



**Carers ACT Response to the Senate Standing Committee on Community
Affairs Inquiry:
'Care and Management of Younger and Older Australians living
with Dementia and Behavioural and Psychiatric Symptoms of
Dementia (BPSD)'**

6 May 2013

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We offer our respects to their Elders past and present, and celebrate the continuation of the Ngunnawal people's living culture and valuable contribution to the ACT community.

Carers ACT sincerely thanks all carers who have contributed to the research and consultation activities which inform its policy and representation activities.

Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 carers living in the Australian Capital Territory.

These carers provide ongoing unpaid care for people with disabilities, mental illness, chronic conditions, drug and alcohol dependencies, or who are aged and frail. Carers ACT currently provides direct support to around 7000 families through our counselling, information, respite support, education, social support and case coordination services. We continue to meet national accreditation standards for delivery of our services to carers at a high level.

Carers ACT has a constitutional mandate to represent the voices of carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations, and works with other State and Territory colleagues to share knowledge and facilitate improved health and wellbeing outcome for caring families.

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Introduction

Carers ACT supports the Carers Australia response to the Senate Standing Committee on Community Affairs Inquiry, and agrees that flexible and appropriate respite services is a particular area of need for carers' health and wellbeing and, secondly, contributes to delaying admission to residential care.¹ This submission to the Inquiry into the care and management of younger and older Australians living with dementia and Behavioural and Psychological Symptoms of Dementia (BPSD) focuses on:

- early diagnosis and early intervention as key to improving the provision of care and management of people living with dementia, including Younger Onset Dementia and BPSD, and their carers
- carers' experiences of the scope and adequacy of respite services for people living with dementia, including Younger Onset Dementia, and BPSD
- end of life care for people living with dementia, including appropriate recognition and management of pain.

Carers ACT experiences in responding to the needs of carers of people living with dementia has given its staff an appreciation of the importance of early diagnosis and flexible respite as critical factors in the spectrum of appropriate supports of people with BPSD and/or Younger Onset Dementia. These views are reinforced by evidence-based research findings.

Carers ACT provides respite in the ACT for people living with dementia and their carers through The Cottage, located in Deakin. This respite provision is designed to be flexible to meet the needs of the person living with dementia and their carers and families – day programs for male care recipients, general day care programs, overnight accommodation, and a Home Host program.

Early Diagnosis: Early Intervention and Prevention

The early diagnosis of dementia is critical for the management of symptoms and the establishment of appropriate supports for people with dementia and their carers.² Carers ACT looks forward to the report of the 2012 Standing Committee on Health and Ageing Inquiry into 'Dementia: Early Diagnosis and Intervention'.

Early diagnosis assists people with dementia to make choices about treatments, negotiate employment options, and put in place family supports and advance directives. Early identification enables early intervention, including the mobilisation of appropriate supports. For example, people with Younger Onset Dementia and their carers may have different challenges relating to employment, housing, family dynamics, future planning for their family's security, and planning for and management of finances.³

There are key barriers to early diagnosis, namely education and awareness, and stigma associated with dementia. General practitioners may not be appropriately trained to identify Younger Onset Dementia; nor does the Medical Benefits Scheme currently resource GPs to undertake comprehensive assessments.

¹ W Bruen and A Howe, 2009, *Living with Dementia "It's more than just a short break"*, Alzheimer's Australia Discussion Paper 17, p.7.

²W Bruen and A Howe note that early diagnosis is critical for ensuring that respite care becomes an integral component of the care trajectory in the community setting; Lyn Phillipson, Christopher Magee, Sandra Jones and Ellen Skladzien, 2012, *Exploring Dementia and Stigma Beliefs: A Pilot Study of Australian Adults Aged 40 to 65 Years*. Alzheimer's Australia Paper 28.

³Alzheimer's Australia, 2013, *Younger Onset Dementia: A New Horizon?* Report, National Consumer Summit.

Diagnosis can be uncertain, and relies on a range of assessments: there is no definitive test for diagnosing dementia.⁴ Currently, a formal diagnosis of dementia can take about three years from onset of symptoms. For people with Younger Onset Dementia, the period leading to diagnosis may take longer.⁵

Research undertaken by Alzheimer's Australia indicates that people with dementia experience stigmatisation and discrimination largely related to a lack of understanding in the community.⁶ The prevalence of stigma and lack of dementia awareness and education may impact on people's willingness to seek help; it may also relate to people's concerns relating to disclosure among family, friends, and the workplace for fears of social exclusion and/or discrimination.⁷ The authors of a study into the prevalence of stigma beliefs identify a need for programs and strategies to reduce stigma and to support timely diagnosis.⁸

A Carers ACT counsellor reported that carers of people with dementia may feel shame and embarrassment when out in public, particularly when the loved one displays disinhibited behaviours. In addition, it is not uncommon for carers to experience a lack of understanding from extended families. It is not surprising then that carers may also feel socially isolated and excluded, not only as a result of their demanding caring roles but in direct response to the community stigma they experience.

