

# **Inquiry into palliative care services and home and community care services in Queensland**

**Submission to Health and Community  
Services Committee**



**August 2012**

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## Background

The Karuna Hospice Service Ltd (Karuna) is a Brisbane based organisation with Charitable and Public Benevolent status. It was established in 1992 to relieve fear and suffering in relation to death and dying. Karuna is a knowledge-based organisation that combines the wisdom of the Buddhist tradition with evidence-based best practice to provide health care and life education. Karuna aims to enrich and transform lives with a holistic approach to care.

Karuna currently provides home based interdisciplinary specialist palliative care services within the Queensland Health Metro North District. The boundaries of the geographical area covered by Karuna are:

- Elimbah and Donnybrook (north of Caboolture) to the north
- Wights Mountain and Kenmore to the west
- Moreton Bay (including Bribie Island) to the east
- Brisbane River to the south

It is estimated that the population in the area covered by Karuna is 800,000 – 1,000,000.

The specialist disciplines include nursing, social work, bereavement support, pastoral / spiritual care and counseling. In addition to these professional services, Karuna also provides comprehensive in-home volunteer services to support clients and their caregivers. In addition to the holistic care services, Karuna offers support to the broader Queensland community by way of information, education and meditation.

Karuna's clinical service is consistent with a Level 3 Palliative Care Service, according to the Queensland Health Clinical Services Capability Framework Palliative Care Module (CSCF) version 3<sup>1</sup>. Karuna does not employ a medical specialist; all clients have access to a medical specialist with credentials in palliative medicine in a shared care arrangement. This can be a General Practitioner or from a specialist team. Karuna participates in the Palliative Care Outcomes Collaboration and the National Standard Assessment Program.

The Palliative Care Helpline for Queensland is operated by Karuna. This Helpline aims to provide immediate information and support to people across Queensland. The Helpline and the clinical services are partly funded by the Queensland Government, with additional funding sourced through charitable donations and fundraising events. Karuna currently employs 24 (FTE) staff and assists over 2000 Queenslanders each year.

Karuna is a non-Government organisation providing community palliative care services in Queensland. Therefore this submission intentionally comments on community palliative care service provision in Queensland.

## **Karuna's Position**

Karuna believes that care of the dying is everybody's business and responsibility. It is not the sole domain of hospitals and health professionals. Communities need to be supported to care for people with a potentially life limiting condition (including all chronic diseases and cancers) in their location of choice.

Karuna calls on the Health and Community Services Committee to consider the following:

- Queenslanders should have equitable access to health services, particularly palliative care and end of life care
- Strategic plans and funding models should enable Queenslanders to be cared for and die in their setting of choice
- Queenslanders who are approaching the end of life should have access to a full range of health professionals to address all their physical and psychosocial needs
- Queenslanders should have a choice of community care providers that can support their individual cultural and belief systems for their end of life care.

## Response to Terms of Reference

### *1. Capacity and future needs of community based services:*

It is well documented that when asked, people who require palliative care choose to be cared for and die at home. However, less than half of them are able to do so in Queensland. Community palliative care services are operating at capacity and most services have waiting lists which is incongruent with quality palliative care service delivery and client choice.

Queensland's growing and aging population indicate that the demand for community palliative care services is going to grow considerably over the next fifty years. Further, the burden of disease in Queensland is predicted to increase with the significant rise in chronic diseases and dementia across the state. Currently, according to Palliative Care Outcome Collaboration (PCOC) data<sup>2</sup>, 85 – 90% of people accessing specialist palliative care services have a malignancy as their primary diagnosis. This figure suggests that access to specialist palliative care services is already falling very short of requirement for non-malignant diseases in Queensland. Palliative care service delivery has reflected funding models and traditionally, funding has been sourced through cancer services. This needs to change as a matter of priority.

The delivery of quality palliative care requires 24 hour access to medical, nursing and support services. In the community setting, this is rare. Very few services provide comprehensive 24 hour support, which includes home visiting. General Practitioners are the lynchpin of community palliative care but it is uncommon for GPs to provide 24 hour care or home visiting, again resulting in hospital or hospice admissions. Karuna believes there is a direct causal relationship between the lack of 24 hour community support and the number of inappropriate and unnecessary hospital admissions of palliative care clients outside normal business hours.

