



# **Palliative Care Queensland**

Submission to the Queensland Parliament's  
Health and Committee Services Committee Inquiry into:

**Palliative Care and Home and Community Care Services**

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## **Contact**

John-Paul Kristensen  
Chief Executive Officer  
Palliative Care Queensland  
(07) 3256 2486  
0408 924 767

[j.kristensen@palliativecareqld.org.au](mailto:j.kristensen@palliativecareqld.org.au)

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## Palliative Care Queensland

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Palliative Care Queensland is the peak advocacy organisation for palliative care in Queensland, representing the interests and aspirations of all who share the ideal of quality care at the end of life for all Queenslanders. As a member of the Palliative Care Australia network, Palliative Care Queensland aspires to meet Palliative Care Australia's national aims at State level.

Palliative Care Queensland's Vision:

"Quality care at the end of life for all Queenslanders"

Palliative Care Queensland's Role:

- To improve awareness and understanding of palliative care in the general community;
- To influence the development of public policy in relation to death, dying and end of life;
- To support the professionals and volunteers who provide palliative care;
- To provide health professional education;
- To develop and distribute palliative care educational resources;
- To provide information, support and advocacy to people affected by terminal illnesses, and
- To provide support and professional representation to Palliative Care Queensland members.

## Inquiry Terms of Reference

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That the Health and Community Services Committee inquire into and report on Queensland's chronic, frail and palliative care services.

That, in undertaking this inquiry, the committee should consider:

- The capacity and future needs of these services (including children and adolescents palliative care)
- The effectiveness, efficiency and adequacy of palliative, frail and chronic care services
- Examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services, and
- Consideration of segmenting the current Home and Community Service system, based on age of the client, needs of the client, their carer and providers.

Further, that the committee take public submissions and consult with key industry groups, carers, health workers and relevant experts.

## Foreword

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Technological advances have radically altered the way we will live. Improvements in healthcare standards mean that Queenslanders can now expect to live longer than ever before.

Dying, however, remains an inevitable outcome for every person, and the way that we care for our dying and the care and support we provide to their families, is a reflection of the value we place on our people and our communities. The challenge therefore, as a society, is to embrace dying as a normal part of life, to plan for it as best as possible and to seek help with managing the symptoms of end of life when the time comes.

On the world stage, palliative care is now viewed as a sophisticated, evidence-based area of health care, capable of managing even the most complex of symptoms associated with dying, whether physical, psychological, social or spiritual. It also provides patients and families with the ability to choose where they would like to die, the majority preferring to die at home.

The healthcare sector in Queensland now has the opportunity to develop the most effective processes to ensure that all Queenslanders have access to the specialist care required to experience quality of life at the end of life, regardless of their location, diagnosis, age, culture or socio-economic status.

## Executive Summary

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Palliative care<sup>1</sup> is an approach to care that improves the quality of life of patients and their families who are facing the problems associated with a life-threatening or terminal 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.

Improved access to high quality multidisciplinary palliative care services in all settings is essential in order to enable people living with a terminal illness and their families to make the most of each day and to experience comfort and support at the end of life, wherever possible in the place of their choosing.

Palliative care is for anyone living with or caring for someone with a terminal illness (including children) and should be accessed early after diagnosis. Although a large percentage of people receiving palliative care in Queensland have cancer, palliative care can benefit people with many other end stage chronic diseases such as motor neurone disease, heart failure, emphysema, kidney disease or advanced frailty or dementia.

### Queensland Statistics

In some areas of Queensland, the demand for palliative care grows by as much as 25-30% each year. In Townsville, referrals to the specialist palliative care team in 2010 increased by 30% in six months, and on the Sunshine Coast over the last few years, referrals have increased from 250 per year to 100 per month. On the Gold Coast, referrals to palliative care have doubled in the last two to three years to over 1,500 per year. Overall, referrals to specialist palliative care are expected to double from 11,834 in 2010 to 22,320 in 2050.

In 2010, 27,289 Queenslanders died; of these people, 90% died following a period of chronic illness, such as heart disease, cancer, stroke or a neurological illness that would have benefited from palliative care.<sup>3</sup> Although surveys indicate that home is the preferred place of death for 73% of Australians,<sup>4</sup> in Queensland only 28% of people died at home, whilst 56% died in hospital, 15% died in a residential aged care facility and only 1% died in a hospice.<sup>5</sup>

The demand for residential aged care in Australia is also anticipated to increase more than threefold by 2045.<sup>6</sup> Currently, almost one third of people who are admitted to a residential aged care facility as high care residents die within six months of admission and 61% will die within one year.<sup>7 8</sup> International studies also demonstrate that on average, providing palliative care in the last year of life has a cost saving of 30%, as many of these patients are currently receiving care in the acute care sector in hospital.<sup>9 10</sup>

In Queensland, the average cost of a critical care bed is \$4,000 per day compared with \$950 per day for an in-patient palliative care bed (high complexity and acuity),

\$600 per day for a moderate complexity hospice bed, \$200 per day for a low complexity Residential Aged Care Facility (RACF) or hospice bed and as little as \$65 per day for a community patient supported by family and either unpaid volunteers or carers at home.<sup>11</sup>

## Queensland Palliative Care Service Delivery Framework

Queensland has no state-wide plan, equitable funding or service delivery framework to support the provision of palliative care across Queensland. Several service delivery models have been endorsed and promoted by the palliative care sector, however no central or regionalised service delivery model or equitable population based funding framework has been adopted by the Queensland Government.

There are 17 hospital and health services in Queensland, including a State-wide Children's Health Service. 12 of these provide limited specialist in-patient and community palliative care services, the remaining five accessing sporadic specialist palliative care service from another district via an informal, somewhat ad hoc, poorly funded hub and spoke model. It is difficult to accurately identify the number of specialist palliative care beds in Queensland, however Palliative Care Queensland estimates that there are 174 public designated palliative care beds state-wide.

Five non-government specialist palliative care services provide a combination of hands on palliative care support or specialist consultancy. Four stand-alone hospices provide in-patient support. Three are partially funded by Queensland Health and one is privately funded. All of these services are located in South East Queensland.

Private in-patient palliative care services are located throughout Queensland; however most of these services, with the exception of St. Vincent's Brisbane and the Wesley Hospital, do not operate under the supervision of or in close formal contact with a specialist palliative care physician.

Specialist palliative care staffing should include palliative care medical and nursing specialists, allied health, loss and grief counsellors, pastoral care workers and volunteers.

There were three state-wide palliative care projects funded by Queensland Health to provide education, research, information and support and advocacy;

- The Centre for Palliative Care Research and Education (CPCRE);
- The Palliative Care Helpline, and
- Palliative Care Queensland.

Palliative care research is also undertaken by;

- CPCRE
- Mater Medical Research Institute
- Brisbane South Palliative Care Collaborative
- The University of Queensland, and
- Queensland University of Technology.

## Funding for Specialist Palliative Care Services

The total amount of funding provided to specialist palliative care services in Queensland is \$77.81M, including \$8.1M of Commonwealth funding.

This includes:

- \$8.1M provided by the Commonwealth under the National Palliative Care Program to purchase community palliative care services;
- \$51.35M in bed days (54,053 beds days at \$950 per day);
- \$4.6M for government and non-government providers of palliative care and other counselling, information, education and research organisations;
- \$5.9M for St Vincent's Brisbane to provide palliative care services;
- \$1.5M for Mater Public Hospital to provide palliative care services;
- \$27M for operational NPA funding for three years, and
- \$4.5M NPA capital spending.

*Note: For more information regarding funding, refer to Appendices 4, 5 and 6.*



## Response to the Terms of Reference

### TOR 1 - The capacity and future needs of these services, including children and adolescents palliative care

#### Background

Queensland is currently experiencing a huge growth in demand for specialist palliative care. This growth can be seen in all areas; paediatric palliative care, adolescent palliative care, young care (patients less than 65 of age) and older adults. Specialist services struggle to cope with increases of more than 20% annually in the volume of referrals. As a result, patients and families directly suffer as specialist palliative care services are forced to stretch funding by limiting access to services and the amount and type of care that can be provided, in order to decrease demand.

Some examples of forced access block are:

- No non-cancer patients;
- No RACF patients;
- No patients with a prognosis of greater than three months, and
- No home-visiting.

Inevitably, many referrers and their patients are unable to access specialist palliative care and these patients end up in Accident and Emergency and occupy acute hospital beds instead of receiving community or inpatient palliative care. The acute care they receive is more expensive, often results in inappropriate in-hospital care and poor symptom management, with little or no advance care planning or family/carer support.

Few specialist palliative care services across the state have the capacity to offer 24 hour community care even on a consultation basis to generalist services, which means that the home death rate is low even for palliative care registered patients (15-28%). Where there is funded capacity to offer this 24 hour community care (e.g. St. Vincent's Brisbane) the home death rate is much higher (50-60%). At \$950 per day, this is potentially a very significant saving, both in a funding sense (63% of \$950 per day = \$600 per day) but also in relieving bed-block and giving patients and families their choice of preferred place of terminal care.

Consultancy-liaison services have been shown world-wide to be very cost effective in decreasing the average length of stay in acute care beds, decreasing inappropriate or 'futile' care at the end of life and increasing the chances of early referral to palliative care.<sup>12</sup>

#### Paediatric Palliative Care

As the care of terminally ill children and adolescents differs greatly from adults, paediatric palliative care services require somewhat different expertise, as well as a modified model of care to support the growing number of terminally ill children who will experience declining health over a lengthy period. Paediatric palliative care also differs from adult palliative care because the number of children who die each year

is small compared to adults. Furthermore, many of the illnesses treated are extremely rare and many children receive palliative care for years, often until age 18 and beyond.

The time scale of terminal illnesses in children varies from a few days to months, and may extend over many years. Illnesses are often familial, with more than one child affected in the family, and care needs to embrace the whole family, not only the child. As terminally ill children are still growing, care must support the child's ongoing physical, emotional and cognitive development, and clinicians must be aware of and responsive to each child's changing levels of communication an ability to understand their illness, treatments and prognosis. Care also needs to incorporate provisions for education and play when a child is sick.

For these reasons, paediatric and adolescent specialist palliative care warrants additional consideration, planning and resourcing.

Often the families of children receiving palliative care suffer needlessly, because care is not always streamlined or flexible, and service providers have difficulty coordinating care and effectively communicating changes in treatment and other factors. Families spend many hours at hospitals providing care to their children, usually in an environment that is not family friendly or intuitive to the practical and psycho-social needs of families.

One of the most difficult issues, particularly for families with newly diagnosed children, is navigating and negotiating the health care system in order to effectively access the information, agencies and service providers required to obtain a reasonable standard and amount of care.

Children cannot always die in the family's preferred location, usually because the needs of the child are complex or funding for community service providers to enable children and families to receive palliative care in their home is not available. A limited knowledge of paediatric palliative care on the part of GPs and community nurses is also a contributing factor in preventing children from dying at home. Insufficient resourcing of the paediatric palliative care team is the major reason why more education for generalist clinicians is not more freely available.

An inability to access sufficient respite is a huge problem for families, putting pressure on families, and often leading to carer burnout and unnecessary hospital admissions. Following the closure of Zoe's Place in 2009, families are often forced to seek in-patient respite in Sydney, as there is no paediatric hospice in South-East Queensland to support out of home respite, both routine and emergency, or to provide a place for families to care for their child at the end of life. This ongoing stress is made significantly worse by the acute shortage of child and adolescent counselling and bereavement support services across Queensland.

Care is also expensive, and the financial burden of caring for one or more terminally ill children is one of the most significant issues faced by families. Funding can be

difficult to locate, especially for equipment and incidentals, and it is often very hard for families to access funding from Disability Services Queensland (DSQ).

The specialist palliative care team also struggles from a lack of specialised allied health expertise such as pharmacy, physiotherapy, social work, psychology, occupational therapy, nutrition, music therapy and other expressive therapies such as art therapy and pastoral care.

There are also gaps in care for paediatric non-cancer patients, including a gap in the provision of after-hours telephone based support. Limited specialist services are available to support peri-natal patients, and the existing model does not effectively meet the needs of disabled patients, as well as children with cardiac, metabolic and neurological diseases.

### TOR 1 - Recommendations

#### Adult Palliative Care issues

- Improved access to specialist palliative care, irrespective of diagnosis or prognosis for all patients and their families facing end of life issues (last 12 months of life).
- 24 hour community care with access to specialist palliative care services when needed is seen as a basic standard.
- Adequate funding for multidisciplinary consult teams in all hospitals with more than 300 beds (and access by smaller hospitals to these teams).
- All advanced disease outpatient clinics and care planning meetings to have a specialist palliative care physician and nurse attending

#### Paediatric issues

- Improved access to palliative care for children, including the development and funding of a children's hospice/respite facility in South East Queensland.
- Improved access to counselling and bereavement support, including the establishment of a designated counselling and bereavement service for children and young adults.
- Additional respite support for the families of children and young adults with terminal illnesses.
- Regular up skilling of clinical staff (paediatric palliative care issues) in regional adult palliative care services.

## TOR 2 - The effectiveness, efficiency and adequacy of palliative, frail and chronic care services

Queensland has the potential to be a world leader in the provision of specialist palliative care, and to provide world class treatment to those who are terminally ill, frail and chronically ill. Lack of coordination, poor and inequitable resourcing and the failure of our previous State government to acknowledge palliative care as a priority, have resulted in Queensland being one of the worst performing states in relation to palliative care. This includes the capacity for patients and families with complex needs to have equitable access to specialist palliative care services.

### Principal Issues

- Lack of care coordination across care settings and time;
- Inconsistent models of care;
- Ineffective funding and inequitable resource allocation models;
- Insufficient allied health support particularly in terms of:
  - counselling and bereavement;
  - occupational therapy;
  - physiotherapy;
  - pharmacy and
  - Pastoral care.
- Insufficient access to respite services;
- Workforce shortages, including a poorly educated and unskilled workforce;
- Poor access to specialist palliative care by non-malignant diagnosis groups;
- Limited or no access for those in regional, rural and remote areas, and
- Poor representation of specialist palliative medicine/care at advance disease care-planning meetings.

Palliative care services have evolved erratically (*see appendix 6 for palliative care funds by HHS and per head of population in Queensland*) and continue to operate in a patchwork fashion that fosters duplication and overlap in some regions, while other regions have little or no access to specialist palliative care services. In order to be able to meet the demand for specialist palliative care services in Queensland, the sector requires a new and improved model that can more successfully underpin planning and coordination, funding, resource allocation and service delivery. *Appendix 1* provides an overview of a draft formalised regionalised Consortia model for Queensland, based on the current Victorian and New Zealand models.

