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6 August 2012

Health and Community Services Committee
Parliament House
George Street
BRISBANE QLD 4000

To the Health and Community Services Committee,

It is with great pleasure that **Queensland Kids** responds to the invitation for submissions by the Health and Community Services Committee for the *Palliative care services and home and community care services inquiry.*

As an organisation committed to the advocacy of paediatric palliative care in Queensland, and dedicated to the support of Queensland families with children affected by life-limiting conditions, we lodge this submission as a qualified voice for change. We have actively engaged key paediatric palliative care stakeholders including the Paediatric Palliative Care Service at the Royal Children's Hospital and Palliative Care Queensland to ensure this submission achieves optimal positive outcomes for the paediatric palliative care landscape of Queensland.

This submission:

- Introduces Queensland Kids and Hummingbird House;
- Provides a robust methodology and framework for qualified lodgement;
- Addresses the four Terms of Reference with strong community-based evidence;
- Presents sample case studies and stories of families and professionals who have a wide range of experiences with paediatric palliative care; and,
- Provides links to two video clips of our organisation sharing some stories of families we support and raising community awareness of the need for a paediatric palliative care facility in Queensland.

We look forward to engaging further with the committee at the public hearings and future stakeholder conversations on behalf of Queensland families affected by life-limiting conditions.

Yours sincerely

Mr Paul Quilliam
Cofounder/Board Chairman
QUEENSLAND KIDS
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0439005125

Palliative care services and home and community care services inquiry

> *"You matter because you are you and you matter to the*
> *last moment of your life. We will do all we can to help you, not only to*
> *die peacefully, but to live until you die"— Dame Cicely Saunder*

submission by

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About Queensland Kids

Queensland Kids (QK) is an incorporated charity (CH2066) that has identified a critical need in Queensland:

> ***There is no paediatric respite and hospice care facility for children with life-limiting conditions and their families in Queensland. Families need a home away from home option that provides the flexibility to access respite and hospice care when home or hospital care can no longer meet their needs*.**

With Australia's population of almost 23 million, there are only 2 children's hospices nationally and none of them are in Queensland. The UK's population of almost 63 million boasts 44 children's hospices.

The QK vision:

> ***To build an innovative and sustainable respite and hospice facility for children and their families affected by life-limiting conditions.***

At the heart of QK is a desire to see the synergies of individuals and organisations working together to meet the needs of palliative children and their families in their communities within Queensland.

Since its incorporation in February 2011, QK has sought to establish relationships with the key stakeholders and care service providers of paediatric palliative care (e.g. Paediatric Palliative Care Service at the Royal Children's Hospital (PPCS); Palliative Care Queensland (PCQ); Xavier Children's Support Network). It has also developed relationships with other care service provides such as Anglicare Southern Queensland (ASQ), St Vincent's Brisbane (SVB) and YoungCare to explore the potential of a joint venture with QK, in an effort to provide more comprehensive paediatric palliative care services.

Collaborative discussions with these key service providers have validated QK's assessment of the gap in 'out of home' respite and hospice services within the paediatric palliative care sector.

QK's vision to build Hummingbird House has compelled significant organisations such as Bank of Queensland and Global Philanthropic to partner with us to build this facility.

While QK continues to be an advocacy voice for the families affected by life-limiting conditions, it will raise the necessary capital funds to establish Hummingbird house. QK firmly believes in representing a population of people that desperately needs this much needed facility and services.

More information about Queensland Kids can be accessed through our website www.queenslandkids.org

The Paediatric Palliative Landscape

The following information, where not otherwise referenced, has been provided by the Paediatric Palliative Care Service based at the Royal Children's Hospital, Brisbane. There are approximately 1200 children in Queensland with a life-limiting condition. A life-limiting condition is defined as one where the child is likely to die before the age of 18 years. All of these children will require a general paediatrician and general practitioner to oversee their care. They also require a "local" hospital where they can be admitted for symptom management and inter-current illness.

It is estimated that at least half of these children (i.e. 600) will need access to palliative care services at any given time. This would include specialist palliative care services in regional and rural areas (e.g. Gold Coast, Sunshine Coast, Toowoomba, Townsville and Cairns) and availability of hospital outreach nurses (e.g. Regional Case Managers, CNC Liaison Nurses) or community nurses (e.g. Bluecare, Ozcare, ASQ, amongst others). Within Brisbane, a specialist Paediatric Palliative Care Service is available to consult on children living in the metropolitan area and also complex cases outside of Brisbane when requested (this may be due to complexity of the case or related to patients being referred back to a regional or rural centre from the tertiary centres).

There are approximately 400 – 500 children dying in Queensland each year, and over 25 % of these are aged less than 12 months.

New advances in medicine have improved survival among children with any life-limiting condition - extending that last phase of life. When the hope of cure and prolonged survival dwindles, families and care givers may face tremendous stress. Care at this stage requires a holistic approach to the patients' and families' physical, emotional, and spiritual needs.[1]

Palliative care for adults is now a recognized specialty worldwide; the same is not true for paediatric palliative care. Palliative care for children is in a much earlier stage of societal acceptance, and is only beginning to receive its rightful place in the spectrum of health care services. The strongly held belief that "children are not supposed to die" creates societal barriers to facing this reality.[2]

Palliative care for children is different from adult palliative care in several ways[3]:

- the number of children dying is small, compared with the number of adults
- Many of the individual conditions are extremely rare with diagnoses specific to childhood, although the child may survive into early adulthood (aged 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. There may be more than one child affected in the family.
- Care embraces the whole family. To support the family who are going to be the people who will live with their loved one's death beyond that dying
- A characteristic of childhood is continuing physical, emotional and cognitive development. Children's palliative care providers need to be aware of and responsive to each child's changing levels of communication to understand their illness, treatments and prognosis.
- Provision of education and play when a child is sick is essential.

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[1] Young JL, Jr, Gloeckler Ries L. (2006) Cancer incidence, survival, and mortality for children younger than age 15 years. Cancer;58:598–602

[2] Davies B, Sumner L. (2004) *Special consideration for children in palliative medicine*. In: Doyle D, Hanks G, Cherny NI, Calman K, editors. Oxford Textbook of Palliative Medicine. 3rd ed. Oxford: Oxford University Press

[3] Association for Children's Palliative Care (2009), A Guide to the Development of Children's Palliative Care Services, Bristol.

Methodology for Submission

QK acknowledges the following definitions and strategies as a framework from which we will address the terms of reference. We are resolute in underpinning our comments and recommendations upon current evidence and practice based models and systems. At the same time, we wish to publically recognize and applaud the current work that is already being done by Queensland paediatric care service providers and advocacy groups.

World Health Organisation Definition of Paediatric Palliative Care

It should be clearly noted that there is a distinct and differentiated WHO definition for paediatric palliative care. As it is recognised on a world platform as separate to the adult definition, we will be addressing these terms of references in light of the paediatric palliative care definition (refer Appendix 2).

National Palliative Care Strategy

As an organisation, QK believes our submission and recommendations align with the four goal areas of the National Palliative Care Strategy: Awareness and Understanding; Appropriateness and Effectiveness; Leadership and Governance; Capacity and Capability (refer Appendix 3).

Palliative Care Australia Standards (PCAS)

QK recognises that PCAS have stipulated special consideration must be given to children requiring and receiving palliative care. The 13 PCA Standards are integral to QK's vision and submission. In particular the **uniqueness of the patient** (Standards 1 and 6); **the needs and wishes of the child** (Standards 2, 3 and 5); the **community capacity** to respond to these needs (Standard 9) and **access based on age** (Standard 10).

Palliative Care Outcomes Collaboration (PCOC)

QK will utilise the Palliative Care Phases as outlined by PCOC to address our observations regarding the efficiencies, effectiveness and adequacy of current paediatric palliative care services within Queensland (refer Appendix 4).

Other Australian State Paediatric Palliative Care Initiatives

QK acknowledges and commends the long standing work of the two paediatric palliative respite and hospice facilities in Australia, serving as exemplary service providers outside Queensland:

- Very Special Kids http://www.vsk.org.au/
- Bear Cottage http://www.bearcottage.chw.edu.au/

QK has a strong relationship with both these organisations, and can attest to the positive impact they have on families in their respective states. QK has visited each hospice and seen firsthand how they have supported interstate families. Both organisations are examples of the WHO definition for paediatric palliative care being implemented in the Australian context. We believe Hummingbird House will also be a reflection of these organisations in our Queensland state context.

Global trends

We believe through collaborative work such as this State Government Inquiry, Queensland paediatric palliative care services as a whole can be strengthened. QK believes a similar document to the ACT[4] Manifesto (refer Appendix 6) must be developed and implemented both at a state and national level. This type of paediatric focused document could be developed through the current PCA Standards and would require national consensus. Many of our recommendations will be based around our mission to help expand paediatric palliative care services in order to bring Queensland into line with current developed nations care service provision.

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[4] ACT is part of the UK's leading paediatric palliative advocacy organisation. On 1 October 2011 ACT (Reg'd charity 1075541) merged with Children's Hospices UK (Reg'd charity 1103795) and all its activities and assets were transferred to the new charity, Together for Short Lives (Reg'd charity 1144022)

Methodology for Submission (continued)

Stakeholder Engagement

In the development of this submission, Queensland Kids has engaged with individual and organisational stakeholders.

