



KinCare

RESPONSE TO PARLIAMENTARY COMMITTEE INQUIRY INTO PALLIATIVE CARE SERVICES AND HOME AND COMMUNITY CARE SERVICES IN QUEENSLAND

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Background

KinCare (incorporating Stanhope Nursing Services) is one of Australia's leading specialist providers of in-home care and community nursing services, employing almost 2,000 staff and supporting 9,800 clients. Operating across seven states and territories, we have extensive experience in provision of assessment, intervention and support services within the fields of aged care, nursing, allied health and disability. Our capabilities are further enhanced by the expertise and resources of other members in our KinCare Group including National College Australia (RTO) and Teleresponse Australia.

Our service portfolio includes:

- HACC programs Personal Care, Domestic Assistance, Community Nursing, Social Support - Dementia Monitoring, Respite, Young Carers
- Packaged Aged Care (Community Aged Care Packages , Extended Aged Care in the Home (EACH) and EACH Dementia packages)
- Transitional Aged Care Programs
- Generalist palliative care
- NRCP, including Dementia Live In Respite
- Disability Respite and In Home Care
- Veteran's services and Community Nursing
- Disability Housing
- Private services

In Queensland, our head office is based in Springwood, and services extend across the Gold Coast, Brisbane, Sunshine Coast, Townsville and Toowoomba. A large proportion (97%) of our clients are aged 65 years or over, and 39% are aged 85+, providing us with good insight into the needs of older people and their families. Our views on home and community service provision for younger people is based on not only our smaller contingent of younger clients in Queensland, but also on our experience in other states.

Home and community care is an essential part of the health continuum, aligned with strong preferences of community members to live safely, with dignity in the comfort of their own home. This right should be extended to all age groups, in a manner which considers the needs of both the care recipients and carers. Many would also choose to receive palliative care at home, though it is acknowledged that some would prefer to receive end of life care in a hospital/hospice setting and in some circumstances, this is indeed necessary.

We commend the Health and Community Services Committee for initiating a review into capacity of the sector to meet future needs and develop sustainable solutions.

Capacity and Future Needs

HACC Target Group

In recent years, the Queensland Home and Community Care (HACC) sector has attracted funding for considerable expansion of capacity to provide basic support services for frail older people and younger people with a disability who have ongoing functional restrictions, and their carers. These services range from domestic assistance and transport, through to social support, respite, personal care, allied health and community nursing.

This works to support the intended target group to stay at home, however, with the level of demand set to increase significantly, the current HACC program needs to be extended or supported by more active or restorative service options. Such approaches designed to improve an individual's functional capacity would potentially reduce service dependency and therefore demand. To make this effective, changes would be required to HACC service definitions and policies at national and state levels.

While HACC services were not originally intended to handle complex care needs, in the current funding environment we frequently see individuals accessing a high volume of HACC services from a variety of providers. Some HACC service providers are retaining clients with high level complex care needs – we are aware of instances where providers are supplying up to 28 hours of service per week to a client with dementia. At the same time, the packaged aged care sector has capacity to provide additional services, however, is not funded for this volume of support. There are a number of draw backs to this approach:

- Informed decisions can be difficult for many clients with complex needs who do not receive appropriate care coordination support
- Inefficiencies and inconveniences arise as service users must participate in multiple assessments and manage multiple administration systems
- The real cost and responsibility for payment is often masked
- Providers are less accountable for outcomes due to shared/blurred responsibility

Our State Office currently receives phone calls at least once/week from individuals who are unhappy with their community care or looking for information which they haven't been able to obtain from other providers. In our experience, capacity to meet the needs of the community is being undermined by fragmentation within the service delivery system, and competition for small buckets of funding, in some instances, discourages cooperative working relationships and service efficiency. While there is a place for small niche providers and larger providers alike, organisational interests should not outweigh the interests of the service user.

Palliative Care

A palliative care system generally involves multiple service providers including primary health care, hospital, medical specialists, specialist palliative care teams and community care services. Some individuals only require primary care support; others will also need community care services; and those with very complex issues will require the support of a specialist palliative care team. Complexity may arise due to an array of physical, psychological or situational issues.

The extent of services varies between regions, with more options available in metropolitan areas, for example, the Gold Coast offers a range of primary, secondary and tertiary palliative care services including specialist hospital inpatient care, hospice care and a multidisciplinary community support team in addition to primary and community care services.

