



Palliative Care
Queensland
Matters of life and death

2024

Queensland Budget Submission



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About PCQ

Palliative Care Queensland (PCQ) is a leading charity and independent peak body representing palliative care providers, people experiencing a life-limiting illness, dying, death and grief, as well as those with an interest in palliative care in Queensland.

PCQ represents its members as the peak body and leading voice for the palliative care community in Queensland.

We work for our members in promoting and supporting quality palliative care for everyone, everywhere. Established in 1988, we are an incorporated association and registered charity that is supported by local and state government, membership, funding stakeholders, donations and other community groups and associations. As part of the Palliative Care Australia federation, we work with other states and territories to influence national policy and initiatives, representing our members to the highest levels of government to achieve our principal roles.

Our Organisational Priorities

We advocate, educate and support a Queensland where people:

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

2022-2025 Strategic Plan

Our 2022-2025 Strategic Plan outlines our roadmap to ensure we meet our organisational goals and priorities, driving our mission to influence, foster and promote quality palliative care for all Queenslanders.



Recommendation Table

Recommendation	Solutions	Funding
<p>1. Increase access to palliative care for Queenslanders under 65.</p> <p>PCQ recommends increasing access to palliative care services for those under 65, including both National Disability Insurance Scheme (NDIS) participants and those ineligible for NDIS support.</p>	<p>A. Develop seamless palliative care integration for National Disability Insurance Scheme (NDIS) participants under 65.</p>	<p><i>nil – Commitment required by Queensland Government to ensure community palliative care is funded and available (see recommendation 1C)</i></p>
	<p>B. Negotiate with the Australian Government to expand access to social care supports to individuals under 65 requiring palliative care, but ineligible for NDIS support.</p>	<p><i>administrative costs to Queensland Government only.</i></p>
	<p>C. Extend funding to support people under 65 years with palliative care needs 24/7, 365 days a year within the community.</p>	<p><i>cost neutral if utilising existing funding under the strategy but will need a Queensland Government commitment to forward year funding to sustain the anticipated growth in community palliative care.</i></p>
	<p>D. Develop targeted specialised palliative care programs addressing the unique needs of younger individuals requiring palliative care.</p>	<p><i>\$120,000 (GST excl) one off cost to develop concept – ongoing cost of program to be decided by Queensland Government</i></p>
<p>2. Increase funding and support for hospices and palliative care services in the community.</p> <p>PCQ recommends there be increased funding for hospice and community palliative care services throughout Queensland. By</p>	<p>A. Increase financial resources dedicated to community palliative care and hospices.</p>	<p><i>to be assessed by Queensland Government</i></p>

<p>strengthening community-based palliative care services and hospices, greater dignity, comfort, and quality of life for individuals facing life-limiting illness can be promoted, while also providing much-needed support to their families and caregivers.</p>	<p>B. Build public awareness by educating and raising awareness in the community about the importance of palliative care services and end-of-life care.</p>	<p><i>\$320,000 (excl GST) one off cost</i></p>
	<p>C. Allocate resources to ensure funds are distributed equitably for optimal service delivery and improvements for palliative care initiatives (e.g. an app that identifies need and available services by location for the community setting).</p>	<p><i>\$600,000 (excl GST) one off cost</i></p>
<p>3. Continue funding quality palliative care and dignified end-of-life care for Queenslanders accessing aged care.</p> <p>PCQ recommends increased funding to provide dignified end-of-life care for the elderly, both within aged care facilities and in the community. PCQ also recommends continued funding and support by the Queensland Government for the Specialist Palliative Care in Aged Care (SPACE) project.</p>	<p>A. Continue funding for Specialist Palliative Care in Aged Care (SPACE) as an ongoing program in residential aged care and expand this program to community aged care.</p>	<p><i>ongoing funding from the Australian Government for the extension of the project and matched funding commitment by the Queensland Government with expansion to community aged care</i></p>
	<p>B. Aged care providers to enhance aged care facilities to enable provision of dignified end-of-life care for residents.</p>	<p><i>Nil – responsibility of Australian Government</i></p>
	<p>C. Provide specialised training to aged care staff, tailored to the unique needs of residents.</p>	<p><i>\$305,000 (GST excl) over two years</i></p>

	D. Develop holistic care programs that focus on the social, emotional, physical and spiritual wellbeing of aged care residents.	<i>cost to be determined by Queensland Government</i>
<p>4. Grow initiatives that educate and engage the community to build compassionate communities.</p> <p>PCQ recommends that increased funding be made available to promote community-centric initiatives, aimed at educating, engaging and empowering people to foster compassionate communities.</p>	A. Increase community engagement by developing and implementing initiatives that engage community members in understanding and supporting palliative care.	<i>\$550,000 (GST excl) over two years</i>
	B. Invest in educational initiatives which enhance death literacy and empower people to create compassionate communities, to support those experiencing life-limiting conditions, dying, death, caregiving and grief.	<i>\$57,000 (GST excl) one off cost</i>
	C. Build compassionate communities to forge partnerships between local organisations to grow a network of support for compassionate care initiatives.	<i>cost neutral - PCQ already provides these services and will continue to</i>

	D. Increase funding for the compassionate communities' model, that allows the introduction of coordinators to help liaise with palliative care services.	<i>\$2.38 million (GST excl) recurrent annually</i>
<p>5. Increase resources and funding directed toward grief and bereavement services and spiritual care.</p> <p>PCQ recommends that increased funding be allocated to resourcing grief counselling, bereavement support and spiritual care services across Queensland.</p>	A. Allocate funding to enhance grief counselling and bereavement support services.	<i>\$1.6 million (GST excl) recurrent annually</i>
	B. Allocate funding to increase access to appropriate spiritual care services.	<i>\$10.8 million (GST excl) recurrent annually</i>
	C. Increase community access to grief and bereavement services.	<i>\$3.94 million (GST excl) recurrent annually</i>
	D. Increase training and support for professionals offering grief and bereavement services.	<i>cost to be determined by Queensland Government through establishment and guidance of a steering group</i>
	E. Increase support for spiritual care practitioners.	<i>cost to be determined by Queensland Government through establishment and guidance of a steering group</i>

