

**Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia**

20th March 2012

Senate Enquiry into Palliative Care

Dear Committee Members,

ACH Group welcomes the opportunity to make a submission to the Senate Enquiry into Palliative Care. This submission builds on our submission to the Productivity Commission in July 2010 (Submission number 111 of that Enquiry). In that submission we made reference to the need for reforms around support for people with dementia to access palliative care.

ACH Group is a leading not for profit provider of aged care services in South Australia and Victoria. ACH Group has over 50 years experience of supporting people with dementia and over that time has seen the incidence of dementia increasing as the population ages and lives longer.

ACH Group -

- **Has contact with over 30,000 Australians every year through its residential, health, community and housing services.**
- **Operates over 1300 aged care packages of care with people in their homes**
- **Manages 8 Residential Aged Care Services that have over 650 places**
- **Provides restorative, therapy and health maintenance services to over 5,000 older people, including through a specialist residential transition care facility**
- **Promotes Good Lives for people with Dementia**
- **Supports people with dementia and other neurological conditions and their families and carers through our specialist dementia services. It is our experience that over 40% of people who we are supporting have some form of neurological condition, the most prevalent being some form of dementia particularly Alzheimer's Disease. In our residential services,**

70% of residents have dementia. Increasingly we are seeing more people with early onset dementia and dementia caused by substance abuse, vascular disease and other co-morbid conditions

- Delivers palliative care in the community and in residential facilities to many older people each year including a number of older people from CALD communities (including Italian, Dutch, Cambodian, Indo-Chinese and Polish) and older Aboriginal people.

As an aged care provider, ACH Group has recognised gaps in access to services and has worked to improve services and palliative care to people with degenerative conditions such as dementia. Our award winning Palliative Dementia Care Resource kit and education program has been implemented across our services in metropolitan and rural areas of South Australia and Melbourne, and the kit made available to other services across Australia. The Planning Ahead booklet, which is a part of this kit, is provided to our clients in SA to ensure they have access to information about advance care directives applicable in SA. We recently adapted that information into a DVD for Aboriginal Elders in rural SA to ensure they have access to information in a culturally appropriate form. We were pleased to have some funding recently to purchase syringe drivers to provide pain management for our clients who live in the community and use our services to support them to be able to die at home. This has enabled us to provide quality palliative care for people living at home in rural areas.

We work in collaboration with specialist palliative care services in SA, referring clients, seeking consultation, advice and training regularly. However we experience delays at times in gaining access to community palliative care packages and for those services to be available over extended periods of time during slow decline, to support the person with dementia and their family carers. Similarly we experience a lack of support services and bereavement support to family carers of people with dementia across metropolitan and rural areas.

It is ACH Group's experience that most Palliative Care Services are geared towards people who have cancer where the prognosis is clearer and decline is rapid. – these services should continue. However for people with dementia the prognosis is one of slow, progressive, cognitive and physical decline with a 100% mortality rate. The combination of dementia with other age related and co morbid conditions makes the needs of people affected more complex and of longer duration. – it is this group of people in particular that ACH Group considers need many more services than those provided within the current care system.

To address the needs of people with dementia and their family members for palliative care, support is needed throughout the course of the condition, not just at end of life. At diagnosis' advance planning, health and lifestyle planning is needed; through the course of the condition, support services, carer education and coaching and reviews of advance care plans are needed; and at end of life, specialist services

are needed to support individualised aged care, manage end of life symptoms and support the carers and family. Bereavement support services are needed for carers and families to adjust after a long period of a terminal illness and decline of their relative. Ongoing education of aged care staff about clinical palliative care, end of life care for people with dementia and advance care planning needs to be provided locally. A particular focus is needed to adapt palliative care to the needs of people with dementia and their families.

National consistency in advance directives law and a central register of advance care directives is especially needed for people with dementia who lose capacity to plan ahead or to express their wishes well before end of life.

To address these gaps in the provision of services, ACH Group believes

1. There should be a Dementia portal established through the National Gateway Agency.
2. That portal should
 - a. set up a means tested eligibility for dementia support at various levels of dependency
 - b. People deemed eligible through the means test ought to be paid a Dementia Support Allowance according to levels of need and the stage of the disease – particularly when they reach the need for Palliative Care (Palliative Care Allowance)
 - c. Provide information and referral for people who are diagnosed with dementia
 - d. Support people to develop advance directives in relation to having their wishes carried out as the disease progresses
 - e. Work closely with the national peak bodies in the field (eg Alzheimer's Australia and Palliative Care Australia) in their work towards progressing national strategies to cure, treat and support people with dementia to the end of life.
3. The levels of allowances for the Dementia Support Allowance and the Palliative Care Allowance need greater financial modelling and ought to be subject to a further study within the Senate's investigation. ACH Group would observe that the current levels of support for people in palliative stages in community aged care, residential aged care etc for people with Dementia are vastly inferior to the current level of support for people in specialised Palliative Care Services. This indicates to us a level of inequality based on disease type rather than any other salient or intellectually sound basis of argument.
4. Agencies should be funded to provide more concise information and support services for people diagnosed with dementia. The basis of that funding ought

to be built around agencies working with people with dementia and their families and carers to

- a. Establish life pathways that plan ahead
 - b. Ensuring that people continue to live and build a life
 - c. Manage pain and other symptoms of dementia
 - d. Coach on behavioural management issues and refer for intervention if and when they arise
 - e. Reduce carer stress
 - f. Avoid hospitalisation and more expensive forms of care if possible
 - g. Provide bereavement support services for carers and families.
5. That an electronic health record be set up that is in synergy with the Dementia Pathway approach recommended
 6. That more funding needs to go into education around dementia as well as research into its cure, treatment and ways to support people through the progression of the condition to end of life..

ACH Group commends the Senate Committee on Community Affairs for enquiring into the provision of palliative care in Australia and supports the review of the needs of an ageing population, particularly the impact of increasing dementia prevalence. We believe that most older people prefer to remain living in their own home, in control of their lives and use of services. We suggest a dementia pathway through a National Gateway Agency as an efficient way of improving access to palliative care services for people with dementia and their families and to ensure services for older people in a place of their choice.

Yours sincerely,

Dr Mike Rungie
Chief Executive officer
ACH Group