



2nd May 2012

Mr Steve Georganas MP
c/o Committee Secretary
Standing Committee on Health and Ageing
House of Representatives
PO Box 6021
Parliament House
Canberra ACT 2600
By email: haa.reps@aph.gov.au

Submission No. 047

mal (Dementia)

Date: 02/05/2012

Dear Mr Georganas,

Re: House Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention

Aged and Community Services Australia (ACSA) welcomes the opportunity to provide feedback to the House of Representatives Standing Committee Inquiry into Dementia: Early Diagnosis and Intervention terms of reference.

ACSA is the national peak body for aged and community care providers representing faith based, charitable and community based organisations providing residential and community care services, housing and supported accommodation for older people, younger people with a disability and their carers.

As the Committee's Terms of Reference recognise, early dementia diagnosis and intervention has been shown to improve the quality of life for people living with dementia, as well as their family members and carers. But early diagnosis of itself without appropriate care and support arrangements is of limited value. Hence ACSA observes that resourcing for support services and workforce training has been and still remains a major barrier to addressing dementia in the community.

ACSA notes and welcomes the recent initiatives contained in the Australian Government's aged care reform package, *Living Longer. Living Better*, which goes some way in helping to address early diagnosis and intervention issues, as well as helping to increase awareness amongst health professionals in how best to manage people presenting with behavioural and psychological symptoms.

ACSA acknowledges the clinical challenges posed in making early and accurate diagnosis of dementia. Putting aside these challenges, ACSA's comments below centre mainly on the specific questions raised in the terms of reference concerning how early diagnosis and intervention can improve outcomes, including how they need to be complemented by adequately resourced support services.

Improve quality of life and assist people with dementia to remain independent for as long as possible.

There are many causes of dementia, with each exhibiting different patterns of behaviour and outcomes. This means an early and accurate diagnosis will give sufferers clearer information about their prognosis and the likely symptoms to expect, which will in turn positively impact on the care and lifestyle of the person with the disease, their carers and families.

Although there is currently no known cure for the majority of dementias, as more effective treatments become available in the future, early diagnosis will become essential to halt or postpone the destructive patterns of the disease. It is also believed that some of the current medications used to treat Alzheimer's disease may be more beneficial if given early in the disease process. For some individuals, timely medication may help to maintain daily functioning and quality of life as well as stabilising cognitive decline.¹

Early diagnosis can provide answers as to why someone has been exhibiting unusual behaviours and help reduce the stress associated with these behaviours and not knowing their cause. It also means that the financial cost of undergoing multiple tests by multiple clinicians trying to source the problem can be avoided.

Early diagnosis would also allow timely access to counselling, information, education and support through carer support groups to enable individuals and their families to make informed decisions and plan better for the future. It enables them to address the grief the diagnosis of dementia can bring – the lack of a cure, fear about the future and help them to plan and adjust to lifestyle changes. Learning how to share their story with friends, neighbours and colleagues will make it easier to build a support network for the person with the dementia.

Earlier access to restorative care and rehabilitation programs that address specific motor, visual and or language difficulties, advice on aids and equipment, home modifications or individually tailored exercise programs can also assist in remediating difficulties and maintaining function longer.

Contact with Aged Care Assessment Teams (ACAT) can be arranged to assess the care and support needs of the individual and put them in contact with the relevant services, make recommendations about the level of care required and approve eligibility for support packages to suit the needs of the individual. This assistance can enable them to remain independent and stay at home longer.

Increase opportunities for continued social engagement and community participation for people with dementia.

To ensure people with dementia do not become socially isolated, it is important to build support networks and safe social situations for those in similar circumstances. This can be done in conjunction with flexible respite services. Funding should also be provided to run activities and to train volunteers, who can provide a link between the individual and the community and community social activities. This not only keeps the person with dementia connected, but can also provide some relief to harried carers.

¹ Early Diagnosis of Dementia, Alzheimer's Australia, Paper 10, March 2007

Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements.

It is very important for people to have the opportunity to make preparations for their future while they still have the cognitive capacity to participate in making decisions around their financial and legal affairs, including arranging enduring powers of attorney and guardianship orders. Health care planning and advance care plans can also be prepared before crisis situations develop.

Early diagnosis will also help primary health and age care service providers to respond more effectively with the provision of community, residential, respite care and other services. It is universally recognised that support for carers is fundamental in enabling people with dementia to stay at home longer. An early diagnosis would allow for timely carer support arrangements to be made.

How best to deliver awareness and communication on dementia and dementia-related services into the community.

Understanding, awareness and acceptance of dementia not only vary between geographical communities, but within subgroups within communities. The stigma that can be associated with dementia in some communities will sometimes lead to families trying to hide it for as long as possible, meaning they are often in crisis before they seek assistance.

Access to information and resources needs to be adapted to suit the characteristics of specific groups. Making better use of community leaders and organisations to help educate people and make them aware of the services and assistance that is available would be helpful.

A major problem in many parts of the community is the misunderstanding that dementia is only associated with ageing. It is important to get the message out that dementia is an illness and not all old people get it, and not all people with dementia are old.

People who have concerns about symptoms popularly associated with dementia, such as memory issues, should be encouraged to seek help either through their local GPs or Memory Clinics.

Whilst ACSA and its membership have more involvement with dementia from an aged care perspective, younger onset dementia can present with a range of different or additional problems. For example, the person may still be in employment and looking after a family. This can cause considerable anxiety and stress not knowing how the family will be financially taken care of as their condition deteriorates. The spouse, who may take on the caring responsibility, may also need to leave their employment adding to financial woes. Families often have difficulties adjusting to the changed circumstances and the strange behaviours of their loved one. This can cause friction and affect school outcomes etc.

Recommendations

ACSA makes the following recommendations, whilst recognising that the Government's Living Longer. Living Better Aged Care Reform package will go some way to addressing some of these recommendations.

- Funding is provided to undertake a national dementia awareness campaign to increase community and professional awareness of dementia to reduce the stigma and isolation associated with living with dementia.
- Funding and support be provided for culturally diverse community groups to increase awareness and understanding of dementia and dementia services within their communities. How the funding is used needs to be flexible to suit the circumstances and culture of each group.
- Funding is provided to develop and implement strategies to improve assessment and diagnosis of dementia in General Practice and in aged care settings. This should be done in conjunction with a review of the effectiveness of previous strategies to improve professional awareness of dementia.
- Health workforce planning takes into account the need to train more specialist gerontologists, psychogeriatricians and neurologists in order to give people greater access to these specialties.
- Additional funding is provided to increase the availability of flexible respite services which combine education and counselling services to support people living with dementia and their carers.
- Additional support is provided for people living in rural and remote areas to travel to regional centres for diagnosis and treatment. This will ensure equal access to medical and diagnostic facilities. Support could cover the cost of travel and allowances for overnight stays for the individual and their carer where necessary.
- Additional training is provided for community and residential age care staff caring for people with dementia.

We look forward to the release of the final report and would be happy to provide any further assistance.

Yours sincerely,

Adj Prof John G Kelly AM
Chief Executive Officer