Palliative Care in Australia

Submission to Senate Standing Committees on Community Affairs

karuna

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Background

Karuna Hospice Services 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 currently provides home based, interdisciplinary specialist palliative care services within the Queensland Health Metro North District. The specialist disciplines include nursing, social work, bereavement support, pastoral / spiritual care and counselling. In addition to these professional services, Karuna also provides comprehensive in-home volunteer services to support clients and their caregivers.

Karuna is consistent with a Level 4 Palliative Care Service, according to the Queensland Health Clinical Services Capability Framework version 3 (March, 2011). Although 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 is a non-Government organisation providing palliative care services in Queensland. Therefore this submission intentionally comments on palliative care service provision in Queensland.

Response to Terms of Reference

The current issues in palliative care in Queensland have been repeatedly and consistently documented over the past ten years. These issues include:

1. Inadequate provision and resourcing of psycho-social, spiritual and bereavement support services.

2. Inadequate funding for community services. Sub-acute funding, although welcome, has been directed to increasing beds and hospital based services. This does not promote enabling people to die in their location of choice.

3. Multiple system level barriers to the provision of equitable service delivery. These barriers include:

   I. Service delivery models which focus on quantity of interactions rather than promoting quality
   II. Funding models which create a competitive environment for service providers, instead of a collaborative one (for example, service tendering)
   III. Inequitable access to services. Level of access and funding depends on individual District criteria.
   IV. Inequitable governance and quality requirements between Government and non-Government services

Karuna’s Position

Karuna contends 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.

Recommendations

Model of Service Provision:

Karuna recommends a model that supports people with a potentially life limiting condition being cared for at home in a way that benefits individuals, their caregivers, their families, their friends and their communities. The model promotes equitable and collaborative care across the continuum from diagnosis, through treatment and death, to bereavement. Patients, their caregivers and their families are at the centre of this model, with service providers working in collaborative partnerships to provide care and support.

The recommended model includes the following essential components:

a) *In-home Services*

The availability and accessibility of clinical services in the community is paramount. People with potentially life limiting conditions should have access to a full range of in – home services and support. This includes (but is not limited to) nursing, medical and allied health support. This is consistent with the notion of providing the right care in the right place at the right time.

b) *Telehealth*

Queensland is a geographically diverse State. The provision of quality services in the regional, rural and remote areas of Queensland is challenging. The recommended model includes a robust telehealth system where primary care clinicians can access specialist support when required. Functions and capabilities of the telehealth system information and support for the general public, in-home clinical consultations, peer support and peer mentoring.

c) *Hub and Spoke Service Provision*

Traditionally, hub and spoke models of service planning and provision designate the large, tertiary service provider as the ‘hub’. Consistent with our position, this model proposes that the primary care level services are the ‘hubs’ and they are supported by specialist, secondary and tertiary level palliative care services (in this case, the ‘spokes’). Care is coordinated through the primary care service provider who can access support and refer to secondary and tertiary level services when required. This model promotes case management at the primary care level. It is expected that this will reduce hospital visits (including outpatient visits) as well as hospital admissions.

d) Care Coordination

Care of the dying cuts across all age groups, diseases and geographical locations. As such, people with potentially life limiting conditions often have a diverse range of needs, equipment and service requirements. The health care system is complex and difficult for people to navigate. Therefore, the recommended model includes designated care coordinators (at the primary care level) for each patient and family.

e) Collaboration

The current funding and service delivery models in Queensland promote siloing, resulting in reduced access and choice to services and organisations for patients and families. An essential component of the recommended model is the promotion of partnerships between services and organisations. Such partnerships will nurture and enable collaboration which will benefit the individual and family through improving access to services. The community will benefit through the efficient utilization of community resources.

f) Bereavement and Spiritual Support

Bereavement can be a severe stressor that can trigger the onset of physical and mental disorders[1]. Access to bereavement and spiritual care services usually occurs during the last few months of life or post death. This model promotes equitable access to bereavement and spiritual care services (for individuals who may benefit) through direct care or telehealth facilities.

A review of the literature regarding bereavement support has demonstrated that routine intervention in bereavement is not empirically based and intervention is only indicated for individuals experiencing complicated grief [2].Therefore, prevention of complicated grief syndromes is paramount. This model promotes building capacity in individuals, families and communities through early intervention and augmenting community awareness of loss and grief.

1. **Funding Model:**

Karuna recommends the implementation of an appropriate funding model that will ensure the delivery and fulfillment of the essential components of the recommended service delivery model.

a) Guiding Principles for the Funding Model:

Karuna recommends the following:

- Significant investment in primary care services – redirecting sub-acute funding to primary care services.
- Investment in infrastructure such as telehealth and education provision.
- Investment in non-Government organisations
- Reduction of duplication
- Promotion of collaborative working practices and partnerships

- Promotion of choice for individuals and families

b) Risks:

There has been an increasing trend of service tendering in Queensland. Karuna contends that there are inherent risks in this process. The outcome of tendering is that one service provider in a district / area health network receives a contract for services. This does not promote individual choice and potentially reduces the provision of culturally and philosophically appropriate care to certain cohorts of the population. This is not consistent with the National Palliative Care Standards[3]. Additionally, the tendering process is mainly concerned with cost of service provision, rather than quality indicators. Again, this is incongruent with the National Palliative Care Standards[3].

Conclusion:

This submission calls for primary care to be the recognised home of palliative care services in Australia. Benefits of this model include:

- Provision of support across the trajectory, from diagnosis to bereavement.
- Reduction of burden on hospital based services such as emergency departments, acute beds and outpatient's clinics.
- Provision of care in the location of choice – when asked, most people say they would like to die at home[4].
- Support more people for longer due to more efficient cost of primary versus tertiary care.
- Intangible benefits such as reducing the prevalence of uncomplicated grief through community capacity building programs.

References:

1. Hall, C. (2011). 'Beyond Kubler-Ross: Recent developments in our understanding of grief and bereavement'. InPsych, 33 (6): 10-11

2. Schut, H. & Stroebe, M.S. (2005). 'Interventions to enhance adaptation to bereavement'. Journal of Palliative Medicine, 8: 140-147.

3. Palliative Care Australia (2005). 'Standards for Providing Quality Palliative Care for All Australians'. PCA, Canberra

4. Foreman, L. M. (2006). 'Factors predictive of preferred place of death in the general population of South Australia'. Palliative Medicine, 20: 447.