The specialist services that operate are understaffed, under-resourced, mostly have insufficient beds, and do not have the capacity to provide adequate community care and after-hours cover. As a result they are failing to successfully meet the demand for the comprehensive multidisciplinary care required for all patients and families from the moment of terminal diagnosis. In our resource-strapped sector, only the sickest of patients often have access to specialist palliative care. The chronically ill (especially non-cancer), frail aged patients and those in residential aged care often miss out.

## TOR 2 - Recommendations

### Coordination

- The development and implementation of a state-wide service plan for palliative care in Queensland that can ensure 24 hour access to high quality needs-based palliative care for all patients and families regardless of age, diagnosis, culture, location, setting or socio-economic status.
- Development and utilisation of an effective and efficient model for providing palliative care, including the care of children and young adults, which recognises the rising demand for palliative care services, equipment and consumables.
- Establishment of a dedicated palliative care policy and development team within Queensland Health's corporate office.
- Establishment of a stand-alone state-wide palliative care clinical network that can engage all clinicians working in palliative care to help provide equitable state-wide palliative care access to all Queensland patients and their families.

### Access

- Improved access to counselling and bereavement support, including a designated counselling and bereavement service for children and young adults.
- Additional respite support for the families of children and young adults with terminal illnesses.
- Greater access to specialist palliative care for patients with non-cancer illnesses such as frailty and dementia, motor neurone disease, heart failure and respiratory disease.
- Improved access to specialist palliative care for regional, rural and remote patients.
- Ensuring that all cancer and advanced disease care planning meetings and outpatient clinics in any district have a palliative medicine physician and specialist palliative care nurse attending.

### Workforce

- Adequate provision of allied health services: pharmacy, OT, physiotherapy and pastoral care for all level 4-6 palliative care services across the state.
- Implementation of a coordinated plan to up-skill and increase the specialist palliative care workforce, including a brief to focus on up-skilling and building the capacity of generalist service providers across all settings to provide end of life care.
- Ensuring that appropriately skilled and experienced clinicians are available when and where required using a formal regionalised framework that decreases the risk of burnout and provides consistently high quality care for complex patients and their families.

## Funding

- Quarantining a specific allocation or percentage of National Partnership Agreement sub-acute funding to palliative care.
- Equitable distribution of the National Partnership Agreement subacute funding, including the allocation of \$81M or 25% of the total Queensland allocation of NPA funding to the palliative care sector in Queensland between 2010 and 2014.
- That all service agreements between the systems manager and the Hospital and Health Service (HHS) contain a clear section on the need for an HHS to:
  - Develop an end of life strategy for the last twelve months of life;
  - State clearly what amount of palliative care services will be purchased and measured by the 'systems manager' in Queensland (including the quality of palliative care services - measuring outcomes using nationally validated measures, and standards using measurements of integration of the national palliative care standards and patient and family experience), and
  - That clear purchasing intent measures are set up to purchase less acute care and more subacute/palliative care in the population of patients facing the last 12 months of life. This end of life care should be flexibly purchased in consultancy-liaison, community and inpatient settings.

### TOR 3 - Examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services

The current palliative care system in Queensland is built on the principle of collaboration, and would not be able to function as successfully as it does otherwise. Across Queensland on a daily basis, agencies work alongside each other to provide high quality care, often having developed sophisticated methods for segmenting roles, responsibilities and funding streams. Typically, funding for a home based patient may involve care and funding from two to five agencies and up to five separate sources of funding.

Collaboration also occurs between peak bodies and support organisations in order to maximise potential outcomes in relation to professional education, public awareness raising, research and advocacy. These organisations typically share knowledge, expertise and resources in an effort to achieve individual key performance indicators but also to work towards achieving an aligned vision of seamless quality care.

Momentum is also growing among palliative care and generalist providers to work collaboratively to raise awareness of end of life issues, and in so doing promote the uptake of advance care planning and Advance Health Directives, that include the preferred place for terminal care. There is now a shared realisation that planning ahead can provide better patient outcomes and reduce costs.

Expensive and needless treatments can be avoided if the wishes of the patient are known and a surrogate decision maker has been appointed and involved in the advance care planning processes. Patients can be made aware of palliative care as a treatment option much earlier, and if health professionals are prepared to work

together to achieve quality of life rather than promote futile attempts at cure that are often invasive and expensive, patients and families have a far better chance at achieving quality of life, including dying in the setting of their choice.

### Principal Issues

In some instances, poor patient outcomes have resulted from too many agencies being involved in the care of the one patient leading to a lack of coordination between these services. Case management is underfunded, resulting in fragmented care in the community. This has also led to situations where long term patients have been 'handed over' to another agency at the most vulnerable phase, terminal stage, to receive end of life care, in some cases without the support of the family.

In other instances, agencies without 24 hour cover, who are not linked to specialist palliative care providers, have not been able to adequately manage the care of patients right through to the end. Some have struggled to recognise dying, and some have given up on impeccable symptom assessment and management prematurely.

The general public in Queensland has a very limited understanding of palliative care and the importance of advance care planning. Far more funding is required to educate the public about end of life issues in the hope that forward planning can lead to better outcomes for patients, and a reduced health economic burden.

Although there is currently a great deal of collaboration between agencies to maximise education, advocacy, research and clinical care, there is no centralised coordination and limited coordination of care at local level due to funding challenges based on activity, not coordination considerations.

All chronic disease group services, including heart failure services, renal services, end stage respiratory services and services that provide end stage care to patients with multiple co-morbidities, need to provide better and earlier end of life care and refer the more complex cases to the specialist palliative care team. There should also be a specifically funded requirement that all specialist palliative care services outreach to RACFs.

### TOR 3 - Recommendations

- Development of a state-wide end of life care strategy for Queensland for the last 12 months of life.
- Development of a state-wide community awareness campaign to educate Queenslanders about palliative care, death and dying in order to promote effective decision making at end of life.
- Promote the uptake of advance care planning, Advance Health Directives, Enduring Power of Attorney and "preferred place of care" documents in Queensland.
- Queensland Ambulance Service to act consistently with regards to Advance Health Directives and advance care planning documents and requests.

TOR 4 Consideration of segmenting the current Home and Community Service system, based on age of the client, needs of the client, their carer and providers.

Home and Community Care (HACC) services are commonly not provided for palliative care patients, even though many of their care needs are generalist in nature and some others are more specialist. Not using HACC funding leads to a major drain on scarce specialist palliative care community funds, leading to more frequent hospital admissions or inappropriate admission to RACFs. This problem needs urgent redress.

Although HACC is generally the first line of funding used to support people with terminal illnesses in the community, Commonwealth guidelines stipulate that HACC funding is not meant to be used to provide palliative care and cannot be used where funding from another source is being accessed. On occasions, HACC funding has been authorised by the district HACC manager for patients who are also receiving Palliative Care Program (PCP) funding, however it has usually been assigned on the premise that specialist and generalist care is required simultaneously.

There needs to be better linkage rather than exclusivity between HACC, CAPS, EACH and EACH-D service providers. This is very confusing for care providers, let alone patients and families. Palliative care coordinators should be able to work across all these areas to secure the most appropriate care and equipment for their patients and families, in order to be able to best support their clients at home.

Respite care is an essential part of community palliative care. Targeted family/carer support and can potentially avoid unnecessary hospital admissions. Respite care needs to also include overnight respite care if we are to adequately support families who are caring for someone dying at home.

With regard to collaboration with chronic disease, disability, aged care and community services, the more care can be shared and the capacity of existing community care providers enhanced, the better the outcomes for patients. Capacity needs to be increased within the currently inadequate specialist palliative care workforce, and 'Purchasing Activity' that involves training and supervising the generalist or non-palliative care specialist workforce. These clearly defined purchasing agreements should encourage specialist palliative care teams to build the capacity of the generalist workforce, and should be introduced as part of the new service agreements between the Systems Manager and the HHS.

Building collaborative and formal partnerships with other community care providers is vital for efficient and seamless community care round-the-clock. However, if patient and family safety and care quality are to be maintained, then this requires a significant amount of capacity for training and supervision, plus on-call availability of the specialist palliative care service providers, as well as measurement of outcomes and standards using nationally validated measures. The development of formal regionalised networks of Consortia (*refer appendix 1*) which function across settings



and at all hours, is vital for care to be equitably available to people in all parts of Queensland.

Currently people under the age of 65 who are unable to go home because of their complex care needs end up spending a very long time in hospital (3-5 months or more) whilst they are awaiting assessment by Disability Support Queensland (DSQ) for eligibility of further community care and support. For palliative care patients, 99% of the time the answer is "no" and then the Aged Care Assessment Team (ACAT) needs to be consulted, a process that is a lot shorter (1-3 weeks). The patient is then usually placed in an RACF. This process is in urgent need of streamlining for palliative care patients and families.

The move to make all patients under 65 come under state funding arrangements may further segment care and lead to further waste of time as the system is made even more complex and inequitable.

#### TOR 4 - Recommendations

- Palliative Care program funding should be able to be used alongside HACC services when required.
- A more flexible, person-centred, based on assessed need, funding model, should be developed so that all registered palliative care registered are entitled to a flexible funding package to fund care, family support or equipment in the best setting, to meet patient and family needs.

# 1 Palliative Care in Queensland

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## Definition of Palliative Care

Palliative care<sup>13</sup> is an approach to care that improves the quality of life of patients and their families who are 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.

Palliative care - adults:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness, and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care - children:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family;
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease;
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress;
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited, and
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

## Population Trends and Statistics

With a population of 4.5 million people, Queensland has the second highest rate of population growth in Australia. 55% of Queenslanders reside in the South East Queensland region, and a growing number of these people are reaching or have reached retiring age.<sup>14</sup>

In 2008, 27,335 Queenslanders died, 25,558 of who died expected or anticipated deaths from a variety of chronic illnesses, including cancer, heart disease, dementia and respiratory disease.<sup>15</sup>

**Table 1 - Projected population and projected deaths 2010 – 2050**

Based on data from the Queensland Office of Economic and Statistical Research

|                                       | 2010      | 2020      | 2030      | 2040      | 2050      |
|---------------------------------------|-----------|-----------|-----------|-----------|-----------|
| Projected Population                  | 4,517,050 | 5,488,667 | 6,492,453 | 7,498,377 | 8,519,091 |
| Deaths<br>(0.60% of total population) | 27,289    | 32,932    | 38,955    | 44,990    | 51,115    |

According to the Queensland Office of Births Deaths and Marriages, of the 27,335 Queenslanders who died in 2008, 56% died in hospital, 15% died in a residential aged care facility, 28% died at home and less than 1% died in a hospice.

**Table 2 - Place of Death in Queensland 2008 - 2011**

Based on data from the Queensland Office of Births, Deaths and Marriages

|                                | 2008            | 2009            | 2010            | 2011            |
|--------------------------------|-----------------|-----------------|-----------------|-----------------|
| Hospital                       | 15,502<br>(56%) | 14,853<br>(56%) | 15,304<br>(56%) | 15,203<br>(54%) |
| Residential Aged Care Facility | 3,985<br>(15%)  | 3,835<br>(15%)  | 3,809<br>(14%)  | 3,808<br>(14%)  |
| Hospice                        | 237<br>(1%)     | 226<br>(1%)     | 231<br>(1%)     | 215<br>(1%)     |
| Home                           | 7,611<br>(28%)  | 7,402<br>(28%)  | 7,945<br>(29%)  | 8,778<br>(31%)  |
| Total Deaths                   | 27,335          | 26,316          | 27,289          | 28,004          |

It is estimated that 10,234 terminally ill Queenslanders receive specialist palliative care per year, however this figure only includes patients and does not include family members, many of whom will need to receive counselling or bereavement support.

**Table 3 - Projected annual referrals to specialist palliative care 2010 – 2050**

Based on data from the Queensland Office of Economic and Statistical Research and Palliative Care Australia's Service Planning Guide

|  | 2010   | 2020   | 2030   | 2040   | 2050   |
|--|--------|--------|--------|--------|--------|
| Projected annual referrals to specialist palliative care | 11,834 | 14,378 | 17,009 | 19,645 | 22,320 |

Designated specialist palliative care beds are difficult to measure. In 2010, it was estimated that there were 186 dedicated specialist palliative care beds in Queensland, including 102 public and 84 private beds.<sup>16</sup> However Palliative Care Queensland recommends that only Clinical Services Capability Framework Level 4 – 6 beds should be counted as specialist palliative care beds. Therefore, despite the fact that experts estimate that 6.7 beds per 100,000 are required to provide best practice palliative care,<sup>17</sup> there are currently only 174 specialist palliative care beds in Queensland.

**Table 4 - Projected specialist palliative care bed numbers required 2010 – 2050**

Based on Palliative Care Australia’s Service Planning Guide

|                                 | 2010      | 2020 | 2030 | 2040 | 2050 |
|---------------------------------|-----------|------|------|------|------|
| Projected bed numbers (current) | 301 (174) | 368  | 435  | 502  | 571  |

In 2012, Queensland Health funded 67,000 bed days for palliative care, including 9,000 bed days that were provided by private contractors.<sup>18</sup> Based on the growth in bed equivalent days purchased over the last four years, Queensland should expect a significant rise in bed days over the following 10 – 15 years.