	<p>F. Increase training for all health professionals and workers in supporting spiritual needs, particularly for Aboriginal and Torres Strait Islander people.</p>	<p><i>cost to be determined by Queensland Government through establishment and guidance of a steering group</i></p>
<p>6. Prioritise funding, education, training and recruitment for a more culturally diverse palliative care workforce.</p> <p>There is low diversity in Queensland’s palliative care workforce, and a need to encourage health professionals and workers to engage in the palliative care sector and to support their retention. This requires increased funding, education, training, recruitment and retention strategies to develop a more culturally diverse and sensitive palliative care workforce.</p>	<p>A. Develop educational programs to increase cultural competence and provide culturally safe and sensitive palliative care training and workplaces for palliative care workers, with an initial focus on supporting staff in regional, rural and remote areas.</p>	<p><i>to be decided by Queensland Government in consultation with Aboriginal and Torres Strait Islander, and CALD health and community groups</i></p>
	<p>B. Implement strategies to recruit and retain a diverse workforce – increasing both Aboriginal and Torres Strait Islander and CALD representation across the workforce. This requires a retraining and reshaping of the workplace to ensure cultural safety for all workers.</p>	<p><i>to be decided by Queensland Government in consultation with Aboriginal and Torres Strait Islander, and CALD health and community groups</i></p>
	<p>C. Integrate multidisciplinary and interdisciplinary mentorships into diverse communities, to provide culturally sensitive care.</p>	<p><i>to be decided by Queensland Government in consultation with Aboriginal and Torres Strait Islander, and CALD health and community groups.</i></p>
	<p>D. Include local cultural ambassadors in the design and development of palliative care services both in the hospital and in the community.</p>	<p><i>individual costs to be borne by each Hospital and Health Service</i></p>

<p>7. Improve community pharmacy support and services.</p> <p>PCQ recommends funding be allocated to:</p> <ul style="list-style-type: none"> introduce dedicated palliative care training programs for community pharmacy workers to develop knowledge and increase support for people in the community. continue advocating for enhanced pharmacy support and services that focus on meeting the palliative care needs of people in the community regardless of their location across Queensland. 	<p>A. Ensure availability and supply of necessary medications in palliative care settings, including regional, rural and remote.</p>	<p><i>to be determined by Queensland Government in consultation with the pharmacy sector</i></p>
	<p>B. Introduce dedicated palliative care training programs for community pharmacy workers to develop knowledge and increase support for people in the community.</p>	<p><i>\$800,000 (GST excl), over years one and two, with \$200,000 recurrent annually thereafter</i></p>
	<p>C. Advocate for enhanced pharmacy support and services that focus on meeting the palliative care needs of people in the community regardless of their location across Queensland.</p>	<p><i>\$200,000 (GST excl) with any further costs to be determined by Queensland Government following consultation</i></p>
<p>Total funding required</p>		<p>\$21.672 million (GST excl) over year one and two, \$18.92 million per annum recurrent, and 13 measures that require costing by Queensland Government</p>

Recommendation Analysis

Recommendation 1 (Under 65s)

Increase access to palliative care for Queenslanders under 65

PCQ recommends increasing access to palliative care services for those under 65, including both National Disability Insurance Scheme (NDIS) participants and those ineligible for NDIS support.

The Challenge

Palliative care is crucial in providing holistic support and symptom management for individuals confronting serious illness, regardless of their age or disability. However, current funding limitations restrict access to palliative care services for many individuals under 65, especially those with disabilities requiring specialised and tailored care approaches to address their unique needs.

In Queensland, roughly 19.1% of the population, or nearly 1 in every 5 Queenslanders, lives with a disability. Among them, approximately 306,400 individuals across all age groups have a profound or severe disability. PCQ has engaged with consumers and stakeholders who have highlighted the challenge faced by people under 65 with disabilities who are living with life-limiting illnesses or conditions. These individuals are regularly unable to access the necessary palliative care nor support for daily activities through the National Disability Insurance Scheme (NDIS) or other Queensland-funded services.

Unfortunately, the NDIS framework is not designed to assist individuals under 65 experiencing functional decline due to life-limiting illnesses. PCQ supports Palliative Care Australia's 2024 Federal Budget submission which calls for the Australian Government to:

- establish an interim program of non-clinical care and support for people under 65 living with a life-limiting illness, including those with a disability, who need support with the activities of daily living to remain at home and out of hospital.

For people under 65 to be appropriately supported within the community the Queensland Government must increase funding to ensure community palliative care clinical services are available across the state. With an increase of funding in this area, equitable access to high-quality palliative care services can be ensured for all individuals, irrespective of age or disability, aligning with their specific care needs and preferences.

Furthermore, increased funding to extend access to palliative care for individuals under 65 will contribute to enhancing health outcomes, improving quality of life, and reducing healthcare disparities in this demographic. Many individuals under 65 facing serious illness, including those with disabilities, require comprehensive palliative care services to manage symptoms, address psychosocial needs, and boost overall well-being. Investing in broader access to palliative care will enable individuals under 65 to receive timely and suitable care aligned with their aspirations and preferences, ultimately fostering dignity, comfort, and quality of life for everyone facing serious illness, death, and dying, regardless of age or disability.

The Solution

A. Develop seamless palliative care integration for National Disability Insurance Scheme (NDIS) participants under 65. This requires the Australian Government to ensure that all eligible NDIS participants are given access to the NDIS in respect of their primary disability and regardless of their palliative status. It also requires the relevant state/territory government to ensure adequate general and specialist palliative care is available both in hospitals and in the community (see Solution 3).

In working with the Australian Government, it is recommended that the Queensland Government point out that the National Disability Insurance Agency (NDIA) must not discriminate against people on the basis of their life expectancy, with regard to providing NDIS access and funding for personalised supports related to the person's disability support needs.

It should also be acknowledged that palliative care supports are the responsibility of relevant health systems and should be provided alongside the relevant NDIS supports including during the last 12 months of life and at end-of-life. A life-limiting diagnosis with a prognosis of less than 12 months does not mean that the need for disability supports is diminished. The NDIA retains responsibility to provide such supports through NDIS access for people under 65 "who have a permanent disability that affects the person's capacity for social or economic participation and results in substantially reduced functional capacity to undertake one or more of the following activities:

- communication
- social interaction
- learning
- mobility
- self-care
- self-management

(and) be likely to require support under the NDIS for the person's lifetime." ⁱ

Funding required: Nil – Commitment required by Queensland Government to ensure community palliative care is funded and available (see recommendation 1C).

