Supplementary Submission to the Productivity Commission Inquiry: Caring for Older Australians

October 2010

Dementia Care in Residential Aged Care- Specialised care or Core Business?

Introduction

At the technical workshop on 15 September Commissioner FitzGerald asked about the future of residential care for people with dementia. This further submission responds to that question in more detail than was possible at the time.

The majority of individuals in residential aged care experience some form of cognitive impairment[i] and it is one of the most common triggers for entry into residential aged care. Dementia can no longer be considered an issue effecting a small population of older adults in aged care but must be seen as part of the core business of aged care provision.

Although there is a move towards higher utilisation of community care there will continue to be social pressures that lead to many individuals, particularly those with cognitive impairment, to seek residential care. For example, Alzheimer's Australia predicts a gap of over 98,000 informal family carers by 2030[ii].

So how can aged care facilities best meet the needs of increasing numbers of individuals with dementia?

Currently a small proportion of individuals with dementia who enter aged care are placed in Special Dementia Care Units. These are most often individuals with more severe behavioural and psychological symptoms of dementia (BPSD) who are ambulant and in many cases specialised care is their only option for care as main stream services will not accept them due to their high care requirements or concern about disruption to other residents [iii] There is relatively little known about the quality of care in these facilities or units, but there is some evidence to suggest that there is little difference in quality of care between mainstream facilities and dementia-specific care[iv].

The vast majority of individuals with dementia who are entering residential aged care (over 90%) receive main stream aged care services[v] and they make up the majority of total aged care residents (63%)[vi]. It is estimated that up to 90% of residents in high care may have some form of cognitive impairment[vii]. Aged care facilities therefore need to be capable of providing high quality dementia care regardless of whether they have a 'dementia specific care unit', in fact the majority of their residents require this type of care. Many of the principles of good dementia care are beneficial to any resident regardless of cognitive status (i.e. Individualised care, flexibility in routines). This paper will provide an overview of the current state of dementia specific residential aged care in Australia and recommendations for how to improve the overall quality of residential care for individuals with dementia.

Characteristics of individuals with dementia

It is impossible to discuss the care needs of individuals with dementia without first recognising that individuals with dementia are a diverse group with a wide range of care needs. Like other older Australians, individuals with dementia come from a variety of backgrounds, cultures and experiences and this can impact on their care needs and preferences.

The care of individuals with dementia is often complicated by BPSD. These symptoms can include agitation, depression, psychosis, lack of inhibition and aggression. Research suggests that over 90% of nursing home residents may exhibit at least one behavioural symptom.[viii] Individuals with dementia will have different levels of BPSD at different points in the disease, with some people progressing from no BPSD to severe BPSD in later stages of disease. Other individuals may stabilise and have reduced BPSD when in an appropriate care setting. [ix]According to the Brodaty triangle[x], 40% of individuals with dementia in the community may have no BPSD, 30% are estimated to have mild BPSD and 20% moderate BPSD. Individuals with mild to moderate BPSD can usually be cared for in the community or in main stream residential care facilities. Psychosocial interventions may be used to minimise the frequency and severity of BPSD in these individuals.

The remaining 10% of individuals with dementia have severe to extreme BPSD. This equates to approximately 25,000 individuals which may use 10-14% of the total 181,000 aged care beds in Australia. [xi] This group is likely to require more specialised, intensive care and may benefit from a specialist multidisciplinary team, or care in a psychogeriatric unit. These individuals, often younger[xii], are often cared for in dementia specific care and have difficulty getting placed in mainstream services due to their high care needs and concerns about the disruption of other residents.[xiii]

Care for individuals with severe BPSD and/or comorbid psychiatric disorders is challenging and requires coordination of aged care and mental health services. These individuals often face problems with continuity of care because of structural barriers between the mental health and aged care systems. Victoria has provided a model of continuity of care through their Psychogeriatric Nursing Homes which provide targeted care for individuals with severe BPSD[xiv]. These homes provide ongoing behavioural assessment and rehabilitation with the goal of discharging residents to mainstream facilities. The Psychogeriatric Nursing Homes are funded through the *Aged Care Act* but are topped up with funding from the state government to provide high levels of mental health support. A Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders[xv] made several recommendations on how to improve the care provision for people with BPSD. The report notes that main stream aged care facilities with good design and dementia services can play an important role in preventing the escalation of behaviour

problems. The Dementia Behavioural Management Advisory Services (DBMAS) has provided support for main stream facilities that have residents with BPSD.

