Affairs Inquiry on the Future of Australia's Aged Care Sector Workforce, page 5

Staff working in aged care need to be suitably trained and equipped to work with residents and consumers who have palliative care needs, and their families. People 'who require care in residential aged care facilities (RACF) will continue to have more complex healthcare needs because they have remained within the community until they can no longer be safely cared for in that setting. This will require a more highly skilled RACF workforce including skills in palliative care and end-of-life care'<sup>21</sup>.

This includes the ability to recognise deterioration, the need for pain and other symptom management, and the signs of impending death<sup>22</sup>, confidence with medications, especially PRN (when needed) medications and education to 'enable staff to understand symptom management, including pain relief before personal care'<sup>23</sup>. With the high numbers of people receiving aged care who have a dementia, mandatory training including on caring for someone with advanced dementia is required.

Understanding what palliative care is, is essential, and the need for specialist palliative care is not always recognized, and even if the need is recognised, not all State specialist palliative care services provide service into aged care facilities.

It is also important for registered nurses and personal care workers to be trained in 'soft skills' such as communication. Lack of communication skills, limited time and attention to communication and lack of comfort holding discussions about dying leads to poor planning for end of life. Staff need to be confident in talking to families about what to expect toward the end of life; to understand the person's wishes for end of life; where they want to die and what is important to them. Confidence in chairing family meetings and case conferences are essential skills for delivering palliative care in aged care. Training alone however is not sufficient for embedding skills in these areas. Providing ongoing mentoring and modeling helps to reinforce these skills and builds confidence through provision of feedback.

Multipronged approaches to empower residential aged care facilities to better deliver palliative care are needed including free education, clinical assessments and onsite mentoring. A lot of education and projects only get funded for short periods with one off funding, and when they end and there is no follow up. The same problems appear a few years later.

Successful programs such as PEPA and ELDAC have recognised the importance of making available additional support to enable learning to be translated into practice. The Program of Experience in the Palliative Approach (PEPA) provides education, clinical placements and Reverse PEPA Placements where a specialist palliative care staff member travels to the applicant's place of employment to facilitate learning<sup>24</sup>. End of Life Directions for Aged Care (ELDAC) includes the option of ELDAC facilitators to support providers who wish to develop palliative care and advance care planning

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<sup>21</sup> RACGP submission to the Senate Community Affairs References Committee: Inquiry into the future of Australia's aged care sector workforce, 2016, page 8

<sup>22</sup> PCA Media Release, "Budget Shows Palliative Care Should be Core Business in Aged Care," 8 May 2018.

<sup>23</sup> Johnston N, Lovell C, Liu W-M, et al. BMJ Supportive and Palliative Care, *Normalising and planning for death in residential care : findings from a qualitative focus group study of specialist palliative care intervention* downloaded from <http://spcare.bmj.com/> on August 13, 2017

<sup>24</sup> <https://pepaeducation.com/>

activities within their organisation<sup>25</sup>. Without ongoing support, management commitment and service based champions, staff turnover and time constraints erode progress made.

There is a need to ensure all staff are aware of issues around grief and bereavement, as often long-term and close relationships are formed with residents and their families<sup>26</sup>. Upskilling the workforce in this area would not only assist in supporting the families and carers of the person who has died, but also foster an environment of support for other residents and the staff themselves, an important component of self-care and staff retention.

Staff turnover and lack of consistency in staffing are issues which impact a facility being able to deliver quality palliative care. Undervaluing the work of caring for people in aged care impacts on staff retention. Pay parity for registered nurses and the need for personal care workers to be paid appropriately for the work they do, is key.

Queensland has experienced an increasing number of places available for people to complete a Certificate III in Individual and Personal Support. This has led to an influx of professional caregivers in to the market. Whilst the numbers are adequate to meet the demand, the quality of staff is an ongoing issue. Newly qualified care staff require significant mentorship and support for their first 12 months. This is placing increasing burden on aged care organisations, and particularly experienced aged care staff within those organisations.

The longevity of staff working in aged care is also problematic. Many staff move on to different careers when they have experience and this depletes the pool of experienced staff further. The question of whether current staffing levels in aged care is sufficient for future workloads is difficult to answer. This depends on the policy and service development framework in future. Service models inevitably need to evolve as the older population grow as the current service proposition is unsustainable. These changing models of care will create different skill mix needs that potentially require different training, knowledge and skills.

#### **8. *Is the mix of staff appropriate for different settings within the aged care sector?***

For community care it seems the mix is appropriate, however from reports in residential aged care, there is a lack of registered nurses (RNs) on evening and night duty which can cause problems if a resident deteriorates and needs clinical attention in the middle of the night. Without RNs on night duty, the default position is to have the resident transferred to hospital which would often be unnecessary if qualified staff (RNs) were on duty to make informed clinical decisions.

The current Royal Commission in to Safety and Quality of Aged Care has heard numerous examples of inadequate staffing in residential aged care. PCQ has had reports of RACFs in Queensland who have one registered nurse available for over 100 residents. The clinical risks associated with such ratios is extremely high. There are currently no recommended or mandatory ratios for aged care but PCQ supports a policy framework that includes ratios to ensure the safety of residents.