- Community Forums (x3) were hosted by Palliative Care Queensland (PCQ) and facilitated by QK, providing significant evidence for comment regarding the *Terms of Reference*
- Queensland paediatric palliative care statistics have been provided by the Paediatric Palliative Care Services (PPCS) at the Royal Children's Hospital, Brisbane
- Family stories have been developed and composed through interviews conducted by children's author Renee Bennett and supported by professional photographers (refer Appendix 8)

Terms of Reference

TOR1: The capacity and future needs of paediatric palliative care services

Current Issues

(a) **WHO Definition**

There is a distinct WHO definition for paediatric palliative care that was not included in regards to the terms of reference for this inquiry (refer Appendix 2).

(b) **Out of home Respite**

There is limited 'out of home' respite and hospice care available for children and families affected by life-limiting conditions within either metropolitan or rural areas

(c) **Palliative Care Specialists**

There are an insufficient number of paediatric palliative care specialists within Queensland. Indeed there is only one paediatric palliative care specialist in Queensland. A minimum of 67 adult specialist palliative care physicians are required to successfully meet the end of life care needs for a population the size of Queensland. Despite this, only 22 adult specialist palliative care physicians are employed state wide. There are also shortages of specialist palliative care nurses and allied health personnel across the state, despite Palliative Care Australia's guideline[5] recommending 6.5 hours of nursing care per in-patient per day.

(d) **Allied Health**

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 (e.g. art therapy). This includes education (professional development and post-graduate studies), direct funding for palliative care services and research initiatives.

(e) **Service Providers**

Currently there is a significant duplication of specialist and primary services for adult palliative care in the South East Queensland. Sadly, paediatric palliative clients do not have the luxury of a similar duplication of services. There are relatively few specialised paediatric palliative care service providers in Queensland which limits care options and in home respite opportunities. This becomes an even greater issue if the family resides outside metropolitan areas. It is also difficult for families to access information about the appropriate agencies and service providers with ease. There is a significant lack of efficient information dissemination about the most appropriate care service providers for these children and their families. It can be difficult for families to negotiate the health care system as each child and family often has unique needs and multiple agencies are often required.

RECOMMENDATIONS

- Paediatric palliative care must be seen as a distinct area of care and treated with the same consideration for funding and support as afforded to adult palliative care. Children in palliative care have needs that are quite different from those of adults receiving similar care[6]. The identification of paediatric palliative care as a care sector in in's own right is imperative to the capacity and future needs of these services.
- Establish a specialised paediatric respite and hospice facility: this care gap has been identified by QK in the current capacity of services and this future need can be addressed by Hummingbird House. The breakdown of preferred location of death (home, hospital or hospice) for children reported in other centres is approximately equal (i.e. 1/3 of children dying in each of these locations)[7].

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[5] Palliative Care Service Provision in Australia: A Planning Guide, 2003, www.palliativecare.org.au

[6] Hurwitz CA, Duncan J, Wolfe J. (2004) Caring for the Child With Cancer at the Close of Life "There are people who make it, and i'm hoping i'm one of them" JAMA;292:2141–9.)

[7] Siden H et al. (2008) A report on location of death in paediatric palliative care between home, hospice and hospital. Palliat Med.22(7):831-4].

- Resolute effort must be directed towards recruiting appropriately skilled professionals or strategies devised and implemented for the professional development and up skilling of current trained medical professionals in the specific area of palliative care. This is in conjunction with the establishment of a specialised community based paediatric service outside of the PPCS service. This is imperative to the future capacity of services within paediatric palliative care.

TOR2: The effectiveness, efficiency and adequacy of paediatric palliative care services

QK would like to address the issues of effective efficient, adequate paediatric palliative care provision in light of the PCOC phases of palliation: Stable; unstable; deteriorating; terminal; bereavement (See Appendix 4)

General issues identified:

- Queensland has no standardised and coordinated state wide plan for providing paediatric palliative care. This creates difficulties in access to appropriate services, and creates difficulties to implement strategies to reduce wasteful duplication issues.
- Advocacy for the child rests heavily upon the parent or carer. The family is the child's advocacy voice, however, if the family is marginalised or do not possess the necessary skills, advocacy is impeded or diminished.
  "You are the mum last….you have to be the therapist, nurse, equipment specialist before you get to be the mum who is just so worried about their child".[8]

RECOMMENDATIONS

- Development and implementation of a population based state wide strategic plan for palliative care service delivery in Queensland. This will lead to more centralised control of funding and improve the state's capacity to maximise the efficient use of resources. [9]
- Development of clear referral process to either hospital or community based advocacy groups to support the child and family. This advocacy development could also include avenues for more effective and efficient information dissemination and provide established pathways for families to access appropriate support services.

During the Stable Phase:

(a) Respite Issues:

The trajectory of paediatric life-limiting conditions often means living while dying. This can translate to 24/7 care needs, even when the child is relatively stable. The chronic sleep deprivation inhibits coping mechanisms and decision making for parents/carer's; this in turn impacts on family life, social interaction and job security. There is a limitation to the amount of respite available to children due to funding limitations and the complexity of care of some children's needs, 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 and hence provision of routine and elective out of home respite is often not possible.

RECOMMENDATION

- Establish out of home respite facilities to support the community based care model currently in place. By providing regular respite, parents/carers home based care becomes physically, mentally and emotionally more sustainable. Respite support can also help reduce parental/carer burnout and subsequent social issues.

(b) Sibling support issues:

Even when the sick child is relatively stable, the parents/carers attention and energies are often focused on the constant care activities out of shear necessity. This can have a detrimental impact on the, physical, social, mental and emotional resilience and development of the siblings and other members within the family.

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[8] Parent comment

[9] PCQ Federal Senate Inquiry Submission

RECOMMENDATION

- Sibling support programs must be developed and incorporated into the palliative 'care plan' for the child and family. Sibling support programs could provide the well sibling continuity of care from the diagnosis of their siblings' life threatening condition through to the death and bereavement of their sibling.

(c) After Hours Support Issues:

Parents/carers are often experts in their child's care, but if a deviation from the 'norm' for their child occurs outside of 'office hours', their only avenue of support is via the emergency department of the local hospital which can snowball into hospital admissions. Often parent's feel they could avoid this escalation process if they could access after-hours advice.

RECOMMENDATION

- There is a need for a dedicated after hours telephone support service for both cancer and non-cancer paediatric palliative patients. Such a service could act as a centralised information point. This could be developed as an integrated component of the current Palliative Care Helpline run by Karuna Hospice Service. However, the optimal specialist paediatric after hours service would be achieved through a 1800 number connected to the PPCS team at the RCH or at a specialised paediatric palliative respite and hospice facility. A model of this type of service has already been developed for oncology patients. Through the use of modern communications technology, advice could be provided directly to the patients in their homes or hospitals, or assistance given to the caregivers in the community. This would enable specialized palliative care teams established in tertiary care centres to share their expertise state wide. This type of service is currently being developed through the PPCS Tele/video conference service based out of the RCH. This type of service, with careful negotiation could ensure families have access to afterhours telephone support at the end of life phase and access for care co-ordination during office hours during the stable phase.

(d) Mental Health Issues:

The physical and emotional stresses of caring for a palliative child can often leave the parent/carer vulnerable to mental health issues such as depression and anxiety. Feelings ranging from helplessness and fear to suicidal and homicidal thoughts were expressed by parents who attended the QK community forums:

"The reason my children and myself were in danger was because I had no hope that there was anyone to care for us".

"I was more frightened of dying myself, because no one would be around to care for him, than being frightened of his actual death"[10].

RECOMMENDATION

- Development of mental health care risk management process incorporated into the palliative care pathways.

(e) Equipment

Children with life-limiting conditions often need specialised equipment for their activities of daily living (ADLs). This specialised equipment increases the cost burden for these families. This equipment is frequently being sourced by parents/carers either through 'personal contacts' rather than through designated referral systems, or at is being hired by parents through private companies because it is not available through the hospital service. Often the needs of these children change with little warning, heightening the urgent need for specialised equipment.

RECOMMENDATION

- Need to develop clear pathways for parents/carers to access the appropriate equipment with appropriate funding support. There is a need to allocate a pool of equipment with flexible access for children whose illness trajectory is difficult to determine or project.

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[10] Parent comments from QK Community Forum

During the Unstable Phase:

(f) Hospital Admissions:

There are currently two major tertiary hospitals within Brisbane. And often a palliative child is receiving support via both services due to the complex nature of their illness. It is often challenging to ensure different service providers are providing co-ordinated care. The Mater Children's Hospital has established a Complex Care Service and the Royal Children's Hospital facilitates the Paediatric Palliative Care Service to try and meet this need for children with life-limiting conditions. While there is good collaboration between these two services there can be variances in care provided to children who are referred to these services and those who are not.

