Report to the Australian Senate Community Affairs References Committee

PCA has been requested by the Australian Senate in a follow up to the oral evidence delivered to the Community Affairs References Committee on the 24 April to address some questions in relation to the eligibility and availability of Home and Community Care Program (HACC) to palliative care patients.

What is HACC?

HACC is a joint Australian, State and Territory Government Initiative. The HACC Program provides services such as domestic assistance, personal care as well as professional allied health care and nursing services, in order to support older Australians, younger people with a disability and their carers to be more independent at home and in the community and to reduce the potential or inappropriate need for admission to residential care. Some of the services funded through the HACC Program include:

- nursing care;
- allied health care;
- meals and other food services;
- domestic assistance;
- personal care;
- home modification and maintenance;
- transport;
- respite care;
- counselling, support, information and advocacy;
- assessment.

The HACC Program delivers services in the community that are essential to the wellbeing of eligible older Australians, younger people with a disability, and their carers. The Program aims to support these people to be more independent at home and in the community, and reduce the potential or inappropriate need for admission to a residential care facility.

The Australian Government provides approximately 60 per cent of funding for the program and maintains a broad strategic policy role. The state and territory governments provide the remaining percentage of funding, and are the primary point of contact for HACC service providers and consumers. The state and territory governments are also responsible for program management, including the approval and funding of individual HACC services in their jurisdictions.

The HACC Review Agreement of 2007 expressly excluded specialist palliative care services from the program scope. However, this does not preclude people from the HACC target group who are in receipt of specialist palliative care services receiving non-specialist HACC services.[1]

Problems arise with interpretation of HACC access for palliative care patients from state to state, and even from region to region.

In some places a request for HACC services on the basis that the person has cancer will be refused as it is misinterpreted that HACC would be used to provide palliative care services. If the request is made in such areas on the basis of functionality, eg neuropathy in hands and feet as a consequence

[1] http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-eligibility-services-outside-scope.htm

of chemotherapy means that the client has difficulty dressing and walking long distances, then it is more likely to be successful.

This requirement to be 'innovative' in descriptions of need in order to access basic services for people in need is demeaning for clinicians, making them feel that they are acting untruthfully.

In most places there are problems with availability of HACC services. It is not an entitlement, and service providers must prioritise clients. This can have negative consequences for palliative care patients as priority to receive HACC may be given to clients receiving no other funding packages. In some cases HACC will not be provided if there is another adult in the household, even if that adult is a teenager already busy with end of life care for a parent.

The use of multiple funding packages including HACC for people receiving palliative care is common and reflects the needless complexity and inadequacy of Australia's health and social care systems to accommodate the needs of those at the end of their lives and increases the barriers to people achieving their wish to die with dignity in a place of their choosing.

Whilst there are many problems with access to HACC, there is a further problem that there is no program similar to HACC for younger patients receiving palliative care in the community.

The apparent use of HACC funding as a 'top-up' to existing funding packages like the PCP (see Appendix 1) package in Queensland, EACH (see Appendix 1) and CACP (see Appendix 1) packages in other states and territories reflects the inadequacy, inappropriateness and inequity of current funding patterns throughout Australia in palliative care.

The difference in application of the rules for use of HACC funding varies throughout the states and territories both within and between jurisdictions. It seems that depending on where the HACC service is provided (metro or rural), who provides it and access to other funding packages, the use of HACC can be discretionary depending on interpretation of the HACC eligibility criteria, history of use of the Program and personal values of HACC funding managers within facilities.

In Victoria there is a good complementary relationship between the palliative care providers and HACC services. Palliative care clients are able to receive HACC funded services, with the palliative care service addressing the specific palliative care needs, such as pains and symptom management. A metropolitan palliative care service reported that once a HACC client requires palliative care they are likely to lose the HACC funded service. Again this illustrates the differences between metropolitan and regional areas.