**Table 5 - Projected bed equivalent days 2008 - 2025**

|                                     | 2008   | 2012   | 2015   | 2020   | 2025    |
|-------------------------------------|--------|--------|--------|--------|---------|
| Palliative Care Bed Equivalent Days | 56,000 | 67,000 | 75,366 | 91,695 | 111,562 |

According to expert estimates, the recommended number of full time equivalent specialist palliative care physicians required per 100,000 population is 1.5.<sup>19</sup>

**Table 6 - Projected specialist palliative care physicians required 2010 - 2050**

Based on Palliative Care Australia’s Service Planning Guide

|   | 2010    | 2020 | 2030 | 2040 | 2050 |
|---|---------|------|------|------|------|
| Projected specialist doctors required (current) | 68 (23) | 82   | 97   | 112  | 128  |

## How Palliative Care is provided in Queensland

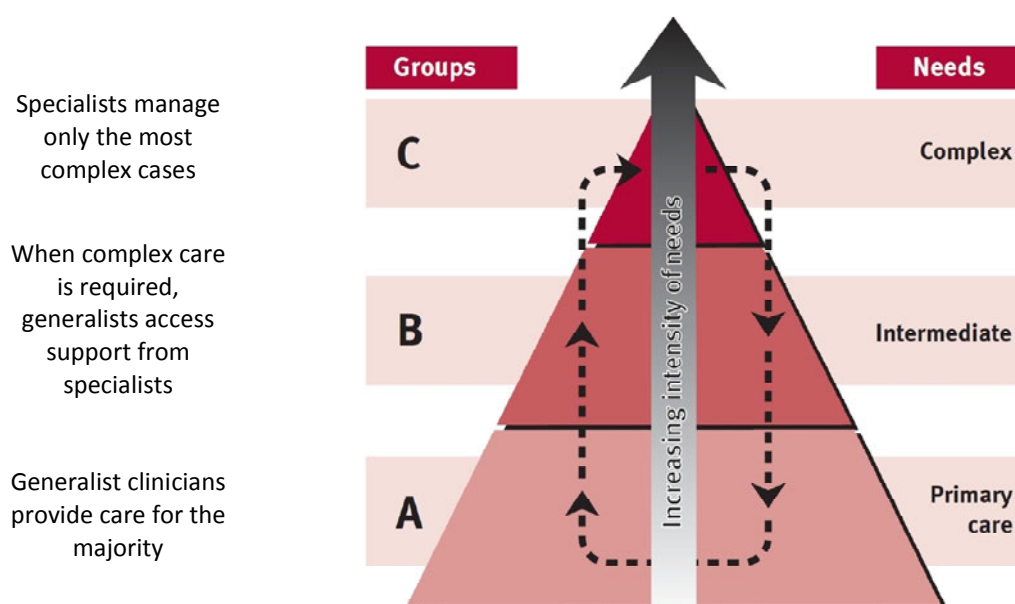
In Queensland, most models of palliative care service delivery are based on the premise that the majority of care at the end of life will be provided by generalist providers, such as GPs and community nurses, as the majority of deaths in the hospital and community settings are uncomplicated and can be managed by primary health care providers.

The majority of Queenslanders will therefore be cared for by their local GP and community nursing and allied health service at the end of life.

Most models also include the capacity for generalist clinicians (GPs, non-palliative care specialist physicians, community nurses and allied health personnel) to access specialist support and advice when required for more complex cases. This often involves referral to the local specialist palliative care team for consultation, and may involve temporary admission for symptom management and subsequent referral back to the primary provider for coordination of future care. Fewer Queenslanders will require a combination of generalist and specialist level care at the end of life.

**Figure**

Breakdown of client groups and level of need



Generalist palliative care, lower level specialist care, or a generalist palliative approach to care in Queensland is provided in:

- General medical and surgical units in hospitals, sub-specialty units including cancer wards, respiratory wards, cardiac wards, stroke units, ICU and CCU;
- Hospices where there is little/no access to specialist palliative care services;
- RACFs and
- At home in the community by generalist service providers.

Unfortunately, there are currently no monitored standards for generalist or non-palliative care specialists who provide end of life care. An evidence-based suggestion comes from the Australia and New Zealand Society for Palliative Medicine End of Life Clinical Working Group, which defines evidence-to-practice gaps for end of life care in five main domains, including:

1. Symptom management (especially pain, dyspnoea, mood – anxiety/ depression), and
2. Advance Care Planning (documentation of prognosis and goals-of-care discussions, surrogate decision-maker selection, preferred place of care selected and Acute Resuscitation Plans discussions).<sup>20</sup>

### Specialist Palliative Care

Only a relatively small number of Queenslanders will require referral to a specialist palliative care team for the bulk of their care. Specialist palliative care services almost always manage the most complex cases only, including the care of patients who have difficult symptoms that cannot easily be managed by primary health care providers or generalist level clinicians. On average, referrals to specialist palliative care services increase by 10 to 25% per year.

Specialist palliative care in Queensland is provided in:

- Specialist palliative care units;
- Other hospital wards via a specialist palliative care consultancy service;
- At home via a community based specialist palliative care service, and
- Some hospices, including those where workforce development and training is given at a specialist level and where there is easy access to a specialist palliative care service.

### Organisations that Provide Palliative Care

Palliative care services in Queensland are delivered by both government and non-government agencies, this includes:

15 Queensland Health and Hospital Services provide palliative care, including:

- Cairns and Hinterland;
- Central Queensland;
- Children's Health Queensland;
- Darling Downs;
- Gold Coast;
- Mackay;
- Mater Public Hospitals;
- Metro North;
- Metro South;
- North West;
- Sunshine Coast;

- Townsville;
- West Moreton;
- Wide Bay, and
- St Vincent's Hospital.

Six non-government service providers are also contracted to provide palliative care, including:

- Little Haven Hospice Service;
- Cittamani Hospice Service;
- Karuna Hospice Service;
- Ipswich Hospice;
- Toowoomba Hospice, and
- Hopewell Hospice Service.

### State-wide Support Services

There are three state-wide palliative care projects that are also funded by Queensland Health, including:

- Centre for Palliative Care Research and Education;
- Palliative Care Helpline, and
- Palliative Care Queensland.

### Models of Care

Palliative care service delivery in Queensland is made difficult given the many varied models of palliative and end of life care that exist from region to region, and service to service.

Varying models currently exist for:

- Queensland Health Specialist In-Patient Palliative Care Services;
- Queensland Health Specialist Palliative Care Community and Consultancy Services;
- Non-Government In-Patient Specialist Palliative Care Services;
- Non-Government Specialist Palliative Care Community and Consultancy Services, and
- Private Palliative Care Services.

### Cost of Palliative Care

The total amount of funding provided to specialist palliative care services in Queensland is not known, however the following information has been published by Queensland Health:

- \$8.1 million provided by the Commonwealth to purchase community palliative care services;
- \$51.35M in bed days (54,053 beds days at \$950 per day);

- \$4 million to support Govt and NGO providers of palliative care and other counselling, information, education and research organisations, and
- \$12.6 million to St Vincent's Brisbane to provide a range of in-patient services that include palliative care.

At a cost of \$950 per patient per day, an in-patient palliative care bed is far more expensive than the average daily cost of caring for a palliative care patient in the community, approximately \$63 per day or \$1875 per month.

### Palliative Care Research

Palliative care education and research is undertaken by the Centre for Palliative Care Research and Education, Brisbane South Palliative Care Collaborative, Mater Medical Research Institute, The University of Queensland and the Institute for Health and Biomedical Innovation at Queensland University of Technology.



## 2 Coordination

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It is reasonable to suggest that the delivery of any service, health or otherwise, whether local, state or national in focus requires coordination. Nationally, all states and territories maintain a palliative care strategy or service delivery plan or are in the process of updating expired plans and strategies, including:

- New South Wales: *Palliative Care Strategic Framework 2010 - 2013*
- Victoria: *Strengthening palliative care: Policy and strategic directions 2011–2015*
- South Australia: *Palliative Care Services Plan 2009-2016*
- Tasmania: *Tasmanian Palliative Care Plan*
- ACT: *Palliative Care Strategy 2007 – 2011*
- WA: *Cancer and Palliative Care Network Palliative Care Model of Care*
- Northern Territory: *Palliative Care Strategy 2005-2009*

### Queensland Health's Draft Palliative Care Strategy 2011

In 2011, following some consultation with palliative care sector stakeholders, Queensland Health developed a draft strategy for palliative care. The *Draft Queensland Health Palliative Care Strategy 2011 (April V9)*, loosely mirrored the National Palliative Care Strategy. It did not include a population based model of care for specialist palliative care service provision, was not consistent with the Clinical Services Capability Framework and did not provide a solid basis for the future operationalisation of services and funding throughout Queensland. The draft strategy was viewed by most in the palliative care sector as a 'conversation starter' in relation to the planning of future palliative care services, and was not viewed as a credible strategy for successfully underpinning future palliative care service delivery.

### The Clinical Services Capability Framework

In 2010, Queensland Health developed the palliative care services module of the Clinical Services Capability Framework (CSCF) for Public and Licensed Private Health Facilities. This framework was developed to provide a standard set of minimum capability criteria for service delivery and planning, as the capability of any health service is recognised as an essential element in the provision of safe and quality patient care.

The Framework outlines the minimum service requirements, staffing, support services and risk considerations for both public and private health services to ensure safe and appropriately supported clinical service delivery. When applied across the state, a consistent set of minimum standards and requirements for clinical services will safeguard patient safety and facilitate clinical risk management in public and private health services.

The palliative care module of the CSCF, although widely accepted by the sector and senior palliative care clinicians, has not been operationalised by Queensland Health.

**Table 7**  
**Palliative Care Module of the Queensland Clinical Services Capability Framework**

| Clinical Services Capability Framework – Level 1  |   |
|---|---|
| <ul style="list-style-type: none"> <li>• Provided primarily by RN with generalist qualifications, and</li> <li>• Registered Medical Practitioner support.</li> </ul>  | <ul style="list-style-type: none"> <li>• There is 24/7 access to specialist palliative care services (SPCS) with communication and collaboration maybe via telehealth;</li> <li>• access to bereavement support; may have access to NGO nursing;</li> <li>• access to syringe driver for symptom management;</li> <li>• access to equipment hire, and</li> <li>• providers have relevant knowledge of the principles of palliative care and seek advice as appropriate or refer to SPCS.</li> </ul> |
| Clinical Services Capability Framework – Level 2  |   |
| <ul style="list-style-type: none"> <li>• Community-based ambulatory services;</li> <li>• Access to in-patient beds for nursing support (although these may not necessarily be designated palliative care beds), and</li> <li>• Access to Specialist Palliative Medicine support via telehealth or other.</li> </ul>     | <ul style="list-style-type: none"> <li>• <b>as per level 1 +</b></li> <li>• access 24hrs to a Level 4-6 service for advice/guidance;</li> <li>• Access 24hrs to tele-health services and equipment, and</li> <li>• Access to NGO support services/dom nursing.</li> </ul>   |
| Clinical Services Capability Framework – Level 3  |   |
| <ul style="list-style-type: none"> <li>• Ambulatory and/or inpatient setting. Identified as dedicated service;</li> <li>• Established links with higher level palliative care services, and</li> <li>• Provides seamless continuum of care patients moving between community and inpatient settings.</li> </ul>         | <ul style="list-style-type: none"> <li>• <b>as per level 2 +</b></li> <li>• Care coordination of palliative services is centrally managed;</li> <li>• Regular patient reviews by specialist palliative care staff, in person or by telehealth, and</li> <li>• May have access to regular on-site specialist palliative care clinic, service in community or inpatient setting.</li> </ul>   |
| Clinical Services Capability Framework – Level 4  |   |
| <ul style="list-style-type: none"> <li>• Ambulatory and/or inpatient setting moderate complexity symptom mx needs;</li> <li>• Direct care or support primary providers;</li> <li>• Inpatient- designated beds, and</li> <li>• Coordinated by HP experience, knowledge, skills PC &amp; access Allied Health.</li> </ul> | <ul style="list-style-type: none"> <li>• <b>As per level 3 +</b></li> <li>• Close liaison DEM (where available), and</li> <li>• Access to relevant Mental Health service.</li> </ul>  |
| Clinical Services Capability Framework – Level 5  |   |
| <ul style="list-style-type: none"> <li>• Capacity to manage full range of clinically and or psychologically complex patients;</li> <li>• Provides allocated in-patient beds (+/- unit), and</li> <li>• Networked to off-site ambulatory,+ 24hr medical staff + access higher level services.</li> </ul>                 | <ul style="list-style-type: none"> <li>• <b>As per Level 4 +</b></li> <li>• Provision of complex symptom management (including access to invasive procedures);</li> <li>• Provision of procedural medicine (taps);</li> <li>• On-site bereavement service;</li> <li>• Access to consultation/liason psych, and</li> <li>• Access to interventional pain management.</li> </ul>  |
| Clinical Services Capability Framework – Level 6  |   |
| <ul style="list-style-type: none"> <li>• Palliative Care unit that manages highest level of patient risk/complexity-◇ Mx;</li> <li>• Intrinsically linked to level 5/6 other disciplines, and</li> <li>• Provides an extensive range of interventional and diagnostic services.</li> </ul>                              | <ul style="list-style-type: none"> <li>• <b>As per Level 5 +</b></li> <li>• Regular MDT meetings with other level 6;</li> <li>• After hours service provision available for other services regarding highly complex symptom management issues;</li> <li>• On-site interventional pain management, and</li> <li>• Access to invasive procedures, high-risk patient.</li> </ul>   |

## Other Relevant Queensland Service Plans

Although a number of current Queensland Health service plans include reference to palliative care, none provide a comprehensive plan or strategy for coordinating either end stage malignant or non-malignant disease or specialist palliative care.

The *Queensland Statewide Cancer Treatment Services Plan 2010–17* includes future projections in relation to palliative care bed numbers, as well as provisions for palliative cancer treatments. The underlying premise of the plan however sees specialist palliative care services as separate to cancer services.

The *Queensland Statewide Renal Health Services Plan 2008–17* includes reference to end of life care, but does not include or recommend an appropriate framework for providing palliative care to renal patients.

The Queensland Strategy for Chronic Disease 2005-2015 is the only plan that includes formal strategies for providing palliative care. These strategies include:

- *31. Support the development and implementation of a state-wide, integrated framework for palliative care;*
- *31.1 Review Queensland Health's Strategic Directions for Palliative Care Services 2000-2005;*
- *31.2 Support the development and/or implementation of standard protocols for the appropriate referral, access and treatment of people with chronic disease requiring palliative care;*
- *31.3 Formalise existing networks of services and providers through improved integration across relevant agencies;*
- *31.4 Increase the capacity to provide palliative care services, including provision of culturally appropriate training for providers working with Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds;*
- *31.5 Develop or increase the capacity to provide palliative care services in-home or in other culturally appropriate settings, and*
- *31.6 Support public awareness initiatives, aimed at both the wider community and health care workers, to increase understanding, acceptance and use of palliative care services for all chronic diseases, beyond cancer.*

## Coordination by Queensland Health Corporate Services

Currently, palliative care in Queensland is managed and loosely coordinated by a number of departments across Queensland Health's Corporate Services Unit. Contract management and the monitoring of service deliverables is managed by the Community Services Unit. Policy and service development is coordinated by the Older Person's Health and Extended Care Unit. Other areas, including Infrastructure Development and Intra and Inter Governmental Relations also provide transient and specialist input and coordination from time to time.

