

# Time for excellent palliative care in Queensland

*2018/2019*

*Palliative Care Queensland  
Pre-Budget Submission*



**PalliativeCare**

QUEENSLAND

1988-2018 CELEBRATING 30 YEARS

## Executive Summary

PCQ FOCUS AREA	INITIATIVE	ESTIMATED COST
 <b>Individuals Matter</b>	Create a Statewide Palliative Care Consumer Advisory Group and Support Hub	\$300,000 over three years
 <b>Communities Matter</b>	Support the growth of Queensland Compassionate Communities	\$600,000 over three years
	Create a Statewide Palliative Care Volunteer Hub	\$750,000 over three years
 <b>Care Matters</b>	Increase the Specialist Palliative Care Workforce to meet nationally recommended levels of care	\$100 million over three years
	Develop and implement a state-wide introductory palliative care education program for all health professionals	\$1 million over three years
 <b>Government, Systems and Policies Matter</b>	Develop a mandatory Queensland palliative specific minimum dataset	\$1 million
	Appoint a state-wide Palliative Care Coordinator in the Department of Health	\$600,000 over three years
 <b>PCQ Matters</b>	Increased funding for Palliative Care Queensland	\$200,000 over three years

**“I think a way that a society or community is able to determine its health is to look at how it treats or deal with its most vulnerable.”**

*Parliamentary Committees: Palliative and Community Care in Queensland: Towards person-centred care (2013) p.xix<sup>1</sup>*



### What is palliative care?

- a part of life
- holistic
- provided by specialists, generalists, aged and community services
- everyone's business

### PCQ advocates for excellent palliative care for all Queenslanders

#### By which:

- All providers who care for people at the end of life are appropriately educated in palliative care
- There are good linkages within and between service providers in relation to palliative care.
- People are aware of the palliative care services available in their community.
- Community networks are able to support each other to understand and deal with loss, ageing, death and grief as a part of life.

#### This is achieved by:

- A Specialist Palliative Care Workforce which meets nationally recommended levels of care
- Supporting the growth of Queensland Compassionate Communities
- Creating a Statewide Palliative Care Volunteer Hub
- Improving accountability and transparency, service efficiency and effectiveness.

Approximately **29,500** Queenslanders **die** each **year**



Despite **most Queenslanders** expressing a **wish to die at home**, the vast majority **die in hospital**



Queensland currently has **50%** of the required number of **Specialist Palliative Care** services to meet the community's needs

**“Better death related outcomes are achieved not only by preventing the death but also by improving the quality of the end of life experience”**

*Chief Health Officer, Queensland*

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## 2018-19 Pre-Budget Submission Summary

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### Individuals Matter

We need to provide relevant up to date information about palliative care to the individuals with a life-limiting condition and their carers.

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INITIATIVE	ESTIMATED COST	BENEFITS
<b>Create a Statewide Palliative Care Consumer Advisory Group and Support Hub</b>	\$300,000 over three years	<p>Most services providing palliative care across Queensland are informed by consumer representatives, working with the health care providers to improve care.</p> <p>In collaboration with Health Consumers Queensland (HCQ) and Council of the Ageing Queensland (COTA-Q), we propose the development of a Palliative Care Consumer Advisory Group and Support Hub which promotes connectedness through providing training, networking opportunities and resources, as well as identified themes which can be discussed at statewide forums and the chair of this group would also sit on the National Palliative Care Consumer Advisory Group.</p> <p>The state-wide hub will enable this essential palliative care consumer knowledge to be captured and progressed in to national channels. It will also provide support and networking opportunities for the many consumers across Queensland.</p>

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**“The Australian Government’s reforms aim to incorporate ‘consumer directed care’ into the planning and management of care. This approach allows consumers and carers greater “power to influence the design and delivery of the services they receive.”**

*Parliamentary Committees: Palliative and Community Care in Queensland: Towards person-centred care (2013) p.4<sup>1</sup>*



## Communities Matter

We need to build supportive networks around people at the end of life

INITIATIVE	ESTIMATED COST	BENEFITS
<b>Support the growth of Queensland Compassionate Communities</b>	\$600,000 over three years	<p>Compassionate communities initiatives build the capacity of local Queensland communities to support people with life limiting illnesses in their daily lives, reducing isolation and promoting kindness.</p> <p>They also enable communities to discuss dying, death and bereavement in better-informed and more confident ways.<sup>2</sup> Such initiatives include:</p> <ul style="list-style-type: none"><li>• Building health sector and community partnerships</li><li>• Developing Queensland wide community asset mapping</li><li>• Supporting compassionate neighbours, workplaces and schools initiatives</li><li>• Fostering community engagement</li><li>• Supporting community development activities</li></ul>
<b>Create a Statewide Palliative Care Volunteer Training and Support Hub</b>	\$750,000 over three years	<p>Effective training is critical to the recruitment, activity and retention of volunteers in palliative care. A state-wide training hub would promote consistency and connectedness for volunteers.</p> <p>Consistent, evidence based volunteer training builds confidence and competence, enabling a broader role in their local communities and with service providers.</p> <p>Ongoing support and networking for volunteers values and connects them into a more integrated effort to help support people, their families and communities.<sup>2</sup></p>

**“The committee considers that volunteers could make a significant contribution to more palliative care services, provided they are adequately trained and supported.”**

*Parliamentary Committees: Palliative and Community Care in Queensland: Towards person-centred care (2013) p.77<sup>1</sup>*



## Care Matters

We need to support Queensland services who are delivering end of life care to provide coordinated quality care and have staff who are well prepared to provide quality care.

