



**Alzheimer's Australia NSW Submission
Productivity Commission
Issues paper - *Disability Care and Support***

Thank you for the opportunity to respond to the Issues Paper on the Future of Disability Care and Support. Of particular concern to Alzheimer's Australia NSW is the discussion around the definitions of eligibility with regard to people with dementia under the age of 65.

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, is more likely to be the main health condition resulting in disability and is very likely to be associated with multiple health conditions.

Younger onset dementia

Younger onset dementia comes in many forms. Alzheimer's disease is the most common, but it is less common among people under 65 when compared with Alzheimer's disease in people aged 65 years and over. Other forms include vascular dementia, fronto-temporal dementia, and dementia with Lewy bodies. 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 that the prevalence of dementia for persons under 60 years of age is around 1.2 percent of males and 0.6 percent of females aged between 64 years of age, which translates to an estimated 16,000 people with younger onset dementia across Australia. That number does not include their carers.

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

Challenges faced by those with younger onset and their carers

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 future plans no longer viable. A diagnosis of younger onset dementia means carers may be faced with the double responsibility of caring for the person with dementia as well as raising children and managing finances. Friendships often become strained as people struggle to accept that younger people can have dementia and children may have strong reactions to a parent who has been diagnosed. The person diagnosed with younger onset dementia, their carer and family members can often become increasingly isolated from support services, extended family and friends.

The consideration of the Commission to specifically exclude people with dementia in someone aged 60 years or more from the Terms of Reference

because the aged care industry has “developed strong capabilities for the management of such disabilities” is not recommended. (p.19). There is strong evidence that those with younger onset dementia, which includes people diagnosed with dementia well before 60 years of age, are not currently well served by aged care services and often have difficulty accessing appropriate financial support.

Recommendations

- 1) Alzheimer’s Australia NSW requests the Commission consider dementia in those under the age of 60 in its determinations to establish eligibility criteria for a future national disability care and support scheme. This approach would be consistent with the COAG determination that disability services will include people with younger onset dementia under the age of 65. The Commission should consider people living with younger onset dementia as included in the definition of disability and in “significant need of support.” (p7) As a progressive, disabling health condition, dementia meets many of the criteria for eligibility the Commission is considering.
 - Dementia is not a normal part of ageing
 - Increasing numbers of Australians under the age of 65 are being diagnosed with dementia
 - Dementia is a degenerative, irreversible condition
 - Until a cure is found dementia is always fatal
 - Dementia can be co-morbid with other disabling conditions in those under 65 such as Multiple Sclerosis, Motor Neurone Disease, Parkinson’s disease, AIDs and Downs syndrome.
- 2) That specific services needed to support people with younger onset dementia are developed and appropriate financial support will be included in any scheme of reform of funding for services for people with a disability.
- 3) Provision must be made to include the development of services such as long term respite and appropriate residential care that can respond to the needs of people with dementia under the age of 65 and financial models such as consumer directed care that can respond to meet their specific needs of each person. These services may still be provided by the aged care system with funding covered for those eligible under the new disability care and support scheme.

References

Access Economics, 2010, *Caring Places: Planning for Aged Care and Dementia 2010-2050*, Report for Alzheimer’s Australia.

