Professor Brian Draper, MBBS, MD, FRANZCP
Conjoint Professor, School of Psychiatry UNSW
& Director Academic Dept for Old Age Psychiatry
Prince of Wales Hospital
Barker Street, RANDWICK
NSW 2031, Australia

Submission to Senate Inquiry on Adequacy of Existing Residential Care Arrangements for Young People

Professor Brian Draper, University of NSW, Sydney

This submission will focus solely on one type of disability – younger onset dementia. A key consideration for this type of disability is that it is usually progressive with increasing care needs over time.

Dementia predominantly occurs in the older population but between 2-3% of cases develop in people under age 65. Empirical research that we undertook in Sydney estimated that the prevalence of dementia in the community in people aged 30 to 64 years was 68.2 per 100,000 (Withall et al; 2014), a higher rate than previously reported in the UK, which is important as Australian estimates used by AIHW (Dementia in Australia, 2012) and the Alzheimer's Association have been based on this earlier UK research. In subsequent yet to be published research in the NHMRC funded Inspired Study that is examining the care needs of younger people with dementia, about 20% of our sample is residing in nursing homes, which perhaps gives a general indication of the quantum of residential care requirements for this particular population. My anticipation is that the number of people who develop dementia under the age of 65 will continue to increase commensurate with the demographic changes associated with the baby boomer generation.

Dementia in younger people has some features that impact on their residential care needs. There is a different pattern of dementia types in younger people compared with older people, with younger people having higher rates of frontotemporal dementia, alcohol-related dementia and dementias secondary to other diseases. Some of these types of dementia result in high rates of challenging behaviour in part due to the greater likelihood that the dementia involves damage to the frontal lobe of the brain and also because dementia in younger people is more common in males. Persistent behavioural changes are frequently the precipitant for placement into residential care.

Prevention or delay of institutionalisation is usually desirable but hard to achieve. Alcohol-related dementia, often described as alcohol-related brain damage or Korsakoff Syndrome, accounts for around 10% of young-onset dementia cases and is a possible exception. With early identification and treatment, cognitive decline can be stabilised and to a certain extent reversed. Efforts to better identify and treat younger persons who are showing early signs of this disorder will likely avoid the need for residential care.

Carers get burnt out, community respite and support services have limitations in the extent of service provision available even when maximal services are used. One concern with NDIS is that it doesn't appear to fund carer support. The anticipated increase in numbers of younger people with dementia over the next 20 years is going to require at least a commensurate increase in services just to tread water.

Currently there are very few facilities in Australia that specialise in caring for younger people with dementia. The majority that require long term residential care are placed, by default, in residential aged care facilities (RACFs). This can be inappropriate for a number of reasons. The type of physical environment and activities that younger people need differs from older people. Younger people are more physically fit and require a much more robust activity and exercise program as well as age appropriate diversional activities. This age group is much more likely to want wi fi connections, to use tablets, smartphones and PCs - even at this level of cognitive impairment. The previously mentioned behavioural changes include a lower ability to tolerate frustration, (for example, boredom with activities, inability to exercise adequately), and this can be a precipitant for aggressive outbursts. These can be a challenge for staff to manage, particularly if there are frail elderly in the same area. Obviously this also puts the frail elderly at risk too.

Some RACFs have set up sections of their facility for younger people and have developed age appropriate activity programs, an approach that is much better than the most frequently observed style of trying to integrate the younger people with the older residents. As it will always be difficult

to have sufficient facilities that solely focus on younger people, it would be useful to encourage more facilities to have sections organised in this way. Facility design is critical for people with dementia in all age groups but more so in younger people. There are currently too few well designed dementia facilities in Australia.

An alternative model, as has been developed in parts of the Netherlands, is to have small stand alone cottages or units that might accommodate 4-8 people in a type of group living arrangement. Again these need to be well-designed and to be adequately staffed. This style of residential care has the potential to be more home-like, personalised and could be regarded as an alternative to institutional care. It can help in maintaining family ties by providing an environment that visitors feel more at ease. How costly this might be could be a limiting factor.

In conclusion, the number of younger people with dementia is increasing and this will be challenging for provision of quality care irrespective of whether they reside at home or in institutional facilities.