

Committee Secretary  
House of Representatives Standing Committee on Health and Ageing  
PO Box 6021  
Parliament House  
Canberra ACT 2600

*mal* **Submission No. 009**  
**(Dementia)**  
**Date: 20/04/2012**

## **Inquiry Into Dementia: Early Diagnosis and Intervention**

### **Introduction**

Home Instead Senior Care is a private non-medical provider of companionship and home care services supporting older people to live independently at home.

Home Instead offers flexible, client-centred and client-directed services that allow clients or their families to choose the frequency and length of services to meet their specific needs - these services and schedules can be changed by clients or their families as needs change.

With an ever increasing number of Home Instead clients having some form of dementia it has become increasingly important for Home Instead CAREGivers to be able to identify clients who may be in the early stages of dementia so that they can provide them and their families with appropriate advice, support and client-centred care.

In 2007 Home Instead Senior Care partnered with Alzheimer's Australia (QLD) to develop a specialised dementia care training program for all Home Instead CAREGivers. This training program develops the skills and understanding of Home Instead CAREGivers and assists them to help families understand dementia and help them live with and care for their loved one. Appropriate training is also important in ensuring that Home Instead CAREGivers are able to care for clients with dementia to keep them safe and secure in their home for as long as possible.

The Home Instead CAREGiver dementia training program covers three key areas in dementia care: identifying types of dementia; effective communication with people who have dementia; and understanding behaviours of concern and how to manage them. Home Instead has taken a proactive approach to help improve dementia care in Australia by ensuring that our CAREGivers understand dementia and have the skills to assist people living with dementia and provide support to their families.

An international network of over 900 offices, Home Instead Senior Care is an ISO 9001:2008 Quality Certified organisation and commenced its wholly Australian owned operations in Brisbane in March 2005. Currently there are 19 Home Instead independently owned offices across Australia.

Home Instead Senior Care is not a 'government funded organisation'. Clients and their families pay directly for their services. However every Home Instead offices collaborates very closely

with health care organisations and government funded community care providers to deliver high quality care services for people with dementia.

### **Our experience with dementia care**

The experience of Home Instead Senior Care offices around the country providing services to clients with dementia and support to their families are as follows:

- Families want to keep their loved one living with dementia at home for as long as possible but the current system does not provide them with adequate support or assistance to enable them to do this.
- Many people do not understand or cannot fully comprehend what dementia is, how it affects a person or how they can best care and communicate with someone who has dementia. This includes families living with someone who has dementia, the general public, clinicians including GPs, nurses and allied health professionals.
- Some families are in denial when a person shows signs of having dementia which means that they do not seek an early diagnoses, assistance or plan for the care of their loved one until a serious or catastrophic event occurs or they find themselves no longer being able to cope.
- Caring for people with dementia requires specialist knowledge, training and understanding.
- Some people never fully understand dementia and despite their close relationship with the person with dementia, their lack of understanding about dementia may prevent them from providing appropriate care
- Carers of people with dementia
  - o want to choose when and where care services are provided and be able to change these services as their family circumstances, preferences or rapidly changing needs of the person with dementia require
  - o want access to flexible, responsive care services at any time of the day or night including weekends and public holidays (many government funded services only provide care Monday to Friday during business hours).
  - o want continuity and consistency of home care services and do not want to have to negotiate and manage a number of different services or service providers.
- Early intervention and diagnosis of dementia is important in identifying or eliminating other diseases which may be treatable and reduce some of the dementia symptoms in the short term.
- A planned approach to dementia care is very important and requires involvement of all family members and friends who wish to be involved.
- In the early stages clients can communicate and make their own decisions and should be involved in the decision making process as much as they can.
- Providing care to someone with dementia can severely impact the lives of their partner's families and friends and can place great stress and anxiety on them especially as dementia progresses.
- Families need assistance in planning for the future care needs of a person diagnosed with dementia. They do not know about or understand all the options available to them.

They need personalized advice from a trained advisor and or case manager and do not want to be overwhelmed with brochures or other forms of literature.

- Some family members are embarrassed to ask for assistance and feel that they should be able to manage the care of their loved one on their own especially if they do not have any other health issues. The challenge for some families is to get their mother or father to admit they need help to care for their spouse/partner.
- Professional caregivers who are trained and understand dementia play a vital role providing advice, respite and support to family and friends to reduce the burden of stress and allow them time out from their loved one
- Standard packages of care services or a one stop shop approach to dementia care at home does not meet the individual and personal needs of a person living with dementia as everyone's situation and needs are different.
- Many families (eg adult sons and daughters) want to and will fund the care of a parent living with dementia to help them to continue to live in their own home
- Unless a person with dementia has other chronic diseases it is rare that they need complex clinical care to attend to their needs 24 hours a day, however they may require round the clock care to ensure their physical and emotional safety especially if they become disorientated, agitated or are prone to wander
- It is important that that a person with dementia has appropriate directions in place with an authorized and trusted person so that they can step in to make decisions when needed
- GPs, clinicians in hospitals and other health professional often do not consider the fact that a patient may have dementia especially in the cases of younger onset Alzheimer's. This can create problems for the person with dementia who may not be able to communicate about their health issues and for the clinician who may not be able to rely on the information provided by the patient.

## **Our philosophy**

All dementia clients are unique individuals with personal needs and preferences which should be respected, supported and encouraged.

Care services provided for someone with dementia should be personalized reflecting the person's current situation and also their former lifestyle, work history, hobbies, recreational and social interests, travel and significant life events.

People with dementia:

- Are more comfortable both physically and emotionally in their own familiar environment amongst family and friends which provides them with a greater quality of life.
- Will generally retain a greater sense of control over their life for a longer period of time if they can live at home in a familiar environment and by their own schedule; for example sleep and eat when they want to and not be required to meet the schedule of an institution.
- Will retain their cognitive and physical functionality for longer if they are provided with appropriate mental and physical stimulation on a regular basis.

## **Our recommendations to Government**

In light of the recent announcement regarding community care and dementia care, Home Instead supports the government's intentions to:

- Include dementia awareness as part of key public health campaigns and issues.
- Increase the number of GPS gerontologists and clinicians experienced in diagnosis of dementia especially in the early stages and training programs to assist clinicians in the early diagnosis of the disease.
- Support the development and delivery of dementia training for professional carers.
- Provide a national advisory portal / website and hotline for access to information about dementia.

## **Our Key recommendations**

1. Appoint /create a local (as opposed to a national) dementia specific access point staffed by people trained and experienced in dementia care who can ask appropriate questions, provide information, and advise on the range of local care and link people into to these local services. ie not just send out a pack of brochures but tailor their advice to meet the specific needs of the individual making the enquiry.
2. Fund dementia trained advisors/case managers who can assist in the development and review of personalized care plans and services to meet the individual needs and situation of the dementia client and their families.
3. As the government has recognized there are substantial economic benefits to providing dementia care in the home in comparison to the costs of providing care in an aged care home especially in the early and mid stages of the disease, we recommend that the government also consider the following;
  - a. Make means tested funding for in-home care services payable directly to the person diagnosed with dementia so that families can choose to fund care services that best suit their situation, change services and provide supplementary funding for services as required.
  - b. Make non-medical home care services more affordable by removal of taxes eg GST and by providing tax relief where payments for in-home dementia care services are made from taxable income.
  - c. Subsidise the hire of equipment and minor modifications to the home to facilitate the provision of care and safety of people living with dementia in their own home
  - d. The continuation of funding for research into dementia, its causes, diagnosis and treatment

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