Managing Carer Burnout

International and Australian studies show that access to flexible support, information and respite services remain key needs for family carers, together with workplace and community understanding. All carers need to be valued, and evidence suggests that comprehensive, multidimensional dementia-specific training is of benefit.⁹

Carers ACT counsellors are familiar with the 'utter exhaustion and frustration with the system' that carers live with on a daily basis. Caring for someone with dementia has physical and mental consequences for the carer. Carers may be living in situations where they are forced to deadlock the house at night to keep their loved one secure, going to bed with fears about their own safety as well as the safety of the person with dementia. Some carers of people with BPSD are living at risk of physical and emotional abuse.¹⁰ Not surprisingly, many carers live in constant worry, and as the disease accelerates, may be worn out by repetitive questioning, relating to short-term memory loss, and sleep disturbance. A member of the Carers ACT counselling team said that it was not uncommon for carers to feel they have no time to attend regular health checks, as they find it difficult to have a break from their caring role.

⁴Alzheimer's Australia, 2007, *Early Diagnosis of Dementia*, Paper 10.

⁵Alzheimer's Australia, 2013, *Younger Onset Dementia: A New Horizon?* Report, National Consumer Summit, p. 7.

⁶Lyn Phillipson, Christopher Magee, Sandra Jones and Ellen Skladzien. 2012. *Exploring Dementia and Stigma Beliefs: A Pilot Study of Australian Adults Aged 40 to 65 Years*. Alzheimer's Australia Paper 28.

⁷Lyn Phillipson, Christopher Magee, Sandra Jones and Ellen Skladzien. 2012. *Exploring Dementia and Stigma Beliefs: A Pilot Study of Australian Adults Aged 40 to 65 Years*. Alzheimer's Australia Paper 28.

⁸Lyn Phillipson, Christopher Magee, Sandra Jones and Ellen Skladzien. 2012. *Exploring Dementia and Stigma Beliefs: A Pilot Study of Australian Adults Aged 40 to 65 Years*. Alzheimer's Australia Paper 28.

⁹Access Economics Pty Ltd, 2009, *Making choices. Future dementia care: projections, problems and preferences*. Alzheimer's Australia, p. iv.

¹⁰Brian Lawlor notes: 'All aspects of BPSD can be associated with caregiver burden, but paranoia, aggression and sleep-wake cycle disturbance appear to be particularly important drivers of caregiver burden and institutionalisation.' In *Managing behavioural and psychological symptoms in dementia*, British Journal of Psychiatry 2003:181:463-468.

Case Study 1

A member of the counselling team has been supporting a carer who has been married for 50 years, who for the past five years has been caring for their partner living with dementia. The care recipient's behaviours had gradually escalated, for example, following the carer to the toilet, banging saucepans, not allowing the carer out of sight. The care recipient also started becoming aggressive. The carer's partner refused to go to respite care although did finally allow paid care workers in the home for short visits.

The carer began to experience health issues: giddiness, aches and pains, loss of balance, and exhaustion. They were finally able to get the recipient into respite care, but were phoned by respite staff and asked to take the care recipient home as they were displaying behaviours that the service could not cope with.

The carer has now placed the care recipient into permanent care and the carer's health has improved. However, the carer continues to experience a lot of guilt and is worried the service might phone and return the person living with dementia.

Compounding the consequences of stigma are service barriers and gaps faced by people with Younger Onset Dementia and/or BPSD and their carers. Research findings indicate a dearth of age appropriate services available for people with Younger Onset Dementia.¹¹ In addition, people with BPSD are at risk of falling through service gaps due to lack of appropriate services or a silo approach to service provision. A key issue for the Carers ACT counselling team is assisting carers of people with disinhibited or at risk behaviours to access respite facilities. This issue is paralleled in research findings.¹²

Furthermore, given the intersections between mental illness and BPSD, improvements in the diagnosis and management of BPSD and care coordination between psychiatric and geriatric services are critical.¹³ The repercussions of already vulnerable people with mental illness having a greater propensity to fall between service gaps directly as a result of comorbidity issues compounds the suffering and distress as well as the safety of people with BPSD and their carers, particularly as the disease and the associated symptoms accelerate. In summary, these issues point to a general lack of accessible and appropriate dementia specific respite services and a person-centred care approach for people living with dementia. There is concern that this situation may be exacerbated with the national health (Living Longer Aged Care) and disability (DisabilityCare Australia) reforms, particularly the diagnosis and early intervention of Younger Onset Dementia, and of people with mental illness.