INITIATIVE	ESTIMATED COST	BENEFITS
<b>Increase the Specialist Palliative Care Workforce to meet nationally recommended levels of care</b>	\$100 million over three years	<p>Increasingly, evidence indicates that access to specialist palliative care when needed leads to improved quality of life, increased length of life and reduced costs of health care.<sup>3, 4, 5, 6</sup> People approaching end of life should have access to Specialist Palliative Care when needed, for the benefit of the individual, their families and the broader health system.</p> <p>The Specialist Palliative Care workforce should be mapped to the National Palliative Care Service Delivery Framework 2018.<sup>7</sup></p>
<b>Develop and implement a state-wide introductory palliative care education program for all health professionals</b>	\$1 million over three years	<p>Increased quality of life for patients and families; decreased stress on the health system; reduced levels of unnecessary presentations to emergency departments and transfers of patients at end of life to Intensive Care Units. All these benefits potentially reduce health costs.<sup>1, 8, 9, 10</sup></p> <p>Generalist staff must have a clear understanding of how to access medicines, equipment and expert advice as part of a rapid response to changing needs. Specialist Palliative Care staff should be able to demonstrate how they have helped develop the capability of generalist staff to understand and support the physical and psycho-social needs of dying people.<sup>2</sup></p>

**“Specialist palliative care services have an important role in supporting GPs and other health providers, however that support is not consistently available... An investment in specialist services to provide consultation services and support home-based care would be offset by a reduction in acute hospital costs from unnecessary and unwanted hospital admissions.”**

*Parliamentary Committees: Palliative and Community Care in Queensland: Towards person-centred care (2013) p. xxiii<sup>1</sup>*



## Government, Systems and Policies Matter

We will be recognised as the pre-eminent voice of the end of life sector in Queensland and advocate on behalf of all stakeholders

INITIATIVE	ESTIMATED COST	BENEFITS
<b>Develop a mandatory Queensland palliative specific minimum dataset</b>	\$1 million	<p>Standardised high-quality data supports outcomes-focused care, recognising community need and supporting allocation of resources.</p> <p>The success of the Palliative Care Outcomes Collaboration (PCOC) data set indicates that meaningful data can be routinely collected and reported upon in all palliative care settings. PCOC enables participating services to improve patient and family outcomes by routinely collecting and reporting clinical assessment data and providing feedback and service to service benchmarking.</p> <p>The development and implementation of a mandatory data collection framework in palliative care will complement the PCOC dataset to further inform state-wide and local strategy, service planning, service development and resourcing.<sup>11</sup></p>
<b>Appoint a state-wide Palliative Care Coordinator in the Department of Health</b>	\$600,000 over three years	<p>The current fragmentation of palliative care in Queensland needs addressing by appointing a <b>Queensland Palliative Care Coordinator</b> in the Department of Health. The focus of the Coordinator should be on assessing the efficiency and effectiveness of services in supporting individuals faced with life-limiting illness and their families to live as well as possible to the end of life, and enable support in grief and bereavement. This would involve any duplication and scoping issues related to equity of access.</p> <p>Specifically, the Coordinator needs to:</p> <ul style="list-style-type: none"><li>• Improve coordination of processes across all providers, including public, private and non-government services</li><li>• Facilitate consistent approaches to supporting the palliative care sector across all settings</li><li>• Examine existing palliative care services across all settings, including public and private</li><li>• Promote quality palliative care service provision, consistent with the National Palliative Care Standards 2018<sup>12</sup></li><li>• Assess the needs of different populations, in particular Aboriginal and Torres Strait Islander people, rural and remote populations and Queensland's culturally and linguistically diverse populations.</li></ul>



## PCQ Matters

We need to ensure Palliative Care Queensland has long-term sustainability to give you the confidence that our work will continue

INITIATIVE	ESTIMATED COST	BENEFITS
<b>Increased funding for Palliative Care Queensland</b>	\$200,000 over three years	<p>With the ageing population, increased complexity of care needs and higher community expectations around dying, Palliative Care Queensland has seen a significant increase in requests for support, education, advocacy and information from local community groups, the health sector and individuals.</p> <p>Palliative Care Queensland is the peak body for palliative care in Queensland with over 300 members and has been operating for 30 years. In comparison to other peak bodies our association receives minimal funding. Currently PCQ operates with 1FTE CEO and a casual administration officer (both working from their homes), as well as a temporary part time project coordinator (for a PHN funded project).</p> <p>PCQ connects the sector with the community and builds partnerships which promote support and increased information flow. With increased funding PCQ can achieve greater outcomes for palliative care, particularly providing increased support for the community, individuals and the sector.</p> <p>With this increased funding PCQ would conduct two statewide community engagement activities annually (total 6 in 3 years) with an expected reach of over 1million people, promoting greater awareness and open discussions about palliative care. In addition PCQ would increase their palliative care support networks to promote partnerships, identify innovations and reduce duplication.</p> <p>Increased funding would assist PCQ's ability to support the sector and community in line with the sector growth.</p>

**“Greater awareness and open discussions can enable people to make choices about where and how they want to be treated as they approach the end of life.”**  
*Parliamentary Committees: Palliative and Community Care in Queensland: Towards person-centred care (2013) p.xxv<sup>1</sup>*



## References:

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12. Palliative Care Australia 2018 National Palliative Care Standards. PCA, Canberra. Accessed via URL: <http://palliativecare.org.au/standards>, 27 February 2018

**“It might not be raining hard yet,  
but we can be sure it will be soon”**

*It is time for excellent palliative care in Queensland*



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