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<sup>25</sup> <https://www.eldac.com.au/tabid/4887/Default.aspx>

<sup>26</sup> PCA, Economic Research Note 4, 2017

In community aged care, our members report that staffing levels and skill mix are generally adequate to meet the needs of the people requiring care, reflecting the fact that older people needing care at home generally have fewer care needs than those requiring residential aged care.

**9. Do aged care staff receive training that is appropriate and adequate to prepare them for the work?**

Other than initial training for professional caregivers, PCQ is not aware of any ongoing, standardised education or training beyond the mandatory annual health and safety training. Registered and enrolled nurses in aged care are subject to the Australian Health Professional Registration Authority (AHPRA) rules regarding continuing professional education (a minimum of 20 hours per year).

PCQ's members report that education and training opportunities depend on the individual facility manager or organisational education policy. Staff are generally expected to attend education in their own time (unpaid). PCQ would like to see mandatory training and education introduced for palliative care and dementia care for all staff working in residential aged care (clinical and ancillary).

**10. What are the costs to the public health system of caring for elderly people in hospitals whilst they are waiting for residential aged care places to become available?**

There are several costs associated with extended length of stay in an acute facility, including:

- The additional costs per bed day – an acute hospital bed costs approximately \$1000-\$1500 per day, depending on the hospital.
- Several studies have pointed to detrimental impacts that prolonged hospitalisations have on older people such as iatrogenic illnesses (e.g. infection), cognitive and functional decline.
- The occupation of an acute hospital bed with a non-acute patient reduces activity and productivity of the acute hospital.

**11. Are suitable health care services being provided within residential aged care settings and/or aged care providers?**

PCQ's position is that most residential and community services are providing the best care they can within the current funding model. The aged sector is subject to several system level barriers which complicate the delivery of quality care. These include (but are not limited to):

- Poor remuneration for nursing staff (benchmarked across health)
- Poor engagement by GPs with aged care (for many reasons)
- Increased community expectation of what aged care can deliver
- Bureaucratic systems that rely heavily on compliance rather than quality
- Siloed health care systems that prohibit, or make extremely difficult, the sharing of information and multiagency care planning

**12. *Is the current aged care system making an appropriate contribution to the health of older Queenslanders, within the context of the broader health system in Queensland?***

PCQ's position is that the current aged care system is providing adequate care for most older Queenslanders. However, there is room for improvement and many Queenslanders are experiencing delays in care and inadequate, poor quality care in some cases. Whilst PCQ acknowledges that there are a few individuals/organisations behaving poorly in the industry, the majority of issues are systemic and should be addressed as a matter of urgency to ensure safe, quality care for older Queenslanders.

**13. *How can the delivery of aged care services in Queensland be improved?***

Addressing the systemic issues already mentioned is critical to improving care for older people at the population level. This requires cooperation and collaboration across all levels of government, as well as improved funding and reporting frameworks that adequately remunerate those providing the care.

**14. *Are there alternative models for the delivery of aged care services that should be considered for Queensland?***

Whatever model is developed should be mandated to consider palliative care service development implications, including access to Specialist Palliative Care.

PCQ's position is that development of integrated care models will greatly improve management of care, and therefore the older person's experience. The barriers around funding (Federal v. State) need to be torn down to facilitate primary and secondary/tertiary care working together for the benefit of older people. An example of an innovative, integrated model is the Metro South Hospital and Health Service CARE-PACT model which aims to increase quality of care to frail older people in RACFs while reducing demand on the hospital sector. The original CARE-PACT model has four main components:

1. Telephone triage to reduce avoidable emergency department presentations using a single point of contact to enable specialist emergency nursing clinical assessment of deteriorating patients.
2. An ED and inpatient resource to maximise early discharge back to GP or residential aged care facility through collaborative discharge planning.
3. An ED-equivalent mobile assessment service in the aged care facility to reduce avoidable presentations to ED.
4. A pathway to expedite referral to specialist services directly from the RACF or substitution of these services within the aged care facility by a variety of community services according to key eligibility criteria.

A recent expansion (2018) to CARE-PACT has seen the implementation of a chronic wound service, mobile x-ray service, nurse navigator mediated case management and a Nurse-Practitioner position which will allow the treatment of these older patients in the familiar surrounds of their own environment. Also, further development of clinical pathways will improve implementation of an evidence-based approach in the emergency department.