The Cottage Model of Respite Care

A model of respite care which Carers ACT has found to be appropriate for people with Younger Onset Dementia and BPSD and their carers is its home-type program. In an evaluation of The Cottage, a stand-alone house in a Canberra suburb managed by Carers ACT, the service is described as follows:

¹¹ Alzheimer's Australia, 2013, *Younger Onset Dementia: A New Horizon?* Report, National Consumer Summit; Michael Bird and Ruth Parslow. 2001. *Future Directions: Consultancy Report to the Alzheimer's Association of Australia.*

¹² See, for example, Michael Bird and Ruth Parslow. 2001. *Future Directions: Consultancy Report to the Alzheimer's Association of Australia.*

¹³ Brian Lawlor, 2003, *Managing behavioural and psychological symptoms in dementia*, British Journal of Psychiatry 181:463-468; Carers ACT counselling team findings; Henry Brodaty, Brian M Draper and Lee-Fay Low, 2003, *Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery*, Medical Journal of Australia, Volume 178.

The purpose of the program which funds The Cottage is to provide 'normalisation' in the lives of people with dementia, a Home from Home Respite Cottage. It is a totally different model to residential aged care facility respite. It demonstrates innovation, flexibility such as longer respite sessions during the day, group client mix as appropriate and is culturally and gender specific when needed.¹⁴

The Cottage staff have found that clients maintain for longer their dexterity and cognitive levels by participating in cooking, setting the table, gardening, feeding the animals, and washing; in general, all activities which they would normally do at home. The Cottage works to keep client independence, dignity and respect. Clients have choices, and their rights and decisions are respected by the staff. Bus trips target Younger Onset Dementia clients to provide opportunities for participating in external activities in the community.

A member of the Carers ACT counselling team describes The Cottage as 'the saviour for many families' because it is small scale and home-like (as opposed to large-scale, institutional), and provides personalised, flexible care that can be tailored to individual needs. The Cottage fills a gap in respite services, particularly for those people with Younger Onset Dementia or people with BPSD. Small groups of clients attending allows for challenging behaviours to be well managed, and carers of people with BPSD have received respite at The Cottage during times when no other respite service options have been available. The Cottage provides regular respite care for carers of people with Younger Onset Dementia that is tailored to individual requirements and is appropriate to age and symptoms, and offers one-on-one care in a homelike environment.

Case Study 2

'Jane' was diagnosed with Younger Onset Dementia, and attended The Cottage in her late 20s. She was assessed to participate in the in the Home Host program in a staff member's house. This program was appropriate for Jane's support needs as she was young and was better cared for in the community with the ratio of one staff member to one client. Jane could continue to enjoy aspects of a younger person's lifestyle – movies, coffees, afternoon teas, shopping to buy makeup, having a manicure. Home Host allowed Jane not to be in a dementia unit with older, frail dementia clients, and this helped maintain her self-esteem and dignity.

'Jane's' more appropriate person-centred respite in the earlier stages of her dementia allowed her family members to 'choose' to maintain their employment, while lessening the emotional and stressful impact of 'Jane's' diagnosis.

In a focus group comprising 15 carers who use or have used its services, the following key themes about The Cottage services emerged:

- difference and innovation: 'a special place and totally different to most institutions'
- appropriate care: 'activities relevant to my partner's ability'
- home from home model: 'each client is treated as a person'
- flexibility with longer hours of care and overnight care, essential for employed carers: 'The Cottage has metaphorically saved my life as the carer'.¹⁵

¹⁴Carol Flynn & Associates Pty Ltd, 2011, *Carers ACT: The Cottage Focus Group*, p. 3.

¹⁵*Ibid.*, pp. 3-4.

End of life care and pain management

Appropriate end of life care for people living with dementia, including pain management, continues to be a concern for carers and families. Most people living with dementia and their carers and families wish the end of life care to be as home-like as possible, where people retain their dignity and are as comfortable as possible in an appropriate facility, such as a hospice.