Navigating the hospital system can be extremely exhausting, challenging and daunting for parents/carers. As a child progresses along the life-limiting conditions trajectory, acute hospital admissions become more frequent. *"Parents are educating parents in the hallways about what to do, where to go and how to access stuff"*[11] Parents are expected to remain with their child throughout any admission and during the QK community forums, parents voiced their concern around the continuity of care provided for their child throughout hospital admissions. These concerns stem from constant staff changes and information handover processes. Parents also raised issues around the level of staff training for specific equipment used for their complex needs child.

RECOMMENDATIONS

- The process of hospitalisation needs to be streamlined (e.g. fast tracking through the emergency department) and the hospitalisation process made as family friendly as possible (e.g. flexibility with visiting rules, assistance with parking / 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 rather than the acute medical problem they are presenting with.
- Development of pathways to improve the 'memory making' culture amongst hospital staff to help create 'memories' for families with a dying child. The family is often so caught up with the care of the palliating child that opportunities to create special mementoes are often overlooked until it is too late.
- Develop procedures/pathways integral to current handover processes that allow for a specific parental input into the child's care plan handover. Care plan development must include the parent/carer because the carer/parent is often the 'expert' regarding their specific child's care. Parents/carers need to be able to contribute to the handover process and deserve this form of recognition
- Promotion of centralised care by 1 lead paediatrician. This helps decrease confusion and helps increase clear communication between allied health and different departments
- Increase in hospital staff education around complex care issues for paediatric palliative patients
- Hospitals could develop parent connect forums and provide clearer referral pathways for a parent to access the Patient's Rights liaison Hospital representative. This would include improving the accessibility of the complaint/comment feedback process as well as mandatory access to the Health Care Charter within the hospital
- Hospitals could seek consumer input when consider commercial tenders for equipment used by paediatric complex care palliative patients such as feeding pumps or portable syringe drivers, as parents/carers are the regular users of such devices.

During the Deteriorating phase

(g) Advanced health care directives:

As the palliation process progresses parents/carers attending the QK community forums highlighted the issues around the lack of advanced care planning strategies for paediatric patients. Challenges were identified in relation to the timing of information provision i.e. the fine line between being informed and the

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[11] Parent comment from QK Community Forum

parents/carers need for hope. One parent's comments "*We were dismissed and almost rebuked by hospital staff, for 'giving up on our child' by having a plan*"[12]

(h) Education and Information:

Parents conveyed their difficulties in being educated about what to expect in many aspects related to the dying process of their child. Information needs ranged from specific illness details to advice about insurance options and funeral procedures. This lack of information led to parents/carers feeling more anxious about the unknown journey ahead of them. While there will always be a degree of the 'unknown' when dealing with the palliation process of a child, there are certain aspects where information frameworks could be provided. QK appreciates the *Journeys*[13] publication and resource list developed by Palliative Care Australia to be used as an information resource to better prepare and equip parents and carers for the many situations and issues they face as they live with their child's life-limiting conditions. However, we firmly believe this should be further developed and strengthened for the Queensland context. For example, it regularly refers to the "where" of end-of-life being always home, hospice or hospital, however, it fails to acknowledge from the outset, that there is no children's hospice in Queensland for these families to access this end-of-life care.

(i) Transition from hospital to home

Because there is no transitionary facility in QLD, such as a paediatric hospice, when the child progresses to the point where no further acute treatment is undertaken, parents have no option but to take their child home to continue the palliation process. Currently, there is little or no support for this transition phase. Indeed one families neonatal experience involved their child being discharged from the hospital with the instructions to re – present when they felt their child was in the *"final stages of life or if the child actually died"*[14].

RECOMMENDATIONS

- Develop Advanced Care Directives integration process into paediatric palliative care pathways.
- Non-government organisations (NGO's) could develop pathways for education and information addressing common topics such as "Funeral Options", "Physical changes to expect after death" "Insurance and Funding Support" etc. Currently this type of information is heavily dependent on the social worker contact a family has within the hospital, which can be very haphazard due to staff and funding restrictions.
- Hospitals or NGO's could develop information and service provider pathways for the transition from hospital to home.
- The option of a paediatric hospice could allow for the provision of end of life care or provide the transitionary care and support if the family chooses to continue care at home.

During the Terminal Phase

(j) Social isolation:

Parents and families can often experience social isolation after death of their child. The strongly held belief that "children are not supposed to die" creates societal barriers to facing this reality[15].

(k) Hospice Care:

Currently children and their parents/carers have little choice for the preferred place of death. The current options are either home or hospital. For varying social, emotional or practical reasons, neither option may be the preferred choice. Many parents feel a hospital setting is too clinical, or feel the sense of responsibility weighs to heavy on them as a parent to have their child die at home. To provide client centred care, a 'neutral' or third option of hospice care must be considered. The model of hospice care not only allows for a broader range of choice for the place of death, but it also supports the continuum of care plan/care service

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[12] Parent Comment from QK Community Forum

[13] http://www.palliativecare.org.au/Journeyschildren/DownloadJourneys.aspx

[14] Parent Comment from QK Community Forum

[15] Davies B, Sumner L. (2004) Special consideration for children in palliative medicine. In: Doyle D, Hanks G, Cherny NI, Calman K, editors. Oxford Textbook of Palliative Medicine. 3rd ed. Oxford: Oxford University Press

to remain the same as home right up to the point of death. If hospice care is introduced early in the disease trajectory of the child, before the active palliation stage, families can gain respite and support with the care of their child. By following the clinical care routines and methods of care, hospice care can also ensure parents/carers can continue seamless care after respite periods.

(l) 'Zoe's Place':

There has been a QLD precedent established for 'out of home' paediatric respite and hospice care through the facility "Zoe's Place". This facility went into liquidation and closed in 2009 leaving a significant gap in respite and hospice services. Parents who had experienced the benefits of 'Zoe's Place' and who attended the QK Community Forums commented that Zoe's Place acted as an 'information pool for parents' in regards to appropriate support services.

RECOMMENDATIONS

- Establishment of a specialised paediatric respite and hospice facility would provide best practice end of life care choice and provide a 'hub' for support and information as well out of home respite services before end of life care becomes necessary. Having a paediatric hospice could provide seamless care support from the point of diagnosis to bereavement and beyond.
- NGO's could develop a services directory for appropriate services and support groups for children and their families receiving palliative care.

During the Bereavement Phase

The death of a child is regarded by Western societies as one of the most painful bereavements.[16] Many individual issues were raised by attendees of the QK Community Forums regarding grief and bereavement connected to the experience of paediatric palliative care (refer Appendix 1). However, the overwhelming common theme concentrated around the lack of grief and bereavement support services for individuals, siblings, families and extended family and friends. 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 e.g. Paradise Kids. It should be noted that bereavement is included within the WHO definition for paediatric palliative care and this area should continue to be a high priority for research.

RECOMMENDATIONS

- Need for post traumatic grief support
- Need for support groups centred on child loss
- Need for male based support groups
- Need for 'couple' grief support
- Need for grandparent support
- Need to support the individual experience of death and dying

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[16] Sheldon F. (1998) ABC of palliative care: Bereavement. BMJ. pp316:456–8.)

TOR 3: Examine opportunities for reforms to improve collaboration and cooperation between paediatric care services, chronic, disability and other health services

(a) Access Issues

Difficulties exist for paediatric palliative care families accessing Disability Services Queensland (DSQ). This is partly due to limited funding that is available for equitable distribution 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. The process can be slow and cumbersome.[17] A lack of flexibility can result in children receiving little or no care if they do not "fit in". Intake criteria for children need to be flexible and inclusive (rather than exclusive) and health professional needs education on providing flexible and individualised care to each child.

(b) Equipment needs and service provision Issues

(E.g. in home respite hours) can be very expensive for disabled children. It is important that disability services and the MASS system is answerable to meet 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 complement and enhance existing funding arrangements (without causing other funders to withdraw) is critical.

(c) Staff education Issues

There is a growing need for staff education and debriefing as this specialised workforce grows. The psychosocial needs of the healthcare professionals should also be considered as an issue for collaboration, as it is recognized that there is a high rate of "burnout" among palliative caregivers. Support from colleagues and the opportunity to share the responsibilities and challenges of difficult cases is most important.[18]

(d) Age based transition between services Issues

As the trajectory of life-limiting conditions can now be greater for children due to improved medical intervention, continuity of care and smooth transition of care is of crucial importance for palliative care. An adolescent or young adult (AYA) patient may start treatment in a paediatric centre but at the time of transition to palliative care may have outgrown a paediatric hospital service either chronologically or in emotional maturity. However, an adult hospital and services are usually populated by older adults or seniors and is not an ideal environment for a young adult. Adult palliative care teams often find the relatively uncommon experience of caring for young adults distinctly challenging as there is a perceived sense of unfairness in the early end of life circumstances for patient and family.[19]

(e) Government agencies

Government administrivia requires greater sensitivity and scope. Current Centrelink paperwork forms only provide space for 'stillborn'. This doesn't allow for neonatal death or provide scope for the fact that a child may have lived a few hours. This lack of flexibility can significantly impact a grieving parent when dealing with their child's death.

