

**Productivity Commission on Caring for Older Australians
Submission from Alzheimer's Australia NSW
Re: Younger Onset Dementia**

“The health and aged care systems do not recognize younger onset dementia.”

NSW Younger Onset Network member

Dementia facts

Dementia is a fatal condition that can happen to anybody, but it is more common after the age of 65. People in their 40s and 50s are also diagnosed with dementia.

Dementia is not a normal part of ageing. While it's more common to be diagnosed with dementia after the age of 65, not just older people get dementia. Dementia can happen to anybody.

The term dementia describes the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning, including a loss of memory, intellect, rationality, social skills and normal emotional reactions. Alzheimer's disease is the most common form of dementia, accounting for between 50-70% of all dementia cases.

An estimated 257,000 Australians currently have dementia and without a significant medical breakthrough that number is set to soar to about a million by 2050. (Access Economics, July 2010)

Dementia has now become the third leading cause of death in Australia. It is also predicted to become the third greatest source of health and residential aged care spending within two decades. These costs alone will be around 1% of GDP.

Dementia is a progressive condition whose impact on the individual's functioning increases with the growing severity of the disease. It is the greatest single contributor to burden of disease because of disability and is more likely than other health conditions to be associated with severe or profound limitations in self care, mobility and communication.

What is 'younger onset dementia'?

The term 'younger onset dementia' is applied to people under the age of 65 who have been diagnosed with dementia and can include people in their 30s, 40s and 50s who have been diagnosed with the condition. Dementia comes in many forms. Alzheimer's disease is the most common form of dementia, but is less common among people under 65 when compared with people aged 65 years and over.

Other forms of younger onset dementia include vascular dementia, fronto-temporal dementia and dementia with Lewy bodies. Younger onset dementia can also be associated with other disabling conditions such as Multiple Sclerosis, Motor Neurone Disease, Parkinson's disease, AIDs and Downs syndrome.

Access Economics estimates there are around 15,000 people under the age of 65 living with younger onset dementia across Australia, with approximately 5,000 people living with younger onset dementia in NSW. (*Access Economics*, 2009)

Challenges faced by those with younger onset dementia

People with younger onset dementia are at a very different stage in their life with onset of the illness when compared with older people. People with younger onset are typically more physically and socially active, and may still be working and driving and have significant financial commitments. They often have younger partners and children. They do not in many cases fit into mainstream dementia services currently offered by the aged care sector.

The burden associated with dementia at a young age is substantial. Unplanned losses can include income, work, self esteem and a sense of purpose with many future plans no longer viable. A diagnosis of younger onset dementia means carers are often faced with the double responsibility of caring for the person with dementia as well as continuing to raise children and manage finances.

Friendships often can become strained as people struggle to accept that their younger, otherwise healthy friend has been diagnosed with dementia, and children can also have strong reactions when their mother or father are diagnosed with the condition. There is also a danger that the person diagnosed with younger onset dementia, their carers and family can become increasingly isolated from support services, extended family and friends.

Major question and issues

There is strong evidence that those diagnosed with younger onset dementia, which includes people with dementia well before 60 years of age, are not currently well served by aged care services. In fact, there are few services available that provide appropriate and flexible care to people with dementia under the age of 65. For example, carers of people with younger onset dementia, who often are still working and may have children, can struggle to find appropriate long term, flexible respite options in order to continue to work and appropriate care for their loved one diagnosed with the condition.

Under the COAG arrangements agreed to in 2010, the Commonwealth will become responsible for all services for people aged over 65 years and the states and territories will be responsible for community care and disability services for those under 65 years of age. Currently that means the states will carry full responsibility for the care of people with younger onset dementia.

The COAG reforms raise the question about what system is best placed to deliver appropriate younger onset services. Should state governments both fund and provide services to those with younger onset dementia, or should there be provision made within aged care for people diagnosed with younger onset dementia? If the aged care system is to provide care, is that care currently adequate, or will changes need to be made in order to provide care to this special needs group? How will state governments and the commonwealth ensure equitable access to funding and services between the two systems?

Right now people diagnosed with younger onset dementia and their carers tell Alzheimer's Australia New South that access to appropriate services is difficult, if not impossible. Currently people with younger onset dementia can access HACC services and aged care services funded by the Commonwealth, however both access and appropriate service provision is not consistent and is severely limited by current service ratios and a lack of understanding on behalf of both government and the private sector of the nature of younger onset dementia.

In the context of current reforms it is critical that the Commonwealth and state governments address the special needs of people diagnosed with dementia under the age of 65. Because of the proposed changes to funding and service provision between the states and Commonwealth, the provision of services needs to be considered across both tiers of government in order to deliver accessible, appropriate and flexible services for people with younger onset dementia.

The following are recommendations to be considered in the context of the COAG reforms of the health and aged care systems and the Productivity Commission Inquires into the provision of disability and aged care services.

Recommendations

The Commonwealth and NSW governments ensure

- 1) access to dementia services is based on a diagnosis of dementia regardless of the person's age. In the case of younger onset dementia, funding could be through the State governments, but delivery of services would be through the aged care system, which is the responsibility of the Commonwealth. Access to services would be immediate, regardless of the age of the person diagnosed.
- 2) consistent access to the various entitlements such as disability payments and carers allowances through Centrelink.
- 3) younger onset dementia should be defined as a 'special needs group' across both state and Commonwealth government departments. Specific services should be developed that are designed to meet the needs of people with younger onset dementia.
- 4) specific services for people with younger onset dementia will be created within the aged care service system that are flexible and based on the needs of the individual, regardless of age. This is consistent with the recommendations of the Productivity Commission around person-centered care.
- 5) seamless transition mechanisms are created between State and Commonwealth systems with regard to coordinating the funding and delivery of services to people with younger onset dementia.
- 6) consistent application of guidelines and protocols across both State and Commonwealth funding and service delivery pathways for people with younger onset dementia.
- 7) regional quotas and artificial boundaries are removed between regions to open access to services for people with younger onset dementia and their families, regardless of their location.
- 8) services are developed that are appropriate for people with younger onset dementia including:
 - i. Long day care centres that support working families caring for a person with younger onset dementia.
 - ii. Day centres that provide appropriate care for people with dementia with challenging behaviors.

- iii. Respite services that are flexible and responsive to the needs of people with younger onset dementia and their carers.
 - iv. Appropriate activities such as outings to theatres, beaches, parks etc.
 - v. More dementia-specific family counseling and support, particularly for families in crisis.
 - vi. More dementia specific case management services for families in need e.g. COPS model
- 9) dementia specific education, including a younger onset dementia component, is a mandatory component in medical, nursing and allied health training.

References

Access Economics (2009) *Keeping dementia front of mind: incidence and prevalence 2009-2050*, Report for Alzheimer's Australia, Canberra, August.