Individuals with severe BPSD need better access to old age psychiatrists for assessment and care and this access needs to be better integrated with residential aged care. In some cases individuals with severe BPSD are best cared for in high dependency units that can provide in-patient psychiatric services, such as the Victorian Psychogeriatric Nursing Homes.

Dementia Specific Care

There is no regulation or standard for the use of the term 'dementia specific care' and as a result there is also a wide range of types of facilities and levels of care which are called 'dementia specific'. In some dementia specific care facilities staff receive special training on BPSD and dementia care, and in others there is little difference between staff working in mainstream services or special dementia care. The lack of definition of 'dementia specific care', and lack of differentiation in the quality of care leads to confusion and uncertainty for consumers who may be think that the best dementia care available will be in 'dementia specific care' which may not always be the case. Individuals with low levels of BPSD may not benefit from 'dementia specific care' which focuses on individuals with severe BPSD.

Individuals in dementia specific care have more frequent and severe BPSD compared to those in main stream services but little is known about the ability of these services to meet the needs of these residents. Research on dementia specific care in Australia suggests that[xvi]:

- Dementia specific care facilities are more modern and provide care in smaller groupings and may be more secure.
- Dementia specific care may have more resident-centred care practices and flexibility and appropriate environments than mainstream facilities.
- There are no significant differences in use of chemical or physical restraints.
- Dementia specific units are more likely to use isolation as a behavioural management strategy than mainstream facilities.
- Other care practices differ little between mainstream and dementia specific care.

Although individuals with severe BPSD are often cared for in dementia-specific units, the research described above suggests that these special care units in Australia are not any more successful in caring for these individuals compared to mainstream services. Dementia specific services are often located in facilities that have better

design and may provide more flexible services, but the lack of difference in outcomes is disappointing. It must be noted that this research was conducted over 10 years ago and it is quite likely that there have been significant changes in 'dementia specific care' and dementia care in mainstream care over that period. There is a need for further research and data collection on current care practices and outcomes in these facilities and how they compare to main stream facilities.

Dementia specific services should not simply be a way of locking away difficult individuals from other residents, but should instead be about providing tailored, multidisciplinary care for individuals who have moderate to severe BPSD which results in better outcomes and quality of life for residents. Due to lack of data and information, it is unclear what role these dementia specific services are currently playing in dementia care.

Dementia Care in Mainstream Facilities

Given the rising numbers of individuals with dementia, and the high proportion of aged care residents who have some form of cognitive impairment - it is key that dementia care is seen as part of the core business of main stream aged care facilities.

For the vast majority of residents with dementia there is no need to separate them from individuals who do not have cognitive impairment in dementia specific care. Facilities should be designed according to dementia friendly principles and the quality of dementia care in mainstream facilities should be improved. Except in cases of moderate to severe BPSD, integrating individuals with dementia with residents without dementia can be beneficial. For example, there are anecdotal reports of the positive effects for all residents when residents without dementia 'look after' other residents who have cognitive impairment and many of the principles of quality dementia care improve quality of care for any resident.

Research suggests that facilities that provide specific tailored activities for individuals with dementia in main stream settings lead to significant improvement in quality of life for individuals with dementia.[xvii] Alzheimer's Australia has produced a number of documents to provide guidance for staff and management of residential aged care facilities on ways to improve the quality of care[xviii]. Some of the key elements of care suggested by Alzheimer's Australia are:

- Accurate and detailed ongoing assessment for development of tailored care plan
- Staff selection, training and education
- Individualised, flexible care

- Specialised services (i.e. continence, dental, speech, occupational therapists, and psychogeriatric services)
- Appropriate and interesting activities
- Well designed physical environments

Unfortunately, there is little incentive for aged care facilities to improve their level of care beyond what is required to meet the standards of the accreditation agency and the current ACFI does not recognise the additional costs associated with providing care to individuals with dementia. In preparing a submission for the review of ACFI Alzheimer's Australia was unable to identify any information to suggest that the dementia supplement had made a difference to the dementia care provided by service providers. There is also a need to better match funding levels to care needs. The ACFI does not recognise the additional time required to support individuals with cognitive impairment, or the time to provide appropriate social engagement and activities. [xix] In order to encourage the improvement of main stream care it will be necessary to consider requiring training, providing adequate funding and improving incentives for quality dementia care.