Specialist Palliative Care

The size of the specialist palliative care workforce is currently not sufficient to meet the growing needs of the ageing population and younger people with terminal illness. There appears to be a limited number of Palliative Care Medical Specialists, especially in rural areas. And yet, the concept of Nurse Practitioners, which have the potential to offer diagnostic and prescribing services within specified scope of practice, has not been embraced within the palliative care workforce. Clinical Nurse Consultants provide a valuable role in training and quality practice as well as Clinical Nurse Specialists who are an important part of care for those with complex palliation needs. Access to allied health in the community is limited, with better access to multidisciplinary teams in sub-acute or hospice-type settings.

Generalist Services

Generalist palliative care depends upon the understanding of health professionals and community service providers of the palliative approach, and their ability to collaborate with specialist services and each other. Limiting factors include:

- The availability of a General Practitioners and their capacity to perform home visits in rural areas.
- Health professionals who are not specifically trained in palliative care are often not comfortable or skilled in counselling and education for individuals requiring palliative care and their families.

In addition to contracted domiciliary palliative care providers, there are a number community aged care providers, such as KinCare, that provide some degree of palliative care in the home, as evidenced by the number of clients on EACH and EACHD who die at home. These providers seek support from treating health practitioners, and where necessary, consult with specialist palliative care services funded through the state health system. Some providers offer 24 hour emergency response including phone advice and home visits. The majority of direct care is funded through the package:

- A community aged care package will generally fund up to 6 hours of in-home care including personal care, domestic assistance, transport, social support, respite care, meal preparation, monitoring, lawn mowing. Where required specialist palliative care teams will often provide specialist advice to support the individual, their family and generalist service providers
- A flexible aged care package offers significantly more hours of direct service provision (12-14 or more/week) in the home, including the above services as well as nursing, allied health support and equipment.
- Eligible veterans may receive assistance through DVA Community Nursing Programs

In order to meet the future needs, further education and training of the workforce is required across all settings, and the development of communication and coordination mechanisms. Palliative Care Australia have developed some excellent educational tools aimed at the residential aged care workforce, however, there has not been an equivalent allocation of resources for community aged care. Specific training modules - on topics such as grief counselling, understanding client needs/wants, technical aspects of nursing support such as use of syringe drivers, and a holistic approach encompassing all aspects of psychological, physical and spiritual care needs - would improve access to appropriate palliative care in the home. Training in a palliative approach also needs to occur in undergraduate courses for medical, nursing and allied health professionals.

Effectiveness, efficiency and adequacy

Palliative Care

The benefits of a palliative approach and specialist intervention when required by people with life limiting illness have been well documented. Although individual organisations may offer wonderful assistance, there remain a number of barriers to effectiveness and efficiency of palliative care in Queensland. For example:

People living in rural and regional areas

- Distances restrict availability and range of care options due to the need for service provider/ health professionals and/or potential service users to travel.
- Individuals who wish to die at home, may be discouraged due to the distance from help in the event of uncontrolled pain or other symptoms. Those preferring a specialist palliative care in-patient setting may only have access to a medical ward.
- Where specific palliative care services are available they are often constrained by Local Government or regional funding boundaries.

Indigenous people

- Many Aboriginal people mistrust mainstream services and medicine, preferring to access services delivered by Aboriginal organisations or individuals. This reduces their access to diagnostic and treatment services, delays identification

of the need for palliative care, and may result in a decision not to take up services available.

- Mainstream services may not provide culturally appropriate care due to a lack of understanding of Indigenous culture, rigidity in systems, and a lack of training of staff in cultural competencies and person centred care. Cultural preferences relating to death are particularly important.

People from culturally and linguistically diverse backgrounds.

- Cultural and religious attitudes to life, death and health care will influence the degree to which palliative approaches and specialist palliative care are understood and accepted within CALD communities. Access to bilingual specialists and palliative care staff is limited, making access to information on services available, diagnostic conditions and disease trajectories harder to access for individuals and families.

People with disabilities

- People with disabilities often have poorer access to financial resources to support care choices and are dependent on government funded services.
- Those with intellectual difficulties will have difficulty making informed choices and communicating these to carers and health professionals.
- When approaching the end of life, their combined difficulties may mean they require higher levels of care for longer, making it harder to stay at home.
- Palliative care staff may lack understanding and skills required to meet the needs of people with disability who require palliative care

Insufficient advanced care planning.

