

PALLIATIVE CARE



KinCare

RESPONSE TO SENATE COMMUNITY AFFAIRS COMMITTEE'S INQUIRY INTO PALLIATIVE CARE

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Background

KinCare Community Services is one of Australia's leading specialist providers of in-home care and community nursing services. Located in four states and territories across Australia, we hold a diverse portfolio and a wealth of experience in the fields of aged care, nursing, allied health and disability support. Our capabilities are further enhanced by the expertise and resources of other members in our KinCare Group, which include a registered training organisation and a teleresponse service.

Our national service portfolio includes:

- Packaged Aged Care consisting of 320 Community Aged Care Packages (CACP), and 306 Flexible Aged Care Packages (201 Extended Aged Care in the Home (EACH) and 105 EACH Dementia packages)
- Transitional Aged Care Programs
- HACC programs Personal Care, Domestic Assistance, Community Nursing, Social Support - Dementia Monitoring, Respite
- NRCP Dementia Live In Respite
- DVA Nursing contracts
- Veterans Home Care

We employ over 700 staff and support 4000 clients per year, providing 9,000 hours of service per week. A large proportion (76%) of our clients are aged 70 or over, and 39% are aged 85+. Many of their carers also have poor or declining health status, and exhibit strain associated with their caring function.

As a result we frequently provide services in the homes of individuals who have progressive, life-limiting illness. We provide generalist palliative care services in consultation with the individual, their family, GP, specialists and other health services as applicable.

Response to Questions

(a) What are the factors influencing access to and choice of appropriate palliative care that meets the needs of the ageing population?

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 access and choice of appropriate palliative care for the ageing population.

Local services & funding arrangements

- The type of services available and their capacity to meet local needs varies greatly between communities. Some communities offer a range of options from hospice, to inpatient, to community palliative care settings, with support structures such as specialist palliative services, palliative care training for health professionals and GP home visits. Other communities offer only generalist community services and in-patient hospital support, providing the population with limited options
- In some instances the appropriate range of options exist, however, funding is not sufficient to meet the total needs of the population. For example, access to in-home palliative care may be thwarted where there is no unpaid carer available to supplement formal service provision in the home.
- Capacity of GPs and palliative care services to perform home visits or in-reach into residential care settings varies, resulting in some unnecessary admissions to hospitals. This can result in adverse impacts on wellbeing, including physical decline, confusion and emotional impacts.

Awareness and commitment to a palliative approach by GP, specialists and other health professionals

- The training of health professionals traditionally emphasises life-saving and restorative interventions with many receiving limited training on a palliative approach. Frequently active intervention continues 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”.
- Health professionals are often not comfortable or skilled in counselling and education for individuals requiring palliative care and their families.

Insufficient Communication between Care Settings

- Community members with progressive, life-limiting illness may be in receipt of care aligned with a palliative approach in the community; however, in the event of a health crisis, lack of communication between health/care providers may result in invasive or unwarranted hospital interventions.
- Alternatively, an individual may receive consultation from a palliative care specialist while in hospital, however, community services received on discharge may not follow a palliative approach due to insufficient communication or consultation.
- There is no single point of contact for palliative care services, and individuals become confused about what is available, who is eligible creating unnecessary additional stress to individuals and their families

Case Example: We were providing an Extended Aged Care in the Home package to an elderly couple in their 80s. Their stated wish was to remain together “til death do us part” in their own home. The husband’s health was in rapid decline and he was hospitalised twice in one month with pneumonia. The wife, as the main carer, was also in poor health, using a walking frame to mobilise and had a history of recent falls. To remain at home the husband required: personal care, 2 person hoist transfers, domestic assistance, transport, chest physio, meal preparation, specialised equipment. When he was admitted to hospital, a case conference was held with the couples’ children where a decision was made to place him in residential care. If KinCare had been consulted as the home care provider we could have provided reassurance about our in-home services available, thus supporting the stated wishes of both husband and wife. The wife does not drive and as a result her access to her husband was restricted by ability to obtain a lift or access community transport.

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

Absence of an unpaid carer (family/friend)

- 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

Family choices and preference

- Family considerations may interfere with an individual’s choices regarding palliative care. For example, a person with a young family may not have the option of dying at home if this creates an unacceptable environment for children. Another may have difficulty accessing hospice care if a facility is not available within travelling distance of family members
- Family disagreement regarding care decisions may interfere with decision making around an individual’s palliative care.

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

Case example: We are working with one family where a woman in her 40's has a progressive neurological disease. She is in receipt of HACC personal care and domestic assistance services, however, her husband is resisting further specialised consultation and case management which would assist with coordinating the advanced care planning and ultimately access to specialised palliative care when required.

Access to counselling and education

What are the particular issues for:

(i) 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.

(ii) 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.

(iii) 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.

To overcome these barriers, we would need champions within these communities to manage education and linkages between health services.

(iv) 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.