B. Negotiate with the Australian Government to expand access to social care supports to individuals under 65 requiring palliative care but ineligible for NDIS support. The Queensland Government should support [Palliative Care Australia's 2024 Federal Budget Submission](#) ⁱⁱ and advocate for Recommendation 2 to be agreed to and implemented in full.

Funding required: Administrative costs to Queensland Government only.

C. Extend funding to support people under 65 years with palliative care needs 24/7, 365 days a year within the community. Whilst PCQ greatly appreciates the uplift in specialist palliative care under the [Queensland Health Palliative and End of Life Care Strategy](#) and the Queensland Health Specialist Palliative Care Workplan ⁱⁱⁱ there is much that needs to be done to uplift community palliative care across Queensland.

PCQ acknowledges that \$54.8m has been invested in community-based services to meet local needs with the majority invested through a contract with BlueCare. Ongoing reports to PCQ from community members and health professionals indicate that whilst the BlueCare initiative has been successful in some regions, there remains limited, if any, access to 24/7, or even seven days per week, community palliative care in many regions. This means that people are unable to remain in their place of choice, particularly as they approach end-of-life due to a lack of clinical support. There is much evidence nationally and internationally that shows the availability of quality community palliative care results in better outcomes for the individual and their family and cost savings for government due to fewer emergency department visits and fewer hospital bed days. ^{iv}

Recommendation: that the Queensland Government directs funding under the community palliative care initiative of the strategy to local solutions in health regions where the current program is proving ineffective. This could be directed through existing hospices to enhance their services or other community health services that have capacity to deliver community palliative care.

Funding required: Cost neutral if utilising existing funding under the strategy but will need a Queensland Government commitment to forward year funding to sustain the anticipated growth in community palliative care.

D. Develop targeted specialised palliative care programs addressing the unique needs of younger individuals requiring palliative care. The ongoing support from both the Queensland Government and Federal Government for Hummingbird House is greatly appreciated, as is the uplift for Queensland Children’s Hospital Palliative Care services under the Qld Palliative and End-of-Life Care Strategy. With over 100 young people under 18 presenting with palliative illnesses in Queensland each year and many more in the 18-to-30-year age group, it is acknowledged that there are limitations to bespoke services offered to these people and their families.

Recommendation: that the Queensland Government funds Palliative Care Queensland (PCQ) to:

- hold a series of discovery and development workshops with specialist palliative care health professionals (doctors, nurse practitioners, nurses, allied health), generalist palliative care health professionals (general practitioners, community health nurses, disability workforce) and younger people living with life-limiting illnesses, their families and those with lived experience, to unpack the gaps, and pros and cons of palliative care for people under 30 years of age; and
- co-create and develop a strategy to meet the needs of this cohort in consultation with Queensland Health and the workshop contributors.

Funding required: \$120,000 (GST excl) one off cost to develop concept – ongoing cost of program to be decided by Queensland Government.

Recommendation 2 (Community & Hospice)

Increase funding and support for hospices and palliative care services in the community

PCQ recommends there be increased funding for hospice and community palliative care services throughout Queensland. By strengthening community-based palliative care services and hospices, greater dignity, comfort, and quality of life for individuals facing life-limiting illness can be promoted, while also providing much-needed support to their families and caregivers.

The Challenge

An increasing number of people express a desire to die in the familiarity and comfort of their own home when questioned about their preferred place of death.^v The concept of "home" varies significantly among individuals, encompassing various living arrangements such as shared homes with family or friends, residing in aged care facilities, hospices or preferring solitude. Additionally, home may extend to rural or remote areas, where community-based care remains feasible until the end of life for many individuals.

Up to 70% of people in Queensland with a palliative diagnosis would prefer to die at home^{vi}. With around 50% of people dying with palliative sensitive conditions or cancers, only 5% die in a home or other setting and around 35% die in residential aged care, with around 60% dying in a hospital setting^{vii}.

Improving palliative care services in the community would decrease the number of people presenting to hospital in an unstable, deteriorating and terminal condition. This in turn will provide a cost saving to governments by reducing the number of days spent in hospital which currently costs upwards of \$2000 per bed day^{viii} which is likely just less than double the cost per bed day of a residential hospice.^{ix} By increasing funding and support for community-based palliative care services and hospices, individuals facing serious illness can receive the care and support they deserve in the setting of their choice, especially when it is their home or a hospice facility.

Investing in community-based palliative care services and hospices is essential for enhancing access to quality end-of-life care, improving patient outcomes, and supporting individuals and families during their most vulnerable moments. By increasing funding for these vital services, access to palliative care can be expanded in underserved communities, the availability of specialised care and support services is enhanced, and the burden on hospitals and other healthcare facilities alleviated. Moreover, by strengthening community-based palliative care services and hospices, greater dignity, comfort, and quality of life for individuals facing serious illness can be promoted, while also providing much-needed support to their families and caregivers.

The recommendations of the Productivity Commission report *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*^x remain relevant, particularly Recommendation 4.1 below.

RECOMMENDATION 4.1 State and Territory Governments should increase the availability of community-based palliative care so that people with a preference to die at home can access support to do so. To achieve this, State and Territory Governments should:

- *assess the need for additional community-based palliative care services*
- *design services to address identified gaps in service provision*
- *establish standards for community-based palliative care services and fund the provision of those services for people who wish to and can die at home. The standards should include integrated and coordinated nursing, medical and personal care.*

- use competitive processes to select providers (or a single provider) to deliver additional community-based palliative care services
 - monitor and evaluate the performance of community-based palliative care services against the specified standards
 - ensure that consumer safeguards are in place so that quality care is provided, and oversight is maintained, as the volume of services provided increases.
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The Solution

A. Increase financial resources dedicated to community palliative care and hospices.

Recommendation: that the Queensland Government costs and implement Recommendation 4.1 from the Productivity Commission report *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*

Funding required: To be assessed by Queensland Government.

B. Build public awareness by educating and raising awareness in the community about the importance of palliative care services and end-of-life care.