RECOMMENDATIONS

- **Specific Model of Care**: There is a need for a specific model of care for children and young people with a disability who have life-limiting conditions. This requires a co-ordinated 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.[20]
- **Multi-disciplinary hospital consultation service:** Because the needs of these children can be so complex, there is an opportunity for a broad range of health professionals who have formal training and qualifications

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[17] PCQ Federal Senate Inquiry Submission 2012

[18] Meier DE, Beresford L. (2006) Preventing burnout. J Palliat Med. 9: 1045-1048.CrossRef,PubMed,Web of Science®

[19] Wein S, Pery S, Zer A. (2010) Role of palliative care in adolescent and young adult oncology. J Clin Oncol. 28: 4819-4824.) Pritchard, S., Cuvelier, G., Harlos, M. and Barr, R. (2011), Palliative care in adolescents and young adults with cancer. Cancer, 117: 2323–2328. doi: 10.1002/cncr.26044)

[20] Queensland Health Disability Services Plan 2011 – 2014

in paediatric palliative care to form collaborative relationships and develop pathways of referral and information sharing. For optimal capacity and sustainability, this type of a service would require multiple staff from each discipline to be involved with service provision and education. Greater professional participation would allow for succession planning and may avert burnout[21].
This type of service would engage and support the current teams at the Mater and Royal Children's Hospital as well as regional hospitals. Once the new Queensland Children's Hospital is functioning this type of service could also be provided to the community through home visits or by videoconferencing via online health services. [22] Queensland Kids commends the work already begun by the PPCS in this area.

- **Teleconferencing/videoconferencing**: Due to the geographical spread of QLD, the further development of online or interactive conference calls and education packages could provide an opportunity for diverse health services to collaborate on a wider and more effective scale.
- **Collaborative Partnerships:** Other opportunities to establish collaborative partnerships across health care services would be in the area of advocacy and hospice care. QK recently met with both ASQ and SVB to discuss partnership options with the vision of achieving the most comprehensive and sustainable model of care for Queensland children with life-limiting conditions. The establishment of a respite and hospice facility may also help to address the difficulties around disabled teenagers 'dying in place'. i.e.: dying in familiar surroundings if their principle place of residence is not their family home. QK also recently engaged with a team member from CanTeen through the QK Community Forums to discuss issues around AYA palliative care. This discussion has led to organisational information sharing and support.
- **Staff Education and Debriefing:** A centralised plan to train additional palliative care medical specialists, nurse practitioners, specialist nurses, specialist allied health personnel and volunteers is essential, to provide adequate palliative care to children in QLD and an opportunity to develop collaborative relationships**.** Possible solutions to promote sustainability and staff retention could include improving peer support by "normalizing" debriefing and having regular opportunities for acknowledging losses between health services. Staff should be encouraged to develop their own personal support systems and to maintain a sense of balance between work and home life – which is often very difficult with a demanding workload. Palliative caregivers should be trained to recognize stress in their colleagues and in themselves and should know how to intervene if necessary.
- **Advanced Care Planning:** The inclusion of advanced care directives within the palliative care pathways of a child could encourage broader collaborative relationships between service providers as they are introduced to the family as the child's disease progresses.
- **Liaison with Government Offices:** NGO's could become the advocacy partner to support the government in streamlining certain documents to provide more comprehensive information gathering.

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[21] A Guide to Palliative Care Service Development: A population based approach. Palliative Care Australia, Canberra, 2005.
[22] PCQ Federal Senate Inquiry Submission

TOR4: Consideration of segmenting the current Home and Community Service system based on age of the client, needs of the client, their carer and the providers.

The proposed split of Home and Community Care funding based on the age and needs of the client will generate further inconsistencies to the already complex and convoluted processes for paediatric palliative care funding access. Currently, there is no central coordination of funding and there is no official funding policy or funding model in place to support the equitable distribution of funding throughout Queensland.

- Specialised palliative care funding is not available to patients who are HACC, CAPS or EACH eligible or to patients funded by Disability Services Queensland.
- Funding for community service providers (e.g. community nursing services) also needs to be available for children and families receiving palliative care in their home. These community nursing providers predominantly care for adult patients – so it is critical they have the support of a specialist paediatric palliative care service when required. Within Brisbane there are service providers who do have expertise in paediatrics and provide palliative care to children (e.g. Xavier Children Support Network and Hospital in the Home based at the Mater).

Other funding issues:

(a) Parents attending the QK Community Forums experienced loss of funding, because of lengthy hospital admissions and the child was deemed “not in the home”. This was in spite of the fact that the parent/carer remained in the hospital throughout the admissions as the child’s carer.

(b) Centrelink payments are difficult to navigate or access for a child with complex care needs or receiving palliative care and cease upon the death of the child with little regard for the associated financial impacts on the family still dealing with expenses related directly to the care of the child.

(c) Inequity of funding access was highlighted through a parent’s experience where the Grandparent and grandson were both eligible for HACC funding, but the grandson’s access was much more difficult because of his age. Funding is often given an ‘adult’ definition and children do not fit that definition.

(d) Population growth, in conjunction with the increased complexity of care and increasing survival rate amongst palliative children, escalates the funding issues. Unofficial policy limits the provision of palliative care community funding to those who have less than three months to live. This policy often prevents community palliative care funding from being provided to patients with illnesses that have a long palliative care trajectory, including patients with motor neurone disease, heart disease or other non-cancer illnesses.

(e) Education around funding schemes such as HACC is needed for organisations so they can in turn support their clients in accessing appropriate funding. It seems there could be some merit in having a specific paediatric section and contact point for paediatric services through HACC.

(f) Transparency at a State Government level is critical for the allocation and distribution of subacute funding.

(g) NGO care service providers of palliative care are heavily reliant on charitable donations to provide core services. Recurrent government funding must become a priority if palliative care services are to remain sustainable within the community.

The Vision of Hummingbird House

By establishing **Hummingbird House**, Queensland Kids will deliver a supportive home away from home for families impacted by a child's life-limiting condition.

The future services of Hummingbird House will include

- 24/7 respite care including physician and nursing support, allied health and volunteer support
- pain and symptom management
- end-of-life care
- grief and bereavement support services and pastoral care support
- sibling support services
- paediatric palliative care community based outreach service
- after hours state-wide telephone support service for carers of children and adolescents with life-limiting conditions

Hummingbird House will be built within the Brisbane region, but will be available to all Queensland children and their families regardless of their geographical location within Queensland.

Hummingbird House will offer similar services to Queensland families that are currently offered by Bear Cottage to NSW families and Very Special Kids to Victorian families. These facilities have a proven longevity of service provision for 17 and 27 years respectively.

QK recognises that Queensland has previously offered similar services to Queensland families through Zoe's Place. The cessation of Zoe's Place was not in any way associated to lack of need of these services.

QK believes it is unnecessary to achieve in Australia the current ratios of children's hospice provision in the UK, (44 children's hospice for 63 million people compared to 2 children's hospices in Australia). This current ratio would equate to Australia deserving 16 children's hospices, however, establishing a third children's hospice in Australia would be the most appropriate pathway to a national strategy of between 6-8 children's hospices for Australian families.

QK would be supportive of including Hummingbird House working towards establishing a national strategic alliance with Bear Cottage and Very Special Kids.

Furthermore, QK has developed a robust *Business Plan* for the establishment of Hummingbird House to ensure sustainability and operational credibility. Included in this *Business Plan*, is the continual exploration of partnerships with lead state-based Care Service Providers to achieve the optimal return of future investment of corporate and government funding. This document would be made available to the HCSC upon their request. This document was developed with significant input from the stakeholders mentioned within this submission.

The establishment of Hummingbird House for Queensland families and servicing a critical gap in the paediatric palliative care landscape is the capstone recommendation of this parliamentary inquiry submission by Queensland Kids. The evidence of need for this type of paediatric facility in Queensland is overwhelming and the moral obligation of the State Government to assist QK in achieving this service for families is compelling.

APPENDIX 1 – Community Forums

In July 2012, Queensland Kids facilitated 3 separate community forums held at Palliative Care Queensland offices. As a result, the following feedback was collated. Any specific comments included in this submission have been footnoted but wish to be treated with anonymity.