Over the last decade, the organisational structure at Queensland Health has changed relatively frequently, as have the personnel responsible for key projects and policy development. At times it has been challenging to locate the key personnel responsible for palliative care projects and policy development in the area of palliative care. Many of whom have occupied palliative care portfolios only briefly, reducing the capacity of projects and policy to be developed in a consistent and coordinated manner.

Also over the last decade, a number of palliative care initiatives, including key reports, service development projects and education programs have been commenced, but have either not been completed or have been terminated early, usually due to a lack of funding. Many of the reports that have been commissioned by Queensland Health in relation to palliative care have been completed, but for various reasons have never been made public.

**Table 8 - Queensland Health Commission Reports - Never Released**

| Report   | Contractor                 | Cost    | Status                                  |
|--|----------------------------|---------|---|
| Mapping of Palliative Care Services in Central Zone<br>2008  | QUT                        | Unknown | Completed but sequestered by Qld Health |
| Statwide Service Delivery Model Consultation Project<br>2010 | Palliative Care Queensland | \$59K   | Completed but sequestered by Qld Health |
| Scoping of Palliative Care Services in Queensland<br>2010    | QUT                        | Unknown | Completed but sequestered by Qld Health |

### Examples of Coordination in other States

Examples of well coordinated palliative care departments in other State Governments are not difficult to locate, the Victorian model serving as the ideal example for most governments.

In Victoria, the Department of Health employs a dedicated team of eight full time equivalent palliative care focussed project personnel known as the Palliative Care Team (PCT). Working in collaboration with the Department's Wellbeing, Integrated Care and Ageing Divisions, the PCT's primary responsibility is to implement Victoria's palliative care plan.

There are also eight Palliative Care Consortia located throughout Victoria, each of which employs a local manager to assist in the implementation of the state-wide plan at district level.

### 3 Funding

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Understanding the way palliative care and end of life services are funded in Queensland can be difficult, largely because there are so many sources of funding, including Commonwealth, State and private funding. The allocation of funding also varies from district to district, just as the criteria for eligibility can vary from service to service and district to district.

#### *Home and Community Care Program (HACC)*

HACC services are funded by the Commonwealth Government, and are generally accessible to those over the age of 65. HACC services can provide general nursing in the home, allied health support, domestic assistance, assistance with home modifications and meals on wheels.

Although HACC is generally the first line of funding used to support people with terminal illnesses in the community, Commonwealth guidelines stipulate that HACC funding is not meant to be used to provide palliative care, and cannot be used when funding from another source is being accessed. Although from time to time HACC has been authorised by the district HACC manager for patients who are also receiving Palliative Care Program (PCP) funding, it has usually been assigned on the premise that specialist and generalist care is required concurrently.

In some regions, providers have successfully negotiated with HACC providers to provide multiple funding streams, in order to avoid PCP funding being drained for general purposes, and in turn avoiding additional hospital admissions and inappropriate admission to RACFs.

There needs to be better linkage rather than exclusivity between HACC, CAPS, EACH and EACH-D service providers. The current system is very confusing for care providers, let alone patients and families. Providers often spend a great deal of time helping families negotiate the different funding silos.

The move to make all patients under the age of 65 come under State funding arrangements may further segment care and lead to additional time wasting for health professionals, as the system is made even more complex and inequitable. Hopefully, this will not be the case and this welcome inquiry will decrease the barriers and funding silos to make care readily available based on need. Flexible funding packages can be one efficient solution to these problems.

#### *Aged Care Packages*

Aged care packages are funded by the Commonwealth Government, and include the Community Aged Care Package (CACP), Extended Care at Home (EACH) and EACH – D (specific for people with dementia). These three packages provide higher levels of nursing care, and are assigned to those who have higher level needs in the

community. As patients age and become terminally ill, these packages continue to fund care until PCP funding is made available.

According to Commonwealth guidelines, aged care packages cannot be accessed when a patient is receiving funding from another source, including PCP funding. Historically, however, funding from both streams has been used simultaneously to provide a higher level of palliative care in the community, particularly when the needs of the patient are complex.

### *Department of Veterans Affairs (DVA) Funding*

A small number of palliative care patients in the community will have access to and utilise DVA funding to support end of life care in the community. DVA packages are funded by the Commonwealth Government.

Applying for DVA funding to support palliative care patients can be time-consuming and complex. For small organisations in particular, this can represent a significant drain on resources.

### *Community Health Funding*

Community Health services are often accessed by palliative care patients in the community to provide allied health support, such as physiotherapy, dietetics and psychology. Community Health services are funded by the Queensland Government, however patients are usually asked to make a small contribution towards the cost of these services.

Community Health services are generally poorly staffed, and there can be long waiting times for patients who require allied health support such as social work, psychology and physiotherapy. There are often geographical limitations imposed by Community Health services that prevent patients in the home from receiving care.

### *Disability Services Queensland (DSQ) Funding*

In some instances, patients who are already under the care of DSQ may use existing DSQ funding to support community care at the end of life.

DSQ funding is often difficult to access, and is not freely available to those who are terminally ill and who have a long term disability, including those with Motor Neurone Disease. DSQ packages are funded by the Queensland Government.

There are often long exhaustive waits for DSQ assessment and funding, both in the community and the in-patient setting. Often the only reason patients remain in hospital and cannot be placed is that they are waiting for DSQ assessment before they can receive an ACAT assessment. These delays result in significant bed block in both acute and subacute areas and come at considerable cost to the health care system.

### *Medical Aids Subsidy Scheme (MASS) Funding*

In some instances, Queensland Government MASS funding can be accessed to provide equipment in the home to support palliative care patients. The process for accessing MASS funding however is extremely complex, and the time spent applying for and negotiating MASS funding continues to drain specialist palliative care services of significant amounts of time and resources.

### *National Respite for Carers Program (NRCP) Funding*

NRCP funding is provided by the Commonwealth Government for the purposes of emergency carer support. Respite care is an essential part of community palliative care, and can potentially help avoid unnecessary hospital admissions.

Respite care and funding needs to include overnight support in order to adequately support families who are caring for patients dying at home. Specialist providers have become very effective at utilising one-off respite funding to keep patients at home, avoiding needless hospital admissions and reducing overall inpatient costs.

### *Private Nursing*

Many Queenslanders are not eligible to receive HACC, Aged Care, DVA, Community Health or DSQ funding. As a result, they may have to pay community agencies such as BlueCare, Anglicare or OzCare for private nursing. The average cost of private nursing in Queensland is \$60 per hour, the majority of which is not supported by private health insurers.

## **Funding of Specialist Palliative Care in Queensland**

### *Palliative Care Program (PCP) Funding*

Queensland Health receives \$8.1M in funding from the Commonwealth Government annually to purchase palliative care services in the community. A proportion of this amount is then allocated to each of the 17 Health Service Districts in Queensland, and used to support the care of palliative care patients in the community. PCP funding is used to purchase nursing care, respite services, dressings and other medical supplies and equipment.

Palliative Care Queensland has been unable to determine the exact amount of Commonwealth funding received by the Queensland Government for PCP funding over the last 10 years. Accordingly to documents from the late 90s,<sup>21</sup> the Commonwealth commitment to the Queensland Palliative Care Program (PCP) from 1998 – 2011, was \$5M annually. More recent documents indicate that the amount of Commonwealth funding received annually between 2008-2012 was \$8.1M.<sup>22</sup>

Lack of access to PCP funding is one the greatest obstacles to the provision of high quality palliative care across Queensland. Huge increases in rates of referral to specialist palliative care services over the last 15 years have not been met with a commensurate increase in the allocation of PCP funding to each Health Service

District. In some instances as a result, strict criteria has been placed on accessing to PCP funding.

In most regions of Queensland, PCP funding is now only available to those who have less than three months to live. This is a direct response to a shortage in PCP funding at local service level, the consequences of which can be devastating. Many non-malignant patients, such as those with end stage organ failure and neurodegenerative illnesses, are therefore ineligible to access PCP funding due to their longer trajectory of decline.

### *Specialist Palliative Care Services – Queensland Health*

Most Health Service Districts in Queensland fund specialist palliative care services from their base funding, whether in-patient, out-patient, in-reach consultancy or out-reach consultancy. Queensland Health has also funded specialist palliative care beds in private hospitals.

Over the past 10 years in particular, funding of Queensland Health palliative care services has not increased at the same pace as referrals to specialist palliative care. Many service struggle to provide care to fewer and fewer patients as a result, having to cut services, staff FTE and training programs in order to provide even the most basic palliative care.

Some CSCF level 4 – 6 specialist palliative care services have been forced to reduce overall budgets because of either local area budget deficits or blanket State Government budget reductions initiatives. The budget for specialist palliative care in Metro North has been reduced over the last few years, despite a significant increase in referrals to the service. As a result, the training program for specialist palliative care doctors has been compromised and the service has placed severe limitations on access to PCP funding.

### *Specialist Palliative Care Services – Non-Government*

Non-government specialist palliative care providers are contracted by Queensland Health to provide either in-patient or community based palliative care services, including domiciliary care and consultancy. Contract funding from Queensland Health usually represents 40 – 60% of the annual operating income for these services, the remainder being accessed via charitable donations and fundraising activities.

Although Queensland Health funding to these services increases annually by the recommended Consumer Price Index (CPI), no additional growth money has been received by most of these services, despite an exponential increase in referrals, workload and operational costs.

NGOs are also heavily reliant on charity to provide core services. At the time of the Global Financial Crisis, there was a subsequent reduction in public donations



community wide. This led to the majority of NGOs experiencing severe hardship, many having to limit services and reduce FTE as a result.

In 2009 and 2010, NGO providers received small one-off payments to support transition to the revised Social and Community Services (SCS) Award. Some of these services have also been successful in accessing funding via the 2010-14 NPA subacute funding round, however this funding was attached to additional key performance indicators.

Overall, NGOs struggle to obtain the income required to meet the demand for services, as increased operational costs (insurance, accreditation, quality and safety standards, Award increases) require greater resources. NGOs provide a critical service, and the structure of contract payments must be modified to ensure that NGOs are funded more appropriately.

## Funding of Other State-wide Support Services

### *Palliative Care Helpline*

The Palliative Care Helpline is funded by Queensland Health to provide telephone based information, support and counselling to Queenslanders affected by terminal illness. The service maintains a database of generalist and specialist service providers across Queensland, and utilises qualified nurses, social workers and counsellors to support over 1,500 callers per annually. The Karuna Hospice Service receives approximately \$200K per year from Queensland Health to manage the Palliative Care Helpline.

### *Palliative Care Queensland*

Palliative Care Queensland receives approximately \$95K per year from Queensland Health to provide information and advocacy to Queenslanders affected by terminal illnesses. Although contract funding increases by CPI annually, the organisation has never received additional funding to support community education or awareness programs, collective advocacy or sector consultancy.

Core activities of the Association over the last three years have included:

- Development and distribution of the Understanding Palliative Care DVD;
- Establishment of the Queensland End of Life Alliance;
- Establishment of the Palliative Care Clinical Network, later taken over by Queensland Health to become the Palliative Care Sub-Network;
- Completion of the Statewide Service Delivery Model Consultation Project Report;
- Hosting of two large and very successful 'Your Death Your Choice' community forums (2011 and 2012);
- Distributing more than \$540,000 worth of medical equipment to over 40 community palliative care services across Queensland, the majority of which were Queensland Health Services, and
- Co-hosting 'Diversity', the Australian Palliative Care Conference 2012, in Cairns.

### *Centre for Palliative Care Research and Education*

The Centre for Palliative Care Research and Education (CPCRE) was established by Queensland Health in 2001 to enhance palliative care services in Queensland through education and research endeavours. CPCRE is led by a consortium of organisations who work with other agencies to improve the quality of care provided to people with a life limiting illness.

Although CPCRE is funded to provide education and to support research across Queensland, it has not received an increase in recurrent funding for many years, despite a significant increase in the services provided, and projects supported

## Health Reform Agenda Issues

### *Health and Hospital Services*

Under the health reform agenda, Queensland now has seventeen Health and Hospital Services (HHS), one State-wide paediatric HHS and a systems manager to monitor for and decrease patient safety and quality variances via purchasing agreements and transparent service agreements.<sup>23</sup>

### *End of Life and Palliative Care Policy*

Developing a rational and evidence based end of life care strategy in the twelve months of life, and a palliative care strategy that aligns with and is implemented and funded in line with the National Palliative Care Strategy will be a challenge. However, if any block funding distribution is population based and uses a version of the Victorian PCRAM Model<sup>24</sup> that is adapted to fit Queensland's geographical and demographic characteristics, and is specifically tagged for palliative care service provision, then we may see the development of an equitable system for palliative care access based on need for all patients and families living in Queensland.

### *Activity Based Funding*

Purchasing agreements based on Activity Based Funding (ABF) for community and consultancy liaison palliative care service provision need to be designed. The Palliative Care Sub-Network is very keen to work with Purchasing Branch to ensure that outcomes measured are evidence based, high quality and patient and family needs focused.

### *ABF and purchasing quality, evidence based EOL Care in the setting of patient choice*

Purchasing agreements under ABF need to be properly designed to buy high quality care, including:

1. Consultancy-liaison services providing initial assessments and shared care, multidisciplinary care coordination with community providers, advance care planning and family meetings, all with the aim of enhancing patient flow and decreasing average length of stay in acute care beds;

2. Multidisciplinary community care and purchased bed-equivalents to maximise high quality out-of-hospital care. There needs to be round-the-clock support for generalist or specialist out-of-hours community nursing care providers, including the provision of respite care in the home;
3. Flexible care packages to be purchased under ABF (as bed equivalents or via some other purchasing mechanism) to allow for the funding of equipment and consumables in the home setting;
4. Inpatient purchasing to be monitored to ensure that care for very complex patients is appropriately designed and that the multidisciplinary nature of palliative care is taken into account as well as the need for family and carer support;
5. Up-skilling and capacity building of the generalist, non-palliative medicine/care specialist workforce, junior staff and medical, nursing and allied health students in high quality end of life care, to be a standard feature of any specialist palliative care service. 20% of time needs to be allocated to education for every discipline in the specialist palliative care service;
6. Standards for the measurement of high quality outcomes for end of life care should be expected of generalists and non-specialist providing 'palliative intent care', if safety and quality care is to be guaranteed and access to quality palliative care based on need is seen as the right for all Queenslanders, irrespective of diagnosis, prognosis, geography, economic status or ethnicity, and
7. Quality, safety and continuous quality improvement are possible in palliative care using two national programs: Palliative Care Outcomes Collaboration (PCOC) and National Standards Assessment Program (NSAP). These complementary national systems allow for excellent continuous quality improvement and benchmarking based on outcome measures, self assessment against national standards and patient and family experiences. These need to form part of standard and expected palliative care practices, and services should be funded appropriately to collect this data and undertake benchmarking processes.

