Time to Build a Palliative Care Culture in Queensland

2017/2018 State Election Manifesto
“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 Qld

Executive Summary

Palliative Care Queensland advocates for the following to ensure the availability of excellent palliative care to all Queenslanders who need it:

We need to build a strong palliative care culture by:

1. Improving access to care ($3.9M) so all who need palliative care are able to access it regardless of where they live

   Palliative care services are put in place so the 70% of people who say they wish to die at home are able to do so. The numbers able to do so currently are far less, and the cost of dying in hospital far outweighs the alternatives.

2. Improving the capabilities of the workforce ($2.55M)

3. Improving accountability & transparency regarding palliative care service efficiency & effectiveness ($1.8M+)

This will enable health and palliative care professionals, through the availability of excellent palliative care, to counter the arguments of euthanasia and assisted suicide advocates that people are dying in unnecessary distress for lack of appropriate end of life care.
Palliative Care is...

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

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

( WHO Definition of Palliative Care )

PCQ advocates building a palliative care culture

by which:

- All providers adopt a palliative care approach for people whose illness is no longer curable.
- 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:

1. improving access to care
2. improving the capabilities of workforce
3. improving accountability and transparency, service efficiency and effectiveness.
Why does Queensland need a palliative care culture?

70% of people say they want to die at home
- Patients who die in hospital spend on average 26.4 days in hospital over the previous 6 months, costing $52,113.
- About half of all deaths in Queensland occur in hospital, costing Queensland approximately $776M per year.

Queenslanders are getting older and increasingly dying at an advanced age
- By 2036, 1 in 5 Queenslanders will be aged 65 years or older, compared to 1 in 8 in 2014; 75% of total health spending is for people under the age of 75 years.
- Chronic conditions of ageing are a high cause of hospital burden.
- Those who are frail or have dementia are more likely to have a long period of relatively poor quality of life before death.

Good end-of-life care is important in order to die well
- High quality end-of-life services bring together health services, home care, personal support and support for carers, but always according to the preferences and circumstances of the dying person.
- When good end-of-life services are available, people are:
  - much more likely to die at home
  - much more satisfied with care and
  - much less likely to be admitted to hospital or emergency.

Voluntary euthanasia & assisted suicide are clouding the issues
- The absence of excellent palliative care for all who need it provides a powerful argument for euthanasia/assisted suicide advocates able to point to instances where patients die in unnecessary pain or distress due to the lack of palliative care.
- Even when voluntary euthanasia & assisted suicide are permitted, they are rare.
- We need to ensure when death inevitably comes for each of us, we will die comfortably, in surroundings we would choose.
1. Improve access to care

Dying people need to have access to essential palliative care services across the state. Access to essential palliative care services include assessment and care co-ordination, clinical and supportive care, respite care and bereavement care.

1.1 Targeted improvement strategies to improve understanding of Queensland Palliative Care needs

Undertake a state-wide assessment of palliative care needs. This should be mapped to current service delivery model mapping per HHS. Information should be reported and available publicly to help provide a benchmark on how Queensland is managing and meeting demand.

[Cost estimate over 4 years: $500,000]

1.2 Targeted improvement strategies to improve access to palliative care in regional, rural and remote areas

Increase regional, rural and remote palliative care Nurse Practitioner positions by four to improve palliative symptom management and care planning, allowing more people to be cared for at home or in their local communities.

[Cost estimate over 4 years: $2,500,000]

1.3 Targeted improvement strategies to improve access to community services, respite care and bereavement services

Expand the PallAssist 24/7 palliative care phoneline to include services for Aboriginal and Torres Strait Islanders, specialist bereavement counsellors and live mapping of locations of available respite beds in every HHS.

[Cost estimate over 4 years: $900,000]
2. Improve the capabilities of the workforce

Workforce and training requirements need to be understood and in line with existing national work. A consistent statewide approach to workforce (including volunteers) training will ensure better quality of care in all regions of Queensland.

2.1 Develop and implement a Statewide Palliative Care Workforce strategy
Task CPCRE\textsuperscript{12} to develop and implement a statewide palliative care workforce strategy to ensure skills, competencies and training programs are aligned across the state. Ensure ongoing linkages with national approaches to workforce training that covers all aspects of palliative care including specialised and palliative approach.  
[Cost estimate over 4 years: $1,000,000]

2.2 Targeted education program for Indigenous nurses/health workers
Develop and implement a targeted palliative training program for Indigenous nurses/health workers, delivered in their communities and combined with a community education program. (Building on existing work achieved by the PEPA\textsuperscript{13} Qld program).  
[Cost estimate over 4 years: $750,000]

2.3 Create a Queensland Palliative Care Volunteer Support Services Programme
Create a program to increase the capacity of palliative care volunteer services and to raise public awareness of their work, including develop a state-wide framework for palliative care volunteer services.  
[Cost estimate over 4 years: $800,000]
3. Improving accountability & transparency regarding palliative care service efficiency & effectiveness

Data collection and reporting must be reliable, consistent statewide, interpreted annually via public reporting and utilized to drive continuous quality improvement activities at service delivery level to produce positive change.

3.1 Undertake a forensic audit of Queensland palliative care and end-of-life care services and systems

Task the Queensland Audit Office to undertake a financial and performance audit of all palliative care and end-of-life care services delivered in Queensland.

[Cost estimate over 4 years: Determined by criteria of audit]

3.2 Develop a Queensland palliative specific minimum dataset

Develop a minimum dataset for HHS to report palliative care activity (including both specialist and palliative approach).

[Cost estimate over 4 years: $1,000,000]

3.3 Undertaking a quality of death study

Undertake a quality of death study in Queensland (including linking to preferred place of care) to identify resource requirements, achievements and specific improvement area.

[Cost estimate over 4 years: $800,000]
REFERENCE
12. Centre for Palliative Care Research and Education.

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

It is time for Queensland to create a Palliative Care Culture which is prepared for the future.