



Palliative Care Queensland

Submission to the
Senate Community Affairs Committee Inquiry into:
Palliative Care Service Provision in Australia

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Contents

1. Overview	3
1.1 Health and Communities Services Committee Inquiry (Qld)	3
1.2 Palliative Care Queensland	3
2. Critical Issues in Queensland	4
3. Background to palliative care in Queensland	7
3.1 Qld Clinical Services Capability Framework	7
3.2 Actual Service Delivery in Queensland	7
3.3 Queensland Statistics	8
3.4 Additional Statistics	8
3.4.1 <i>In-Patient Services</i>	8
3.4.2 <i>Community Based Services</i>	9
3.4.3 <i>Paediatric Palliative Care</i>	10
4. Recommendations	11
Appendices	
Queensland Clinical Services Capability Framework	14
Diagram showing palliative care trajectories	16
References	18

1. Overview

The current situation in relation to palliative care service provision in Queensland is dire and requires immediate review and attention. Overall, the system lacks coordination at all levels:

- There is no state-wide plan for palliative care service delivery;
- Access to palliative care is inequitable;
- Services are poorly funded and inadequately resourced;
- There are severe shortages of specialist doctors, nurses and allied health staff;
- There are significant gaps in education and research at local level, and
- No Queensland specific awareness raising/community education initiatives exist.

1.1 Health and Community Services Committee Inquiry into Palliative Care

On June 22nd, the Queensland Government's Health and Community Services Committee (HCSC) announced that it would be holding an inquiry into Queensland's chronic, frail and palliative care services¹. The HCSC is expected to report its findings to the Queensland Parliament by February 2013.

The terms of reference include an undertaking that the Inquiry will consider;

- The capacity of the 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 between chronic, disability and other health services, and
- Consideration of segmenting the current Home and Community Care Service system based on age of the client, needs of the client, their care and the providers.

Palliative Care Queensland is confident that the Inquiry will lead to a robust examination of palliative care service provision in Queensland, and welcomes the opportunity to work alongside the HCSC to enable strategic reform in this area.

1.2 Palliative Care Queensland

Palliative Care Queensland (PCQ) 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. PCQ's mission is to ensure that all Queenslanders have access to quality care at the end of life.

PCQ provides information and advocacy support to Queenslanders affected by terminal illness, professional education in the area of palliative care, and works to raise aware of palliative care and end of life issues in the general community.

PCQ is a member organisation of Palliative Care Australia (PCA) and as such, aspires to meet PCA's national aims in Queensland.

2. Critical Issues in Queensland

2.1 Poor coordination of services across Queensland

The Queensland Cancer Plan is the only state-wide plan to include a contingency for palliative care. Other chronic disease plans focussing on aged care, dementia, respiratory, renal, cardio-vascular or nervous system diseases, do not include a contingency for palliative care.

There is no state-wide service plan for palliative care in Queensland, and no consistent population based strategy exists to ensure that end of life care is delivered to Queenslanders in a coordinated, consistent, equitable, needs based fashion. In the absence of a state-wide plan for specialist palliative care in Queensland, service delivery is very patchy across the state.

2.2 Queensland Health services are poorly funded

Queensland Health specialist palliative care services are often very poorly funded, and many are unable to meet the demand for specialist palliative care in Queensland. The majority of Queensland Health specialist services have insufficient funding to provide the equipment and nursing care necessary for palliative patients to remain at home or in residential aged care facilities, and most have no funding to provide education or research. Due to the lack of funding in Queensland, some specialist palliative care services have been forced to withdraw support to residential aged care facilities.

2.3 Non-Government providers are very poorly resourced

Seven non-government organisations are contracted to provide either in-patient or community based palliative care. Most of these organisations have not received an increase in recurrent service agreement funding in over 10 years, despite a huge increase in referrals to specialist palliative care services state wide. Organisations are reliant on charity to provide core services.

2.4 Funding is only accessible for patients with less than three months to live

Palliative care program funding, provided by specialist palliative care services to keep patients at home, is generally only accessible if patients have less than three months to live. This Queensland Health ruling often excludes patients with non-cancer illnesses such as MND, heart disease, end stage respiratory illnesses, frailty or dementia from accessing specialist palliative care if they require it. These patients often die over a longer period of time, and as predicting prognostication at end of life for this group can be difficult, they do not meet the current criteria for accessing specialist palliative care funding.