Spiritual care is a core component of end of life care. However, access to spiritual care services (beyond the mainstream faith based approach) is severely lacking in Queensland. Several studies have demonstrated the importance of spiritual care at the end of life<sup>3</sup>. A recent systematic review of the literature about spiritual care at the end of life in the UK concluded that education and training in spiritual care is lacking<sup>4</sup>. The report made ten recommendations which included the urgent need to develop spiritual care policy and practice in community settings to support people who are dying at home. The situation in Australia is similar to the UK. The same evidence base is available but there is a lack of resources, education and training for spiritual care. Current funding models privilege medico-nursing care but do not adequately support people's psychosocial and spiritual care needs.

### *2. Effectiveness, efficiency and adequacy of palliative care services:*

#### *Effectiveness:*

The Australian Government funds a number of national projects to improve and enable quality, effective palliative care delivery. The Palliative Care Outcomes Collaboration (PCOC) involves the routine collection of outcomes data and measures against national agreed clinical benchmarks. The National Standards Assessment Program (NSAP) involves self-assessment of services in relation to the National Palliative Care Standards.

Both PCOC and NSAP are voluntary programs and they provide valuable processes for specialist palliative care services to improve quality. Not all community services who provide palliative care are participating in PCOC and / or NSAP. In the absence of agreed clinical indicators in palliative care, PCOC and NSAP are ideal vehicles for demonstrating effectiveness.

*Efficiency:*

The efficiency of community palliative care service provision is largely unknown. Access to services is currently based on funding sources, rather than individual needs. For example, if a community palliative care client lives longer than expected (regardless of symptoms and care needs), palliative care program funding can be withdrawn and services are ceased. The client will be transferred to another service provider (perhaps one that receives 'block funding') or no longer receives services. The latter scenario often leads to an admission to hospital. This model has created a fragmented system of care providers and a competitive operating environment.

*Adequacy of services:*

Community palliative care services in Queensland are inadequate. The need for services already outstrips availability and the reality of an increasing, aging and sicker population will add further pressures to this failing system. Hospital admissions (especially those outside normal business hours) could be significantly reduced by investment in community palliative care services. This will also enable people to be cared for and die at home which is most frequently, the setting of choice.

There are a significant number of community palliative care providers in Queensland, operating at all levels of the CSCF<sup>1</sup>. The collaboration and communication between these services is poor and often non-existent. This could be, in part, due to the competitive funding environment but it translates in to fragmented care for clients and families. A model which includes robust and consistent care coordination could help to overcome this issue.

A major shortfall for palliative care patients in the community setting is the lack of access to multidisciplinary support. This is particularly true for Allied Health professionals, spiritual care and pastoral support. The current funding mechanisms privilege the medico-nursing model. Palliative care is fundamentally multidisciplinary and it is essential that funding models reflect this.

The World Health Organisation (WHO) definition of palliative care recognises that palliative care may be provided by non-specialists<sup>5</sup>. However, in some circumstances, specialist palliative care support is necessary. Access to specialist support for community patients is patchy and depends on the preference of the local specialist provider. Service Level Agreements and Memorandums of Understanding between community palliative care providers and specialist palliative care providers are not common. This can make it difficult for non-specialist community providers (such as GPs or domiciliary nursing services) to access this support on behalf of their clients. It is an inherent requirement of the Queensland Health CSCF that higher level services formally link with lower level services (and vice versa) but this still does not happen routinely.

*3. Opportunities for health reforms to improve collaboration and cooperation between services:*

The full impact of the current health reform agenda on community palliative care services remains unclear. The creation of the Hospital and Health Services and the phenomenon of local planning could bring a number of opportunities. However, for these to be realised community palliative care providers (including GPs and domiciliary services) need to be included in the planning discussion.

