



Australia 2020 Summit submission

Strengthening communities, supporting families and social inclusion

Social inclusion and the special disadvantages of people with dementia

The 225,000 Australians with dementia and their family carers represent some of the most vulnerable people within our communities. The increasing number of people with dementia challenges us as a society to address the issues and barriers that currently exist for people with dementia and their family carers.

- Awareness and reduction in stigma

The community needs better information on dementia. Unlike other chronic diseases there has been no major public awareness campaign to promote a wider community understanding of dementia and its implications, how people with dementia might be supported and approaches to reducing risk of dementia.

- Promote Social Engagement

People with dementia progressively lose many of the activities and relationships on which their lives have been built. Community support and networks are needed to promote social engagement in activities that have been part of individual lives before diagnosis. Social engagement which recognises individual interests should be part of programs such as respite care. For example, there is scope for programs that promote social interaction through music and the arts.¹

- People with Younger Onset Dementia²

The 10,000 Australians with younger onset dementia (some as young as 35 years) experience particular social disadvantage. This group often experiences severe stress and isolation due in part to serious delays in obtaining an accurate diagnosis, compared with older people.

¹ For more information on art and dementia, see, Patricia Banes (2007) "Nurturing the heart: creativity, art therapy and dementia" *Quality Dementia Care Series* prepared for Alzheimer's Australia, available at <http://www.alzheimers.org.au/upload/ArtTherapy.pdf>

² More information on Younger onset dementia is available at <http://www.alzheimers.org.au/content.cfm?infopageid=914>

Once a diagnosis has been made, younger people and their family carers often fall through the net of services and support, due to the stereotypical association of dementia with older age.

People with younger onset dementia and their family carers have unique and complex needs due to their stage of life. They may be bringing up children, financially supporting the family and have life expectations which they need to dramatically revise.

We need to have appropriate and accessibility services and support for this potentially vulnerable group of people to improve their quality of life after diagnosis.

- Human rights

Legal, financial and care planning is crucial for people with dementia, as soon as possible after diagnosis.³ They will at some point in time lose decision-making capacity and should have the right to have a say about what happens to them, before losing capacity. It is important, that all Australians are adequately informed of the need for advance planning, and encouraged and assisted in planning for their future.

The current patchwork of legislation relating to advance planning is complex, varies significantly across jurisdictions, is confusing and recognition of different laws across States and Territories is particularly problematic. Lack of education and support to make an advance plan is a major impediment.

We need quality advance planning legislation and education, which supports the rights of people with dementia, reduces carer burden and enables individual wishes to be respected.

- Life does not end with a diagnosis of dementia

Protecting the rights of people with dementia and their family carers and enabling them to be socially engaged will help improve quality of life.

³ See, Alzheimer's Australia, "Decision making in advance: Reducing barriers and improving access to advance directives for people with dementia" Discussion paper 8, available at http://alzheimers.org.au/upload/Decision_Making_in_Advance_May_2006.pdf