The evaluation of the original CARE-PACT model concluded *'this model of care will generate a 610% return on investment for every Queensland Health dollar invested, with a total value of savings over the first two years of the project (including implementation phase) of \$17.1 million. This will be realised in released capacity. CARE-PACT aligns with hospital avoidance and integrated care strategies, and aims to increase quality of care to frail older persons in residential aged care facilities (RACF) while reducing demand on the hospital sector.'* (Metro South Hospital and Health Service website, April 2019)

**15. How will the model of aged care develop with evolving technology and medical practices?**

PCQ's position is that the advancement in technology will give rise to a plethora of opportunities with regard to improving aged care services. The implementation of the integrated electronic Medical Record (ieMR) across Queensland Health facilities and services will enable rapid access to information at the point of care. This will be critical for integrated care models. Also, the emergence of virtual health models will help to manage the medical and care needs of older people in their own home, rather than in the acute care setting. This is particularly important for older people living in outer regional, remote and very remote areas of Queensland.

There are also challenges with evolving technology. The cost to implement large scale virtual health programs may be prohibitive. PCQ would like to see economic evaluations included in all trials to understand the actual costs and benefits of new innovation. Sharing information across organisational boundaries can be problematic, as well as the different (and competing/incongruent) platforms on which the technology is often based. Whilst these are major barriers, they are not insurmountable.

**16. What are the key priorities for the future?**

PCQ believes the following are key priorities for the Queensland Government in the delivery of aged care services:

- Development of integrated care models
- Investment in integrated care (at state level)
- Collaboration between providers
- Collaboration and cooperation between governments

PCQ believes the following are key priorities for the Federal Government in the delivery of aged care services:

- Significant increase in funding that support better staffing ratios and recognise expertise and responsibility
- Development of models that improve quality rather than compliance
- Review of Medicare Benefits Scheme item numbers regarding care in RACFs and older people in the community

## End-of-life and palliative care

### **17. What are the palliative care services offered in Queensland?**

Generalist palliative care support is offered via General Practitioners, Residential Aged Care Facilities (RACF), acute hospital care and community home support services.

Ancillary palliative care support services and education initiatives include PCC4U (Palliative Care Curriculum for Undergraduates), caring@home project, Caresearch, Queensland Health End-of-life Care project including its work on Advance Care Planning, PEPA (Program of Experience in the Palliative Approach) placements and education.

Palliative Care Queensland - Peak organisation in the State for policy direction, strategic advice, education, awareness raising, as well as linking state and community service sectors

PallAssist – information phone line (offered 0700-1900 7 days a week) operated by Cancer Council Queensland.

Centre for Palliative Care Research and Education (CPCRE)

Compassionate Community and community capacity building initiatives such as Dying to Know Day, National Palliative Care Week, Advanced Care Planning Week, local palliative care community collaborations via some PHNs

- Home Based Community Support Services for palliative care clients and their carers – private and public
- Commonwealth Home Support Program (CHSP)
- NDIS (specific eligibility criteria to be met, select client group only)
- DVA Gold Card entitlements (very select client group)
- Queensland Community Care service and Home Care Packages
- Palliative Care Program funding for home-based community nursing support
  - Prolific range of private home-based support services
- Integrated Carer Support Service (national program commencing Sept. 2019)

### **18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?**

No – there are major unmet need areas due to barriers in accessing the existing services through programs such as the CHSP, Home Care Packages, and very limited funding for the State Government Palliative Care Program. (Please see the attached document outlining the barriers to service access)

Need for enhanced access to specialist palliative care physicians and nurse practitioners trained in palliative care – particularly for people in rural and remote communities.

Need for more trained staff and staff numbers in RACFs to provide adequate end-of-life care for residents with palliative care needs.

Residential care facilities would benefit from access to an A/H palliative care nurse practitioner for support in managing end-of-life care for residents with more complex needs (which would help reduce hospital presentations and admissions for these residents).

Need for government subsidised residential care facilities to be mandated to offer at least one planned residential respite bed per facility, so carers have more potential to plan for breaks from the carer role. Need for increased funding support to offer in-home respite options through community service providers.

**19. *Do the standards of palliative care and end-of-life care provided in Queensland meet clients' and the community's expectations?***

No. Clients and carers have an expectation that if they choose to die at home that there will be adequate community services (including specialist palliative care nursing support) to enable this to occur. At present whilst approximately 70 % of Australians say they would like to die at home, only about 14% will be able to do so (Palliative Care Australia, 2017) due to inadequate home-based community support services.

There is also a community expectation that if a person is an aged care facility resident, they will receive a high standard of palliation for end-of-life care. This is often not the case because residents may need to be admitted to hospital from an aged care facility to enable adequate symptom management for end-of-life care. It is likely there will be many stories submitted to the Aged Care Royal Commission about inadequate palliative care symptom management for residents in aged care facilities.

**20. *How will demand for palliative and end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?***

There is likely to be a significant increase in demand for home based palliative care services in the future, to allow more people to die in their own homes. An idea that needs full consideration is establishment of palliative care home care packages (PCHCP) – with the allocation of approved funds being made in accordance with the client's needs and in accordance with medically determined life prognosis predictions. PCHCP funding can be directed to a provider of the client's choice, and it will be the provider's responsibility to ensure sufficient funds are available to meet the need for increased nursing support, equipment and potential after hours support as the person approaches the terminal phase of care. (Palliative Care Australia 2018, National Palliative Care Standards 5th Edition, p 5. Accessed 15 January 2019.)