### *Wider benchmarks development for Palliative Care Service planning across all settings*

Benchmarks for the specialist workforce need to be developed and accepted via purchasing agreements under ABF for all settings, including community, consultancy-liaison and inpatient. Currently the only service planning guidelines are those provided by Palliative Care Australia in 2003, based on expert opinion. It should be noted that these expert opinions are gaining more standing over time both here, in the United Kingdom and in Europe.

Some examples of generally used ratios are:

- 1.0-1.5 Specialist doctors /100,000 population;<sup>25</sup>

- Case loads for community staff e.g. 50-75 patients for shared care coordination with generalist community care providers for CN level specialist palliative care nurse or 75-100 patients for a CNC Level nurse;
- Inpatient Unit nursing hour's baseline is 6.5 nursing hours per patient per day. This is to allow for complex care and support of families/carers. It must be noted however that recent modeling done in Townsville used PCOC data to analyse dependency scores for complex patients and families referred to specialist palliative care. As a result, it would seem that a baseline of 7.5 nursing hours per patient per day would be closer to the necessary service benchmark to avoid staff burnout in a CSCF Level 4-6 specialist palliative care unit. There needs to be further work done on defining complexity and functionality/dependency measures to allow for transparent increases in this ratio at times, in order to avoid nursing 'staff burnout'. In addition, the role of social workers, occupational therapists, physiotherapists, pharmacists, allied health assistants, personal care assistants and adequately trained and supervised volunteers needs to be properly considered.

The palliative care needs of a population must be adequately estimated and adapted for Queensland geography and vulnerable populations demography (indigenous, CALD, lower SES, frail and elderly, patients with dementia etc.). Until this occurs, meaningful palliative care service planning, especially in community or consultancy-liaison, will be impossible. Therefore, many specialist palliative care services will have to continue to limit access in order to avoid staff burnout.

Examples of these types of population needs estimates exists in W.A,<sup>26</sup> N.Z<sup>27</sup> and the UK.<sup>28</sup> With additional resourcing, Queensland's Centre for Palliative Care Research and Education (CPCRE) is ideally placed to conduct this type of population-based needs assessment for Queensland.

## 4 Access

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Access to specialist palliative care services is not freely available to all Queenslanders, largely due to geography, resourcing, workforce constraints and poor coordination.

### *Aboriginal and Torres Strait Islanders (ATSI)*

There are various cultural reasons why indigenous Queenslanders cannot or do not readily access specialist palliative care services. A survey of Aboriginal and Torres Strait Islander Communities commissioned by Queensland Health in 2010 provided the following suggestions for improving end of life care:

- Better support for families, carers and communities;
- More training for ATSI Health Workers;
- Improved Communication;
- Awareness of culture, spirituality, love, compassion and understanding;
- More ATSI Health Workers;
- Respect for the wishes of ATSI people, and
- Promoting Healthy Eating.

The report also recommended that specific ATSI cultural awareness education and training be made mandatory for all providers of end of life care.<sup>30</sup>

### *Culturally and Linguistically Diverse Communities*

Modern Queensland is culturally diverse, with growing numbers of overseas born residents contributing to the fabric of our communities. Shifts in workforce trends, largely the result of increased mining, have led to a rapid increase in the number of culturally and linguistically diverse residents moving to rural and remote communities in Queensland.

A report commissioned by Queensland Health in 2010<sup>31</sup> acknowledged the following issues in relation to the provision of palliative care and end of life care in Queensland:

- More time is required for non English speaking people during interactions with the health system due to interpretation, and this is not currently catered for;
- More interpreters and translating services are needed in the healthcare system and these need to be available free of charge, and
- There is not enough information regarding end of life care available for people from CALD communities.

The report recognised that the following strategies could be implemented across the health system broadly, not just for end of life care:

- Improved access to free interpreters;
- Translation of information brochures into other languages;
- Cross cultural training in all health organisation should be mandatory;

- Recruitment profiles should reflect cultural diversity, and
- Intake and pre-admission processes need to gather as much information as possible regarding the patient's cultural context.

### *Rural and Remote Patients*

Approximately 45% of Queenslanders live in regional, rural and remote locations outside the metropolitan area or the south-east corner. Rural and remote communities are often not well served by support services and networks in palliative care.<sup>32</sup>

Although access to palliative care is a fundamental right for people in Australia and endorsed by government policy, there is often limited access to specialist palliative care services in regional, rural and remote areas.<sup>33</sup> There are a range of unmet needs for rural palliative care patients and their families, including access to palliative care services, specialist palliative care consultancy, specialist in-patient beds, information about illness, practical care and support.

There are also often less GPs in rural and remote areas, meaning less medical input and less choice when being cared for at home. Access to after-hours care can be problematic. Distances to travel to regional centres in conjunction with a lack of transport are also very real issues.

Palliative care services in rural areas also have unmet needs in terms of support, educational requirements, access to specialist symptom management and ways to facilitate communication between service providers. Primary healthcare providers in the absence of a palliative care service will also face many of the same issues.

### *Allied Health Support*

Allied health professionals are part of the interdisciplinary team that provide palliative care services to people at end of life. Allied health professionals work in partnership with patients and their families on their palliative journey, to help them find new options to improve the quality of their lives and to be able to do the things that are meaningful to them.<sup>34</sup>

There are limited allied health staff in dedicated palliative care positions in specialist units and in the community. This impacts on a patient's ability to maintain or slow down the rate of functional decline at the end of life when related to de-conditioning, their length of stay as an in-patient, and their ability to spend time in their preferred place of care, which is often at home.

There are also limited allied health staff working in the community. Allied health professionals in the community support people to stay at home for as long as possible in conjunction with community nursing and medical staff. There is currently a model of care project underway in Townsville investigating the impact of increased allied health staff (occupational therapy and physiotherapy) in the community and the impact on average length of stay of people in a specialist palliative care unit.

## 5 Palliative Care Workforce Issues

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### Professional Education

Ongoing, concerted professional education is required to ensure that the health workforce at all levels in Queensland is equipped, trained and competent to provide care to patients at end of life. Much work has been done to incorporate palliative care in undergraduate nursing degree programs, notably the work funded by Department of Health and Ageing, PCC4U and Queensland University of Technology.

PCC4U promotes the inclusion of palliative care education as an integral part of all medical, nursing, and allied health undergraduate and entry to practice training, and ongoing professional development. Many initiatives are in place to support scholarships and ongoing education in aged care, but palliative care specific education is still yet to be strongly targeted.

However not all courses incorporate palliative care as a mandatory subject, it is often an elective for certificate III courses which are the baseline qualification for all personal care workers/AINs, the group that provides the majority of end of life care.

The Centre for Palliative Care Research and Education (CPCRE) is currently working on a project to deliver core competencies for generalist nurses in palliative care and for advanced competencies for specialist nurses. Hopefully this work can provide a framework to ensure that standards of palliative care are promoted in every setting where palliative care is delivered; community, RACFs and specialist units.

### Building Workforce Capacity

The key feature of palliative care is that it is provided by a multidisciplinary team (MDT), resulting in truly holistic care which aims to maintain the patient's quality of life. Many different professionals contribute to the MDT. The role of informal carers and volunteers cannot be underestimated and there is a need to strengthen the role of volunteers in the system, without which the system in Queensland could not maintain the relatively high quality of care that it currently provides.<sup>35</sup>

### Doctors

According to Palliative Care Australia's guidelines, a minimum of 67 full-time equivalent specialist palliative care physicians are required to successfully meet the end of life care needs for a population the size of Queensland. Despite this, there are less than 22 full-time equivalent specialist palliative care physicians employed across the state.

In the Toowoomba Darling Downs Region, only one palliative care medical specialist working part-time (0.5 FTE) is employed to cover an area with a population of 300,000.

## Nurses

Workforce shortages in nursing are endemic, despite many strategies being suggested to resolve the issue, including increasing migration and training places, changing skill mix or nurses' roles, redesigning nursing work, and greater use of unregulated or unlicensed workers.<sup>36</sup>

Without significant change in approach to workforce development, Australia will continue to experience increasing demand for health care workers at a rate that will challenge Australia's training and service delivery systems'.<sup>37</sup>

Assessment of the national and state skill shortages identifies that Australia has a national shortage of registered nurses, with palliative care registered nurses being listed as professional groups in shortage in all states and territories of Australia except the Northern Territory.<sup>38</sup>

Palliative care is recognised as a speciality in nursing, but it is not mandatory for nurses working in the area to have specialist qualifications. An increasingly ageing population, and increased numbers of people affected by cancer and end stage chronic disease, presents a challenge for nursing services in relation to workload, workforce issues and the need to provide cost effective care. Palliative care nurses face major challenges in trying to provide quality palliative care in a healthcare environment that is experiencing widespread nursing shortages and inadequate funding to palliative care services.

Palliative Care Australia identifies that there is a low turnover of nurses in the sector. Although new recruits are being drawn into the available palliative care workforce pool, the long term risk remains that the overall growth in the available workforce may be insufficient to meet the needs in the future, particularly in the rural and remote communities.<sup>39</sup>

Table 9

Number and percentage of allied health professions in capital cities and rural and remote regions

| Allied Health Profession | Number       | Major Capital | Rural and remote (% of number) |
|--------------------------|--------------|---------------|--------------------------------|
| Dietitian                | 1996         | 1508          | 488 (24.4)                     |
| Hospital pharmacist      | 1713         | 1367          | 346 (20.2)                     |
| Occupational therapist   | 5339         | 3989          | 1350 (25.3)                    |
| Physiotherapist          | 10249        | 7679          | 2570 (25.1)                    |
| Psychologist             | 9318         | 7406          | 1912 (20.5)                    |
| Social worker            | 9108         | 6823          | 2285 (25.1)                    |
| Speech Pathologist       | 3006         | 2166          | 840 (27.9)                     |
| <b>Total:</b>            | <b>52388</b> | <b>39882</b>  | <b>12497 (23.9)</b>            |



### *Allied Health*

Optimal palliative care requires the support of a multidisciplinary team such as occupational therapists, physiotherapists, dieticians, speech pathologists, social workers and bereavement counsellors. All of which have a significant role within the team. Access to allied health in palliative care can be a challenge, especially in the rural and remote areas in Queensland.

In Australia little attention has been paid to allied health skills shortages, resulting in the poor development of studies of allied health recruitment and retention. The absence of the Australian Government to accept allied health as a standard component of the healthcare system has also contributed to this.<sup>40</sup>

Where people have no experience of a particular type of service, they will often be unaware of its potential benefits and may not express demand for it. It is therefore essential to raise awareness in rural and remote communities, about the roles of allied health professionals and their skills in palliative care.

### *Assistants in Nursing (AINs)*

In palliative care, the AIN workforce is frequently involved in providing supportive care at the end of life through Commonwealth funded programs in the community such as the Home and Community Care Program, Community Aged Care Program and Extended Aged Care Packages, as well as within RACFs. The workforce in these programs is predominately staffed by AINs, the issue in terms of palliative care being that most AINS are unskilled and ill equipped to effectively assess and manage distressing pain and other symptoms at end of life.

## 6 Palliative Care in Aged Care

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The average period of occupancy in a Residential Aged Care Facility (RACF) in Queensland is nine months, as a result, RACFs are now considered to be major providers of end of life care and are viewed as ‘modern day hospices’.

RACFs are poorly staffed, many with only one registered nurse qualified to provide complex assessments in relation to symptom management, caring for up to 120 patients. Registered nurses are usually supported by enrolled nurses and unlicensed AINS, the majority of whom lack sufficient training in palliative care to enable quality outcomes. GPs are the primary medical providers for RACF patients, many of whom have difficulty managing patients with complex symptoms as most have only basic training in end of life care.

The majority of patients in RACFs die of dementia and frailty related issues, many of whom experience severe symptoms in the lead up to death. In the majority of cases, specialist palliative care is not available to these patients, largely because local specialist palliative care services are inadequately resourced to provide specialist consultancy and ongoing professional education.

Although RACFs are Commonwealth funded and regulated, one significant issue for the State Government is the lack of funding available to provide dedicated consultative support to RACF residents with complex care needs. In the absence of specialist consultancy and support to manage complex symptoms, many will be admitted back into the acute sector at significant cost.

Palliative Care Queensland and Palliative Care Australia calls for:

- End of life care to be acknowledged as a basic competency for aged care workers (regardless of the setting in which they work) and included in the core curricula of aged care worker education and as an element of ongoing training;
- The development and implementation of nationally standardised referral criteria for patients with palliative care needs that promote needs-based service provision, supported by a national roll-out/education campaign;
- Aged care services, including residential aged care facilities, to develop and implement workforce and service development plans that acknowledge their end of life care responsibilities as part of needs-based service provision. This is likely to require increased levels of staffing with practitioners who can prescribe and administer pain and symptom management drugs;
- The introduction of systems for coordinating the management of pain and symptom relief for residents in residential aged care facilities that address limitations in who can prescribe and administer medication to ensure residents’ care needs are met in a timely and ongoing manner, and
- Full integration of the National Palliative Care Standards with the Aged Care Accreditation Standards.<sup>41</sup>

## 7 Paediatric Palliative Care

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Palliative care is provided to children who have a life limiting condition, which is generally defined as a condition that will cause the death of the child before that age of 18.

There are significant differences between adult palliative care and paediatric palliative care, including:

- The number of children who are dying, which is small when compared with the number of adults;
- Many of the individual conditions treated are extremely rare with diagnoses specific to childhood;
- Children may survive into early adulthood, or to the age of 18 and over;
- The time scale of children's illnesses is different; palliative care may last only a few days or months, or extend over many years;
- Many of the illnesses are familial, and as such, more than one child in the family may be affected;
- Care embraces the whole family;
- Care acknowledges the principle that a child needs to develop physically, emotionally and cognitively;
- Children's palliative care providers need to be aware of and responsive to each child's changing levels of communication, in order that the child understands their illness, treatments and prognosis and
- The provision of education and play when a child is sick.

### *Statistics*

There are approximately 1,200 children in Queensland with a life limiting condition, and all of these children will require a general paediatrician and general practitioner to oversee their care. It is estimated that half of these children with a life-limiting condition in Queensland will need access to palliative care services at any given time. This would include specialist palliative care services in regional and rural areas and the availability of hospital outreach nurses or community nurses.<sup>43</sup>

Approximately 400 – 500 children die in Queensland each year.<sup>44</sup> Over 25% of these are aged less than twelve months, indicating that there is a definite need to develop peri-natal palliative care services. The paediatric palliative care service currently receives seventy referrals each year.