1. Mental Health

Issues

- Social isolation after death – nobody knows how to approach you
- Suicidal and homicidal thoughts: "The reason my children and myself were in danger was because I had no hope that there was anyone to care for us"
- "I was more frightened of dying myself, because no one would be around to care for him, than being frightened of his actual death".
- Mental health issues around the siblings and the carers are devastating
- "What reason do you have to live if your child dies and you know that your genetic makeup is the cause, and you are still a carrier with the potential for this to happen to any of your other children?"…parents can be left with a sense of hopelessness
- Hospital admissions isolate you…mental exhaustion….you get "batty"…you have to manage your own mental health during the admissions
- Sleep deprivation inhibits coping and decision making
- 'Outside' people do not know you child is dying, difficulty of having to explain or justify behaviours
- The child can look well, but they are dying

Recommendations

- Need to have a mental health care risk management and focus incorporated in the palliative care process
- The experience, although devastating has shaped me in a positive way

2. Siblings

Issues

- Parents are passionate to help the siblings live fully
- The impact if the siblings only experience of being a sister or brother is being a sibling to a dead child
- Siblings are missing out on normal experiences…being told to be quiet in the hospital
- Need for sibling support programs during illness and post death
- Stress on the marriage/partnerships siblings does not stop when the child dies

Recommendations

- Develop sibling support programs in conjunction with Palliative Care plans of care for the sick child and the family

3. Grief and Bereavement

Issues

- All the help was post death, no palliative care grief support prior to death
- Men and women grieve differently
- No follow up for the neonatal death
- The concept that "this is forever"…the palliative experience does not stop with the death
- Child death 'taboo'
- People pretend it didn't happen
- Cultural barriers i.e.: indigenous cultural practices can make grieving process more difficult if you can't name the deceased child
- Pre-emptive grief when your child is newly diagnosed
- "There is no cure" – immediate response is: plan a funeral….but that could end up being years away
- The whole family has the disease/ is impacted by the disease
- Don't want to talk about the child dying when the child is not actively dying
- Needing contact with the hospital 'family'
- Grief over the loss or 'cut ties' with hospital staff and support services staff after the child has died
- Male voice is often missing
- 'We missed the boat, our son had no palliative care." Child is offered palliative care service the day he dies

Recommendations

- Need for post traumatic grief support
- Need support groups centred around child loss
- Need male based support groups
- Bereavement support in WHO
- Couple need their own time to maintain their relationship
- Need for grandparent support
- Support the individual experience of death and dying

4. Hospital Admissions

Issues

- Practical costs - $800 parking in 6 months
- Dealing with caring 24hrs a day in hospital because a carer is expected to stay with the child
- Navigating the hospital system, advocating for your child and physical care requirement is too much
- Dealing with social issues in shared/public rooms while your child is unwell or dying

- Trust issues for the carer while their child is in hospital…untrained or ill equipped staff will not provide the appropriate care
- Parent's told by senior hospital staff to 'Lower your expectations" regarding the care of their dying child.
- Child is medicated so that the parents can rest/sleep, but then they miss out on time with their alert child – vicious cycle in a timeline that is so limited
- The fight against the system is exhausting
- Advanced health care directives were dismissed by hospital staff, parent's were told they were 'giving up on their child' by having a plan
- "You are too attached to your child's care"… a parent can never be too attached to wanting the best for their child
- Staff were not trained with equipment specific to the child
- The ward did nothing to protect the privacy of the family during palliation
- The power play between private Dr and public Dr and the family gets caught in the middle and care is compromised
- Public patients can get a better deal…better access to subsidised scripts etc crossover of public/private service e.g.: paying for syringes as a private pt vs given syringes as a public
- Lack of communication within the hospital system
- No transparency in the hospital system
- The adolescent in hospital is removed from their peer group – they are not adults but they are not young paeds
- Current palliative care for neonates, to be discharged from hospital and return when child has died or is in active palliation phase
- Difficulty of getting Hospital in the Home support as a private patient
- Oncology treatment does not give time to prepare for death and grief

__Recommendations__

- Needs to be an opportunity for a specific handover which includes the parent/carer because the carer/parent is the expert. Parent needs to be able to contribute to the handover process. Parents are the experts and need that recognition
- Centralised care by 1 lead paediatrician helps decrease confusion and helps increase clear communication between allied health and different departments
- There must be more training for staff in complex care
- Complaint system must be more accessible to parents and carers within the hospital
- There needs to be a hospital advocate person to contact to find out their rights
- Parents need a copy of the health care charter to be informed of their rights or what they can expect
- Hospitals should develop parent connect forums
- Tenders for the equipment within hospitals should have consumer input to be as comprehensive as possible for the consumers

5. Information Dissemination

__Issues__

- There is a fine line between information and need for hope – the timing of the information pathway
- The challenge of the DNR process
- Hospitals had not introduced parents, parents had to introduce themselves
- Lack of efficient information dissemination

__Recommendations__

- NGO's (non-government organisations) like QK, PCQ could develop pathways for education and information.

6. Service Providers

__Issues__

- Equipment is being sourced through 'personal contacts' rather than through designated referral systems
- Equipment is being hired by parents through private companies because it is not available through the hospital service
- Karuna wouldn't provide care because of the child's age

__Recommendations__

- Need for a community based paediatric service outside of the RCH service
- Need a new model of care for paediatric pall care
- Subsets within 'paediatric'
- Need to develop subsets within the 'paediatric' framework. i.e.: neonate, toddlers, teens etc. The child's mental development may not match their physical growth

7. Advocacy

__Issues__

- The family is the child's voice, you are the mum last….you have to be the therapist, nurse, equipment specialist before you get to be the mum who is just so worried about their child
- Parent has to advocate for **themselves** and their **child** while in hospital
- Parents were considered abusive or trouble makers in hospital because they were advocating for and protecting their child and the care necessary.
- Parents needing guidance: "please tell me when enough is enough"
- Parents who were needing respite and support hoped to win $30 million lotto to build a house and provide the support they were not getting!
- Parents can become apathetic and bitter due to the constant struggle to advocate
- What happens if you are not 'switched on'
- Children can die before they should because their carers are not 'switched on' to access the most beneficial services

__Recommendations__

- The value of being able to call an advocate to step someone through the process i.e.: Call PCQ, QK
- Need a case manager from a centralised service

- Future needs = collaboration of support services e.g.: QK/CanTeen/SilverChain
- Need to reform the cultures of hospitals to help create memories

8. Funding

Issues

- Lengthy hospital stay resulted in loss of funding, because the child was not 'in the home"
- Centrelink payments are difficult or ceased with death of child
- Government paperwork for neonatal death only provides space for 'stillborn' doesn't allow for the fact that they may have lived a short time.
- Grandparent and grandson were both eligible for HACC funding, but the grandson's access was much more difficult because of his age
- Funding is often given an 'adult' definition and children do not fit that definition
- HACC flexibility is positive, if it is changed, funding will become harder to access.
- Kids are surviving longer and the government can't cope with the issues arising from the longer illness trajectory
- Increased population, with increased complexity with increased survival rate increases funding issues
- Dying child does not fit the appropriate categories, so funding is unavailable or scarce
- Organisations don't know about HACC
- DSQ assessment – very difficult and convoluted and long
- Inequity of oncology/vs non oncology funds

Recommendations

- Comparative cost between community care ($63/day) and acute hospital care (up to $1000/day). Hospice care (approx. $500/day)
- More collaboration between organisations so that broader knowledge around available funding is shared.

9. Transition from hospital to home

Issues

- Little or no support when transitioning from hospital to home
- Currently neonates are discharged from hospital, sent home and must present in active palliation phase or after the child has died

Recommendations

- Information and service providers pathways are developed by the hospitals or NGO's

10. Education

Issues

- Need to be educated from the range of insurance issues, to diagnosis, to funding options
- Parents are educating parents
- Parents need education around the death process, what to expect, funeral options etc.
- Lack of trained specialists
- Lack of information about the disease, parents are educating themselves
- Information is social worker dependent – if you don't have a consistent social worker you miss out on information
- Difficulties in the sector reflect the community's inability to talk about death

Recommendation:

- Short education courses developed by NGO's: this is what happens, photo options, how to start preparing siblings etc.
- Need a pathway of information sharing
- Have a standard checklist of info developed by the hospitals
- Need a 'hospital for dummies' book published
- Need info to help with the 'nice touches"
- Need clear info or definition by the Dr or medical staff to say clearly: 'He is dying' to help prepare for the event