Palliative care belongs in the community. Care provided by a multidisciplinary, generalist team will meet the palliative care needs of the vast majority of Queenslanders. Only a small percentage requires complex medical care which can only be provided by the Level 5 and Level 6 (of the CSCF) services. Currently, it is these high level services that drive policy decisions and hold the funding. The national health reforms provide an opportunity for palliative care planning and delivery to be transferred to the community. The Medicare Locals have an opportunity to create local community palliative care committees to establish needs, establish capacity and plan service networks. This committee could have the role of being the primary point of reference of the Hospital and Health Services regarding purchasing of all levels of palliative care services.

*4. HACC and community palliative care services:*

The multi-level and multi-source funding structure that exists for community care in Queensland makes access to care inconsistent and inequitable. People who require palliative care are currently not eligible for HACC funded services. This means that many people who have similar needs to current HACC clients (but who are also at the end of life) are unable to get services. This is especially true if the palliative care program funding fund holders (the Queensland Health specialist palliative care services) do not agree to fund the patient. The only option for the patient is to remain at home without services or be admitted to hospital until an alternative care arrangement (or funding source) is found.

It certainly seems to make sense that HACC funding be extended to include community palliative care. If this is the case, it is essential that appropriately skilled and equipped providers are eligible to provide the care. Participation in the palliative care quality programs (PCOC and NSAP) could be an indicator of such services. Further, it is important to ensure any changes to the funding system make it less complex but still flexible to meet individual client needs. There is potential to further complicate the HACC funding structure and this would be detrimental for people requiring access to palliative care (and HACC) services.



## Recommendations

Karuna recommends the Health and Community Services Committee considers the following areas for priority in their inquiry:

*1. Funding of community palliative care services:*

A shift of care is needed from hospital based services to community care services. In order to reduce the burden of palliative care patients in hospitals (and especially emergency departments), a redistribution of the funding from hospital based services in to community palliative care is needed urgently.

Urgent investment is required in bereavement and psychosocial care services across Queensland. Funding for these services need to include family members and friends (as separate episodes of care) of people who are dying.

*2. Improvement of collaborations and partnerships between different levels of service:*

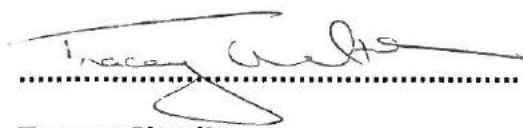
The Queensland Health CSCF provides minimum requirements for the provision of health services in Queensland. The purpose of this document is to guide a coordinated approach to health service planning and delivery. The CSCF recommends that 'service networks' are underpinned by documented processes to facilitate collaborative care arrangements. This does not happen routinely. Karuna recommends that any Queensland palliative care or end of life care strategy should include the development and identification of service networks (based on the CSCF) and these should be formally documented.

*3. Integration of palliative care with Home and Community Care Services.*

In principle, Karuna supports the integration of these services as it gives palliative care a community care focus. When deliberating this, Karuna requests the following be considered:

- A broader range of disciplines (beyond the medico-nursing model) be included. Allied Health, social work, spiritual care and counselling would need to be funded under HACC.
- There would need to be support for currently (block) funded community palliative care services to transition and become HACC service providers. Karuna is an example of this.

**Signed on behalf of The Karuna Hospice Service Ltd.**



**Tracey Charlton**  
**Chief Operating Officer**  
**1<sup>st</sup> August 2012**



## References:

1. Queensland Health Clinical Services Capability Framework – Palliative Care Module. Version 3. March 2011. Available at URL:  
[http://www.health.qld.gov.au/cscf/docs/24\\_palliative.pdf](http://www.health.qld.gov.au/cscf/docs/24_palliative.pdf)
2. Outcomes in Palliative Care – Queensland.. Report 11 January to June 2011. Palliative Care Outcomes Collaboration. Available at URL:  
<http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow114542.pdf>
3. Gijssberts MJ, Echteld MA, van den Steen JT, Muller MT, Otten HJ, Ribbe MW, Deliens L. Spirituality at the end of life: Conceptualization of Measurable Aspects – a Systematic Review. *Journal of Palliative Medicine*. 2011; 14(7): 852:863
4. University of Hull. Spiritual Care at the End of Life: a systematic review of the literature. 2011. Department of Health, UK.
5. World Health Organisation Definition of Palliative Care. Available at URL:  
<http://www.who.int/cancer/palliative/definition/en/>