Recommendation: that the Queensland Government funds Palliative Care Queensland (PCQ) to co-create with hospices, community palliative care services and consumers, a social media campaign on community palliative care, services available, benefits of hospice and how to die well at home or in a place of choice in the community.

Funding required: \$320,000 (excl GST) one off cost.

C. Allocate resources to ensure funds are distributed equitably for optimal service delivery and improvements for palliative care initiatives (e.g. an app that identifies need and available services by location for the community setting).

Recommendation: that the Queensland Government fund the development of an application that collects community palliative care providers information and consumer need data and identifies locational alignment, enabling Governments to deliver the correct funding to the right locations and consumers to find the available services in their location.

Funding required: \$600,000 (excl GST) one off cost.

Recommendation 3 (Aged Care)

Continue funding quality palliative care and dignified end-of-life care for Queenslanders accessing aged care.

PCQ recommends increased funding to provide dignified end-of-life care for the elderly, both within aged care facilities and in the community. PCQ also recommends continued funding and support by the Queensland Government for the Specialist Palliative Care in Aged Care (SPACE) project.

The Challenge

Queensland is experiencing rapid population growth, with projections indicating an increase from 5.22 million people in 2021 to a range of 6.40 million to 8.27 million by 2046. This growth is anticipated to continue, reaching between 6.99 million and 11.74 million individuals by 2071.

The older population (aged 65 and over) in Queensland is expected to reach 1.0 million around 2025 or 2026. By 2071, it is estimated that 24.9% to 26.6% of Queensland's population will be aged 65 or older, with 1 in 4 Queenslanders falling into this age group.

Many older adults increasingly require specialised palliative care to manage complex symptoms and maintain their comfort and quality of life in their final days. However, limited funding and resources often result in gaps in palliative care provision for them, leaving vulnerable individuals without the support they need during this critical time.

The Royal Commission into Aged Care Quality and Safety Report released in March 2021 made several observations leading to recommendations regarding palliative care in aged care, most notably:

“The most common areas of substandard complex care we heard about involve dementia and challenging behaviours, mental health, and palliative care”^{xi}

“While the evidence before us has reflected a wide range of concerns about aged care quality and safety, we have singled out four concerns for immediate attention: food and nutrition, dementia care, the use of restrictive practices, and palliative care.”^{xii}

“High quality palliative care is essential to ensuring that an older person can live their life as fully and as comfortably as possible as they approach death. Compassionate, respectful and individualised support for older people approaching the end of their lives is a necessary component of aged care services.”^{xiii}

Recommendation 58 sought amendments to be made, by 1 January 2022, to the National Health Reform Agreement to ensure that funding be available:

- so that all people receiving residential care or personal care at home to have **access to palliative care based on clinical need**
- for delivery through Local Hospital Network-led **multidisciplinary outreach services**
- to include **a recurrent and sustainable funding mechanism** to stimulate outreach services
- for a model that includes:
 - a. provision of **services in a person's place of residence** wherever possible
 - b. multidisciplinary teams, including nurse practitioners, allied health practitioners and pharmacists.
 - c. access to a core group of relevant specialists, including ... **palliative care specialists** ...
 - h. a specific focus on **palliative care outreach services**^{xiv}

To date, it is unclear how much, if any of the Royal Commission recommendations relating to palliative care have been implemented.

In 2018-19, three years prior to the release of the Royal Commission Report, the Australian Government committed to fund the Comprehensive Palliative Care in Aged Care (CPCiAC) measure. In October 2020, the Queensland Government matched the Australian Government funding and implemented the Specialist Palliative Care in Aged Care (SPACE) project with an end date of 30 June 2024.

Over three and a half years, SPACE has provided vital services to help fill the gap in the palliative care of people in residential aged care facilities (RACFs) requiring specialist palliative care. There are challenges to general practitioners (GP) delivering services in these facilities. Furthermore, GPs visiting RACFs are struggling with providing time and expertise for more complex symptom issues, complex family concerns and lack of advance care planning discussions with residents and family members. Previously many residents were sent to hospitals, generally busy and over-crowded emergency departments (EDs) for no added benefit to their often general, expected deterioration. Since the inception of SPACE, there has been a reduction of hospital transfers and increased number of deaths in RACFs, which are people's homes. Families have been grateful to have received expert advice and care from professional teams supporting the resident, their families, the RACF staff and GPs. Other teams that have seen a huge benefit from the SPACE project bridging a gap in specialist palliative care in aged care have been the local Residential Aged Care District Assessment and Referral (RADAR) / Residential Aged Care Facility Support Service (RaSS) and Geriatric ED Intervention (GEDI) teams.^{xv}

By continuing to invest in quality palliative care for individuals accessing aged care, we can ensure that older adults receive the compassionate and dignified care they deserve as they approach the end of life. Adequate funding will enable aged care facilities to enhance their palliative care programs, provide specialised training for staff members, and improve access to essential palliative care services and medications. Moreover, prioritising palliative care within aged care facilities will not only improve the quality of life for residents but also alleviate the burden on families and caregivers, who often struggle to navigate the complexities of end-of-life care without adequate support.

To date there has been no further commitment to continue the Australian Government's CPCiAC or the Queensland Government SPACE funding, and already many of the projects under SPACE have wound up due to lack of funding certainty.

The Solution

A. Continue funding for Specialist Palliative Care in Aged Care (SPACE) as an ongoing program in residential aged care and expand this program to community aged care.

Recommendation: that the Queensland Government:

- continues advocating that the Australian Government make the SPACE project funding under the Comprehensive Palliative Care in Aged Care (CPCiAC) Measure recurrent and expand funding to include palliative care in community aged care, ahead of the current agreement's cessation on 30 June 2024.
- commits to match the current Australian Government funding for SPACE on a recurrent basis and identify and commit to the amount required for the expansion into community aged care.

Funding required: Ongoing funding from the Australian Government for the extension of the project and matched funding commitment by the Queensland Government with expansion to community aged care

B. Aged care providers to enhance Aged Care facilities to enable provision of dignified end-of-life care for residents.

Recommendation: that the Queensland Government proposes to the Australian Government that Outcome 5.7 of the Aged Care Quality Standards is prioritised and actively monitored across providers so that it is fully implemented.

Funding required: Nil – responsibility of the Australian Government.