Conclusion

Among the many issues raised by the accessibility of HACC funding for palliative care patients, the main issues appear to be a complex mix of interacting factors such as regional differences; personal interpretation of HACC eligibility criteria; personal values of fund holders; lack of funding and accessibility of funding packages; ambiguous polices; to name a few. These factors play a significant role in compounding the complexity and inadequacy of Australia's health and social care systems.

They highlight the inappropriateness and inequity of current funding patterns throughout Australia in palliative care and contribute to poor wellbeing and quality of life for those with a life threatening illness and particularly those at the end of their lives.

PCA understands that the HACC program will come under the control of the Australian Government in 2015. It is in the interests of both the palliative care patient their carers and families that PCA is consulted in the planning and establishment of the proposed Commonwealth administered HACC program.

Appendix 1

Other acronyms explained:

EACH - Extended Aged Care at Home packages are individually planned and coordinated packages of care, tailored to help frail older Australians to remain living at home. They are funded by the Australian Government to provide for the complex care needs of older people. EACH packages are very flexible and are designed to help with individual care needs. Generally a person who requires high level care could be eligible for an EACH package, and the types of services that may be provided as part of an EACH include:

- registered nursing care;
- care by an allied health professional such as a physiotherapist, podiatrist or other type of allied health care;
- personal care;
- transport to appointments;
- social support;
- home help; and
- assistance with oxygen and/or enteral feeding.

Extended Aged Care at Home (EACH) Dementia packages, which are EACH packages for people who experience behaviours of concern and psychological symptoms associated with dementia. The first EACH Dementia packages were implemented in March 2006.

CACP -Community Aged Care Packages provide a lower level of community care to assist frail older Australians to remain living in their own homes. Community Aged Care Packages (CACPs) are individually planned and coordinated packages of care tailored to help older Australians remain living in their own homes. They are funded by the Australian Government to provide for the complex care needs of older people. CACPs are very flexible and are designed to help with individual care needs. The types of services that may be provided as part of a package include:

- personal care
- social support;
- transport to appointments;
- home help;
- meal preparation; and
- gardening.

ACAT - Aged Care Assessment Teams assessments are required for residential aged care (permanent and respite care), Community Aged Care Packages (CACPs), Extended Aged Care at Home packages (EACH), EACH Dementia (EACHD) packages.

NRCP - National Respite for Carers Program contributes to the support and maintenance of caring relationships between carers and their dependent family members or friends by providing access to information, respite care and other flexible respite support appropriate to individual carer need and the needs of the people for whom they care. The NRCP provides information and support to carers of frail older people and carers of people with disability through the following:

- Commonwealth Respite and Carelink Centres, which provide a single point of contact for members of the community, carers, health professionals and others needing information about community care and other support services in local areas to assist people to live independently. This information can be provided over the phone (by using a Freecall 1800 number) or in person at one of the 54 centres around Australia. Centres have a pool of funding that can be used to purchase short-term or emergency respite for carers.
- the provision of respite through community based agencies which can be arranged by direct approach to the respite care provider, or can be coordinated by a Commonwealth Respite and Carelink Centre. The program also funds other support for carers (for example domestic assistance or personal care) where the primary purpose of the assistance is to provide some relief to the carer.
- the delivery of professional counselling through the National Carer Counselling Program, and carer advisory and information services through the Carer Information and Support Program. The aim of the Counselling program is to provide short-term emotional and psychological support services to carers to help reduce the carer's stress, improve the carer's coping skills and facilitate, wherever possible, the continuation of the caring role. Counselling can be offered in different ways to suit the different needs of carers, with individual face-to-face sessions, telephone or group counselling sessions offered. The Carer Counselling Program, along with carer advisory and support services, is delivered through the Network of Carer Associations in each state and territory.

PCP - Palliative Care Program is a Queensland funded program. The Queensland PCP receives both Australian Government and state funding. The quantum of funds provided each year by Queensland Health is not governed by any matching arrangements. Essentially, Australian Government funding is allocated to the 38 Health Service Districts for direct service provision. However, the funds may be used to purchase palliative care services from the non-government sector where required. Queensland Health's funding contribution to the Palliative Care Program is directed to the non-government organisations (NGOs) providing community based care and hospice services.