Evidence indicates that people living with dementia are more likely to die in a nursing home or in residential care than in a hospice. Together with the evidence of inadequate levels of care in both long-term institutions and hospitals, and given that people with dementia do not seem to gain access to specialist palliative care services, the implication is that there are needs for palliative care – particularly in the last year of life – that are not being met.¹⁶

The National Aged Care Alliance (NACA) in its Palliative Care position statement stated:

Dementia care is palliative care. Dementia care as palliative care requires a different approach than palliative care for conditions such as cancer as the *process* will take place over a longer period of time, involves early engagement in advance care planning, and requires more flexibility than palliative care approaches to other diseases. This is because unlike cancer, where a person at the end of their life is likely to be similar in personality and cognitive ability to the person first diagnosed, the course and prognosis of dementia means that most people with the disease will be subject to significant changes in cognition, functional abilities, and possibly behaviour, emotions and personality.¹⁷

Hughes *et al* writing in the *Advances of Psychiatric Treatment* journal identified that dementia and end of life care is a field in which there is growing interest and literature, but where there is no generally agreed way in which services should be provided. They stated:

... a difficult problem emerges in the context of dementia since it is often not seen as a life-threatening illness. Palliative care can be regarded as a spectrum. At one end, the palliative care approach equates to good-quality, person-centred dementia care. At the other, the terminal stages of dementia may well require specialist palliative care (involving more detailed knowledge and skills, for example in pain relief).¹⁸

There is growing recognition that clinicians do not always recognise pain in people with dementia or that they under-treat it. Pain in people with dementia has also been identified by NACA and Palliative Care Australia (PCA) in their positions statements or in end of life policies. This issue is significant as older people and people with dementia often do not express pain in ways that the general population does. Hughes *et al* identified that people in nursing homes and residential care without cognitive impairment received three times the amount of opioid analgesia than those with advanced dementia. NACA recommended the provision of tools to enable carers to collect evidence of pain so they can advocate for good pain management of people living with dementia.¹⁹

In its position statement, *Carers and End of Life*, PCA recommended that carers must be recognised as both a key partner in the care team and a recipient of care in accordance with the palliative care provision model. PCA also identified that carers need special training, equipment and support for the role in end of life of care, and also support during bereavement.²⁰ Carers ACT believes that this recognition of and support for

¹⁶Hughes Julian C *et al*, 2007, *Palliative care in dementia: issues and evidence* *Advances of Psychiatric Treatment* 13: 251-260.

¹⁷National Aged Care Alliance, 2012, *Aged Care Reform Position Statements – Palliative Care*.

¹⁸ Hughes Julian C *et al*, 2007, *Ibid.*, p.251.

¹⁹National Aged Care Alliance, 2012, *ibid.*

²⁰Palliative Care Australia, *Carers and End of Life Position Statement*.

carers of people living with dementia during the end of life care is critical, particularly due the impact on carers and families because of the lengthy caring role associated with dementia.

Recommendations

Carers ACT recommends that the Inquiry Committee consider the benefits of greater investment by government into:

1. dementia community education and awareness campaigns and resources, particularly associated with Younger Onset Dementia
2. dementia specific training for health professionals, including nursing staff and community sector workers as well as general practitioners
3. resourcing the provisions for early diagnosis, including:
 - a. analysis of the benefits of early diagnosis for people with Younger Onset Dementia and their families, including future planning, impact on employment prospects and their financial situation, access barriers to insurance and loans, and family and social dynamics
 - b. the establishment of a dementia assessment MBS item for general practitioners
 - c. further investigation into dementia screening instruments
4. tools to increase dementia diagnosis in people with mental illness and to ensure timely access to dementia services in the changing structure of the health and disability sectors
5. the expansion of Younger Onset Dementia appropriate respite options that meet the needs of the person living with dementia and their carers and families
6. the expansion of respite to reflect the diverse and changing needs of people with dementia and their carers, such as those represented by The Cottage model of care
7. improved support for end of life care for people living with dementia, including:
 - a. a commitment to increase the supply of hospice end of life care places
 - b. training and education for health professionals to recognise the specific needs of end of life care for this cohort
 - c. improved recognition of pain and appropriate management to ensure the alleviation of pain
8. inclusion of carers as a key partner in the end of life care team, including:
 - a. development of a tool that supports their ability to identify pain in the person living with dementia
 - b. provision of specific training and equipment and support for their end of life care role
 - c. provision of extended support to carers during bereavement.