- Advanced care planning is intended to identify an individual's values, wishes and interests around care and support needs, in order to support the person in the event they lose capacity to make decisions or manage their own affairs. This may include a range of mechanisms including development of advance care plans, discussion of preferences for life-sustaining treatment with family, formal appointment of an enduring guardian, appointment of a power of attorney or formal advanced care directives.¹
- In the absence of clear advanced care directives, health professionals and family members may err on the side of active treatment which may not be aligned with a palliative approach or the individual's wishes
- A pilot study completed through ASLARC² showed that barriers to advanced care planning were largely a result of the attitudes and beliefs of health professionals

¹ NSW Department of Health (2005) Guidelines for end-of-life care and decision-making

² Cartwright C, Phillips J, Rodwell J. A Multi-disciplinary approach to Advance Care Planning Pilot Study Report, ASLaRC June 2006

The most effective, efficient setting of care will depend upon complexity of care needs, the home support situation, workforce parameters and personal preference.

Hospital Palliative Care

Hospital care is often not the most appropriate option for palliative care (other than for acute episodes) because:

- It is not homelike and patients can find it alienating and confusing.
- They are frequently noisy environments
- Shared rooms are often not appropriate for the patient or the grieving family members
- Many staff do not understand palliation, being trained in curative practices
- Active intervention may continue after it becomes clear that the person has reached the end stage of a disease process, requiring interventions aimed at comfort and a "good death".

Subacute Palliative Care Facilities or Hospices

Subacute palliative care facilities or hospices are effective when purpose built, centrally located near transport, and appropriately staffed. These become impractical where populations are dispersed, making access and staffing difficult.

Residential Care

Residential care can be an effective and efficient care setting where the facility has undertaken specific training and has suitably qualified and oriented staff and equipment to provide the levels of pain relief and comfort required. In some instances specialist services provide support through an in-reach model. The benefits are that the individual has access to 24 hour support and can avoid the disruption of being transferred to hospital; ideally they remain in the care of people who know them and their wishes. Barriers include:

- Facilities without suitably trained staff
 - Insufficient staffing ratios
 - Difficulty hiring RN staff
 - Specialised equipment
-

Domiciliary palliative care

Domiciliary palliative care is an effective and efficient way to meet the needs of more people with limited resources. It requires suitably trained staff who must be supported by specialist consultants and equipment if required. Where symptoms are not fully controlled, access to 24 hour in-home emergency support is necessary. This is a reasonably cost-effective model, provided volume of activity is sufficient to staff and support the service appropriately. New providers face entry barriers where subcontracting arrangements do not take this into consideration.

Barriers to effectiveness of domiciliary palliative care include:

- Lack of awareness of service options amongst community members, GPs and the healthcare system
- The home environment cannot be modified to accommodate necessary equipment
- Situations where the family and/or individual do not wish to be cared for at home
- In some instances, homecare can be distressing for family members and individuals may experience high levels of anxiety about how they will cope when young children live at home
- Lack of GP, medical specialists or specialist palliative care teams to provide in-home consultation
- Lack of 24 hour emergency support
- Sub-optimal communication between professionals and care settings. For example, in the event of a health crisis, lack of communication between health/care providers may result in invasive or unwarranted hospital interventions.
- In the absence of an unpaid carer, end of life and palliative care choices become more restricted, unless individuals can finance additional private care to supplement government funded services

In regions which lack community and hospice support options, individuals often spend weeks or even months in hospital prior to their death. This can result in adverse impacts on wellbeing, including physical decline, confusion and emotional impacts, and is a costly and less desirable support option.

Other In-home Care

Frail Older People who are palliative being referred too late for high level EACH and EACHD packages. Issues include:

- Delayed identification of need
- Lack of awareness by primary care providers of community care options for this target group
- Delay between identification of need and ACAT assessment
- Delay when provider identify that someone on an EACH need to upgrade to a specialised EACHD package as ACAT consider other clients not receiving service more urgent. Under Living Longer Living Better, the dementia

supplement which can be applied to all package levels will help alleviate this, so long the assessment process for the supplement doesn't present additional barriers.