Respite

Respite care is a crucial component of support for carers and can enable individuals with dementia to continue to live at home for as long as possible. Unfortunately, many family carers of individuals with dementia have difficulty accessing respite services that meet their needs. For every three carers who have used respite, there are two dementia carers who need respite but have not used it.[xx] Respite is provided through five different streams: Home and Community Care Program, National Respite for Carers Program, Veterans Home Care, Community Aged Care Packages, and Residential care.

Alzheimer's Australia made a number of recommendations to the Productivity Commission Inquiry to aged care regarding improving the flexibility and access to respite. In this section we will focus on respite provided within residential care. .

Take-up of residential respite care is well below the allocated 3 beds per 1000 aged 70 and over. This may be due to carers concerns about the quality of care or lack of flexibility in services.

Carers not only want a break from providing care but also want services that meet the needs of the person with dementia, including age and culturally appropriate social and community engagement. There is a need to professionalise the provision of respite services and for respite to serve as an opportunity for both physical and mental rehabilitative and restorative therapies. Respite should provide support to enable individuals to continue to live in the community for as long as possible. The majority of individuals who receive residential respite care return to the community,

with an average length of stay of 3.3 weeks but 16% stay on in residential aged care.[xxi] Many carers choose not to put their person with dementia in respite as they are concerned that their behaviours and confusion will increase after a period in respite, or that they will never leave the residential aged care facility.

In a recent publication, 'Respite Care for People Living with Dementia'[xxii] Alzheimer's Australia has made a number of recommendations to enhance flexibility, quality and monitoring of implementation and evaluation. These include:

- Transferring funding for residential respite care to the NRCP to be used as brokerage funds that can be applied flexibly to meet consumer needs for different kinds of respite services. This transfer could be made in 2 steps with an initial allocation of funding equivalent to 1 respite bed per 1000 (currently being unused) to be provided to NRCP with the eventual transfer of all residential respite funding to NRCP. The initial transfer of 1 respite bed per 1000 would in effect increase the program budget for NRCP by 40%.

Increasing the budget of NRCP is sensible given that this program is working to address carers concerns about quality and flexibility. Providers of NRCP are required to report on how they address the needs of people with dementia, and there are strategies to improve quality through increasing consumer direction. Increases in the brokerage funds of NRCP has led to more variety and innovation in respite services including host family respite, and work based respite.

In summary respite care in residential care needs to be a specialised function not an add on when beds are vacant. Alzheimer's Australia believes that to achieve that this residential respite should be provided through the NRCP. Action should be taken to address other recommendations in 'Respite care for people living with dementia', namely:

- Reducing barriers to uptake of dementia for people living with dementia through expansion of carer education and training and conducting an audit of respite services to identify best practice

- Giving priority to dementia respite services in funding of new respite services to address unmet needed

- Adopting a process of designation of residential respite services that incorporate links with community based services and recognise these services through financial and other incentives

- Australian Government work with the Aged Care Standards and Accreditation Agency to advance the quality of respite care by improving reporting, adding expected outcome for respite care and only funding respite care that meet these standards including training in respite and dementia care for staff.

Summary and Recommendations

The majority of individuals in residential aged care experience some form of cognitive impairment during their stay. Care for individuals with dementia is often complicated by BPSD. Individuals with more severe BPSD are often best managed outside of mainstream residential care and need a more integrated system with better access to appropriate assessment and care. In some cases this may be available in 'dementia-specific care'. Due to a lack of definition and no recent information on quality or outcomes it is difficult to know what role 'dementia-specific care' should play for individuals with severe BPSD. It is clear that dementia care is core business of aged care facilities and quality dementia care and facility design needs to be encouraged. One possibility would be to introduce incentives for providing better care and environment for individuals with dementia.

1. **Better integration of mental health and aged care is needed in order to provide the best quality and continuity of care for individuals with very severe BPSD.** Victoria's psycho-geriatric nursing homes are possibly a model for how to bridge the gap between aged care and mental health services while maintaining a goal of rehabilitation and return to mainstream care.