**21. How can the delivery of palliative care and end-of-life care services in Queensland be improved?**

Through the creation of palliative care home care packages.

Details about issues and proposed solutions can be found in Attachment 2

**22. What are the particular challenges of delivering palliative and end-of-life care in regional, rural and remote Queensland?**

- a) Geography – This limits the availability of domiciliary Palliative Care Services (most contracted service accept referrals up to 50 km, but not all).
  - Palm Island has no contracted domiciliary nurse currently (though this will change),
  - Home visiting and access to specialist services including the delivery of equipment such as hospital beds.
  - Equipment that supports the carer to look after their own at home in the preferred place of care and without which there will likely be utilisation of acute hospital services. (e.g. to get a hospital bed to Hughenden or Mt Isa from Townsville would be a very expensive and time consuming effort of more than 2 days)
- b) Geography – limits access to specialist services including education and support
- c) Remote and Rural Clinicians are trained to do what they can in their community and are probably more inclined to have a go at Palliative Care and End-of-life care rather than calling the most local specialist Palliative Care Service
- d) Funding does not seem equitable throughout the regional, remote and rural areas compared to the metropolitan services – funding should follow the population’s needs to be equitable.
- e) Clinicians working in Regional, Remote and Rural areas have to pay more travel and accommodation costs than the metropolitan clinicians to get to the same educational opportunities; those costs can be prohibitive.
- f) The patients and relatives and clinicians’ expectations of what Palliative Care looks like are different in rural and remote areas – they expect and accept less quality.
- g) There are far fewer specialist Palliative Care Clinicians in remote and rural areas than in metropolitan areas, especially down the middle Western Corridor of Queensland. There should be 2 clinicians per 100,000 of the population.

**23. What are the particular challenges of delivering palliative and end-of-life care for Aboriginal and Torres Strait Islander communities?**

There is no Specialist Palliative Care Service available in the Torres Strait Islands. PCQ is aware of visits by PEPA Queensland involving palliative care nursing and medical staff, including Dr Edward Mantle, palliative care physician from Cairns and Hinterland HHS, and Prof Janet Hardy, Director of Palliative and Supportive Care at Mater Health Services Brisbane. PEPA has recently conducted visits to Torres Strait to educate the community and Aboriginal and Torres Strait Islander Health Workers about palliative care. PEPA has been successful in encouraging Health Workers to

experience clinical observational placements with specialist palliative care teams in Cairns and Townsville, though numbers are relatively small.

In Cape York, a collaboration between St Vincent's Health Australia and NPAFACS (Northern Peninsula Authority Family and Community Services) has delivered some palliative care education and services. Palliative Care Queensland is also undertaking a project, funding by Queensland Health and Cook Shire Council to scope the development of a multipurpose end-of-life care centre.

PCQ is aware of the significant dislocation of families and elders to Cairns and Townsville when patients are sent there for treatment towards end of life, but the person deteriorates and is unable to come home before their death, therefore reducing their ability to share their legacies, traditions and stories.

Some of the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities include:

- A belief that talking about death, dying, and end of life will attract it into one's life
- The belief by some in the community that illness and death is caused by sorcery and not by natural causes
- Mistrust of the health system because of the part it has played in the past in oppression of Aboriginal and Torres Strait Islander peoples
- Language differences – for some people, English is their third or fourth language, and they might have little understanding of what is being said to them by health care professionals
- Some health care professionals lack cultural sensitivity, engendering distrust on the part of the Indigenous community

**Recommendation:** Palliative care services wishing to engage with the community should create partnerships with Aboriginal Medical Services, which usually are trusted by the community

#### ***24. What are the key priorities for the future?***

Palliative Care Queensland is collaborating with Palliative Care Australia with regards providing input into the Commonwealth Royal Commission into Aged Care Quality and Safety. We request this committee to review the Palliative Care Australia submission into the Commonwealth Royal Commission into Aged Care Quality and Safety.

## Voluntary Assisted Dying

### **1. Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?**

Palliative Care Queensland (PCQ) is neutral regarding VAD legislation, having amongst its membership people strongly supporting VAD and those just as strongly opposed. PCQ believes that legislative change is a matter for Parliament, guided by community views.

PCQ believes that the significant gaps in provision of palliative care and quality aged care in Queensland should not be a reason for the introduction of VAD legislation. In that context, it will be important to consider what needs specialist palliative care could address with additional investment co-designed with the sector and community.

PCQ recommends that if VAD legislation is introduced there needs to be clarification that palliative care and VAD are different. PCQ's position is also that VAD legislation/regulation must include support for those deemed ineligible for VAD. It is essential the following possible assumptions be addressed:

- Not assume everyone who requests to explore VAD will already be receiving Specialist Palliative Care (SPC)
- Not assume SPC will be the main provider of VAD

Early referral to SPC *in general* could reduce the number of people completing VAD due to time to explore and address goals of care and put in supports required. Another issue to consider is whether a person going through the VAD exploration process be given priority access to SPC, which could give rise to equity issues.