C. Provide specialised training to aged care staff, tailored to the unique needs of residents.

Recommendation: that the Queensland Government funds Palliative Care Queensland (PCQ) to host a series of 50 education sessions over two years for the aged care sector across Queensland.

These sessions would provide information tailored to the needs of aged care workers. It would be an adaptation of community education currently delivered by PCQ (see [PCQ Learn](#)) which will aim to educate and inform the aged care workforce on how to have conversations around death, dying, grief and bereavement. This model is in line with the [Queensland Health Palliative and End-of-Life Care Strategy](#) skilled workforce action, to *promote existing resources and informal education and training opportunities to improve understanding of grief and bereavement amongst aged care workers.*

An expression of interest model will be developed for aged care facilities to register and sign up to the training, which will be provided face to face throughout Queensland. Data and feedback will be used to inform future training possibilities and collected data will help inform future palliative care reform.

Funding required: \$305,000 (GST excl) over two years.

D. Develop holistic care programs that focus on the social, emotional, physical and spiritual wellbeing of aged care residents.

Recommendation: that the Queensland Government works with the Australian Government to establish a holistic care program across Queensland for residents of aged care. Whilst aged care is a funding responsibility of the Australian Government, each state and territory government are responsible for the health and wellbeing of their citizens and as such should play a key role in ensuring better health outcomes for older people. Older Queenslanders would greatly benefit from a holistic care program^{xvi} There are already good examples of these programs in some aged care services^{xvixviii} and both the health and aged care sectors, as well as older Queenslanders, would greatly benefit from support from the health system in delivering these consistently across the state.

Funding required: Cost to be determined by Queensland Government.

Recommendation 4 (Compassionate Communities)

Grow initiatives that educate and engage the community to build compassionate communities

PCQ recommends that increased funding be made available to promote community-centric initiatives, aimed at educating, engaging and empowering people to foster compassionate communities.

The Challenge

With a rapidly ageing population and declining working population, Queensland must look to growing community support for people choosing to stay in their own homes or in another community setting throughout their palliative care journey and increasingly at the end of life.

Public sector health services alone cannot provide the amount of support required for people living with life-limiting illnesses and particularly within the last twelve months of life. An increase in compassionate communities across Queensland will significantly reshape and enhance health services and enable Queensland to be a world leader in community supported palliative and end-of-life care.

Queensland communities are already showing great leadership in developing compassionate models of support. Local councils and individuals, supported by PCQ, have been instrumental in developing this space in Townsville and across the region with groups springing up in remote and regional areas, including Richmond and Magnetic Island.

The Charters Towers Compassionate Community group is burgeoning with aims to increase death literacy in their community. They have done this with attendance at markets and meeting the Royal Flying Doctor Service at three nearby townships as well as hosting a Dying to Know Day event at the local library. At each event they provide palliative care, advance care planning and bereavement resources to the community and have hosted a sunset memorial service for their community. PCQ has supported Charter Towers' group through early PalliLearn and Last Aid training, supplying appropriate materials for their development, and we continue to support with auspicing grant proposals so that the group can grow and support more people within their community and beyond.

Mills, et al, note that "Targeted public education programmes, such as last aid training, can make a capacity-building contribution to compassionate communities in increasing death literacy, developing personal skills, and strengthening community action in line with the Ottawa Charter for Health Promotion."^{xix} Last aid being "the provision of practical support and social care in lay community contexts of palliative and end-of-life care."^{xx}

Compassionate communities continue to grow internationally with the key obstacles being the integration with general practice and the health system's readiness to engage in a compassionate community network. This reluctance partly stems from a lack of understanding or constraints related to time or capability. Overcoming these obstacles demands continuous communication and collaboration to better understand, resource, and coordinate care within an integrated network not only within the health care systems, but externally amongst our workplaces and communities.^{xxi}

With almost 62% of Queenslanders actively in the workforce,^{xxii} death literacy is incredibly important, and yet navigating conversations around death, dying, and grief remains a difficult but essential element for fostering a compassionate community. For most, employment is a central part of life, providing financial support, social interaction and independence. Work continuity is often crucial for maintaining a degree of normality and independence.

Training our workforce in conversations around death, dying and grief is crucial for building a workplace culture where employees feel seen, heard and understood, especially when coping with personal grief or confronting life-limiting illnesses. By encouraging open dialogue and offering resources for support, workplaces can empower their staff to navigate these challenging experiences with resilience and compassion, ultimately creating a more supportive and understanding community towards palliative and end-of-life care.

The solution

A. Increase community engagement by developing and implementing initiatives that engage community members in understanding and supporting palliative care.

Recommendation: that the Queensland Government funds Palliative Care Queensland (PCQ) to host a series of 50 [PalliNavigator](#) sessions followed by 50 [Last Aid](#) sessions across various regions in Queensland. These sessions would be delivered over two years. They aim to firstly make communities aware of compassionate communities and how to build them, their benefit and utility; and secondly to enhance community capacity, death literacy and encourage the promotion and awareness of compassionate communities.

Attendees of each session will be followed up by PCQ to support development of their compassionate community and engage them in the Queensland Compassionate Communities Network.

As stated by Georg Bollig, et al, founder of the Last Aid training course, a combination of Last Aid courses and compassionate communities may improve end-of-life care for people dying at home. Last Aid courses can provide basic education for citizens while simultaneously providing an arena in which to discuss and reflect on death and dying in the community.^{xxiii}

Regions and locations will be informed by research findings and outcomes derived from PCQ round table discussions held in the early stages of the 2024-25 financial year and through feedback collected in the 2023-24 financial year.

Funding required: \$550,000 (GST excl) over two years.

B. Invest in educational initiatives which enhance death literacy and empower people to create compassionate communities, to support those experiencing life-limiting conditions, dying, death, caregiving and grief.

Recommendation: PCQ seeks funding support from the Queensland Government to develop two workplace training education modules based on our existing workplace education toolkits. Targeted public education programs, such as palliative care workplace training, can contribute to capacity building in compassionate communities by improving death literacy, developing personal skills, and strengthening community action. With 62% of Queenslanders participating in the workforce, workplaces are the perfect environment to build awareness and promote change.

These modules will cater to managers and HR professionals, as well as employees, aiming to enhance palliative care awareness and support within the workforce. To ensure the modules meet corporate training standards, we plan to collaborate with external consultant companies, ensuring alignment with aesthetic, content and interactive requirements.