Roughly one third of families would prefer children to die at home, one third in hospital and one third in a hospice facility. The figures estimated are the same for both Brisbane and other regional and remotes area.<sup>45</sup>

### *Services in Queensland*

Within Brisbane, a specialist paediatric palliative care service is available to consult on children living in the metropolitan area and those with complex cases outside of

Brisbane. Patients need to be attached to a local hospital where they can be admitted for symptom management and inter-current illness.

Within Brisbane, there are community service providers who have expertise in paediatrics and providing palliative care to children, including Xavier Children's Support Network and Hospital in the Home based at the Mater Children's Hospital.

Other generalist community services across Queensland support paediatric palliative care patients in the community; however these community providers predominantly care for adult patients, so they are usually supported by the specialist paediatric palliative care service.

### *System Issues*

The process of hospitalisation needs to be streamlined, including fast-tracking through the emergency department and further changes to ensure that hospitalisation processes are made as family friendly as possible, including flexibility with visiting rules, assistance with parking and transport and allowing hospital rooms to become as home-like as possible.

A holistic approach is required as some children will require legitimate extended stays in hospital related more to the burden of care of their life-limiting condition, than to the acute medical problem they are presenting with.

A lack of flexibility can result in children receiving little or no care if they do not 'fit in', therefore intake criteria for children need to be flexible and inclusive rather than exclusive. Health professionals need education on providing flexible and individualised care to each child.

The Mater Children's Hospital has established a Complex Care Service and the Royal Children's Hospital has a Paediatric Palliative Care Service to try and meet this need for children with life-limiting conditions. Although there is good collaboration between these two services, the needs of families are often quite great and cannot always be met. Further, there can be a discrepancy in care provided to children who are referred to these services and those who are not.

### *Model of Care*

There is a need for a multi-disciplinary hospital consultation service with health professionals who have formal training and qualifications in paediatric palliative care, operating as either a PCA level three service or at level six on the Queensland Clinical Services Capability Framework.<sup>47</sup> Such a service requires sufficient staff numbers of all disciplines to enable best practice care, including specialist service provision and education, allowing for sustainability by planning for backfill for leave and succession planning.

This service needs to provide support to the teams at both the Mater and Royal Children's Hospital, and also to other hospitals located throughout the state as required.

A home consultation service can be provided within a certain geographical catchment or by videoconferencing to other hospitals. Such a consultative service also needs to be integrated within the new Queensland Children's Hospital.

### *Respite*

There is a limitation to the amount of respite available to children due to the complexity of care of some children's needs and funding limitations, making it difficult to find suitable carers. Some families prefer in-home respite while others will prefer out of home respite.

It can be difficult to provide emergency respite to children and their families although a sub-acute bed stream has increased the Royal Children's Hospital's capacity to provide short break care since July 2011. Nevertheless, there is a lack of out of home respite facilities for children, hence the provision of routine and elective out of home respite is often not possible.

### *Paediatric Hospice Services*

There is a need to re-build bridges post 'Zoe's Place'. This includes consideration of a paediatric hospice in South-East Queensland, working collaboratively with Queensland Health and other service providers. This service needs the capacity to provide out of home respite to families, both routine and emergency, and a third option for families to care for their child at the end of life.

### *Coordination*

It can be difficult for families to negotiate the health care system, as each child and family has unique needs and multiple agencies are often required. It is difficult for families to access information about all of these agencies and service providers with ease. It is also challenging to ensure that the different service providers involved are providing co-ordinated care.

### *Non-Cancer Patients*

While the Paediatric Palliative Care Service provides care to more non-cancer patients than cancer patients, there are more gaps in care for non-cancer patients. The preferred model of care should include provisions for children with cardiac, metabolic and neurological conditions.

There is also a need for an after hours telephone support service for both cancer and non-cancer patients.

### *Disabled Patients*

There is a need for a specific model of care for disabled patients. This requires a co-ordinated and cross-departmental response for these children from Queensland Health, Disability Services Queensland and Education Queensland. Although such a response is achieved for some cases, a more systemic approach is required in order to achieve the most suitable outcomes for all children with both a disability and life limiting condition.<sup>48</sup>

### *Bereavement Support*

In 2010, due to resource constraints, the Children and Young People's Bereavement Service at St Vincent's Hospital closed due to lack of funding. While bereavement services have been established at the Royal Children's Hospital and Mater Mother's Hospital, there is a need to grow these services to keep up with demand. There is also a need to collaborate and support non-government providers of these unique services for children, such as Paradise Kids on the Gold Coast.

### *Workforce*

The specialist paediatric workforce is small, and as such, key sustainability issues such as back-fill for leave and succession planning, must be taken into account when formulating models of care.

There is also a need to develop allied health expertise in palliative care in the disciplines of pharmacy, physiotherapy, social work, psychology, occupational therapy, nutrition, music therapy and other expressive therapies such as art therapy.

Direct funding for palliative care services needs to be available to support both professional development and post-graduate education, as well as research initiatives in the area of allied health. It is also important to up-skill generalist clinicians whose primary role is to provide care to adults.

Pastoral care is a key component of service delivery and there is a need for this discipline to become funded rather than voluntary.

### *Funding*

Funding for community service providers needs to be available to support children and families receiving palliative care in their home. As community providers predominantly care for adult patients, when they receive paediatric referrals, they must be funded appropriately and have the support of a specialist paediatric palliative care service in order to provide safe and effective care.

Difficulties exist for families accessing support from Disability Services Queensland. This in part relates to trying to distribute limited funding equitably to a large number of clients. While a new central intake process has attempted to streamline the process for families, it has resulted in delays in children receiving assessment and then in children ultimately receiving funding for respite and equipment. This process can be slow and cumbersome.

Equipment needs and care, such as respite in the home, can be very expensive for disabled children. It is important that disability services and the Medical Aids Subsidy Scheme (MASS) is responsive to these children's needs and provides equipment and services in a timely manner.

A flexible funding option for children with life limiting conditions, which can both complement and enhance any existing funding arrangements without causing other funders to withdraw, is critical.

### *Technology*

A key area of research in paediatric palliative care in Queensland relates to the use of technology, particularly online health, to support families and healthcare providers. This work has been undertaken within the University of Queensland's Centre for Online Health.

## 8 Raising Awareness of End of Life Issues

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Queensland is similar to the majority of other Australian states and international jurisdictions, in that a culture exists that denies death, including reference to or open discussion of death, dying and terminal illness. Our modern society seems to have shunned the notion that death is normal and natural, instead embracing the concept that we must fight to hold onto life and seek to cure illness wherever possible, despite the huge personal or economic costs that almost always result.

End of life issues and end of life decision making are concepts that all Queenslanders must confront at some point in the trajectory of their own lives. Whether we are caring for an ageing parent, supporting a chronically ill relative, or even confronting a life-limiting illness of our own, it is vital that at some point, we all contemplate and plan for our own end of life.

Planning ahead for our own end of life, is far more likely to result in our wishes and goals being acknowledged, respected and implemented. It is also more likely to result in an overall cost saving to the health care system, as many people's choice at the end of life is to avoid futile and uncomfortable treatments that are often very expensive.

Raising awareness of end of life issues is a challenging task, and one that has not been implemented in Australia as successfully as many of the experts believe. Although the Commonwealth Government funds the annual National Palliative Care Education Initiative, much of which focuses on the promotion of advanced care planning, there is little evidence that this initiative is changing behaviour and leading to more Australians discussing or planning for their own end of life.

A major report commissioned by Queensland Health in 2009 recommended that a community awareness and advance health directive awareness project should be funded and implemented across Queensland. The report also recommended that such a project be offered in all areas and at all levels of health care.<sup>49</sup>

### Advance Care Planning

In line with the National Palliative Care Strategy, *Living Well at End of Life for all Australians*, advance care planning (ACP) is highlighted as a national priority for roll out. Every Australian and every Queenslanders should be given the opportunity to participate in an ACP discussion around future health care choices which may include completion of an Advance Health Directive, discussion around organ donation and or life-sustaining interventions such as CPR, ventilation, dialysis, use of antibiotics at end of life.

To complicate this national priority, there are a diversity of options, even here in our own state of Queensland. Queensland Health developed the Acute Resuscitation Plan (ARP) and a version of ACP. The Queensland Advance Health Directive (AHD) is also available but not widely used. There are also other individual organisations,



private and public, that have introduced versions of ACP, including Austin Health's, Respecting Patient Choices. These documents are still not accepted by all emergency service providers such as the Queensland Ambulance Service.

Evidence and research support the fact that ACP can empower clients with life-limiting illnesses and their families, as early discussion and planning for end of life choices can provide vital information that can aid decision making in a timely manner. Promotion of ACP within all health services, particularly palliative care, is essential. Despite this, ACP is not recognised in Community HACC service provision as an activity worthy of funding. The benefit to clients and families is indisputable, and the potential cost saving clear and undisputed.

Palliative Care Queensland recommends that ACP be considered as an integral and essential component of palliative care service provision, and funding made available to promote ACP in the community.

Further, we recommend that National legislation be developed that would further support the likelihood that ACP and AHDs would be respected across all levels of the health continuum, promoting an individual's right to accept or refuse treatment. This would include an assurance that AHDs, including a substitute decision maker's authority, would be regarded as valid and subsequently respected in all Australian jurisdictions.

## 9 Other Issues

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### Data Collection

In order for governments and the palliative care sector to strategically plan palliative care services, education and research into the future, it is vital that accurate and current data is available to inform the decision making and policy formation processes.

Palliative Care Queensland recommends the need to mandate both the PCOC and NSAP, as well as engagement in benchmarking and peer mentor review processes for continuous quality improvement and accreditation of services providing palliative care.

Review of the mechanisms used at State and Federal level for collecting general population type data relating to mortality and morbidity, may also need to be modified in order to allow for the easy identification of place of death and other key variables at the end of life. Such basic changes could include the amendment of the death certificate in Queensland to enable the collection of more robust data in relation to place of death; home, public or private hospital, residential aged care facility or hospice.

### Electronic Health Records

One of the most difficult operational aspects of providing quality assessment and symptom management, is the ongoing difficulty accessing information regarding a patient's condition and treatment, in order to plan care and respond to the needs of patients who are dying, rapidly and easily. Further, given the growing trend for multiple agencies to share care, there is often a duplication of information, because each organisation maintains and works from separate documentation.

At an individual level, it can also be very challenging sharing information with multiple health professionals and agencies, and being clear about your end of life wishes and advance care planning requirements, because every individual service or professional needs to be familiar with your Advance Health Directive. In Queensland, in order to be confident that your end of life wishes are likely to be implemented by health services, copies of your Advance Health Directive need to be supplied to your GP, primary care providers, treating hospitals, specialists and community agencies. This means that every one of these clinicians and agencies must have a copy on hand that is easily available if required, often during a clinical emergency.

Palliative Care Queensland strongly supports the concept of well controlled, easily accessible electronic patient records. We believe that such records will enable critical clinical information specific to end of life, in particular advance care planning, to be more easily available to clinicians and agencies when required across the health continuum.

## Quality and Safety

Palliative Care Queensland and Palliative Care Australia believe that all Queenslanders have the right to safe, compassionate and appropriate care as they approach the end of their lives. Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist, and support care providers and the community, working together to meet the needs of all people.<sup>50</sup>

Funding requests for all services, including community-developed services, should be subject to:

- rigorous needs and cost-benefit analyses;
- assimilation with strategic plans at the regional, state/territory, and national levels, and
- broad consultation.

To meet the needs of people at the end of life, their carers and families, service providers should meet minimum staffing requirements, as per relevant state/territory and industry standards.

All publicly and privately funded services providing care to people approaching the end of life, including community-developed and funded services, should:

- Meet the requirements of the national palliative care standards;
- Be formally accredited by a recognised accreditation body, and
- Conform to the Australian Health Standards as proposed by the Australian Commission on Safety and Quality in Health Care (ACSQHC).

## Funeral Industry Issues

In February 2012, Palliative Care Queensland held a forum to examine some of the major issues faced by health professionals and consumers of palliative care services in the community following a death at home. Over many years, key issues had been brought to the attention of Palliative Care State Council relating to the behaviour of funeral director personnel, as well as the Queensland Police Service (QPS) and the Queensland Ambulance Service (QAS).

Some of the issues raised over the last few years have included:

- QAS personnel frequently failing to acknowledge or recognise the validity of official forms, including Advance Health Directives;
- QAS attempting resuscitation on deceased patients who were expected to die of a terminal illness, against the wishes of families and palliative care providers;
- Families suffering severe stress and requiring bereavement counselling after watching loved ones being resuscitated unnecessarily;
- In the absence of clear information and documentation, QPS treating the homes of those who have died from anticipated deaths as crime scenes;

- Funeral directors failing to acknowledge individual needs, insisting on following protocols that may not be relevant to the context and which may overly stress the family and complicate the burial process;
- Despite the fact that there is no legal requirement for a 'life extinct' form to be completed before a body can be collected by a funeral director, most funeral directors continue to insist that a 'life extinct' form must be completed before the body can be removed from the home;
- Stressed family members call either the ambulance service or police service when someone dies, rather than the palliative care service, resulting in either resuscitation or the home being treated as a crime scene;
- After hours, there can be significant difficulty locating a clinician to sign a life extinct form, and if QAS personnel are called, they will only pronounce/certify death after performing an ECG;
- At the time of death, because some family/relatives question/argue who has control in relation to treatment and care, health professionals and service providers become confused and are less likely to respond/provide care according to contextual need, and are more likely to engage a risk management framework to minimise risk to themselves or the organisation they represent;
- In some instances, patients/bodies or relatives have not been treated respectfully;
- Although there is no specific time limit on the collection of bodies (however environmental and practical issues such as heat and humidity may have an impact on the body), funeral directors have insisted that there is a time limit, in some instances removing deceased family members before families have had sufficient time to grieve, and
- There has been confusion over the variations in forms used at end of life in the community. Current forms include:
  - Expected Death Form (EDF)
  - Acute Resuscitation Form (ARF)
  - Life Extinct Form (LEF)
  - Advance Health Directive (AHD)
  - Death Certificate
  - QAS – DNR form

## Young Care

Currently more than 7,500 young Australians under the age of 65 with full-time care needs are living in aged care simply because there are few alternatives.<sup>51</sup> There are also 700,000 more young Australians being cared for at home by family and friends, often with limited support, many of whom are suffering from a terminal or life-limiting illness.<sup>52</sup>

Palliative Care Queensland believes that greater attention should be directed towards this population in Queensland. All future models for funding and service provision must recognise the need for end of life care and specialist palliative care for those between the ages of eighteen and sixty five.

