SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO AGED CARE

Alzheimer's Australia recommends that:

1. **All residential aged care should be planned and operated with a view to providing quality dementia care.**
2. **10% of all residential aged care places should be dementia specific for those with severe behavioural and pyschological symptoms of dementia (BPSD).**
3. **Commonwealth and State Governments should give priority to planning psychogeriatric places for those with very severe or extreme BPSD.**
4. **Residential aged care provision needs to respond to the needs of younger people with dementia**

Background

Alzheimer's Australia welcomes the opportunity to make a submission to this inquiry. In the time available Alzheimer's Australia will limit its response to the special needs of people with dementia under term of reference (c), namely:

> "The appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements"

The needs of people with dementia

A framework for addressing the special needs of people with dementia with symptoms such as depression, agitation and difficult behaviours has been developed by Brodaty *et al.* (1). Attached is a tabulated form of their seven-tiered model of service delivery based on severity and prevalence of the behavioural and psychological symptoms of dementia (BPSD).

In summary this framework is based upon the following:

- People with dementia usually experience behavioural and psychological symptoms of dementia (BPSD) during the course of their illness. Currently, in Australia, there is a lack of comprehensive planning for managing and preventing BPSD, and the resources required for optimal care are inadequate and unevenly distributed.
- The seven-tiered model encompasses those ranging from no dementia in the lowest, increasing up tiers in severity of behavioural disturbance to the propensity for extreme violence in a small number of individuals.
- Each tier is associated with different models of intervention. People with dementia may move up or down between tiers depending on their condition, care and the intervention provided.

- Lower level interventions may prevent the need for the more intensive interventions needed when disturbance becomes more severe.

A number of important points emerge from analysis of the Brodaty Triangle.

- There is no one size fits all in dementia care. The intervention appropriate will vary by the individual, cause of dementia and the stage of dementia. The dynamic nature of the condition and changes in the individual have to be the constant focus of dementia care and appropriately tailored responses.
- At any time half those with a diagnosis of dementia will be living in the community. Intervention strategies recommended for the lower levels in the "Triangle" should generally be tried before employing those from higher levels. Many but not all of those people with dementia at end stage will be in residential care. It is nonetheless important to recognise the role of community services in responding to the special needs of people with dementia and provide the support necessary to families and carers.
- The management of people with BPSD is a particular problem in rural and remote areas.
- The numbers of those people with very severe and extreme BSPD is low – about 1% of the total of those with a diagnosis of dementia.

Residential Care

Alzheimer's Australia believes that on the basis of the Brodaty Triangle there are three urgent needs that need to be addressed in respect of people with dementia in the provision of residential care.

1. While many residents have co-morbidities, aged care is in large part dementia care (2). Therefore, all mainstream residential care should offer quality dementia care in a safe environment that, appropriately and sensitively, meets person's needs, while encouraging them to perform whatever self-care and diversional activities they can. Many of those in tiers 3 and 4 are cared for in mainstream residential care. Approximately 30% of people in low care and 60% in high care facilities have a diagnosis of dementia while 54% and 90% of residents in these facilities show some degree of cognitive impairment (3).

2. Alzheimer's Australia believes that those in tier 5 are likely to require special care for some period. These residents are likely to be ambulant and physically strong and to need experienced personal care workers rather than nurses. Alzheimer's Australia believes there are about 8,500 residential care places available for dementia specific care (about 6% of all places) but 17,000 places are needed for those with special care needs who cannot be cared for in mainstream facilities.

   Lack of dementia-specific care for this group is likely to increase overall health care costs as nursing homes tend to transfer patients with

worsening dementia symptoms either to an aged psychiatry service or to the hospital wards. Since some aged psychiatry services do not accept patients with a primary diagnosis of dementia, without another psychiatric illness, many are relegated to hospital wards where care is very expensive and, in most cases, not appropriate (4, 5).

The Government's commitment to introduce the Dementia Supplement by 2006 is an acknowledgement that special funding is needed for those residential care providers who are providing access for those with special needs. In the view of Alzheimer's Australia there are inadequate incentives available to residential providers to provide care for this group currently.

3. Those in tiers 6 and 7 are likely to require psychiatric care as well as dementia care. De-institutionalisation has resulted in a marked reduction of long-term psychiatric wards. As a consequence of this, and the divided responsibilities of the States for mental health systems on the one hand and Commonwealth for aged care on the other, individuals in need of both psychiatric and aged care have difficulty accessing the care they need.