2. **A thorough review of 'dementia specific care' to examine quality of care and outcomes for people with dementia. This should happen alongside a regulation of the usage of 'dementia specific care' which requires the facility to meet specific criteria in quality care**. It is unclear if dementia specific care is providing needed tailored behavioural management for individuals with BPSD or is just acting as a way of separating difficult residents from others. We need to improve our knowledge of what is currently being provided in dementia specific care and standardise the definition of this type of care in order to improve consumer understanding and choice

3. **Incentives for quality dementia care should be considered such as a dementia funding supplement dependent on quality of care for all residents who have moderate to severe BPSD to recognise the extra cost and time involved in providing high quality care for these individuals.** This supplement should be provided only to facilities that can demonstrate that this funding is being used to improve the quality of their dementia care through staff training, improving the environment, provision of specialised services, or appropriate activities.

4. **Allocation of specific care places for individuals with moderate to severe behavioural and psychological symptoms of dementia.** Providing equitable access to aged care should be one of the goals of any reform to aged care. Currently individuals with moderate to severe BPSD are often turned away from residential facilities who find their care to be too demanding

and their behaviours to be disruptive to other residents. Possibly 10-15% of all residential care places are needed for this group.

5. **Funding for dementia specific workforce training beyond what has currently been made available through the Dementia Initiative.** Training is an important element of any strategy to improve the quality of dementia care. Research suggests that a two-day training course for residential staff on person centred care significantly reduced levels of agitation in residents with dementia[xxiii]. Alzheimer's Australia made a number of specific recommendations about training in our recent submission to the Productivity Commission Inquiry into aged care.

6. **Transferring funding for respite from the residential aged care program to the NCRP.** All respite should be funded through the National Respite for Carers Program and action taken to address the recommendations made in Alzheimer's Australia's recent publication 'Respite Care for People Living with Dementia.'

[i] AIHW (2008). Residential Aged Care In Australia 2007-2008: A statistical overview.

[ii] Access Economics (2009). Making Choices. Future dementia care: projects, problems, and preferences. (Commissioned by Alzheimer's Australia).

[iii] Rosewarne, RC, Opie, JR, Ward, SM. (2000). Dementia-Specific Care in Australia: An Overview and future directions. RPAD, 4, 45-68

[iv] ibid

[v] ibid

[vi] AIHW (2008). Residential Aged Care In Australia 2007-2008: A statistical overview.

[vii] Flicker, L (2000). Health care for older people in residential care—who cares? Medical Journal of Australia, 173, 77-99.

[viii] Brodaty, H, Draper, B, Saab, D, et al. (2001). Psychosis, depression and behavioural disturbances in Sydney nursing home residents: prevalence and predictors, International Journal of Geriatric Psychiatry, 16, 504-512.

[ix] DoHA (2008) Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders

[x] Brodaty, H, Draper, BM, Low, L. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. Medical Journal of Australia, 178, 231-234.

[xi] Based on estimates of number of people with dementia and residential aged care places in Access Economics (2010). Caring Places: Planning for Aged Care and Dementia 2010-2050.

[xii] Brodaty, H, Draper, B, Saab, D, et al. (2001). Psychosis, depression and behavioural disturbances in Sydney nursing home residents: prevalence and predictors, International Journal of Geriatric Psychiatry, 16, 504-512.

[xiii] ibid

[xiv] DoHA (2008) Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders

[xv] Ibid

[xvi] Rosewarne, RC, Opie, JR, Ward, SM. (2000). Dementia-Specific Care in Australia: An Overview and future directions. RPAD, 4, 45-68.

[xvii] Rosewarne, R, Bruce, A, & McKenna, M. (1997). Dementia Programme Effectiveness in Long Term Care, 12, 173-182.

[xviii] For example: Alzheimer's Australia (2003). Quality Dementia Care: Position Paper No. 2

[xix] Alzheimer's Australia (2008). Submission to Review of the Aged Care Funding Instrument.

[xx] ABS (2003). Survey of Disability and Carers.

[xxi] AIHW (2008). Residential Aged Care In Australia 2007-2008: A statistical overview.

[xxii] Alzheimer's Australia (2009). Respite care for people living with dementia: "It's more than just a short break".

[xxiii] Chenoweth L, King M, Jeon Y-H, Brodaty H, Stein-Parbury J, Norman R, Haas M, Luscombe G. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*, 2009;8:317- 325.