2.5 Inconsistent access to quality care across the state

There are significant differences in the amount of care and support provided from district to district. In some districts, equipment and nursing care are freely available to patients in the home, but in other districts, funding shortfalls prevent patients from accessing the support that they require.

2.6 Queensland's critical shortage of specialist doctors, nurses and allied health

According to Palliative Care Australia's guidelinesⁱⁱ, 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 is less than 22 full-time equivalent specialist palliative care physicians employed across the state. In the Toowoomba Southern 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.

There are also critical shortages of specialist palliative care nurses and allied health personnel across the state, which is ironic given that true palliative care requires a multidisciplinary approach. More must be done to ensure that allied health personnel are available to ensure such an approach.

2.7 Residential Aged Care Facilities currently function as hospices

The average period of occupancy in a Residential Aged Care Facility (RACF) in Queensland is nine months, and 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 who is qualified to provide complex assessments in relation to symptom management, caring for up to 150 patients. Registered nurses are usually supported by Enrolled Nurses and unlicensed 'Assistants in Nursing', the majority of whom lack sufficient training in palliative care to enable quality outcomes. General Practitioners 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.

2.8 Paediatric palliative care services do not meet the current demand for service

More funding for community service providers needs to be made available to support the children and families receiving palliative care in the community. As these providers predominantly care for adult patients, it is critical that they have the support of a specialist paediatric palliative care service when required.

Equipment needs and service provision, such as home respite hours, can be very expensive for disabled children. It is important that disability services and the Medical Aids Subsidy Scheme (MASS) are adequately responsive to these children's needs and provide equipment and services in a timely manner. A flexible funding option for children with life limiting conditions which can complement and enhance existing funding arrangements without causing other funders to withdraw, is critical.

There is a need for after hours telephone support for both cancer and non cancer patients.

There is a need for a specific model of care for disabled patients. This requires a coordinated and cross-departmental response for these children from Queensland Health, Disability Services Queensland and Education Queensland. Such a response is on occasion achieved for some cases, however a more systemic approach, including policy formation, is required to achieve this for all children with both a disability and life-limiting condition.

Development of a model of care for children with cardiac, metabolic, neurological, neuro-degenerative and neuromuscular conditions, including children with intractable seizures, is also required.

Strong consideration needs to be given to a paediatric hospice in South-East Queensland. Such a facility would work collaboratively with Queensland Health and other service providers to provide out of home respite to families, both routine and emergency, providing the option for families to care for their child at the end of life.

3. Background to Palliative Care in Queensland

3.1 The Queensland Clinical Services Capability Framework

The Clinical Services Capability Framework for Public and Licensed Private Health Facilities has been 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 servicesⁱⁱⁱ.

3.2 Actual Service Delivery in Queensland

In Queensland, the majority of people with a terminal condition will be cared for by their general practitioner with the support of a community nursing and allied health service. 50 to 60% of Queenslanders will die in hospital, usually whilst being cared for in an acute medical unit. Many of these patients will not have appropriate access to specialist palliative care services.

After attending accident and emergency departments in the last twelve months of life, many terminally ill Queenslanders become disconnected from their general practitioner. Most of these patients are admitted into acute care beds. Ideally, if generalist doctors working within both the hospital and community sectors received additional training in end of life care, and if they had access to a specialist palliative care service for advice when they required it, fewer patients would need to be admitted to specialist palliative care units.

A small percentage of patients and their families will have such complex needs that all of their care will have to be provided by a specialist palliative care team. Much of this care and support could be provided at home or in residential aged care facilities if there was sufficient resourcing available.

There is no overarching state-wide palliative care service delivery plan or strategy for Queensland, and as such there is no formal link to the National Palliative Care Strategy. Palliative care service delivery in Queensland is inequitable and very fragmented as a result.

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

^{*} Level 4 – 6 specialist palliative care service (Queensland Clinical Services Capability Framework)

- 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.

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;
- Residential aged care facilities and
- At home in the community by generalist service providers.

Palliative care services in Queensland are delivered by both government and non-government agencies, and are funded either by the Queensland Government via direct or contracted services or by the Federal Government via the National Palliative Care Program (PCP). Palliative care is also provided using funding from the Home and Community Care (HACC) program, aged care packages, Department of Veteran's Affairs (DVA) and other similar schemes.

