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Inquiry into Dementia: Early Diagnosis and Intervention

Submission from Carers Australia

May 2012

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with input from Carers Victoria and other members of the
National Policy Working Group .

Title: Carers Australia's submission to the Inquiry into Dementia: Early Diagnosis and Intervention.

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About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.6 million Australians who provide unpaid care and support to family members and friends with a disability, mental illness, chronic condition or terminal illness or who are frail aged. Carers Australia's members are the eight state and territory Carers Associations.

Our Strategic Plan 2009-2012 has a vision that 'caring is accepted as a shared community responsibility' and a mission 'to lead change and action with and for carers.' Carers Australia advocates on behalf of Australia's carers to influence policies, programs and services at a national level and it does so in collaboration with the Carers Associations.

Carers Australia believes that all carers should have the same rights, choices and opportunities as other Australians. Carers should be able to enjoy optimal health, social and economic wellbeing and to participate in family, social and community life, employment and education.

Carer Support and Services Provided by Australia's Carers Associations

The eight state and territory Carers Associations provide a variety of support and services to carers including carers of people with dementia. While the support and services available differ to some extent between Associations, typically they include information and advice about carer issues and services, family support and advocacy, counselling, respite referral, social groups, support groups including for Indigenous carers, young carers and carers from particular linguistic and cultural groups and training in caring skills. Some Associations offer services specifically for dementia carers. For example Carers ACT provides day, overnight and family host respite for carers of people with dementia. Carers SA offers in Adelaide and across its regional network the six session training and education program *Creative Ways to Care* for carers of people with dementia.

Introduction

There is an extensive international literature on the benefits of early diagnosis of dementia and of early intervention for people with dementia and their carers. A recent report by Alzheimer's Disease International deals comprehensively with the subject.[1] There are also a number of reports from particular countries that address these same issues.[2] At points in our submission we will draw on some of the evidence from this literature, in particular that which supports early intervention. The submission will not go into these issues in depth however - others have done it already. Rather we will focus on a number of matters that pertain to the carers of people with dementia. We will argue that:

(i) family members and carers have a critical part to play in early diagnosis;
(ii) early diagnosis and intervention are important not just for the quality of life of the person with dementia but also for the quality of life of carers, in particular the primary carer;
(iii) while the person with dementia will be the main focus of intervention, some interventions should be directed at the carer;
(iv) the benefits of early diagnosis and intervention should be understood not just in terms of improved quality of life for the person with dementia and their carer but also, and usefully, in terms of cost effectiveness; and
(v) early diagnosis and intervention should be seen as part of a range of supports and incentives that will be needed in the coming years and decades if family members and friends are to care for people with dementia in numbers which the Government's strategy of ageing at home would appear to imply.

In the discussion on (ii) and (iii) reference will be made to the findings of research into the wellbeing of carers undertaken by Carers Australia, Deakin University and Australian Unity in 2007.[3] Reference will also be made to a recent evaluation of the

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[1] World Alzheimer's Report. *The Benefits of Early Diagnosis and Intervention*. Alzheimer's Disease International. September 2011.

[2] See for example: Report by the Comptroller and Auditor General. *Improving Services and Support for People with Dementia.* National Audit Office. London. June 2007.

[3] RA Cummins et al, Australian Unity Wellbeing Index: Report 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing,* Deakin University, Carers Australia and Australian Unity, October 2007.

outcomes of the National Carer Counselling Program undertaken jointly by Carers Australia, Carers Victoria and Deakin University.[4]

(i) Family members and carers have a critical role to play in early diagnosis

Family members and carers of a person with early stage dementia are often the first to notice cognitive decline, changes in mood and behaviour and changes in the person's care needs associated with the onset of the disease. They therefore have a critical role to play in early diagnosis. They can, however, only play this role if they are aware that the changes they notice are changes which are commonly experienced by people with dementia rather than, for example, being assumed to be a consequence of ageing. Unfortunately many people are not aware of the early symptoms of dementia.[5]