Investing in these training modules aligns with the government's commitment to ensure that families and carers are supported while providing care for someone with a life-limiting illness and during bereavement as referenced in the [Queensland Health Palliative and End-of-Life Care Strategy](#).

By empowering managers and employees with the necessary knowledge and skills, we aim to foster a compassionate and supportive workplace environment for all individuals facing palliative care and end-of-life challenges.

These modules will serve as the foundation to a comprehensive corporate "lunch and learn" training package, for implementation across Queensland and which will be self-funded in delivery through a user pays process.

Funding required: \$57,000 (GST excl) one off cost.

C. Build compassionate communities to forge partnerships between local organisations to grow a network of support for compassionate care initiatives.

Recommendation: In line with recommendation 4, solution A, PCQ will seek to form partnerships with local organisations in the selected regions, to help promote and encourage participation for their local communities through Last Aid sessions. PCQ will continue to support locally grown Compassionate Communities across Queensland by:

- auspicing community groups seeking grants,
- continuing to support and facilitate the Queensland Compassionate Communities Network, and
- providing ongoing community and consumer support and promotion of Compassionate Communities through PCQ social media, website enhancements and community events.

Funding required: Cost neutral – PCQ already provides these services and will continue to.

D. Increase funding for the compassionate communities' model, that allows the introduction of coordinators to help liaise with palliative care services.

Recommendation: in line with the Queensland Government Palliative and End-of-life Care Strategy - under Future Areas of Reform regarding volunteers and volunteer coordinators - funding should be provided to each Hospital and Health Service to engage and develop a compassionate community volunteer coordinator to develop a volunteer network and liaise with specialist palliative care, broader hospital and health service areas, patients, PCQ, general practice and PHNs, grief, bereavement and spiritual care services, and compassionate community members. The coordinator will assist palliative care patients to travel a smooth pathway by:

- developing a volunteer network within the HHS to support the patient,
- linking the patient to services, and
- connecting them to compassionate communities in their neighbourhoods via a volunteer.

PCQ will be able to assist in this linkage process through its Queensland Compassionate Communities Network (see solutions 4A and 4C also).

Funding required: \$2.38 million (GST excl) recurrent annually.

Recommendation 5 (Grief, Bereavement & Spiritual Care)

Increase resources and funding directed toward grief and bereavement services and spiritual care.

PCQ recommends that increased funding be allocated to resourcing grief counselling, bereavement support and spiritual care services across Queensland.

The Challenge

The Palliative and End-of-Life Care Strategy and Queensland Health Specialist Palliative Care Workforce Plan provide much needed funding and planning to the Queensland Health Specialist Palliative Care, with some funding allocated towards grief and bereavement and spiritual services. There is, however, much more needed in this space.

Availability of these services is particularly limited for Aboriginal and Torres Strait Islander communities, in the broader community and in rural, regional and remote areas. Further advocacy is needed for increased resources and funding directed across Queensland towards grief counselling and bereavement support services as well as to the delivery of spiritual care.

Adequate funding for grief and bereavement services is imperative to ensure timely access to counselling, support groups and resources tailored to diverse cultural and spiritual backgrounds. By investing in these resources, we can foster resilience, facilitate healthy coping mechanisms and promote holistic wellbeing for individuals facing loss and bereavement.

Moreover, spiritual care plays an integral role in palliative care, offering solace and comfort to individuals and their families during life's most challenging moments. However, limited funding has constrained the availability and accessibility of spiritual care services across Queensland. Increasing investment in spiritual care resources will enable us to expand the reach of chaplaincy programs, spiritual counselling, and culturally sensitive practices. By prioritising funding in this area, we can uphold the fundamental principle of providing comprehensive, person-centred care that addresses the spiritual dimensions of end-of-life experiences, ultimately enhancing the quality of life for those in palliative care.

The Solution

A. Allocate funding to enhance grief counselling and bereavement support services.

Recommendation: that the Queensland Government establishes a grant fund to assess applications and disseminate grants to community organisations across Queensland to establish community-led bereavement groups with support from a local counsellor/psychologist/social worker. The grant fund could be administered by an organisation like PCQ. This would establish 150 community grief and bereavement groups across Queensland meeting fortnightly each year.

Funding required: \$1.6 million (GST excl) recurrent annually.

B. Allocate funding to increase access to appropriate spiritual care services.

Recommendation: that the Queensland Government mandates that each hospital or multipurpose service engage a panel of spiritual care professionals. Spiritual Care services should be available within both hospital and community specialist palliative care. This measure would deliver 70 full-time and 80 part-time (0.6 FTE) Spiritual Care professionals covering every hospital and multipurpose service across Queensland.

Funding required: \$10.8 million (GST excl) recurrent annually.

C. Increase community access to grief and bereavement services.

Recommendation: that the Queensland Government fully funds a grief and bereavement service in every community health service across the state. Full-time services to be funded in larger services and part-time in smaller.

Funding required: \$3.94 million (GST excl) recurrent annually.

D. Increase training and support for professionals offering grief and bereavement services.

Recommendation: that the Queensland Government establishes a steering group to guide development of training and support needs for grief and bereavement professionals and spiritual care practitioners (see solution 5E). The steering group should be established by December 2024 with a recommendation for training, support pathways and proposed costs to be delivered by July 2025.

Funding required: cost to be determined by the Queensland Government through establishment and guidance of a steering group.

E. Increase support for spiritual care practitioners.

Recommendation: see Solution 5D

Funding required: cost to be determined by the Queensland Government through establishment and guidance of a steering group.

F. Increase training for all health professionals and workers in supporting spiritual needs, particularly for Aboriginal and Torres Strait Islander people.

Recommendation: that the Queensland Government establishes a steering group to guide development of training requirements for all health professionals and workers to support the spiritual needs, particularly for Aboriginal and Torres Strait Islander people. The steering group should be established by December 2024 with a recommendation for training requirements and proposed costs to be delivered by July 2025.

Funding required: cost to be determined by the Queensland Government through establishment and guidance of a steering group.