People are not receiving information required to make timely, informed decisions. We regularly receive calls from people who have spoken to several providers who merely

Improving integration, collaboration and cooperation

To meet the growing demand for community and health care across the target groups concerned, partnership between health services, community services and disability sector are essential. To support this, the interface between various inter-related service systems needs review. Enhancements may be driven through customer choice, accountability mechanisms, incentives, standards, innovation and technology.

The local management of hospitals and health services in Queensland provides a new opportunity to explore local partnerships between government and non-government sector in the delivery of in-home and community care. Depending upon the infrastructure and specific needs of each area, opportunities might include:

- **Enablement programs:** Short Term multidisciplinary intervention programs for individuals identified with functional restrictions impacting on their ability to manage daily tasks. Individuals could be referred by GPs, medical specialists, or hospitals for specific programs designed to improve functional capacity to manage daily tasks and reduce or eliminate the need for HACC services. Individuals would participate in an initial consultation to identify needs and develop a personalised intervention plan which might include, for example: gentle exercise program, nutritional/dietary intervention, quit smoking, health education program in group or individual settings
- Hospital substitution programs, subcontracting all or part of the medical, nursing, personal care and in-home support
- Domiciliary palliative care for all age groups and disease types
- Transitional Aged Care – in our experience, community care providers are well placed to manage the logistics of in-home support, and models which broker all services to non-government agencies are a cost effective way to deliver services and reduce the risk to health services.
- Post discharge support

To reduce delays in accessing appropriate services:

- It is essential that general health practitioners and community health services receive training and support on palliative care, services available, and the expertise and roles of other stakeholders
- Public awareness campaigns explaining services and how to access

- Web based tools/portals that enable members of the public to complete eligibility and needs assessments to speed up assessment and access process

To reduce duplication of assessment processes and encourage sharing of important information with client permission:

- Community care, primary health, hospital services, specialists and community members should all be engaged in the roll out of personalised electronic health records.
- Medicare Locals would be an important vehicle for achieving this and the result should be assessed as a key performance indicator
- Standardised eligibility tools used in assessing individuals for HACC

To address barriers of distance and workforce shortages in rural areas:

- Development of telehealth models including monitoring of health indicators and education programs to improve self-care and prevention
- Video-consultations between generalist and specialist services, and between service users and specialists

To overcome barriers to CALD communities in accessing HACC and palliative care:

- We would need champions within these communities to manage education and linkages between health services
- Awareness campaigns in multiple languages and media
- Training for and partnerships between mainstream and CALD organisations should be encouraged

Reduce delays between identification of need, assessment of eligibility for complex care and commencement of services. This is often followed by insufficient level of care or coordination:

- Creation of supplements for dementia (as proposed under Living Longer Living Better) and palliative care for community care and general practice to recognise the additional time required to assess and support such individuals
- Packaged care providers could conduct a standardised assessment and provide to the GP for endorsement of need for such supplements according to set criteria
- ACATs prefer that providers provide simple evidence of behaviours and health status in order to assist with their assessment process. We recommend that a standardised tool be developed to support compliance and efficiency of assessment and streaming to appropriate services

Segmentation of the HACC System

Any aged related boundary is to some extent artificial, and likely to cause disruption to some service users. The proposed separation of funding and regulation of HACC services will have both benefits and drawbacks.

Service Users and Carers

Service users and their carers who are approaching 65 years should be given an option to remain with their current provider if they do not wish to change provider, so long as their needs can be met with existing arrangements and they are not blocking access for other people in need. Ideally this decision would be made after a joint meeting with an alternative agency to explain service options and ensure an informed choice.

- Some individuals will not wish to change providers merely on the grounds of their age, unless their needs have changed and can no longer be met by their current services
- Changes will impact on both service users and their carers. For example, those attending a day centre may need to change days or locations; there may be grief associated with lost relationships built over time with case managers and staff
- The impact on individuals with dementia or reduced ability to adapt to change should be carefully considered and managed eg through a planned, gradual transition process
- In the extreme, undue stress associated with change may jeopardise the caring relationship and the health of both service users and carers
- Identification of suitable services may be complicated by the additional age related criteria

Service Providers

- Referral pathways and acceptance criteria will need to change
- Service directories will need to be reviewed and updated eg Commonwealth Carelink Service
- Additional accountability processes will be required for some smaller services previously operating under contract to only one government agency. This has resourcing issues, but is less of a concern for larger organisations

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