International evidence shows that the request for or completion of VAD is not primarily to address pain, and it is important that this is not the sole focus in considering supports for people who might be considering VAD. It will be essential to outline what suffering is/can be, and this should be addressed early in a person's illness trajectory.

PCQ recommends that if VAD legislation is introduced in Queensland, there is a minimum of a two-year period before it becomes active, to provide time for the Queensland Government to ensure all necessary systems are in place and that there is an opportunity to learn from the Victorian implementation. PCQ has significant concerns regarding elements of the implementation of Victorian VAD legislation such as a communication campaign to consumers with misleading messages regarding palliative care.

### **2. How should VAD be defined in Queensland? What should the definition include or exclude?**

PCQ provides the following for the Committee to consider:

- The definition should include:
  - the meaning of VAD
  - the meaning of decision-making capacity

- In the absence of uniform legislation across Australia, there is an increased risk of eroding safeguards, consumer confusion and health professional uncertainty. Differing terminology has been used in tabled Bills across Australia previously.
- However, given the system in Victoria is yet to commence, it is also important to consider that how VAD is defined within current legislation may require review and reconsideration to meet the needs of Queensland.
- Regardless of how VAD is defined, it is important that mechanisms are in place to ensure palliative care is differentiated as “an approach that intends neither to hasten nor postpone death” per the World Health Organisation definition, and that it is different from voluntary assisted dying.

**3. *If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?***

PCQ acknowledges that where introduced, legislation to allow VAD will pose many ethical, personal and professional issues for health practitioners, non-clinical workers and volunteers working in organisations providing any level of palliative care, across health, aged care and disability care. The need to maintain cooperative and respectful relationships underpinned by effective communication between colleagues, co-workers and people living with a life limiting illness to ensure appropriate care is provided is paramount.

Health practitioners must:

- be supported to work within their own professional or personal ethical values, whilst continuing to provide safe, quality compassionate care to people living with a life-limiting illness.
- be able to conscientiously object to participate in any aspect of voluntary assisted dying, including providing information, referral or assessing patients under the respective scheme.
- ensure that where they are a conscientious objector, a person seeking information about VAD is not abandoned and has a next step, such as a phone number where they can access information about VAD
- have their privacy and confidentiality maintained regarding their decision to be involved, partially involved or not involved in supporting a request for voluntary assisted dying.

**4. *If there is to be a VAD scheme, what features should it have?***

Processes must be in place to ensure:

- there are no barriers to palliative care provision if a person requests VAD
- supports are in place for those who do not meet the criteria for VAD
- support is available for health professionals who choose to participate in VAD
- health professionals choosing not to participate in VAD are protected and supported
- there is no judgment of conscientious objectors or conscientious providers

- provision of advanced communication skills training to all health professionals
- health professionals likely to be in contact with persons who might request VAD be taught skills in assessing and dealing with suffering
- health professionals have easy access to education specific to roles and scopes of practice on the legal frameworks and processes on how to address VAD requests; this must include issues concerning consent, identification of coercion, conflict resolution, conscientious objection, and grief and bereavement
- health professionals, non-clinical workers and volunteers have access to prompt confidential supportive services

**5. Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?**

It would be essential if introducing a VAD system in Queensland that there be detailed consideration of the experience of the introduction of VAD legislation in Victoria. Queensland would be well advised to reflect and gather evidence on the real or perceived need and the impacts, unintended or otherwise, of the Victorian experience. Development of the Victorian VAD legislation was guided by ethicists, lawyers, palliative care health professionals and others – Queensland should have a similar format if developing VAD legislation.

**6. Who should be eligible to access VAD and who should be excluded?**

Changes to eligibility from the already introduced Victorian legislation requires introducing a VAD system in Queensland that allows time to consider, reflect and gather evidence on the real or perceived need and the impacts, unintended or otherwise, of process and systems already in place.

The following persons should be excluded:

- Those under the age of 18 years
- Those not suffering a life limiting illness

**7. Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?**

PCQ's position is that VAD, if introduced in Queensland, should be available only to those aged 18 and over. This is the age at which people are deemed to have the maturity for various other activities such as the right to vote, and it seems that a decision as weighty as voluntary assisted dying should be at least as important as such other matters.

**8. Under what circumstances should a person be eligible to access VAD? Could it be for example, but not limited to, the diagnosis of a terminal illness, pain and suffering that a person considers unbearable or another reason?**

Eligibility for voluntary assisted dying could include:

- Diagnosis of a terminal illness
- Less than 6-12 months to live
- Symptoms that the person finds intolerable

- Certification by two independent medical practitioners that the person meets the relevant criteria, one of those practitioners being a specialist in the life threatening illness the person suffers
- The person is found to be competent to make the decision
- There is no coercion by others to induce the person to request VAD

It is noted from Canada that a large proportion of people who request VAD do so due to social or spiritual issues rather than pain or other symptom distress.

