

Palliative Care in Queensland



Submission to the Health and Community
Services Committee

The Health and Community Services Committee has invited Anglicare Southern Queensland (SQ) to provide a response to 4 main areas in relation to Home and Community Care services and Palliative Care services within Queensland. The 4 main areas for feedback are outlined in the terms of reference and relate to:

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

The following is a summary of the key issues identified for inclusion in the submission to the inquiry.

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1. The capacity and future needs of services (including children and adolescents palliative care)

Anglicare SQ is a primary provider of palliative care across three home and community care regions (Brisbane North, Brisbane South and South Coast). Anglicare SQ's level of palliative care services would be best described as primary palliative care according to the Clinical Services Capability Framework.¹

Our capability includes the provision of clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care. Anglicare SQ has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.

Anglicare SQ's palliative care services are supported by a multi-disciplinary team including access to 24 hours telephone triage support with on referral to specialist palliative care services, clinical nurse specialists, skilled registered nurses, allied health staff, pastoral carers and volunteers. These multidisciplinary teams have a relevant knowledge of palliative care principles and practices and when necessary seek advice from or refer to specialist palliative care services.

Anglicare SQ's capacity to provide quality palliative care services is best demonstrated through its assessments of care and support needs for clients and their families/carers; access to 24 hour telephone triage support; access to bereavement support services; subcutaneous infusion devices for symptom management and access to an equipment hire service for items such as hospital beds.

Anglicare SQ has identified issues of limited choice for people who are palliating within Queensland. Children 0-18 years of age currently have no option of care outside of foster programs or hospital. Access to a paediatric hospice service is limited to interstate travel to Sydney or Melbourne. Younger people aged 18-65 years also have no option of accommodation/care outside of Residential Aged Care or Hospital within Queensland. Rural and remote areas equally have gaps in service provision relating to both in home services and hospice care.

The future demand for palliative care services is expected to increase as a result of an ageing population. Compounding this demographic shift, as described above, Anglicare SQ has summarised gaps in service delivery as described below:

- Affordable, 24 hour in home care provision for people of all ages
- Hospice accommodation for 18-65 year age group
- Paediatric Hospice accommodation for children 0-18
- Rural and remote areas have limited access to either in home or hospice style accommodation for palliative care
- Home and Community Care Program guidelines do not currently support any age group with complex care needs who is palliating

¹ Palliative Care Australia 2005. A guide to palliative care service development: A population-based approach. Canberra: Palliative Care Australia, p39

In order to address these gaps in service delivery, flexibility within current funding models (HACC; Q Health scripting) for palliative care will be required.

A forum with palliative care staff of Anglicare SQ revealed concerns for future planning and consideration of:

- Clients living with HIV
- Young people with disabilities with a life limiting illness
- Single 'middle aged' clients with no formal carer and/or limited social support networks
- Clients who require 24 hour in home support to remain at home to palliate
- Clients living in rural and remote regions of Queensland that do not have ease of access to specialist services as in metropolitan areas (use of telehealth)

2. The effectiveness, efficiency and adequacy of palliative, frail and chronic care services

Anglicare SQ's palliative care services are currently supported/funded mainly by programs such as Home and Community Care and Queensland Health scripting for in home care (at the terminal stage – final 3 months of life). Carers are generally provided with respite services through funding that supplements HACC or Queensland Health PCP funding through National Respite for Carers Program or Commonwealth Carelink Respite Centre.

Each source of funding attracts a different rate to cover the cost of care/support; attracts a different reporting requirement thereby increasing the complexity and reducing the flexibility of care arrangements. The complexity of the funding arrangements can contribute to delays in acceptance of services from hospital due to prolonged negotiation of funding arrangements with public hospitals and sometimes unnecessary hospital admissions due to the expiration of Queensland Health scripting arrangements for terminally ill choosing to be cared for at home. Anglicare SQ clinical staff report that vast amounts of time that could be spent with clients and carers is being spent on the coordination and negotiation of a complex package of funding arrangements.

Inconsistency exists too in the amount of care and support provided between Queensland Health districts (which are also different to HACC funding boundaries). In some districts, equipment and nursing care are available to patients in the home whereas in other QHealth districts, funding shortfalls prevent patients from accessing certain types of support. Where shortfalls exist, hospitals will usually discharge clients without scripting and this places further pressure on providers such as Anglicare SQ to find other solutions for support through HACC funding which is intended for basic maintenance and support.

Compounding this, as a provider of HACC services, Anglicare SQ on the 11 November 2009 received notification of an operational policy statement from Department of Communities with regard to HACC services for eligible clients requiring palliative care:

“Policy Statement

- Specialist palliative care services are outside the scope of the HACC program;
- Eligible HACC clients requiring palliative care, can continue to receive **basic support and maintenance services**, depending on their priority of needs and the capacity of service providers to deliver support within existing resources;
- Palliative care services can broker services from a HACC service provider as appropriate”

Efficiency of services can sometimes also be compromised by the number of service providers delivering primary palliative care services. This can lead to a situation of duplication and overlap of service however it does serve a purpose of allowing clients the freedom to choose their provider of service.