11. Hospice Care

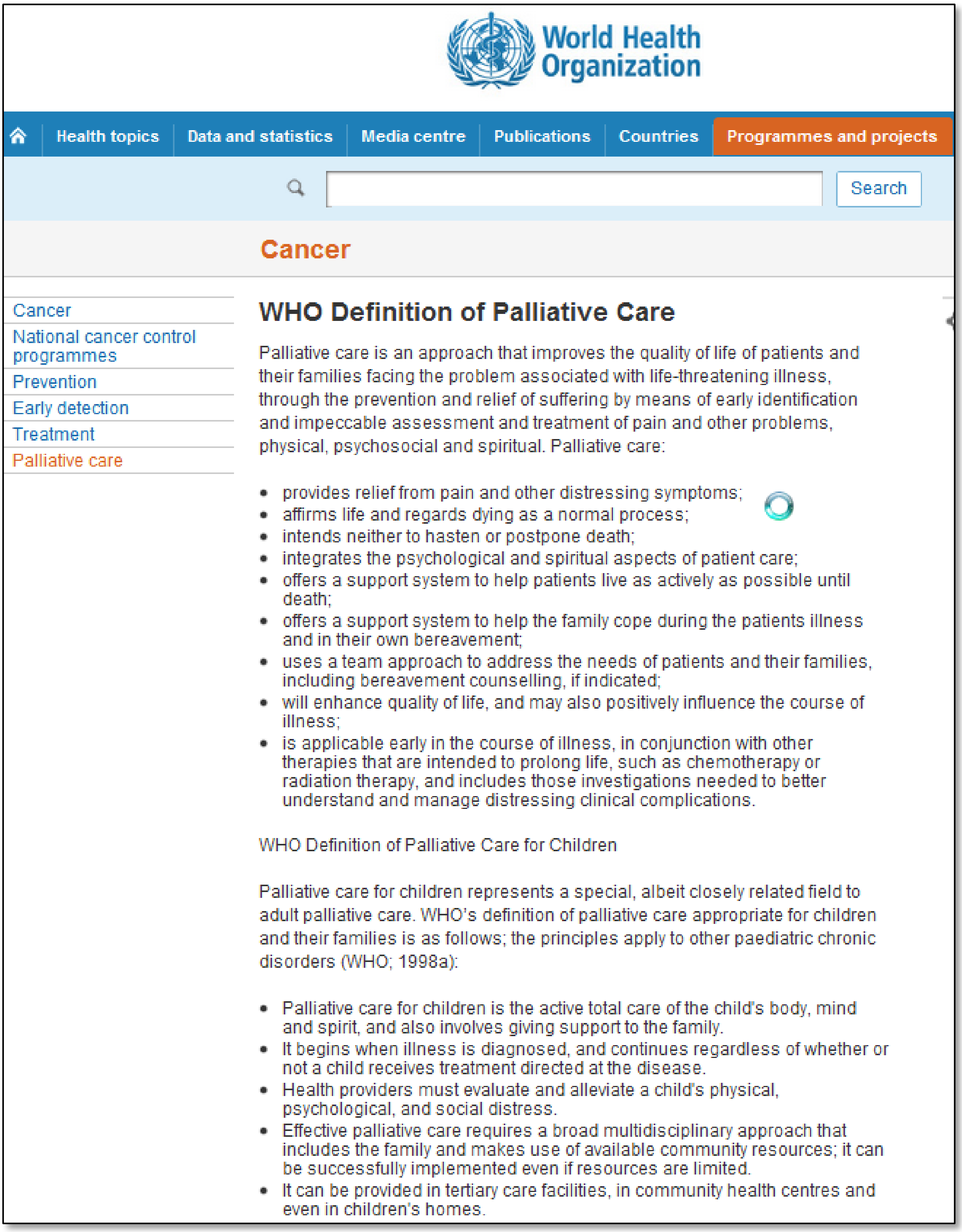
Issues

- Currently parents have no choice…either home or hospital
- Parents are not wanting the child to die at home, it leaves too much responsibility on them
- Client centred care needs to happen

Recommendations

- 'Zoe's Place' was a pool of information for parents. A children's hospice could be a 'one stop' shop for collaborative information about services
- Hospice care allows for the continuum of care plan/care service to remain the same as home. By following the home routine and method of care, parents/carers can continue seamless care after respite
- ALL families need the chance to experience respite
- Hospice could develop a services directory

APPENDIX 2 – World Health Organisation Definitions of Palliative Care



WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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:

- 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;
- 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.

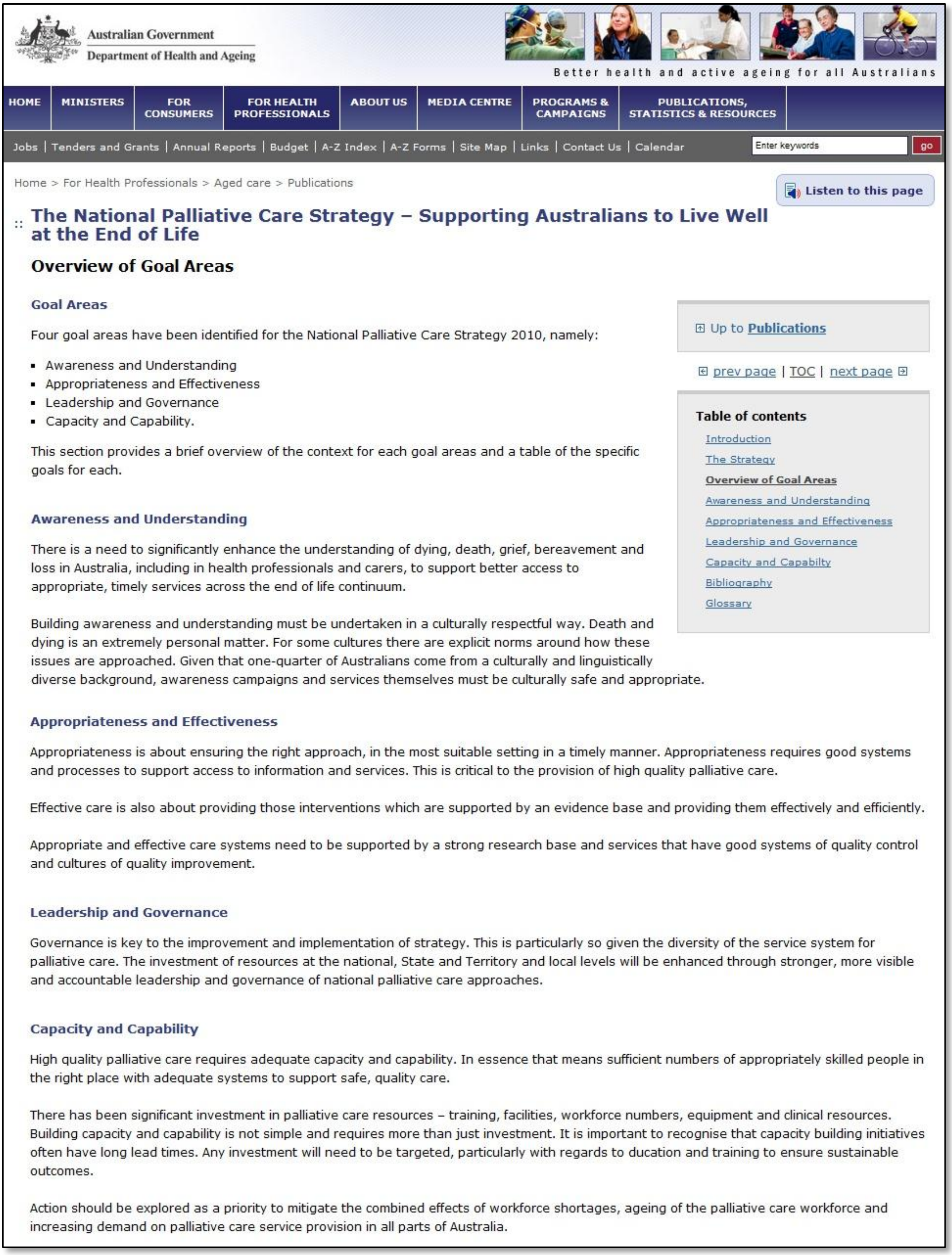
WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- 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.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

http://www.who.int/cancer/palliative/definition/en/

APPENDIX 3 – National Palliative Care Strategy



The National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life

Overview of Goal Areas

Goal Areas

Four goal areas have been identified for the National Palliative Care Strategy 2010, namely:

- Awareness and Understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability.

This section provides a brief overview of the context for each goal areas and a table of the specific goals for each.

Table of contents

Awareness and Understanding

There is a need to significantly enhance the understanding of dying, death, grief, bereavement and loss in Australia, including in health professionals and carers, to support better access to appropriate, timely services across the end of life continuum.

Building awareness and understanding must be undertaken in a culturally respectful way. Death and dying is an extremely personal matter. For some cultures there are explicit norms around how these issues are approached. Given that one-quarter of Australians come from a culturally and linguistically diverse background, awareness campaigns and services themselves must be culturally safe and appropriate.

Appropriateness and Effectiveness

Appropriateness is about ensuring the right approach, in the most suitable setting in a timely manner. Appropriateness requires good systems and processes to support access to information and services. This is critical to the provision of high quality palliative care.

Effective care is also about providing those interventions which are supported by an evidence base and providing them effectively and efficiently.

Appropriate and effective care systems need to be supported by a strong research base and services that have good systems of quality control and cultures of quality improvement.

Leadership and Governance

Governance is key to the improvement and implementation of strategy. This is particularly so given the diversity of the service system for palliative care. The investment of resources at the national, State and Territory and local levels will be enhanced through stronger, more visible and accountable leadership and governance of national palliative care approaches.