**9. What features should be included in a process to allow a person to legally access VAD?**

Canadian statistics on Voluntary Assisted Dying (Government of Canada, 2018) indicate there were 3,714 deaths from 10 Dec 2015 – 31 Dec 2017, with all but one physician assisted rather than self-administered. People requesting VAD should have a choice of physician assisted or self administered administration. There should also be:

- Access to quality Specialist Palliative Care, Generalist
- Respect for people living with a life limiting illness
- Assurance that people requesting VAD will not be abandoned by their health provider, similarly that those not requesting VAD not be abandoned by their health provider
- Respect for people with different views
- A focus on teaching Advanced Communication skills to all health providers likely to be involved in any way in the VAD process
- Access to appropriate professional development as a priority
- Provision of resources for self-care and support for health professionals, organisations and members of the community
- Systematic research and data collection about provision of VAD in Queensland

**10. What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?**

No inclusion of advance prescribing

Health professionals involved in assessment of people following a VAD request must be taught skills to detect any coercion that might have been applied to the person requesting VAD

**11. Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?**

Everyone with a life limiting condition should have access to medical, social, psychological and spiritual support. If VAD is legislated people need to access to quality holistic care that is no different if they request VAD or do not. PCQ does not want to see a system where people request VAD simply to get access to holistic care that would not be available otherwise.

**12. How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?**

PCQ recommends that a VAD scheme needs to consider the impact on people not eligible for VAD of that decision, having hoped that their suffering would be ended by VAD, but not being able to do so.

**13. Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?**

Yes.

They should be able to conscientiously object or conscientiously participate.

**14. If practitioners hold a conscientious objection to VAD, should they be legally required to refer a client to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?**

The principle of non-abandonment of the person is paramount here. While the practitioner may hold a conscientious objection to VAD, the welfare of the patient is central. In Canada, for example, such conscientious objectors are able to provide the patient with the phone number of a service that will provide them information about practitioners willing to participate in VAD. That would seem to be an option that should be acceptable to most clinicians.

## *Attachments*

### *Attachment 1: Gold Coast Health, End-of-life Care: On-line learning curriculum Draft 2, 8 March 2018*

#### *Background*

Care of the dying is an important and valued health service activity. With the continuous movement of trainee staff and graduate entries into the workforce, it is important to ensure staff are aware of on-line learning opportunities that can assist with developing competence in the care of the dying. The End-of-life Care Education Working Group has undertaken a review of freely available online education and established learning outcomes for three levels of staff engagement with care of the dying. The work of Rose Costa, Joanie Shaw, and Laurie Grealish is noted in preparing the End-of-life Care: on-line learning curriculum.

#### *Competency domains*

Five broad competency domains required in end-of-life care have been identified for Gold Coast Health:

1. Communicate with compassion
2. Recognise the dying trajectory
3. Refer, escalate and coordinate care
4. Provide supportive care i.e. manage symptoms and promote psychosocial well-being
5. Act within legal and ethical frameworks

The competency domains are designed to be enacted at three levels of practice. The first level is generalist, that is all professional health service staff. For those staff, where death is uncommon in daily practice, generalist is the minimum requirement. The second level is called intermediate. These educational programs are recommended for staff who commonly care for people near the end-of-life. The third and final level is called specialist. These educational programs are recommended for staff who care for individuals and families who have complex care requirements. Suggested health service areas for each level of education is found in Table 2.

*Table 2. Curriculum selection by health service area*

General	All areas direct health care
Intermediate	A&E, ICU, general medical, neurology, oncology and nephrology
Specialist	Palliative services

### Course offerings by competency domain and level

Available courses that have been assessed as appropriate to develop each competency domain have been identified from available programmes. Some of these are free and others may carry a cost. Individual clinicians are encouraged to discuss their learning needs in relation to care at the end-of-life as part of their regular performance review. A full list is found in Table 3.

### Recommended curriculum

It is recommended that as clinicians develop more confidence in end-of-life care, they move through four programs:

1. General on-line education for five domains
2. Intermediate on-line education for five domains
3. Program of Experience in the Palliative Approach\*
4. Specialist on-line education for five domains

\*More information about the Program of Experience in the Palliative Approach (PEPA) is available from:  
<https://pepaeducation.com/>

### Example curriculum

General	PCC4U: Modules 1, 3, 4 + Topic 1 AND ACPA: Module 1 OR End-of-life Essentials: Modules 1, 2, 3, 5, 6 AND PCC4U: Module 3
Intermediate	PCC4U: Topics 2, 4 AND AHHA: Modules 2, 4, 5, 6 OR End-of-life Essentials: Module 4 AND Advanced elearning: Modules 1, 2, 3 AND AHHA: Modules 2, 4, 5
Specialist	End-of-life Curriculum Project: all modules

**Table 3.** Courses available grouped by competency domain and level Instructions

Gold Coast Health staff are encouraged to select one course in each domain for each level of practice.

Targeting specific domains based on current performance review is also encouraged.