3.3 Queensland 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. In 2008, 25,558 Queenslanders died of expected or anticipated deaths from a variety of chronic illnesses, including cancer, heart disease, dementia and respiratory disease^{iv}. All of these people required end of life care to some degree.

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

3.4 Additional Statistics

3.4.1 Specialist In-Patient Services (QCSCF Levels 4-6)

There are 186 dedicated specialist palliative care beds in Queensland, including 102 public beds and 84 private beds.^{vi} (Please note however that a significant number of beds are used for 'Palliative Intent' throughout the state, and these patients are not being managed by specialist palliative medicine physicians).

- PCQ records currently indicate that, in both the public and private sector, only 174 beds are directly managed by palliative medicine physicians. This includes:
 - 60 - Metro South
 - 47 - Metro North

* Level 1 – 3 specialist palliative care service (Queensland Clinical Services Capability Framework)

- 16 - Gold Coast
 - 12 - Ipswich/West Moreton
 - 8 - Toowoomba/Darling Downs
 - 16 - Sunshine Coast
 - 15 - Townsville
- According to population modelling, Queensland requires more than 300 specialist palliative care beds (6.7 beds/100,000 population).^{vii}
 - Queensland Health funded 67,060 bed days for palliative care including 9,000 bed days from private providers on contract^{viii}. (Please note that this number includes bed days where there is a diagnosis of 'Palliative Intent' and where patients are managed by non palliative medicine specialists. For this reason, it does not provide an accurate estimate in relation to the level of specialist palliative care provided to these patients and their families.)
 - The average cost of a hospital palliative care bed is \$950 per day.

3.4.2 Community Based Services

- 16% of palliative care patients in Queensland die at home in the community.
- Where 24 hr community care is provided by specialised palliative care nurses with access to specialist palliative medicine physicians, it is possible to increase the rate of home deaths* to 50%-60%.
- 11 Queensland Health and five non-government specialist palliative care consultancy services provided expert advice and education to community, hospital and aged care providers.
- The average length of stay on a community palliative care program in Queensland is 45 days^{ix}.
- The current average expense incurred by a palliative care service per day for caring for a palliative care patient at home is \$63, however care provided under the current model is very limited. The actual cost of providing high quality specialist palliative care 24 hours per day in the community is unknown, however for approximately \$450 per day (half the amount of an in-patient bed), a palliative care patient could receive adequate in-home care for at least 12 hours per day. This additional funding and care would provide the family with respite support overnight, and reduce the incidence of inappropriate admissions to hospital for end-of-life care due to carer stress or poor symptom management. This level of care would include care in the terminal phase of life, and could come at a total cost saving of \$178,724 per year per patient for 7 days during the terminal phase.
- Generally, palliative care funding can only be accessed for patients who have less than three months to live. This is the result of specialist palliative care services in Queensland being forced to severely limit their service delivery, often excluding patients with non-cancer diagnoses and those in residential aged care facilities.
- Indigenous patients rarely access palliative care services for many reasons, often the result of a severe lack of community service capacity.

* Figure includes those on the district Palliative Care Register

3.4.3 Paediatric Palliative Care

- There are approximately 1,200 children in Queensland with a life limiting condition, 400 to 500 of whom die per year and 25% of whom are aged less than twelve months. Based on these statistics, it is clear that Queensland needs to develop a peri-natal palliative care service.
- Of the 400 to 500 children who die each year in Queensland, half will need access to palliative care services at any given time. This includes access to specialist palliative care services in regional and rural areas from the Gold Coast to Cairns, and access to specialist hospital outreach nurses and/or community/domiciliary nursing services.
- Within Brisbane, a specialist paediatric palliative care service is available to consult for children living in the metropolitan area. This service provides consultancy support for complex cases outside of Brisbane when requested, with most patients being referred back to a regional or rural centre for ongoing management.
- All of these children will require a general paediatrician and general practitioner to oversee their care. They will also require a 'local' hospital where they can be admitted for symptom management and intercurrent illness.