Recommendation 6 (Diverse Workforce)

Prioritise funding, education, training and recruitment for a more culturally diverse palliative care workforce

There is low diversity in Queensland's palliative care workforce, and a need to encourage health professionals and workers to engage in the palliative care sector and to support their retention. This requires increased funding, education, training, recruitment and retention strategies to develop a more culturally diverse and sensitive palliative care workforce.

The Challenge

According to the Palliative Care Outcomes Collaboration, Aboriginal and Torres Strait Islander peoples made up only 2.6% of people who accessed palliative care services in Queensland between January and June 2023, with 3.7% of people not stating or clearly describing their Indigenous status.^{xxiv} Aboriginal and Torres Strait Islander peoples continue to have a much shorter life expectancy than the broader Australian population and in Queensland account for 4.6% of the population.^{xxv} Clearly with a higher rate of death and illness, Aboriginal and Torres Strait Islander peoples are under-served in terms of palliative care services.

In 2021 there were 28.7% of Queenslanders who reported being born outside of Australia^{xxvi} and yet only 24.7% of the people who received palliative care services during January to June 2023 were born in a country other than Australia.^{xxvii} The elderly population from culturally and linguistically diverse (CALD) backgrounds is experiencing a faster growth rate compared to the older Australian-born, English-speaking population. The needs of different CALD communities and individuals within these communities vary significantly. Recognition of diversity is essential within and among Australia's CALD communities. The CALD population is heterogeneous, characterised by various intersecting factors such as sexual orientation, gender identity, health conditions like dementia or chronic diseases, disability status, palliative care needs, socioeconomic challenges, housing instability, and residency in rural or regional areas.

Investing in education, training and recruitment programs targeted at diversifying the palliative care workforce is essential for delivering high-quality, culturally competent care to all individuals experiencing life-limiting conditions, death, dying, caregiving and grief. By expanding opportunities for individuals from culturally diverse backgrounds to enter the palliative care workforce, we can enhance the delivery of care, improve patient outcomes, and reduce health disparities.

Moreover, by fostering a more inclusive and representative workforce, greater understanding, trust and engagement among diverse communities can be promoted, ultimately advancing collective efforts to provide compassionate and equitable palliative care services across Queensland.

The Solution

A. Develop educational programs to increase cultural competence and provide culturally safe and sensitive palliative care training and workplaces for palliative care workers, with an initial focus on supporting staff in regional, rural and remote areas.

Recommendation: that the Queensland Government:

- urgently invests in developing educational programs to train all health professionals in working sensitively with Aboriginal and Torres Strait Islander peoples and people of CALD background to ensure appropriate referral to palliative care services.

- works with Aboriginal and Torres Strait Islander health organisations and community groups to determine the best form of training that sensitively represents Aboriginal and Torres Strait Islanders' view of sorry business, finishing up, other concepts of death, dying, grief and bereavement and invest in developing and delivering ongoing training.
- works with CALD health and community groups to determine the form of training for palliative care workers that best represents the broad cultural beliefs and rituals associated with death, dying, grief and bereavement, and invest in developing and delivering ongoing training.

Funding required: to be decided by Queensland Government in consultation with Aboriginal and Torres Strait Islander, and CALD health and community groups.

B. Implement strategies to recruit and retain a diverse workforce – increasing both Aboriginal and Torres Strait Islander and CALD representation across the workforce. This requires a retraining and reshaping of the workplace to ensure cultural safety for all workers.

Recommendation: that the Queensland Government invests in developing and delivering:

- a Palliative Care Aboriginal and Torres Strait Islander workforce strategy, and recruitment and cultural safety plans, in consultation and cocreation with Aboriginal and Torres Strait Islander health and community groups
- a Palliative Care Culturally and Linguistically Diverse workforce strategy, and recruitment and cultural safety plans, in consultation and cocreation with Aboriginal and Torres Strait Islander health and community groups

Funding required: to be decided by Queensland Government in consultation with Aboriginal and Torres Strait Islander, and CALD health and community groups.

C. Integrate multidisciplinary and interdisciplinary mentorships into diverse communities, to provide culturally sensitive care.

Recommendation: that the Queensland Government invests in establishing multidisciplinary and interdisciplinary mentorships between palliative care health professionals and a range of Aboriginal and Torres Strait Islander and CALD communities. This must be developed in consultation and cocreation with Aboriginal and Torres Strait Islander and CALD health and community groups.

Funding required: to be decided by Queensland Government in consultation with Aboriginal and Torres Strait Islander, and CALD health and community groups.

D. Include local cultural ambassadors in the design and development of palliative care services both in the hospital and in the community.

Recommendation: that the Queensland Government mandates that each Hospital and Health Service includes local Aboriginal and Torres Strait Islander ambassadors, as well as ambassadors from high population CALD groups in each service in the development and design of palliative care services in hospital and community settings.

Funding required: individual costs to be borne by each Hospital and Health Service.

Recommendation 7 (Pharmacy)

Improve community pharmacy support and services

PCQ recommends funding be allocated to:

- ***introduce dedicated palliative care training programs for community pharmacy workers to develop knowledge and increase support for people in the community.***
 - ***continue advocating for enhanced pharmacy support and services that focus on meeting the palliative care needs of people in the community regardless of their location across Queensland.***
-

The Challenge

As the population ages, the demand for palliative care among older individuals worldwide is increasing rapidly, requiring the involvement of multidisciplinary teams, including community pharmacists. With the emphasis on delivering care in individuals' homes, end-of-life care has become a collective responsibility across the healthcare and aged care sectors. This involves professionals from various non-government organisations (NGOs), such as general practices, Aboriginal health services, allied health professionals, and community pharmacies.

Pharmacy is a vital service for people living with life-limiting illnesses and at the end of life in the community and many individuals, particularly those living in rural and underserved areas, rely heavily on community pharmacies as their primary source of healthcare services. Advocacy is required for enhanced pharmacy support services, particularly community pharmacy; focus on stabilising medication availability and supply; and training for pharmacists to continue to support people in the community with palliative care medication needs.

According to Tieman, et al “people with palliative care needs have additional complexities in how their medicines are managed, resulting from, for example, poor swallowing, the need for subcutaneous administration of medications, and a greater reliance on the carer for medication management. The pharmacist forms an important part of the multidisciplinary care system for older people coming to the end of their life in” healthcare, Residential Aged Care facilities and community settings.^{xxviii}

Queensland has developed strong palliative care and community pharmacy initiatives in the past. Many of these have ceased to be funded and have fallen away in the system. Federally, there continues to be issues in medication supply, particularly for vital palliative and end-of-life drugs, which have a detrimental effect on palliative care patients.