Inconsistency also exists because Queensland Health has not chosen to date to take a state-wide approach to contracting.² There are often multiple approved providers of palliative care services within some districts whilst others such as Townsville HSD have chosen to contract one provider to provide all palliative scripted services. This can lead to a situation of a client receiving Anglicare SQ services prior to an episode in hospital but being discharged to another provider once diagnosed with a terminal phase of illness due to contracting arrangements. Prior to another provider being successful with this 3 year contract, Anglicare SQ had been the sole provider of Palliative Care services in the Townsville Health Service District and the transitioning of clients from one provider to another was problematic and disruptive for families and for staff. The arrangement in all other Queensland Health districts in which Anglicare SQ currently provides palliative care services, is for multiple providers to be engaged for service delivery. Whilst this arrangement may lead to some inefficiency in service delivery for palliative care, the strength of this arrangement is that it promotes enhanced choice for clients as well as service continuity for those clients transitioning from another funded service eg HACC with the same provider.

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

Opportunity 1: Improved Coordination of services across Queensland

Anglicare SQ believes that there is opportunity for the development and implementation of a consistent State-wide Service Plan for palliative care in Queensland to ensure consistency of access and high quality Palliative Care service delivery and reduction of administration costs. Anglicare SQ also believes that consistency of approach would also provide opportunity for better data collection, benchmarking and measurement of patient outcomes (e.g. through Palliative Care Outcomes Collaborative – PCOC).

Opportunity 2: More equitable and transparent funding

Anglicare SQ believes that there is opportunity for the development and implementation of a “flexible, person centred funding models” that would allow consumers to have greater choice and control over decision making.

² It should be noted that Queensland Health have taken a State-wide approach to contracting for Transition Care Services.

There is also opportunity for a review of existing funding sources and a relaxation of the prescription of some of the funding guidelines. This would support a more seamless transition for palliative clients and would achieve a reduction in the administrative costs of providing these vital services. A review of the reporting requirements and consistency between districts would also assist providers reduce the administration of having systems cope with multiple funding rules.

Opportunity 3: Improved access to palliative care services

Anglicare SQ sees opportunity for all people who are palliating within Queensland to have choice around where they wish to be cared for i.e. in home, in a hospice or in hospital. Anglicare SQ sees opportunity to partner with other NGO's with the support of Government and Private Health Funds to ensure this can be realised.

Collaborative partnerships are essential to the provision of robust, sustainable and streamlined services throughout a person's palliation. Cooperation of providers to ensure greater coverage and choice of setting for people is essential. Cooperation to support hours of operational coverage and efficiency in service delivery is also necessary. Anglicare SQ has recently met with Queensland Kids to discuss partnerships options for hospice care and Anglicare SQ has also enjoyed a long association with Karuna Hospice and St Vincent's Brisbane Hospital to achieve strengthened service delivery and operational coverage.

Improved collaboration and definition of the roles and responsibilities of QHealth and its engagement of providers through PCP funding and Department of Communities funding would assist in achieving an improved service delivery model and focus clinical/support staff on care at the bedside/in the home.

Opportunity 4: Greater support for families and carers

Anglicare SQ sees great opportunity for improved holistic support through the linkage of clients and their carers/families with other government and non-government programs like Counselling and Education Services, churches/parishes through the provision of spiritual and pastoral care, improved linkage to respite services and volunteer home visitor programs.

Anglicare SQ also sees opportunity for technology and videoconferencing capability to be utilised for clients and carers to seek convenient and timely therapeutic advice and support from qualified staff or counsellors. This would build capacity to provide more robust emotional support and remote monitoring of clients and their carers. As a provider we continue to be concerned that 73% of older people aged over 85 live on their own. For this reason, technology plays an important part in enabling Anglicare SQ to provide strengthened home support for people (of any age) with limited family support.

Furthermore, there are people living in rural and remote regions of Queensland who are isolated and do not have ease of access to specialist services as in metropolitan areas. For people living within these communities who are diagnosed with a palliative illness, we would see great opportunity for telehealth/videoconferencing to be utilised to enable greater support and access to responsive medical/clinical advice for these people and their families.

4. 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

Anglicare SQ supports any initiative that enables clients living with life limiting illnesses and their carers/families to have access to quality, holistic palliative care services across our State regardless of geographical location. Anglicare SQ appreciates the initiative taken by the government in Queensland for inviting submissions to a State wide Inquiry into palliative care to see much needed improvements to access and equity of care.