4. Recommendations

1. Improved coordination of services across Queensland
 - 1.1 The development and implementation of a state-wide service plan for palliative care in Queensland to ensure access and high quality palliative care service delivery based on need to all patients and families throughout Queensland, regardless of setting.
 - 1.2 Establishment of a dedicated palliative care policy and development team within Queensland Health's corporate office.
 - 1.3 Development and utilisation of an effective and efficient model for providing palliative care, including the care of children and young adults.
 - 1.4 Mandated use of robust tools to collect data and measure patient outcomes.
2. More equitable and transparent funding, including funding policy
 - 2.1 Development and implementation of a funding model that recognises the rising demand for palliative care services, equipment and consumables.
 - 2.2 Quarantining a specific allocation or percentage of National Partnership Agreement sub-acute funding to palliative care.
 - 2.3 Equitable distribution of the National Partnership Agreement subacute funding, including the allocation of \$81M (25% of NPA funds) to the palliative care sector in Queensland between 2010 and 2014.
 - 2.4 That the Independent Hospital Pricing Authority and the National Health Performance Authority convey clear messages about transparency in relation to the clear purchasing intent and measurement of high quality, outcome based palliative care linked to evidence of patient and family preferred choices.
 - 2.5 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:
 - 2.5.1 Develop an end of life strategy for the last twelve months of life, and
 - 2.5.2 State clearly what amount of palliative care services and the quality of palliative care services, including outcomes, national standards and patient and family experience, will be purchased and measured by the 'systems manager' in Queensland.
3. Improved access to palliative care services
 - 3.1 24 hour community palliative care to be made available to all Queenslanders.
 - 3.2 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.
 - 3.3 Improved access to specialist palliative care for regional, rural and remote patients.
 - 3.4 Ensuring that appropriately skilled and experienced clinicians are available when and where required.
 - 3.5 Ensuring that all cancer and advanced disease care planning meetings in any district have a palliative medicine physician attending.

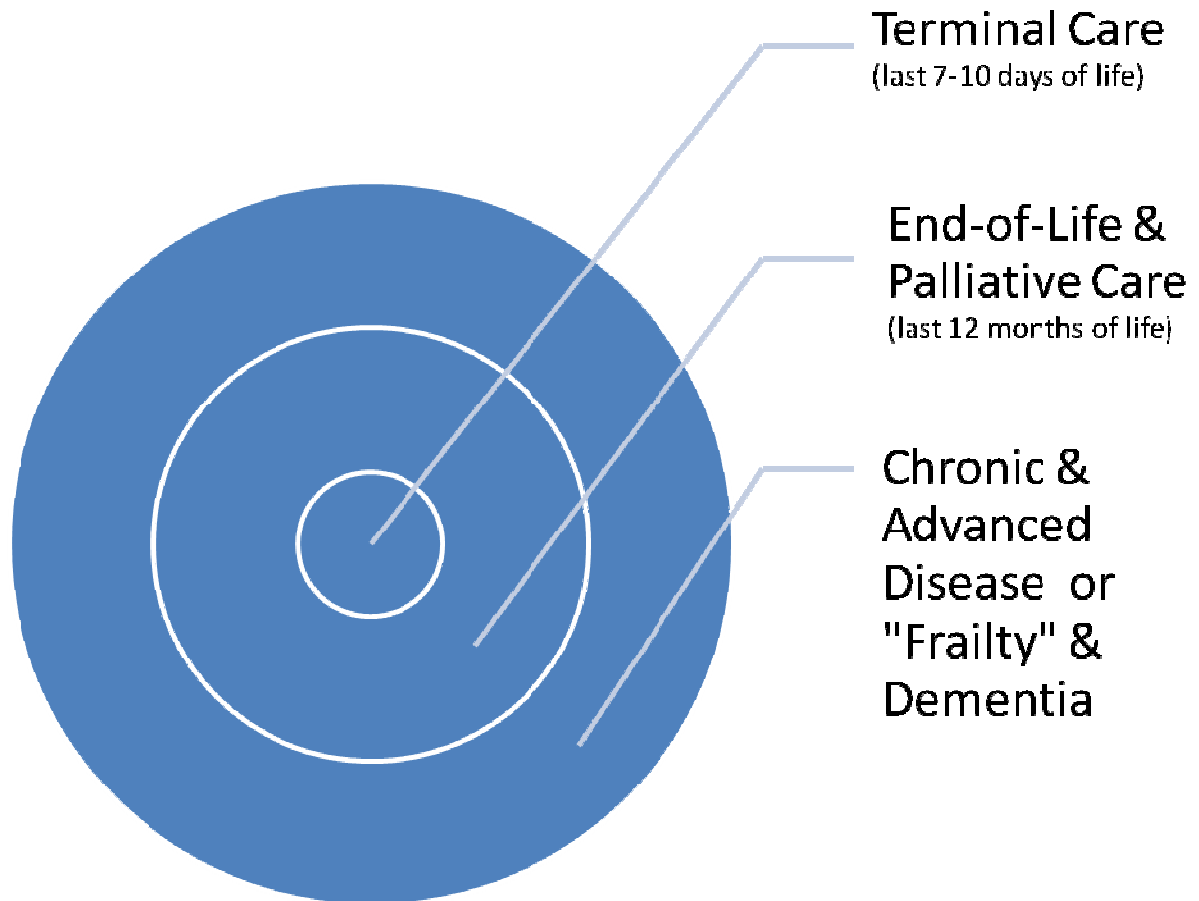
- 3.6 Improved access to palliative care for children, including the development and funding of a children's hospice/respite facility in South East Queensland.
- 4. Greater support for families and carers
 - 4.1 Improved access to counselling and bereavement support, including a designated counselling and bereavement service for children and young adults.
 - 4.2 Additional respite, including additional respite support for the families of children and young adults with terminal illnesses.
 - 4.3 Funded volunteer support programs and adequate high quality training is provided for all palliative care volunteers
 - 4.4 Access to 24 hour support for end of life care.
- 5. Growing and up-skilling the palliative care workforce
 - 5.1 Implementation of a coordinated plan to up-skill and grow the specialist palliative care workforce and build capacity for skilled end of life care by generalist service providers across all settings.
- 6. Raising awareness of palliative care and end of life issues
 - 6.1 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.
 - 6.2 Development of a state-wide end of life care strategy for Queensland for the last 12 months of life.
 - 6.3 Promote the uptake of advance care planning and Advance Health Directives and Enduring Power of Attorney documents in Queensland.