(b) What are the funding arrangements for palliative care provision in aged care, including the manner in which sub-acute funding is provided and spent?

KinCare frequently provides palliative care to older people through federally funded aged care packages. In these instances, we may consult with a specialist palliative care team/professional funded through the state health system, however, most of the direct care is funded through the package. These include:

- 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. In regions where there are specialist palliative care teams, they 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

(c) How efficient is the use of palliative, health and aged care resources?

We are unable to offer a full analysis, however, it would appear that efficiency can be hampered by sub-optimal communication between professionals and care settings and convoluted referral pathways.

(d) How effective are palliative care arrangements, including hospital care, residential aged or community care facilities?

Hospital care is often not the most appropriate option for palliative care because:

- It is not homelike and patients can find it alienating and confusing.
- They are frequently noisy
- 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

Residential care can be an effective 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. The benefits are that the individual and their family does not have the disruption of being transferred to hospital; they remain in the care of people who know them and their wishes. However, many facilities are not equipped to provide good palliative care.

Community care can be effective where staff are suitably trained and can access specialist support and equipment if required. This is only practical where the home environment can be modified to accommodate any necessary equipment and the family/individual are desirous of home-based care. In some instances it can be distressing for family members, and individuals can experience high levels of anxiety about how they will cope. In many more cases, where appropriately supported, a community setting is the most effective way of meeting the individuals preferences to remain in the comfort of their own home.

(e) Can you comment on the composition of the palliative care workforce?

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.

Including:

(i) Its ability to meet the needs of the ageing population.

The size of the specialist palliative care workforce is not sufficient to meet the growing needs of the ageing population. Accordingly it is essential that general health practitioners and community health services receive training and support to provide more informed and appropriate care. In some regions, access to in-home care packages is delayed due to waiting times for ACAT assessments, or lack of package vacancies, impacting on outcomes for people wishing to receive palliative care at home.

(ii) The adequacy of workforce education and training arrangements.

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.

(f) How would you describe the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians?

The standards are generally well accepted amongst the palliative care workforce, and applied in specialist services and hospice settings. However, community care providers and GPs need to become more aware of the standards and are supported to ensure broader application. Many are actively seeking to enhance their ability to provide quality palliative care.

Currently Palliative Care Australia's National Standards Assessment Program provides self-assessment and quality improvement tools to assist specialist palliative care services to align themselves with the standards. They have identified a need to develop tools to support the provision of palliative care in aged care settings but do not have resources to pursue this task at present.

(g) Advance care planning.

One of the biggest barriers to advanced care planning is lack of knowledge, confidence and time amongst the health professionals closest to service users. Despite a wide body of evidence as to the benefits, uptake has been patchy.

Although there have been several research and knowledge translation projects addressing advanced care planning in hospital, primary care and residential aged care settings³⁴, there has been little work done to date to embed practices and philosophies into community aged care. Specific gaps noted through interagency discussions and literature reviews are listed below:

- Actual and desired level of understanding and skill amongst clinicians in relation to advanced care planning in Community Aged Care.
- Actual and desired levels of cooperation between community aged care, hospital and primary health care services
- Actual and desired level of community understanding of advanced care planning and implications
- Understanding of the extent to which advance care planning is being incorporated into community aged care
- Mechanisms to ensure communication of the existence and content of advanced care plans between settings eg hospital, community aged care and residential aged care
- Mentoring programs in community care
- Some GPs have reported they are less inclined to facilitate advanced care planning due to a belief that clients may change their mind during a crisis

³ Shipman, C, Gysels, M, White, P, Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups, *BMJ*:2008

⁴ Hopp, FP, *Preferences for Surrogate Decision Makers, Informal Communication, and Advance Directives Among Community-Dwelling Elders.* *The Gerontologist*, 2000

- NSW Health Connecting Care program aims to reduce repeat hospital admissions by people with chronic and complex conditions, however, does not include advanced care planning to the electronic discharge summary post presentation.
- GPs use a variety software packages with the main two being Medical Director and Best Practice. Neither incorporate a tool for advanced care plans or directives, however, one could be easily imported if developed.

(i) What avenues are there for individuals and carers to communicate with health care professionals about end-of-life care?

There are some opportunities available, and poor awareness of those that exist. While many would expect their GPs or specialists to lead such discussions, this is often precluded by lack of time in their schedules, or lack of specific skills and knowledge. Access to trained counsellors and nurses is also limited.

(ii) Should there be national consistency in law and policy supporting advance care plans? What are the consequences of there not being consistency?

Yes. A consistent set of laws and policy would help establish confidence and good practice amongst health professionals. At present each jurisdiction has a different model.

(iii) What scope is there for including advance care plans in personal electronic health records?

This would be appropriate, allowing the person to document any change of mind, and ensuring that their wishes are made known in all health care settings. Work would be needed on the policies surrounding this, eg in the event that their wishes were ambiguous. A standard form may be preferable, but any clear statement of wishes made in sound mind should be acceptable on a PEHR.

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