## 10 Recommendations

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### TOR 1

#### Adult Palliative Care issues

- Improved access to specialist palliative care, irrespective of diagnosis or prognosis for all patients and their families facing end-of-life issues (last 12 months of life).
- 24 hour community care with access to specialist palliative care services when needed is seen as a basic standard.
- Adequate funding for multidisciplinary consult teams in all hospitals with more than 300 beds (and access by smaller hospitals to these teams).
- All advanced disease outpatient clinics and care planning meetings to have a specialist palliative care physician and nurse attending.

#### Paediatric issues

- Improved access to palliative care for children, including the development and funding of a children's hospice/respite facility in South East Queensland.
- Improved access to counselling and bereavement support, including the establishment of a designated counselling and bereavement service for children and young adults.
- Additional respite support for the families of children and young adults with terminal illnesses.
- Regular up skilling of clinical staff (paediatric palliative care issues) in regional adult palliative care services.

### TOR 2

#### Coordination

- The development and implementation of a state-wide service plan for palliative care in Queensland that can ensure 24 hour access to high quality needs based palliative care to all patients and families regardless of age, diagnosis, culture, location, setting or socio-economic status.
- Development and utilisation of an effective and efficient model for providing palliative care, including the care of children and young adults, and which recognises the rising demand for palliative care services, equipment and consumables.
- Establishment of a dedicated palliative care policy and development team within Queensland Health's corporate office.
- Establishment of a stand-alone state-wide palliative care clinical network that can engage all clinicians working in palliative care to help provide equitable, state-wide palliative care access to all Queensland patients and their families.

## Access

- Improved access to counselling and bereavement support, including a designated counselling and bereavement service for children and young adults.
- Additional respite support for the families of children and young adults with terminal illnesses.
- Greater access to specialist palliative care for patients with non-cancer illnesses such as frailty and dementia, Motor Neurone Disease, heart failure and respiratory disease.
- Improved access to specialist palliative care for regional, rural and remote patients.

## Workforce

- Adequate provision of allied health services: pharmacy, OT, physiotherapy and pastoral care for all level 4-6 palliative care services across the state.
- Implementation of a coordinated plan to up-skill and increase the specialist palliative care workforce, including a brief to focus on up-skilling and building the capacity for generalist service providers across all settings to provide end of life care.
- Ensuring that appropriately skilled and experienced clinicians are available when and where required using a formal regionalised framework that decreases the risk of burnout and provides consistently high quality care for complex patients and their families.

## Funding

- Quarantining a specific allocation or percentage of National Partnership Agreement sub-acute funding to palliative care.
- Equitable distribution of the National Partnership Agreement subacute funding, including the allocation of \$81M or 25% of the total Queensland allocation of NPA funding to the palliative care sector in Queensland between 2010 and 2014.
- That all service agreements between the Systems Manager and the Hospital and Health Service (HHS) contain a clear section on the need for an HHS to:
  - Develop an end of life strategy for the last twelve months of life;
  - State clearly what amount of palliative care services will be purchased and measured by the 'systems manager' in Queensland, and
  - That clear purchasing intent measures are set up to purchase less acute care and more subacute/palliative care in the population of patients facing the last 12 months of life. This end of life care should be flexibly purchased in consultancy-liaison, community and inpatient settings.

## TOR 3

- Development of a state-wide end of life care strategy for Queensland for the last 12 months of life.
- Development of a state-wide community awareness campaign to educate Queenslanders about palliative care, death and dying in order to promote effective decision making at end of life.
- Promote the uptake of advance care planning, Advance Health Directives Enduring Power of Attorney and “preferred place of care” documents in Queensland.
- Queensland Ambulance Service to act consistently with regard to Advance Health Directives and Advance Care Planning documents and requests.

## TOR 4

- Palliative Care Program funding can be used alongside HACC services when required.
- A more flexible, person-centred, based on assessed need, funding model, should be developed so that all Palliative Care Registered patients are entitled to a “flexible funding package” to fund care, family support or equipment in the best setting to meet patient and family needs.

## 11 Conclusion

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Since its establishment as a health specialty in Queensland in 1988, palliative care has developed into a very sophisticated treatment option that has allowed thousands of Queenslanders to experience dignified and comfortable deaths. A growing scientific evidence base, together with well trained multidisciplinary clinical teams, now allows patients and families affected by terminal illnesses to achieve quality of life when time is often very limited.

Poor coordination, a failure of politicians and bureaucrats to see palliative care as a priority and limited and competitive funding, have meant that palliative care has not been delivered effectively across Queensland. All Queenslanders do not have access to the services and supports they need to guarantee dignity and comfort at the end of life, and many suffer needlessly uncomfortable deaths as a result.

Once considered a normal process, dying has now been pushed aside as an unwelcome outcome, replaced instead by a philosophy that values quantity of years and cure over quality of life. Acute medical and critical care wards are now the places where we can expect to die, often following prolonged and agonising cure focussed treatments that are expensive and often futile.

Clinicians and the system itself quite often fails to acknowledge when patients are dying, and to respond appropriately and effectively as a result. As such, there is now a growing belief that if accessed early enough, palliative care can improve quality of life and reduce costs in the last year of life.

Health economic rationalisation is one of the precipitating factors that has led to the latest exploration of the capacity of the palliative care sector in Queensland. Politicians and key bureaucrats, faced with a growing burden of chronic disease, a rapidly ageing population and a generation of baby boomers who have high expectations in relation to end of life care, now look to the palliative care sector to solve a myriad of 'whole of society' and 'whole of healthcare system' problems.

Reorienting the culture of our community and our health professionals to see death as a normal and natural occurrence, is the first step to achieving better outcomes for all Queenslanders affected by terminal illnesses. We need to raise awareness of palliative care and early referral, we need to talk about death and dying, and we need to plan for our end of life just as we would our career or retirement.

We also need to grow and educate our health workforce so that we have appropriate numbers of adequately trained generalist and specialist clinicians, all of whom are sufficiently resourced and educated to provide best practice palliative care, and all of whom understand that end of life care is core business.

Queensland needs to develop a model of palliative care that can meet its own unique demographic and geographic needs. A collaborative model that is needs based, and one which enables access to all regardless of location, age, diagnosis,



culture or socio-economic status. Whether dying at home, in an aged care facility or in a general hospital, quality palliative care should be made available to all Queenslanders.

The system itself also needs to be restructured to allow palliative care to be delivered in a more coordinated and equitable fashion. We need to look to the examples set in other Australian jurisdictions and New Zealand; developing a coordinated state-wide plan with set time lines for palliative care. Such a plan also needs to be implemented by a dedicated Queensland Health funded team in consultation with a statewide palliative care clinical network, and supported by an effective, equitable, transparent and well monitored funding model.

Funding for palliative care at all levels needs to be increased, and all Commonwealth funds quarantined to support the current and future needs of the palliative care sector.

We also need to ensure that all palliative care clinicians and services deliver care according to the thirteen national standards, and that all services participate in standards assessment and data collection programs that allow for benchmarking, peer mentoring and continuous quality improvement.

Education and research are priority areas that, if coordinated and funded appropriately, have the capacity to improve sustainability, increase capacity and promote quality of care.

In essence, Queensland is now faced with a rare opportunity to transition from being one of the most ineffective to one the most effective states for providing palliative care. We have a unique chance to change the way we think about and plan for death, and to develop new and more effective end of life focused policies and processes.

Policies and processes that have the potential to radically reduce the healthcare costs associated with the last year of life, whilst vastly improving the quality of life experienced by dying Queenslanders and their families.

## Appendices

### Appendix 1: Draft concept - Brief Regional Consortia & HHS Palliative Care Hub Proposal (based on population, geography and indigenous demographic profiles)



Potentially **8 Specialist Palliative Care Regionalised Consortia/Hubs** - PC CSCFv3 Level 4/5/6 + Generalists and Level 1-3 Specialist Consortia (these Consortia/Hubs may contain 1-4 Level 4/5/6 Services within their region, based on population size, geographical area, remoteness and demography –age, SES status, Indigenous and CALD population profiles; e.g. per 300,000 population or per 150,000 sq. KM, per 10-20,000 Indigenous, CALD, low SES and >70y pop. etc. Vic PCRAM needs to be analysed as a possible equitable population-based PC funding methodology). Level 4/5/6 Consortia/Hubs must be funded and required to provide community outreach, up-skilling to all generalist EoL Care and Level 1-4 Specialist Pall Care providers in their defined region (direct or via video-link/web-based platforms).

| Hospital and Health Service (HHS)    | Current population | Predicted population 2021                         | Geography: Square KM covered | Indigenous population in 1,000s (%HHS) (%total Queensland) |
|--------------------------------------|--------------------|---|------------------------------|--|
| Cairns                               | 250,000            | 280,000   | 142,000                      | 25.5 (10.2%)(15.6%)  |
| Torres Strait and Northern Peninsula | 11,000             | Marginal increase                                 | Large + TS Is.               | 9.1 (83.4%) (5.8%)   |
| Cape York                            | 13,000             | Marginal increase                                 | 156,000                      | 6.8 (52.6%) (4.5%)   |
| Townsville                           | 240,000            | 290,000   | ?                            | 17.2 (7.2%) (10.3%)  |
| North West                           | 34,000             | Decrease by 4%                                    | 240,000                      | 8.7 (>25%) (5.5%)  |
| Metro North                          | 900,000            | >1,000,000  | 4,157                        | 14.4 (1.6%) (8.7%)   |
| Metro South                          | 1,000,000          | 1,200,000   | ?                            | 20 (2%) (12.7%)  |
| Mackay                               | 185,000            | 230,000   | 69,000                       | 7.7 (4.2%) (4.5%)  |
| Central Queensland                   | 225,000            | 260,000   | (+Whitsundays)               | 11.7 (5.2%) (7.1%)   |
| Central West                         | 12,000             | Marginal increase                                 | 114,000                      | 0.84 (7%) (0.6%)   |
|                                      |                    |   | ?                            |  |
| Darling Downs (Toowoomba)            | 300,000            | 340,000   | ?                            | 10.8 (3.6%) (11.3%)  |
| West Moreton (Ipswich)               | 220,000            | 330,000<br>(largest rate of growth in Queensland) | ?                            | 7.9 (3.6%) (11.3%)   |
| Gold Coast                           | 540,000            | 680,000   | ?                            | 6.5 (1.2%) (3.8%)  |
| South West                           | 26,000             | Marginal increase                                 | 319,000                      | 3.1 (12%) (2.1%)   |
| Sunshine Coast                       | 390,000            | 480,000   | ?                            | 5.9 (1.5%) (3.5%)  |
| Wide Bay                             | 220,000            | 260,000   | ?                            | 6.6 (3%) (4.1%)  |

**N.B.**

**For patient safety reasons and to meet service level capabilities as outlined:**

Level 5/6 Cancer Services need a Radiotherapy Service + a Level 5/6 Palliative Care Service.

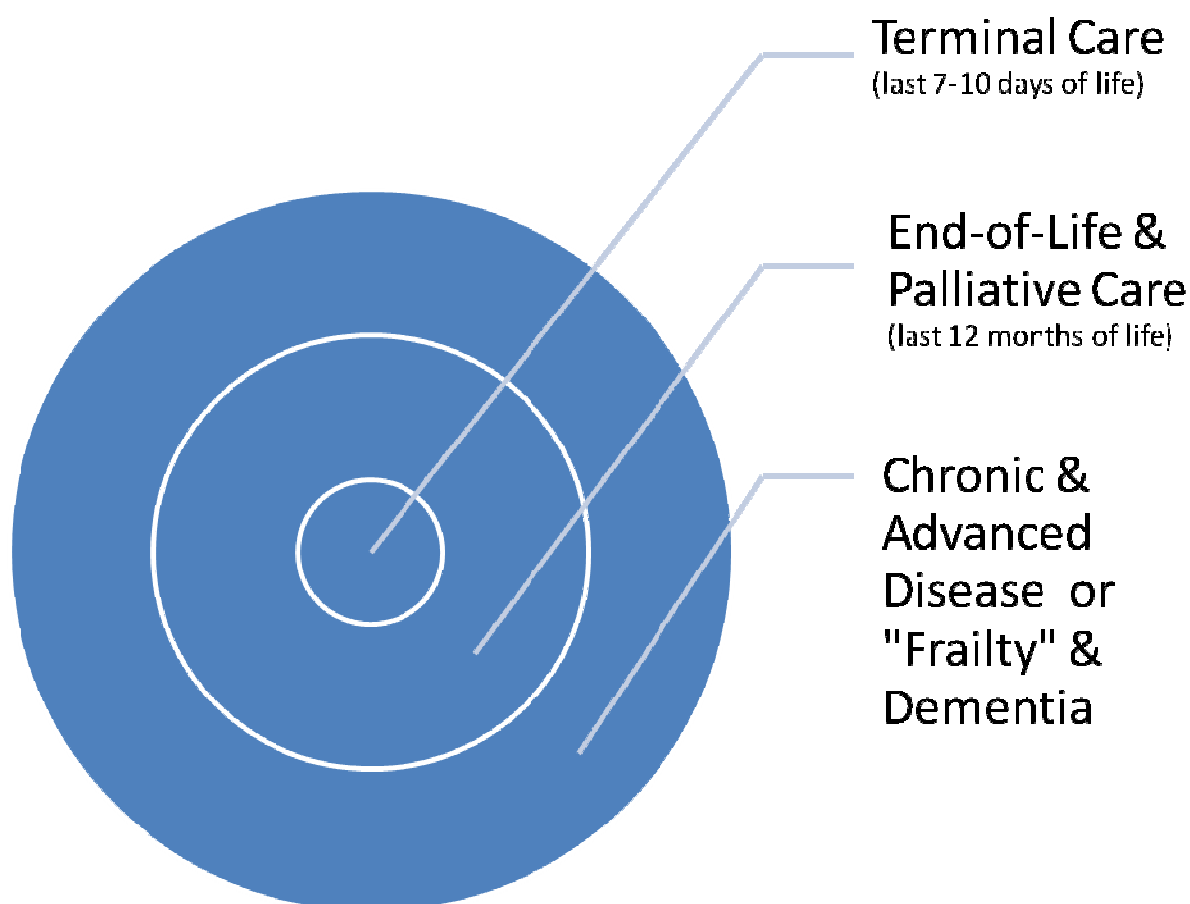
**To be safe and meet service level capabilities as outlined:**

Essential Ancillary **Medical Services** needed for all Level 5/6 Palliative Care Services are - Level 5 Cancer, Radiotherapy and Interventional Pain Management Services.