Appendix 1 - Queensland Clinical Services Capability Framework – Service Levels & Requirements

Service Levels & Requirements	
1 Provided primarily by RN with generalist qualifications Registered Medical Practitioner support	<ul style="list-style-type: none"> •there is 24/7 access to SPCS; Communication/collaboration maybe telehealth •access to bereavement support; may have access to NGO nursing •access to Syringe Driver for symptom management; access to equipment hire service; •providers have relevant knowledge principles PC and seek advice as appropriate or refer to SPC service;
2 Community-based ambulatory services <ul style="list-style-type: none"> •Access to in-pt beds for nursing support (not necessarily pall care) •Access to Specialist Palliative Medicine support via telehealth or other: 	<u>as per level 1 +</u> <ul style="list-style-type: none"> •access 24hrs to a Level 4-6 service for advice/guidance •Access 24hrs to tele-health services and equipment •Access to NGO support services(Dom nursing services)
3 Ambulatory and/or inpatient setting. <u>Identified as dedicated service.</u> <ul style="list-style-type: none"> •Established links with higher level palliative care services •Provides seamless continuum of care patients moving between community and inpatient settings 	<u>as per level 2 +</u> <ul style="list-style-type: none"> •Care coordination of palliative services is centrally managed •Regular patient reviews by specialist palliative care staff, in person or by telehealth •May have access to regular on-site specialist palliative care clinic, service in community or inpatient setting

Service Levels and Requirements	
<p>4 Ambulatory and/or inpatient setting- <u>moderate complexity symptom mx needs</u></p> <ul style="list-style-type: none"> • Direct care or support primary providers • Inpatient- designated beds • Coordinated by HP experience, knowledge, skills PC & access Allied Health 	<p><u>As per level 3 +</u></p> <ul style="list-style-type: none"> • Close liaison DEM (where available) • Access to relevant Mental Health service
<p>5 Capacity to manage <u>full range of clinically and or psychologically complex</u></p> <ul style="list-style-type: none"> • Provides allocated in-patient beds (+/- unit) • Networked to off-site ambulatory, + 24hr medical staff + access higher level services 	<p><u>As per Level 4 +</u></p> <ul style="list-style-type: none"> • Provision of complex symptom mx (including acces to invasive procedures) • Provision of procedural medicine (taps) • On-site bereavement service • Access to consultation/liaison psych • Access to interventional pain management
<p>6 Palliative Care unit that <u>manages highest level of patient risk/complexity→ Mx</u></p> <ul style="list-style-type: none"> • Intrinsically linked to level 5/6 other disciplines • Provides an extensive range of interventional and diagnostic services 	<p><u>As per Level 5 +</u></p> <ul style="list-style-type: none"> • Regular MDT meetings with other level 6 • After hours service provision available for other services regarding highly complex symptom management issues • On-site interventional pain management • Access to invasive procedures, high-risk patient

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?



