



Submission to Senate Committee
30th April 2013

Care and Management of younger and older Australians living with dementia and behaviour and psychiatric symptoms of dementia (BPSD)

Helping Hand (HH) is a large aged care organisation in South Australia, HH provides services to almost 800 people living in residential aged care and approximately 7000 clients per annum across the metropolitan and rural regions of SA.

We provide specific services for people with Dementia including residential care in specialised units and home packages specifically for people with dementia. We also provide respite services to people with challenging behaviours and have two respite houses.

Our first comment relates to the content of the committee, We feel very strongly that the two groups; younger people living with dementia and older people living with dementia need to be considered as separate cohorts. In relation to **younger people** we find:

- That the models of care currently available to these people are framed around older people and therefore do not provide adequate lifestyle to the individual or their families
- The issues are compounded in rural regions where there is reduced choice of care and in some instances almost no care, this poses a problem where the person may have younger children if they are placed further away from the family.
- Many younger people have dementia as a result of other disability such as neurological disorders, these people have dual needs from a disability and the perspective of dementia.
- Many families have a significant financial burden from providing consumables such as incontinence aids, having to juggle work with care and any further purchased requirements which can't be met in usual care models.
- Younger people have different accommodation requirements for example for providers to adequately accommodate younger people there is a significant capital cost, younger people require greater access to open space, these people often need to move around freely.
- Often the care is strongly family centred, younger carers, working carers and children living with the person, these people require better support networks and resources.

For older people the issues are also compounded although they can receive lifestyle appropriate accommodation and home care. These issues are applicable to both younger and **older people** :

- They are often assessed in a system which relates to functional decline rather than psychological decline and therefore funding is inflexible to meet the behavioural needs of people living with dementia.
- People with extreme behavioural issues are very hard to find services for particularly in communal environments.
- Respite community care is inadequate as it tends to fund service provision rather than counselling and focussed on reducing the psychological burden of caring.



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- Respite care in residential facilities is difficult to access as it tends to be in communal, non secure, areas so precludes people who wander or may have challenging behaviours, also many people who have high needs, and receive reduced stimulation and activity, are at risk of decline and possibly may struggle to return home.
- As dementia advances carers of people with dementia are at high risk of injury (physical and psychological), this relates to them caring at home with inadequate training, skills, and equipment. People who care should also have access to other education around such things as nutrition, and other areas of functional decline such as swallowing deficits, signs of illness and/ or infection that may present in other ways compared to someone without dementia, common behaviours that occur in people with dementia and related behaviour management.
- Better and more intense workforce education and support. This needs to recognise workers right across all aged care services not just those workers who are workers directly within programs designed for people living with dementia. Mismanagement is often due to neglect discrimination and a lack of understanding. Given the diversity of our community cultural sensitivity will also be critical.

Helping Hand would be happy to contribute further to the work of the Committee including direct comment.

Contact person

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