	<b>Communicate with compassion</b>	<b>Recognise the dying trajectory</b>	<b>Refer, escalate &amp; coordinate care</b>	<b>Provide supportive care</b>	<b>Act within legal &amp; ethical limits</b>
General	PCC4U: Modules 1 & 4; <sup>a</sup> OR End-of-life essentials: Module 2 <sup>b</sup> PCC4U: Topic 4 <sup>a</sup>	PCC4U: Module 1; <sup>a</sup> OR End-of-life essentials: Modules 1 & 3 <sup>b</sup>	PCC4U: Topic 1; <sup>a</sup> OR End-of-life essentials: Module 5 <sup>b</sup> & AHHA: Module 1 <sup>d</sup>	PCC4U: Module 3 <sup>a</sup>	ACPA: Module 1; <sup>e</sup> OR End-of-life essentials: Module 6 <sup>b</sup>
Intermediate	PCC4U: Topics 2 & 4; <sup>a</sup> OR End-of-life essentials: Module 4 <sup>b</sup> PCC4U: Topic 3 <sup>a</sup> - optional	AHHA: Module 6; <sup>d</sup> OR Advanced eLearning: Module 3 <sup>f</sup>	AHHA: Module 4 <sup>d</sup>	AHHA: Modules 2 & 5; <sup>d</sup> OR	ACPA: Modules 2-6; <sup>e</sup> OR Advanced e-learning: Modules 1 & 2; <sup>f</sup> OR Improving EOLC for RACR: Modules 1-3 <sup>g</sup>
Specialist	End-of-life curriculum project: 2 modules (communication & bereavement); <sup>c</sup>	End-of-life curriculum project: 2 modules (prognostication & transition to death) <sup>c</sup>	End-of-life curriculum project: Module 'home hospice' <sup>c</sup>	End-of-life curriculum project: 3 modules (dyspnoea, opioid conversion, palliative sedation) <sup>c</sup>	End-of-life curriculum project : Module 'overview of palliative care' <sup>c</sup>

**On-line courses (correct as of January 2018)**

- a) Palliative Care Curriculum for Undergraduates (PCC4U) - <http://www.pcc4u.org>.
- b) Target audience is undergraduate health students. Topics are suitable for clinicians. Participants can complete a record of participation.
- c) End-of-life essentials - <https://www.caresearch.com.au/caresearch/tabid/3866/Default.aspx> No specified target audience. Participants are provided with a certificate of completion.
- d) End-of-life curriculum project - <https://www.caresearch.com.au/caresearch/tabid/2470/Default.aspx>
- e) The program is designed as a comprehensive, modular self study resource to teach medical students and health professionals about End-of-life (EOL) and palliative care issues and develop relevant knowledge, attitudes and communication skills.
- f) Australian Healthcare and Hospitals Association (AHHA) - <http://ahha.asn.au/pallcareonline>
- g) Target audience is practice nurses (general practice services) and staff in residential aged care facilities. Provides a certificate of completion.
- h) Advanced Care Planning Australia (ACPA) - <https://www.advancecareplanning.org.au/education-and-training> Provides a certificate of completion. Also offer a range of webinars as well.
- i) Advanced eLearning - <https://www.caresearch.com.au/caresearch/tabid/4086/Default.aspx>
- j) Designed specifically for GP practice nurses. Once initial modules complete there is an ability to unlock further learning. Provides a certificate of completion.
- k) Improving end-of-life care for residential aged care residents (Improving EOLC for RACR) - <https://www.caresearch.com.au/caresearch/tabid/4186/Default.aspx>
- l) Designed for Advanced Care Planning champions in residential aged care facilities. Provides a certificate of completion

## Attachment 2: Examples of system issues, including proposed solutions

There are multiple systemic barriers for people experiencing a palliative illness (and who are seeking to stay home for as long as possible), to be able to access government subsidised home based support services. The majority of the palliative care clients and their carers do not have the financial means to be fully reliant on privately funded home based services. Many informal carers are often stretched to their capacity and experience high levels of carer strain.

The implications are that people do not get the service support they need to manage in their homes and end up having multiple presentations and admissions to hospital or face premature entry into an aged care facility.

### *Potential solution:*

*The State government in partnership with the Federal Government create designated Palliative Care Home Care Packages (PCHCP) to provide support to people whose medical prognosis is considered to be < 6 months. (The State Government continue to fund the Palliative Care Program to cater for people's needs for the most urgent cases when people are more quickly approaching end-of-life care).*

- These packages would operate alongside the existing Federal Government Dept. of Health's model of assessment for Home Care Packages but would have a separate national queue specifically for the PCHCP.
- Initial Referrals could be managed through the existing My Aged Care (MAC) system. MAC staff would need to have upskilling to understand that any referrals for a client with a palliative illness whose medical prognosis is < 6 months, will need to be processed as HIGH priority for triage and assessment by the new streamlined national assessment teams.
- Assessors in the streamlined national assessment team would have the ability to identify highest priority for clients where there is clinical evidence that rapid deterioration is occurring or predicated; and when major carer stress / carer exhaustion is identified.
- People who are already accessing adequate home support services through the NDIS, DVA Gold Card provisions, or a Level 3 or 4 HCPs, would not be eligible. State Government Specialist Palliative Care Services could still operate a smaller budget for Palliative Care Program funding which could top up care in the home with specialist palliative care nursing input as required; and for those people who deteriorate too quickly for a PCHCP to be commenced.
- Home based services could include basic domestic help, basic yard maintenance, shopping assistance, transport to GP and specialist appointments, medication monitoring, personal care, general and specialist palliative care nursing and allied health as required.