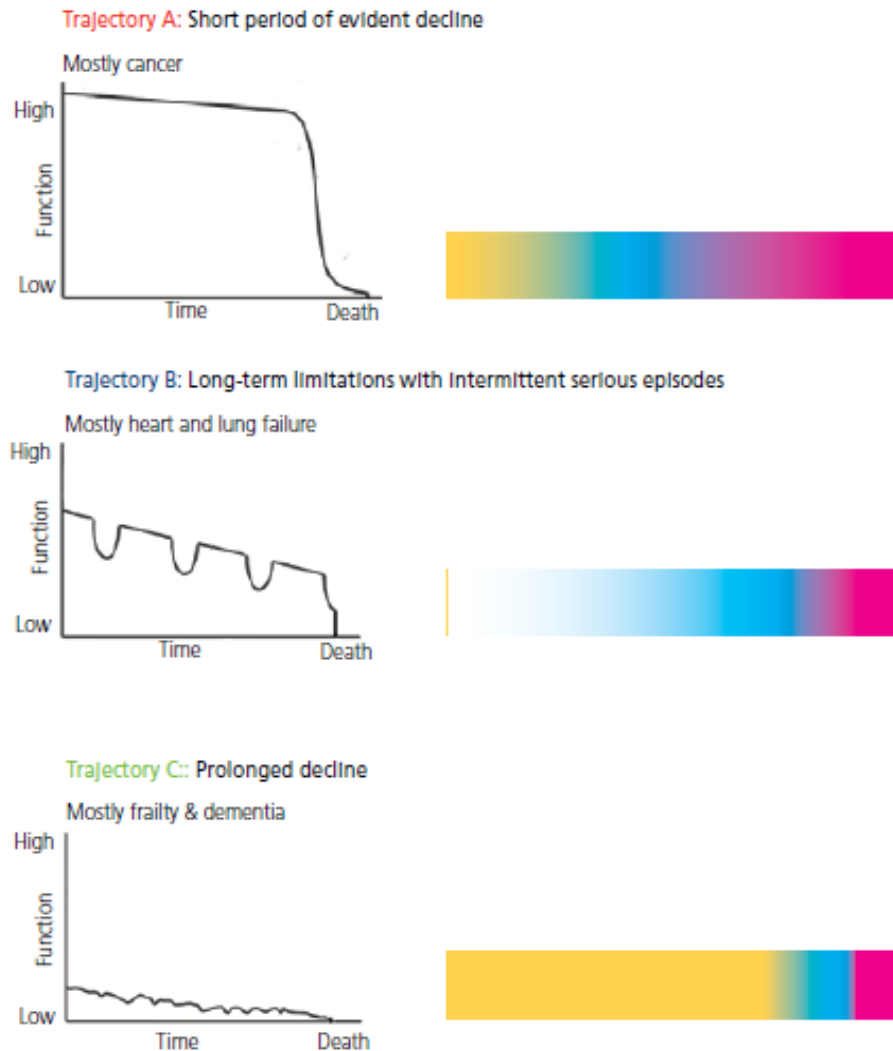
The funds needed to fund Specialist Palliative Care are already largely being spent inappropriately in the acute care sector:

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.

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

- ⁱ Queensland Parliament Website: www.parliament.qld.gov.au/work-of-committees/committees/HCSC/inquiries/current-inquiries/PalCareHAAC
- ⁱⁱ Palliative Care Service Provision in Australia: A Planning Guide, 2003, www.palliativecare.org.au
- ⁱⁱⁱ Queensland Health Website: www.health.qld.gov.au/privatehealth/clinical_framework.asp
- ^{iv} Queensland Office of Economic and Statistical Research: www.oesr.qld.gov.au
- ^v A Guide to Palliative Care Service Development: A population based approach
- ^{vi} Queensland University of Technology, *Scoping of Palliative Care Services in Queensland (report), Executive Summary*
- ^{vii} Palliative Care Australia, *Palliative Care Service Provision in Australia: A Planning Guide*
- ^{viii} Queensland Health, Finance Procurement and Legal Division correspondence
- ^{ix} Metro South Palliative Care Service