By investing in community pharmacy services, the capacity of these establishments to deliver a wide range of essential healthcare services can be enhanced, including medication management, health promotion, chronic disease management and preventative care.

Additionally, increasing funding for community pharmacy support and services will contribute to improving health outcomes and reducing healthcare disparities among vulnerable populations.

The Solution

A. Ensure availability and supply of necessary medications in palliative care settings, including regional, rural and remote.

Recommendation: that the Queensland Government:

- ensures that vital medications required for people with palliative conditions and at the end of life are readily available across regional, rural and remote Queensland. This may require the Queensland Government to work with pharmacy peak organisations to ensure there is a sustainable plan to sure-up supply.
- works with the Australian Government to ensure supply of vital medications required for people with palliative conditions and at the end of life are readily available through the Therapeutic Goods Association approval process.

Funding required: to be determined by Queensland Government in consultation with the pharmacy sector.

B. Introduce dedicated palliative care training programs for community pharmacy workers to develop knowledge and increase support for people in the community.

Recommendation: that the Queensland Government funds the co-creation and design of a training module for community pharmacists and their staff to:

- increase their understanding and capability of a patient's needs during palliative care and at end of life, and
- enable pharmacists to have informed and educated conversations with people they are providing medications to.

This could be a joint project between the Pharmaceutical Society of Australia (QLD), the Pharmacy Guild (QLD) and Palliative Care Queensland (PCQ), with joint delivery both as an online self-paced and an optional face-to-face-version. It would be targeted for delivery to the 1215 community pharmacies in Queensland.

Funding required: \$800,000 (GST excl), over years one and two, with \$200,000 recurrent annually thereafter.

C. Advocate for enhanced pharmacy support and services that focus on meeting the palliative care needs of people in the community regardless of their location across Queensland.

Recommendation: that the Queensland Government hosts a series of 20 roundtables across Queensland with the pharmacy sector, health consumers with lived experience in palliative care, and palliative care sector health professionals to understand the issues that different communities are experiencing regarding palliative care and pharmacy.

Funding required: \$200,000 (GST excl) with any further costs to be determined by Queensland Government following consultation.

References

- ⁱ National Disability Insurance Scheme: a quick guide – Parliament of Australia (aph.gov.au)
- ⁱⁱ Palliative Care Australia Federal Budget Submission; [2024 Federal Budget Submission – investment proposals for better access to palliative care now and in the future - Palliative Care Australia](#)
- ⁱⁱⁱ [Palliative care investment and reform | Queensland Health](#)
- ^{iv} [Supporting palliative care patients who choose to die at home - Palliative Care Australia; Measuring effectiveness in community-based palliative care programs: A systematic review - ScienceDirect; Evidence on the economic value of end-of-life and palliative care interventions: a narrative review of reviews - PMC \(nih.gov\)](#)
- ^v Swerissen, H and Duckett, S., 2014, Dying Well. Grattan Institute
ISBN: 978-1-925015-61-4. <https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>
- ^{vi} Australian Bureau of Statistics (ABS), 'Deaths, Australia.' Accessed 19 February 2022.
<https://www.abs.gov.au/statistics/people/population/deaths-australia/latest-release>; and United Nations, 'UN World Population Prospectus'. UN, Department of Economic and Social Affairs, Accessed 19 February 2022.
<https://population.un.org/wpp/Download/Probabilistic/Mortality/>; in <https://stories.uq.edu.au/policy-futures/2022/reimagining-death-care-for-our-ageing-population/index.html>
- ^{vii} [human-services-reforms-overview.pdf \(pc.gov.au\)](#) pp 9-10
- ^{viii} [Current-public-health-services-fees-2020.pdf \(worksafe.qld.gov.au\)](#) p10 – sub acute item 99802 – palliative = \$2004.per day.
- ^{ix} [0000059.pdf \(parliament.qld.gov.au\)](#) p21 in 2012 Ipswich Hospice cost \$660 per bed day (PCQ estimated Qld hospices at \$900 per bed day) vs Ipswich Hospital at \$1100 per bed day and their ICU at \$4000 per bed day.
- ^x *ibid* p 41
- ^{xi} [final-report-executive-summary.pdf \(royalcommission.gov.au\)](#) p 69.
- ^{xii} *ibid* p 92.
- ^{xiii} *ibid* p 94
- ^{xiv} [final-report-recommendations.pdf \(royalcommission.gov.au\)](#) p 248
- ^{xv} [SPACE Outcome Evaluation Report - Baseline - Summary.pdf \(clinicalexcellence.qld.gov.au\)](#)
- ^{xvi} [What is holistic care and what can that look like in ... | Aged Care Guide](#)
- ^{xvii} [Holistic nurses make big impact to aged care homes - Australian Ageing Agenda](#)
- ^{xviii} [What is Holistic Care in Aged Care? \(aurrum.com.au\)](#)
- ^{xix} [The role and contribution of compassionate communities - The Lancet](#) October 2023
- ^{xx} *ibid*
- ^{xxi} *ibid*
- ^{xxii} [2021 Queensland, Census All persons QuickStats | Australian Bureau of Statistics \(abs.gov.au\)](#)
- ^{xxiii} [Healthcare | Free Full-Text | Last Aid Course. An Education For All Citizens and an Ingredient of Compassionate Communities \(mdpi.com\)](#)
- ^{xxiv} [Reports - University of Wollongong – UOW](#) Queensland Patient Outcomes in Palliative Care – January to June 2023
- ^{xxv} [Queensland: Aboriginal and Torres Strait Islander population summary | Australian Bureau of Statistics \(abs.gov.au\)](#)
- ^{xxvi} [Snapshot of Queensland | Australian Bureau of Statistics \(abs.gov.au\)](#)
- ^{xxvii} [Reports - University of Wollongong – UOW](#) Queensland Patient Outcomes in Palliative Care – January to June 2023.
- ^{xxviii} [What Is the Community Pharmacists' Role in Supporting Older Australians with Palliative Care Needs? - PMC \(nih.gov\)](#)