Capacity and Capability

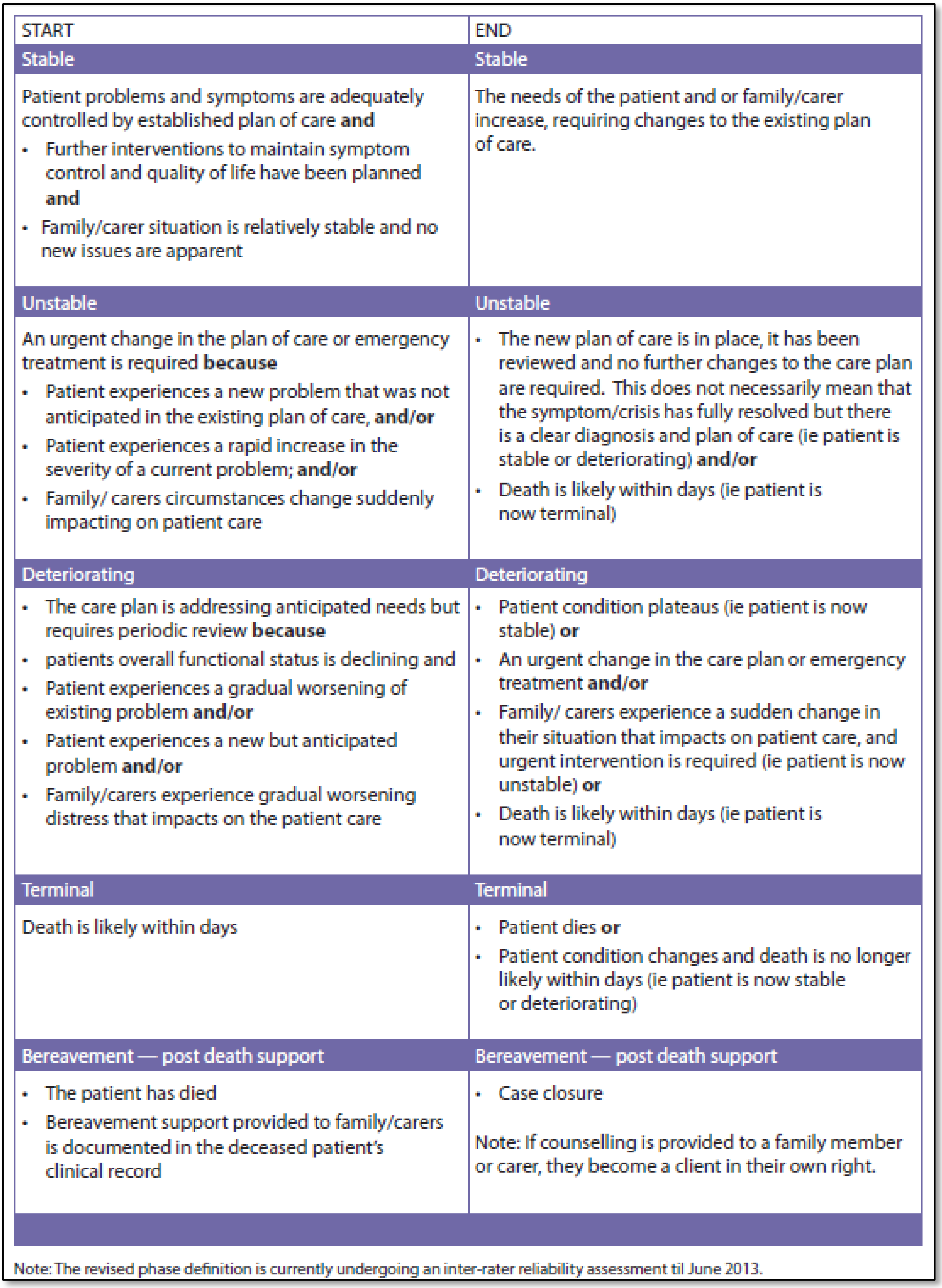
High quality palliative care requires adequate capacity and capability. In essence that means sufficient numbers of appropriately skilled people in the right place with adequate systems to support safe, quality care.

There has been significant investment in palliative care resources – training, facilities, workforce numbers, equipment and clinical resources. Building capacity and capability is not simple and requires more than just investment. It is important to recognise that capacity building initiatives often have long lead times. Any investment will need to be targeted, particularly with regards to ducation and training to ensure sustainable outcomes.

Action should be explored as a priority to mitigate the combined effects of workforce shortages, ageing of the palliative care workforce and increasing demand on palliative care service provision in all parts of Australia.

http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/NationalPalliativeCareStrategy.pdf

APPENDIX 4 – Palliative Care Outcomes Collaboration (PCOC)



START	END
Stable	**Stable**
Patient problems and symptoms are adequately controlled by established plan of care **and** • Further interventions to maintain symptom control and quality of life have been planned **and** • Family/carer situation is relatively stable and no new issues are apparent	The needs of the patient and or family/carer increase, requiring changes to the existing plan of care.
Unstable	**Unstable**
An urgent change in the plan of care or emergency treatment is required **because** • Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** • Patient experiences a rapid increase in the severity of a current problem; **and/or** • Family/ carers circumstances change suddenly impacting on patient care	• The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (ie patient is stable or deteriorating) **and/or** • Death is likely within days (ie patient is now terminal)
Deteriorating	**Deteriorating**
• The care plan is addressing anticipated needs but requires periodic review **because** • patients overall functional status is declining and • Patient experiences a gradual worsening of existing problem **and/or** • Patient experiences a new but anticipated problem **and/or** • Family/carers experience gradual worsening distress that impacts on the patient care	• Patient condition plateaus (ie patient is now stable) **or** • An urgent change in the care plan or emergency treatment **and/or** • Family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (ie patient is now unstable) **or** • Death is likely within days (ie patient is now terminal)
Terminal	**Terminal**
Death is likely within days	• Patient dies **or** • Patient condition changes and death is no longer likely within days (ie patient is now stable or deteriorating)
Bereavement — post death support	**Bereavement — post death support**
• The patient has died • Bereavement support provided to family/carers is documented in the deceased patient's clinical record	• Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

Note: The revised phase definition is currently undergoing an inter-rater reliability assessment til June 2013.

http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow119162.pdf

APPENDIX 5 – Palliative Care Australia Standards

The thirteen Palliative Care Australia *Standards for providing quality palliative care for all Australians* (4th ed).

1 - Care, decision making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families' needs and wishes are acknowledged and guide decision making and care planning.

2 - The holistic needs of the patient, their caregiver/s and family are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.

3 - Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

4 - Care is coordinated to minimise the burden on the patient, their caregiver/s and family.

5 - The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.

6 - The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.

7 - The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

8 - Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.

9 - Community capacity to respond to the needs of people who have a life-limiting condition, their caregiver/s and family is built through effective collaboration and partnerships.

10 - Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

11 - The service is committed to quality improvement and research in clinical and management practices.

12 - Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

13 - Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

http://www.palliativecare.org.au/Standards/Thenationalstandards.aspx

APPENDIX 6 – ACT Manifesto

The UK have produced a ACT's 2010 Manifesto - *Living Matters for Dying Children*

ACT believes that:
Living Matters for Dying Children. Every life-limited baby, child and young person deserves a tailor made and unique package of care and support that is right for their individual journey. All children with palliative care needs living in the UK should have equal access to care and support – no matter where they live.

Families need help too. Coming to terms with the news that your child will die young is devastating. Parents and carers often provide 24/7 care for their children and the pressure of caring for a child with complex health needs is sometimes physically exhausting and unbearable. Siblings' needs must not be forgotten. They bear an enormous emotional burden and need special help and support too

1. Choice of where care is delivered
Give life-limited children and their families/carers a real choice in how and where they receive care and support by resourcing and developing more Community Children's Nursing Teams or District Nursing Teams who can deliver care in the family home, which is where most families want it. Having care delivered in the home can make such a difference.

2. 24/7 care
Ensure that every baby, child and young person with palliative care needs has access to 24/7 care and support. Children with complex health conditions often need round the clock care and support, particularly when they are at their end of life. Parents need support night and day too.

3. Unique packages of care
Give every child with palliative care needs a unique package of care and support. Every child's journey will be different and unique to them; they need access to a personal care plan that supports their needs, wishes, culture and beliefs. This package should be appropriate for their age, whether they are a baby, child or young person.

4. A seamless service for young people
Ensure young people's transition from children's to adult palliative care is a planned and seamless service; and invest in developing age-appropriate services that these young people want and need.

5. Choice of place of death
Give families and children a real choice in their place of death and end of life care. Few babies, children and young people have the chance to die at their family home or a children's hospice; where most families say that they want their child to die. Over 74% cent of children with palliative care needs die in hospital; with only 23% dying at home or in a hospice. For babies with palliative care needs, nearly all die in hospital (over 98%) and less than 1% of these babies are able to die at home with their families. ACT wants the next parliament to change this norm.

6. Universal emotional and bereavement support
Ensure every family is provided with good quality emotional and bereavement support from the point of their child's diagnosis through to their child's death and beyond. The needs of siblings and extended family members must not be forgotten.

7. Sustainable funding
Ensure sustainable funding is available to develop the services children and families need to provide care at home, in a children's hospice or in hospital.

http://www.act.org.uk/news.asp?section=94&itemid=606&search=manifesto

APPENDIX 7 – Video Presentations

Queensland Kids would like to include two media clips as part of this submission.

VIDEO 1: Two journeys… One need… Hummingbird House

This short video clip gives insight into the lives of two Queensland families affected by their child's life-limiting condition (*Produced: August 2012*)

URL: [redacted]

DVD: A hard copy of the video clip will be available on DVD for the public hearings

VIDEO 2: Queensland Kids is turning the light on for Hummingbird House

A short video-clip to help raise community awareness about the need for Hummingbird House for Queensland families affected by life-limiting conditions *(Produced: December 2011*)

URL: http://tinyurl.com/HHvideo2

DVD: A hard copy of the video clip will be available on DVD for the public hearings

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PALLIATIVE CARE QUEENSLAND CEO: John-Paul Kristensen

John Paul is the CEO for Palliative Care Queensland. After watching his brother suffer what he describes as 'the worst death I've ever seen', he decided to get involved in the world of palliative care himself. The journey has taken him from a nursing background specializing in palliative care and running the cancer helpline to now being the voice at a national level for those who are dying.