- Equipment and resource support would include hire of 4 wheel walkers, wheelchairs, hoists, oxygen therapy, hospital beds and pressure care mattresses, continence aids, suction device, and syringe drivers and other specialised palliative care nursing equipment etc.
- Approved PCHCP providers would be expected to work with clients and carers to release funding support for services and equipment depending on need, to ensure maximum support is available as the person's care need's increase and they approach end-of-life care.
- Approved PCHCP would be encouraged to operate in accordance with Australian and State Government standards for Palliative Care, and the National Palliative Care Outcomes Collaborative (PCOC).

### **Current systemic barriers for people experiencing a palliative illness to be able to access government subsidised home based support services**

- DVA - People with access to a DVA Gold Card can be very well supported with home support services. DVA service system is very easy to access for eligible people. This is not an area of concern.
- My Aged Care (MAC) – Services via the Commonwealth Home Support Program, and the Home Care Package program:
  - Designed for people 65 years and over. Younger people with a palliative illness must apply to the NDIS first and test their eligibility. Then once they have a letter from NDIS to say they are not eligible, then they can apply again for services via MAC. For those people who only have a functional disability due to their palliative illness eg. advanced metastatic cancer – we can predict that they will not be eligible for the NDIS. It seems a big waste of very unwell people's limited living time and energy to complete application paperwork that will not be successful.
  - Assessors with both the Regional Assessment Services and the Aged Care Assessment Teams are given strong guidelines to recommend services for people – based on their health and functional abilities on the day of the assessment. Any 'future proofing' is actively being discouraged for assessors. This is not in the best interests of people experiencing a palliative illness such as an advanced metastatic cancer, who often have a disease trajectory where a person can still be managing certain tasks such as their personal care, but then deteriorate very quickly. They may only be approved for a reduced number of services via the Commonwealth Home Support Program, or a low level Home Care Package for this reason. It takes lot of energy to reapply back to MAC for an increase in services.

*Case example: 88 year old lady with a palliative illness (lymphoma) who lives alone rang MAC to request an ACAT assessment to be eligible for a Home Care Package. She was given the third degree of questions by MAC call centre staff regarding what services she needed help with right at this moment. She could not explain to them that she was wanting as assessment because she knew she was deteriorating and wanted to have a plan for more support in place to stay at home for as long as possible. This lady ended up in tears, and just said "I give up".*

- Assessors with the Aged Care Assessment Team have extremely strict criteria to be able to approve people as 'high' priority for their Home Care Packages. Even a life prognosis of <6 months is not adequate to warrant 'High' priority status if there is a carer who is wanting to continue in this role (even if highly stressed or exhausted), and the person is not at risk of entering permanent residential care due to informal service support.

*Case example: A gentleman with a glioblastoma and left sided paralysis, affecting his whole right side required his wife's assistance with feeding, personal care, supervision to transfer and walk, and was dependent on his wife for all cleaning, meal preparation, shopping, and transport. Unfortunately, his wife has a condition where she suffers severe migraines and is confined to bed for days with dizziness, vomiting, and being unable to get up. This case was not approved for 'High Priority' because the carer was not at the place where she was saying she was no longer able to continue in the carer role.*

- The waiting period for the allocation of funding for Home Care Packages (once the ACAT approval has been given) is currently 12-18 months for people given 'Medium' priority. This means that clients, carers, and assessors often consider it is pointless to have the approval for a Home Care Package – as they will most likely be dead before the funding comes through. It feels like people with a palliative illness are being discriminated against in terms of eligibility for the increase in home support services via a HCP – just because they have a limited life expectancy. It should be these people who are prioritised for home support services – because they do not have long to live and will not have an ongoing requirement for service support.

➤ **Queensland Community Care (QCC) Program**

This program is designed to meet basic home support needs for adults <65 years who are experiencing a level of disability due to their health conditions.

- This service has been widely used by palliative care clients 65 years who need assistance with areas such as domestic help, shopping, transport, social support, home maintenance, nursing and allied health services. With the commencement of the NDIS, palliative care clients are now needing to test their eligibility with the NDIS in the first instance (effort and time delays with this application process), and when knocked back – can then apply for QCC assistance.

- QCC funding is changing mid 2019 and scaled back as funding is redirected to the NDIS. There will be less service support available to palliative care clients with this development, and the nursing support component is being removed from the new look QCC program. Palliative care clients <65 years will be at risk of not receiving nursing services with this change.

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