   Some states, notably Victoria have developed an approach through psychogeriatric nursing homes that are funded jointly by the federal and the state government. In this arrangement the federal government pays for the basic nursing home care while the state government provides 'top-up' funding for additional psychiatrically trained staff (6). We encourage this approach because it provides for a group who otherwise cannot gain access to the care they need.

   The needs of this group are complex and there are few studies evaluating overall models of old age specific mental health care (7). Nonetheless, there is evidence to suggest that purpose built residential care is better than traditional psychogeriatric wards for long term care of people with dementia. The planning of such places should be a priority.

Lastly, there are currently no residential care facilities that cater for younger (under age 65) people with dementia. Younger patients have the same symptoms as the older patients; however, they perceive the hostels and nursing homes as places catering to the old and therefore not relevant to them (8). They need an environment in which they can socialise appropriately and activities appropriate to their physically more able bodies. There are currently some 6000 people less than 65 years with dementia (a number that may increase with earlier diagnosis) and it is important to consider the interests of this group when planning residential dementia care.

Alzheimer's Australia
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References:

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3. Rosewarne R, Opie J, Bruce A et al, *Care needs of older people with dementia and challenging behaviour living in residential care facilities*, Canberra AGPS 1997

4. Kuruvilla George: *Abolishing waiting lists in an aged psychiatry service.* Australasian Psychiatry (2003) **11**, 2: 185-188.

5. George T. Grossberg and Abhilash K. Desai: *Management of Alzheimer's Disease.* Journal of Gerontology (2003) **58A**, 4: 331-353.

6. John Snowdon and Tom Arie: *Old age psychiatry service: long-stay care facilities in Australia and the UK.* Psychiatric Bulletin (2002) **26**, 1: 24-26.

7. Draper B and Lee-Fay Low, *What is the effectiveness of old age mental health services?* World Health Organisation http://www.euro.who.int/HEN/Syntheses/mentalservice/20040720_2

8. Angela Beattie, Gavin Daker-White, Jane Gilliard and Robin Means: *'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services.* Health and Social Care in the Community (2004) **12**, 4: 359-368.

Brodaty Triangle

SEVERITY vs TYPES OF CARE FOR PATIENTS WITH BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA

See Brodaty, Draper and Low (2003)

Tier	Description	Tiers 2-7 percentage and number of the estimated 162 000 people with dementia	Level of Disturbance & Intervention Use Cumulative
1	No dementia	+	Strategies to prevent dementia remain unproven, although some evidence exists for protective effects of Vitamin E, Vitamin C, statins, antiacids, low cholesterol, hormone replacement therapy, education, increased social, mental and physical activities, treatment of vascular risk factors and prevention of hypertension.
2	Dementia but no BPSD	39% * 63, 000	Interventions not widely researched, Medications slowing progression of dementia may also prevent emergence of BPSD. For example, galantamine has been shown to lower rate of emergence of BPSD. There is evidence that environmental modifications, general activity programs higher staff ratios and staff training, may prevent emergence. Early intervention programs for dementia such as Living with Memory Loss program run by the Alzheimer's Associations may also prove effective.
3	Mild BPSD	29%* 47, 000	Night time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing. Management through caregiver, staff and general practitioner education, environmental modifications, general activity programs e.g. education of caregivers, multi-sensory stimulation; abilities-focused program; enhanced nursing home environment; education & environmental modifications; client centred care; visual barriers; activities, medication guidelines & educational rounds.
4	Moderate BPSD	21%♣ 34, 000	Major depression, verbal aggression, psychosis, sexual disinhibition, wandering. Management through psychogeriatric consultation with medications and through behavioural management e.g. physical activity programme; individualised music; stimulated presence; behavioural management techniques; bright light therapy; outdoor environments; increased environmental quality; Alzheimer's Australia South Australia's hotline for BPSD.
5	Severe BPSD	10%♣ 16, 000	Severe depression, psychosis, screaming, severe agitation. Management in dementia specific nursing homes or by psychogeriatric team e.g. dementia special care units; individually tailored psychogeriatric management.
6	Very severe BPSD	0.9%♣ 1, 500	Physically aggressive, severely depressed, suicidal. Management in psychogeriatric or neurobehavioural units e.g. CADE units; psychiatric hospitalisation.
7	Extreme BPSD	0.1%♣ 200	Physically violent. Management in Intensive Specialist Care Unit.

Please Note Tiers 2-7 only included in the estimated 162,000 people with dementia in Australia in 2002.

\+ In 2002 there are approximately 2.5 million people aged 65 years and over in Australia and some 162,000 of them have some form of dementia. People with dementia represent 6.6 percent

* Statistics based in clinical observations

♣ Statistics based on Lyketsos et al (2000)