So, **Cancer Centres, Pain Centres** and Level 5/6 Regionalised Palliative Care Service Consortia/Hubs need to be co-located and have defined service provision, specialist workforce development, up-skilling and generalist capacity building responsibilities plus clearly defined on-call advice areas that they cover

1. How can this be achieved across 17 HHS's?
2. How will this be rolled out via the Statewide Paediatric Service in terms of sharing and up-skilling the available Adult Palliative Care infrastructure?

**Appendix 2:** Are Seamless Transitions through Health Care paradigms and across health care settings based on need possible in the last few years of life?

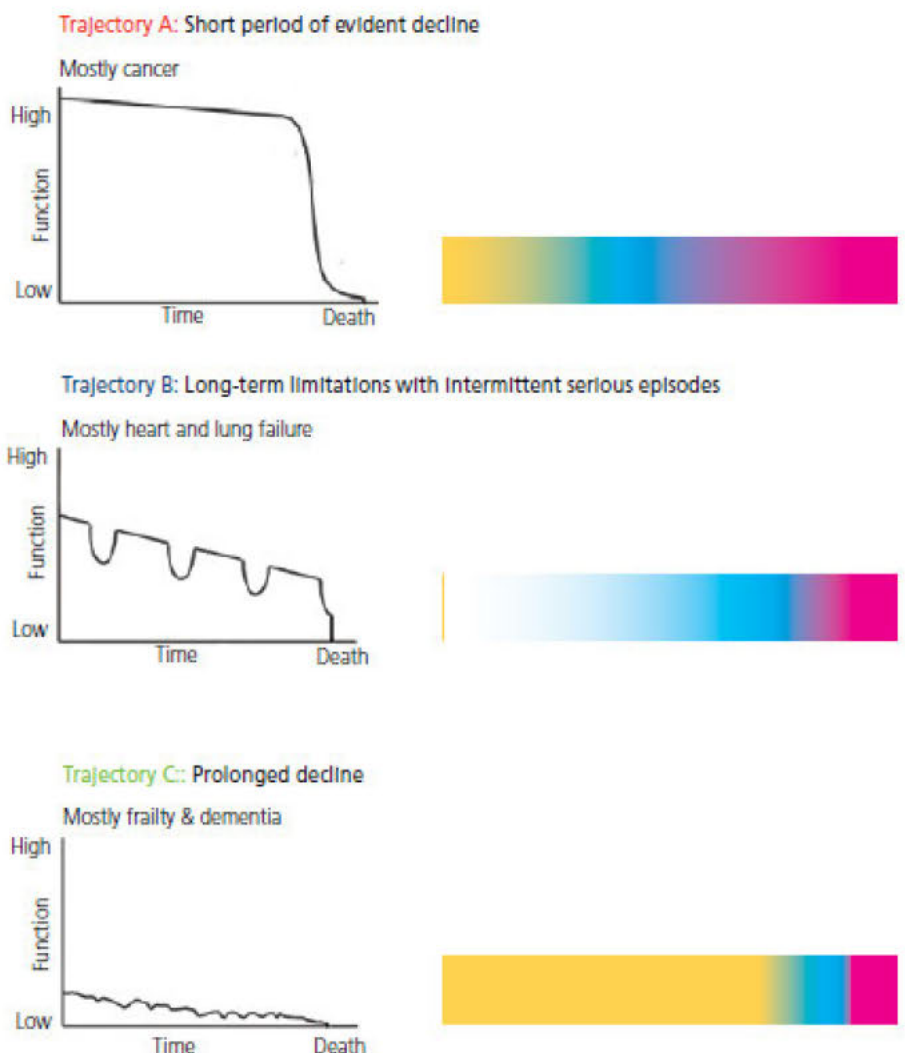





**The funds needed to fund Specialist Palliative Care are already largely being spent inappropriately in the acute care sector:**

More than 60% of patients want to die at home and be cared for out-of-hospital in the last several months of life. However, 60% of people die in hospital transitioning through Emergency Departments to acute care beds and many are not cared for by healthcare providers who have even up-skilled in end-of-life care. Even fewer patients are able to access Specialist Palliative Care Services (especially if they have a non-cancer diagnosis or live in a "nursing home"). Many G.P.s and other non-Palliative Medicine Specialists need urgent up-skilling in end-of-life care. However, education and building generalist capacity for skilled end-of-life care is rarely funded as an essential part of Specialist Palliative Care activity.

**Appendix 3 - Functional decline Vs Time patient trajectories: (extracted and adapted from S.A Palliative Care Services Plan 2009-2016)**

**Figure 3**  
Relationship between the specialist-generalist continuum and trajectories



|   |  |
|---|--|
|  | EoL care provided by generalist providers without assistance from specialist providers of palliative care  |
|  | EoL care led by non-pall care specialists or generalists with some level of continuing or episodic direct input from specialist providers of palliative care |
|  | EoL care led by specialist providers of palliative care on an episodic or ongoing basis  |

**Appendix 4 – Queensland Sub-Acute Funding Allocations (General)**

This information was obtained from Senate Estimates, and was not freely provided by Queensland Health.

**COAG 2010 - Qld Allocations of Subacute Funding (Palliative Care V Sub-Acute Areas)**

|  | <b>\$ Million</b> |
|--|-------------------|
| Palliative Care (9.3%)   | 30.52             |
| Rehabilitation, Geriatric Emergency Management Services, Psycho-Geriatrics (90.7%) | 296.63            |
| <b>Total Subacute Funding</b>  | <b>\$327.15</b>   |

**Appendix 5 - NPA operational funds allocation over 3 years and calculated at per year rate**

This information was obtained from Senate Estimates, and was not freely provided by Queensland Health.

| <b>COAG 2010 - Qld Allocations of Subacute Funding</b>  |  | <b>\$Million total 3 years/1 year</b> |
|---|--|---------------------------------------|
| <b>Palliative care</b>  |  |                                       |
| <b><i>Metro South</i></b>   |  |                                       |
| Queen Elizabeth II Hospital: 10 beds —  |  |                                       |
| Queen Elizabeth II Hospital- Capital funds  |  | \$4.00                                |
| Queen Elizabeth II Hospital- Operational funds  |  | \$8.46 / 2.82                         |
| Redlands- Operational funding for 10 beds at aged care facility                                 |  | \$5.90 / 1.97                         |
| <b><i>Children's Health</i></b>   |  |                                       |
| Royal Children's Hospital - Operational funds for estimated paediatric pall care service at RCH |  | \$3.37 / 1.12                         |
| Royal Children's Hospital - Capital funding for 4 paediatric beds                               |  | \$0.50                                |
| <b><i>West Moreton</i></b>  |  |                                       |
| Ipswich Heart Failure Palliative Care Program in the home - Operational funds                   |  | \$0.64 / 0.213                        |
| <b><i>St Vincent's Hospital</i></b>   |  |                                       |
| St Vincent's - Subacute services includes GEMS, Rehab and Palliative Care 1/3 of Total \$9.44M  |  | \$3.15 / 1.05                         |
| <b><i>Community Services Unit Qld Health</i></b>  |  |                                       |
| Qld Health Community Services Unit - funding for additional palliative care to NGOs             |  | \$4.50 / 1.5                          |
| <b>Total NPA funding used for palliative care (3 years/ 1 year)</b>                             |  | <b>\$30.52 / 10.17</b>                |

**Appendix 6: Estimated Palliative Care Funding for Qld. 2012-2013**

These figures include include Commonwealth NPA funds available until July 2014 (averaged to give a yearly budget)

| <b>Hospital &amp; Health Service</b>                      | <b>Population estimates<br/>(2012)</b> | <b>New NPA Funds<br/>operational budget<br/>allocations only for<br/>2011-2014/yr equivalent<br/>(\$million)<br/>(obtained under RTI by PCQ)</b> | <b>Total Pall Care funds QH +<br/>NPA (\$million)</b> | <b>Pall Care funds/ \$head<br/>population</b> |
|---|--|--|---|---|
| Cairns & Hinterland                                       | 250,000                                |  | 6.35  | 25.40   |
| Cape York   | 13,000                                 |  | 0.12  | 9.23  |
| Central Qld.  | 225,000                                |  | 3.4   | 15.11   |
| Central West  | 12,000                                 |  | 0.15  | 12.50   |
| Darling Downs   | 300,000                                |  | 3.2   | 10.67   |
| Gold Coast  | 550,000                                |  | 7.31  | 13.29   |
| Mackay  | 185,000                                |  | 1.34  | 7.24  |
| Metro North   | 900,000                                |  | 12.89   | 14.32   |
| Metro South<br>(includes Mater & St. Vincent's Pall Care) | 1,000,000                              | 5.84   | 17.3 + 5.84 = <b>23.14</b>                            | 23.14   |
| North West  | 34,000                                 |  | 0.36  | 10.59   |
| South West  | 26,000                                 |  | 0.36  | 13.85   |
| Sunshine Coast  | 390,000                                |  | 5.32  | 13.64   |
| Townsville  | 240,000                                |  | 3.07  | 12.79   |
| Torres Strait Northern<br>Peninsula                       | 11,000                                 |  | 0.05  | 4.56  |
| West Moreton  | 220,000                                | 0.213  | 3.07 + 0.213 = <b>3.28</b>                            | 14.91   |
| Wide Bay  | 220,000                                |  | 3.07  | 13.95   |
| Children's Health Qld.                                    | ?                                      | 1.12   | 0.37 + 1.12 = <b>1.49</b>                             | ?   |
| Community Services<br>purchasing (state-wide)             | ?                                      | 1.5  | 0.03 + 1.5 = <b>1.53</b>                              | ?   |
| <b>TOTAL for whole of state</b>                           | <b>4,356,000</b>                       | <b>8.67</b>  | <b>69.14 + 8.67 = 77.81</b>                           | <b>17.86 (state average)</b>                  |



**Appendix 7: - Expected Adult Palliative Care Bed estimates for each HHS**

- Qhealth uses a weighted population (we use **x1.3** weighting vs state overall benchmark used = **x1.6**) and assumes 20% of Pall Care occurs in Private sector beds - irrespective of presence or absence of Private Pall Med Physicians in HHS;
- PCA uses 6.7/100,000 non-weighted population and makes no delineation for Private or Public sector beds (so to compare projected deficit we have similarly assumed 20% private usage and Specialist Palliative Care serviced).
- Estimated populations for 2016 are based on ABS & Qld. pop. statistics

| HHS                                | Current population (000's) 2012 | 2012 weighted population x1.3 (000's) | PC Beds QH Benchmark (4.9/100,000 weighted pop./ 3.9 public) Assumes 20% private take-up) | PC Beds PCA Benchmark (6.7/100,000 public & private) / (if assume 20% private take-up the public = 5.4/100K)) | Current known <u>Public</u> Pall Care designated beds/<br><b>Deficit (below benchmarks) or Positive (above benchmarks) (QH-PCA)</b> | Projected 2016 approx. population (000's) | Weighted 2016 population x1.3 (000's) | PC Beds QH Benchmark (4.9/100,000 weighted pop./ 3.9 public) | PC Beds PCA Benchmark (6.7/100,000 public & private) |
|------------------------------------|---------------------------------|---------------------------------------|---|---|---|---|---------------------------------------|--|--|
| Cairns & Hinterland                | 250                             | 325                                   | 16 / 13   | 17 / 14   | ?0 or 10 / ?13-17 or 3-4  | 265                                       | 345                                   | 17 / 14  | 18   |
| Cape York                          | 13                              | 17                                    | 1 / 1   | 1 / 1   | 0 / 1-1   | 13  | 17                                    | 1 / 1  | 1  |
| Central Qld.                       | 225                             | 293                                   | 14 / 11   | 15 / 12   | 9 / 2-3   | 243                                       | 316                                   | 16 / 12  | 16   |
| Central West                       | 12                              | 16                                    | 1 / 1   | 1 / 1   | 0 / 1-1   | 12  | 16                                    | 1 / 1  | 1  |
| Darling Downs                      | 300                             | 390                                   | 20 / 15   | 20 / 16   | 4 / 11-12   | 320                                       | 416                                   | 20 / 16  | 21   |
| Gold Coast                         | 540                             | 702                                   | 34 / 27   | 36 / 29   | 16 / 11-13  | 610                                       | 793                                   | 39 / 31  | 41   |
| Mackay                             | 185                             | 240                                   | 12 / 9  | 12 / 10   | 0 / 9-10  | 210                                       | 273                                   | 13 / 11  | 14   |
| Metro North                        | 900                             | 1,170                                 | 59 / 47   | 60 / 49   | 32 / 15-17  | 1,000                                     | 1,300                                 | 64 / 50  | 67   |
| Metro South                        | 1,000                           | 1,300                                 | 64 / 51   | 67 / 54   | 56 / +5-+2  | 1,100                                     | 1,430                                 | 70 / 56  | 74   |
| North West                         | 34                              | 44                                    | 2 / 1.5   | 2 / 1.5   | 0 / 1.5-1.5   | 34  | 44                                    | 2 / 1.5  | 2  |
| South West                         | 26                              | 34                                    | 2 / 1.5   | 2 / 1.5   | 0 / 1.5-2   | 26  | 34                                    | 2 / 1.5  | 2  |
| Sunshine Coast                     | 390                             | 507                                   | 25 / 20   | 26 / 21   | 12 / 8-9  | 435                                       | 566                                   | 28 / 22  | 29   |
| Townsville                         | 240                             | 312                                   | 15 / 12   | 16 / 13   | 15 / +2-3   | 265                                       | 345                                   | 17 / 14  | 18   |
| Torres Strait & Northern Peninsula | 11                              | 14                                    | 1 / 1   | 1 / 1   | 0 / 1-1   | 11  | 14                                    | 1 / 1  | 1  |
| West Moreton                       | 220                             | 286                                   | 14 / 11   | 15 / 12   | 10 / 1-2  | 285                                       | 371                                   | 18 / 15  | 19   |
| Wide Bay                           | 220                             | 286                                   | 14 / 11   | 15 / 12   | 0 / 11-12   | 240                                       | 312                                   | 15 / 12  | 16   |

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- <sup>23</sup>HHS Information web page : <http://www.health.Queenslandgov.au/health-reform/html/hhs-profiles.asp>
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