Palliative Care Queensland is the voice of those in the community who are dying and those who care for them: their families, friends, carers and the professionals who look after them.

We stand up at a government level and argue on their behalf, going in to bat for them in driving both sides of the political argument to find better solutions for the future. We hope that part of these negotiations would include funding for a paediatric hospice. As a part of our national network, we are also responsible for coming up with the guidelines and rationale for what is good palliative care and how it's implemented.

Australia has a very significant need.
Around 1200 children die here each year. We need more respite/hospice facilities. We can quote figures from the UK about how many hospices they have per head of population but it's certainly very, very different here. In terms of disease, it's certainly the non-oncology patients who tend to miss out more than the oncology patients because of their long duration of illness. Queensland has the added tyranny of distance. We need to be able to provide paediatric palliative care across the state, wherever it's needed.

What we know is that Queensland has very different needs to the rest of the country.
This is largely because of the size of Queensland and the way the population is dispersed. If you're dying in a place like Mitchell, there is no palliative care for adults or children. That's why we have telehealth, which gives us the capacity to teleconference with a parent/child over the phone. This provides specialist consultancy, which is a good start.

Once the child gets too sick to be home, they have to go to the first available space where they can be cared for in Brisbane. Parents, a lot of the time, sleep on the floor next to the bed or they can get a motel room or, if there are places available, they can go to Ronald McDonald House. They have to search for places to stay. It's not easy or cheap.

It's a human process, not just a medical process.
You're not talking about kids just being disabled, but dying. There's a lot more emotional need. Kids who are disabled and dying need a lot more than what Disability Services Queensland can currently give.

There's another layer when they are dying and that makes it very difficult for the system to cope when there's very limited funding.

I've heard parents talking about searching for various programs and packages and not knowing where to go or how to find them and eventually finding a maximum of six hours per week – that's the most anyone can get in terms of respite and that's after hours and hours of searching. There's a lack of information and awareness. Parents are very isolated. They are so concerned with looking after the needs of their kids; they don't know what to do when kids deteriorate, or where to go for help. They have to search for themselves.

Kids are chronically ill for much longer and so the model of care they need is very different.
A children's hospice is set up for respite. It's to give dying children an opportunity to go somewhere to be cared for by specialists for a period of time to give Mum, Dad and the family a break.

The child needs things like good play time and education. The family needs to be a lot more involved. Mum and Dad will be there pretty much all of the time. And it needs to incorporate the needs of the family – if there are siblings they need to be kept psychologically healthy throughout the process. Mum and Dad need to be sustained and they need respite. Mum and Dad need time to recharge because it's a full time job.

Dying isn't very sexy.
That's why we don't have a hospice. It's very difficult to talk corporate donors into providing money to an organization that might be a challenge to their image. It's very different if you have a kid's facility where you are going to get treatment for cancer, because you can survive cancer. It's all about cure, about fighting. Palliative care is not about that; it's about facing up to the fact that kids are dying and there is no cure.

In palliative care, one of the biggest sponsors is funeral directors because they benefit directly from people dying. It's pretty logical but it doesn't mean we like it.

Written by Author - Renee Bennett   Photography - Essence of Time

Maggie Leung uses music as therapy for dying children

What does your role of Music Therapist involve?

As a Paediatric Palliative Care Music Therapist, I use music to connect with children and families. By using singing, making music together and song writing, we hope to create positive and valuable memories and experiences for them.

What does a typical day look like for you?

Do you really want to know? I look at the triage referrals from the medical, nursing and allied health team. I review the medical charts of the patients that I am aiming to see. I then meet the families and patient to see whether physically, emotionally and medically they would like to have music therapy that day. If they do, I pack my guitar, laptop and box of instruments. Generally a session can for at least an hour.
With patients and families that I have a long term relationship with, I may get an unexpected page if they would like me to be there while their child passes away.
Sometimes, if we know that a child is coming toward the end of life, I chat honestly with the families regarding what music they would like me to prepare in the room to be used if they would like private time.

Over what period of time do you work with patients?

It depends of whether a child has been deemed as 'short term palliative' or 'long term'. Long term can go on for years where as short term can be as quick as 24 hours or up to 3 months. I often see the patient twice to three times a week.

In your sessions, do you work with just the patient or the whole family?

The music therapy department's mission is to provide a family-centred care service. We believe that every child comes as a unit (family). We have music therapy with the whole family.
With teenagers, this may vary. We want to respect them having a choice. Sometimes they want music therapy to be just their thing. Often they want to use the sessions to create or leave a video/song/message for their families. We do a lot of song writing. This is the most challenging part of my job.

You've written a song yourself. What is it about and what was the inspiration behind it?

'You and I' was inspired by one of my deceased babies. Baby J was healthy until the age of 3 months when he was diagnosed with AML (leukaemia). Baby J's mum had always read this special poem that she wrote for Baby J when she was pregnant with him. I met them in their second week of treatment and we always finished our music therapy session with this special poem. Towards the end of Baby J's life his mum was no longer emotionally capable to read it to him. The poem inspired me to write a song for them.

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What do you see as being the greatest needs of the parents as they journey with a terminally ill child?

They need empowerment and non-judgemental support. These families are going through such a tough time. Not only are they losing the most precious little one in their lives but they are losing their role as a parent and their hope for the future. Due to limited resources, parents are often left with minimal options and no control. They don't have any control over their child's medical team's decisions or the nursing care or procedures, like bathing and feeding. The have minimal options on where their child will stay. Hospital is such a clinical/medical environment but their child requires the care. We often try to get the children home, but due to their fragility this is not always a safe option.
Families are very strained from the 24/7 hour care their child needs.

How then would a place like Hummingbird House help these families?

It is so important to have a 'home away from home' for these families, a place where parents can trust the professionals to look after their children but in a more family welcoming environment. A place where they have control and familiarity. They need an option other than home and hospital. It would provide somewhere they could have more power over decision making, privacy and permission to be together as a family.

These families also need respite. Palliative is not a diagnosis. It is a journey, a process and a phase, which can go for a long time. These parents need some space at times to look after themselves. They need practical assistance so they can still go to work, sleep through the night without waking every hour to check their child, or even just for themselves.

Hummingbird House could also provide much needed bereavement support for parents and siblings.

Can you describe what it is like to be allowed in the room with a family in the most intimate moment of saying goodbye to their child?

To be honest, I don't think any words can truly describe the experience...but I think it is the most humbling and loving experience in life. It is a privilege to be there.
Intellectually you try very hard to hold yourself together to sing the best you can...to provide music that you know will stay in these families minds forever. At the same time you want to be emotional about it so you are truly creating music that is full of genuine love and care.

SO WHY HUMMINGBIRD HOUSE?

Somewhere today in our vast world, is the smallest of birds, known as the Hummingbird. Though small in stature, it is an extraordinary creature.

For this very reason, we have chosen to call this, Hummingbird House.

Though small in stature, children living with a long term palliative disability are nothing less than extraordinary!

Hummingbirds are continuously hours away from starving to death and are able to store just enough energy to survive overnight. They do not spend all day flying as the energy cost would be prohibitive. The majority of their activity consists of simply sitting or perching. The sad reality is that for these children, death could be just moments away and a lot of their energy is used in just trying to live.

The Hummingbird's name was derived from the hum caused by the rapid beat of their wings, up to 110 beats per second. It could be said that a Queensland Kid's life song is often composed by their valiant efforts to live...the 'hum' they and their family generate as they make the most of each day.

While a hummingbird rapidly beats it's wings, it does this just to hover and remain suspended in the air. The journey of a child with a life-limiting condition can often seem suspended in time. Many never move forward on the journey of normal growth or development.

Hummingbirds are the only bird in the world that can fly backwards. The journey of a child with a life-limiting condition is often one of backward motion...moving away from a full future.

Hummingbirds don't use their feet to walk but for perching. Queensland Kids are often wheel chair bound and spend most of their life just sitting and waiting.

Indeed, many Hummingbirds die in their first year of life during hatching and leaving the nest. If they do survive they can live as long as 10 years but the average lifespan is 3 - 5 years. Such a life span is similar in length when compared to a child with a life-limiting condition.

Many species of the Hummingbird have bright plumage with exotic colouration. This comes from prism like cells within the top layers of the feathers. When light hits these cells varying degrees of intensity are revealed. By a mere shift of its position and a ray of light, the colours of a Hummingbird can be transformed from grey to fiery red or vivid green. When looking at a child with a life-limiting condition, one can be caught by a sudden look of engagement or expression in a child's face that breaks through the façade of the physical symptoms which can make a child look unattractive or blank.

Hummingbirds are capable of covering astounding distances – Queensland Kids' and their families are capable of doing astounding things within their lifetime and making an astounding impact on those around them.

Written by Children's Author – Renee Bennett