Even if a carer is informed about the disease and they suspect that the person for whom they care may have early stage dementia, they may be deterred nonetheless from voicing these suspicions. The person suspected of having early stage dementia may be unwilling to have others in attendance at a GP consultation or discourage their participation if they do attend. GPs may be reluctant to speak to a patient's relatives on account of concerns about patient confidentiality even if that concern has not been tested with the patient.[6]

It should be recognised too that family members, like the person with symptoms suggesting dementia, may be reluctant to face the truth for reasons that are to some extent understandable. Stigma still attaches to dementia and the consequences of stigma such as ostracism and social isolation can impact not just upon the person with a diagnosis of dementia but also their families. People diagnosed with dementia can, for example, experience difficulties obtaining travel insurance, again a problem which may impact on other family members as well as the person with a dementia diagnosis.

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[4] RA Cummins et al, *Carers Counselling Intervention Study 2011,* Deakin University, Carers Australia and Carers Victoria, July 2011.

[5] In an English study, where carers of people with dementia explained why they had delayed consulting a doctor, 70% said they were not aware of the symptoms of dementia and 58% thought the person's symptoms to be just normal ageing. See *Improving Services and Support for People with Dementia,* p24.

[6] Ibid. p25.

The Committee has indicated its interest in raising community awareness about dementia. Clearly this is necessary. An initiative in awareness raising would need to be targeted broadly and address not just community ignorance but also prejudice and in some cases commercial practice. As a society we need to be less inhibited in talking about dementia. Health professionals need to be encouraged to consult with and involve family members and carers when diagnosing and treating a person exhibiting early stage dementia symptoms. In the ‘Statement for Australia’s Carers’, a Schedule to the *Carer Recognition Act 2010*, Principle 7 states:

> Carers should be considered as partners with other care providers in the provision of care acknowledging the unique knowledge and experience of carers.

This idea of carers being considered as ‘partners in care’ could usefully be incorporated into a dementia awareness initiative.

There would also seem merit in the suggestion made in Alzheimer’s Australia’s submission to the Committee that new items be included in the Medical Benefits Schedule which allow for the possibility of independent consultation with carers as part of a comprehensive assessment and management process for the disease.[7]

(ii) Early diagnosis and intervention are also important for the quality of life of carers

The objectives of improved quality of life and continued social engagement, mentioned in the first and second dot points of the Committee’s Terms of Reference in relation to people with dementia, should equally be seen as objectives with respect to carers of people with dementia.[8]

It is now well recognised that there can be considerable costs in caring. In the Australian context this has recently been highlighted in the Productivity Commission’s report *Caring for Older Australians*.[9] Carers have poorer physical and mental health, less social contact and are financially disadvantaged compared with

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[7] Alzheimer’s Australia National Office, Submission to the House of Representatives Standing Committee on Health and Ageing, *Inquiry into Dementia: Early Diagnosis and Intervention*, 2 May 2012, p19.

[8] This point is made in the recent report *Dementia: A Public Health Priority*, Alzheimer’s Disease International and World Health Organisation, 2012, p72.

[9] See discussion on this subject at chapter 13 of *Caring for Older Australians*, Vol 2, June 2011.

non-carers. The strains on dementia carers seem especially acute, especially in later stages of the disease when increased supervision, personal care and often physical exertion are required and when behavioural and cognitive changes caused by the disease can be a source of great distress within the family. Extreme fatigue is common amongst carers but perhaps of most concern is the extent of mental illness. A systematic literature research conducted for a recent major international report on dementia suggests that 22% of dementia carers have a depressive disorder, 1 in 3 have anxiety disorders and between half and three quarters exhibit depressive and anxiety symptoms.[10]

These indicators of dementia carers' mental health are consistent with the findings of a major study into the wellbeing of carers undertaken by Carers Australia in conjunction with Deakin University and Australian Unity and published in 2007.[11] The measure of wellbeing used in the study was the Personal Wellbeing Index which scores a person's average level of satisfaction across seven aspects of personal life.[12] Measures for depression and stress were also incorporated in the study. The carers surveyed for the purpose of the study were not exclusively carers of people with dementia but many of these carers would have been included. The report found that carers had the lowest collective wellbeing of any group previously investigated. The survey also indicated that the average carer is experiencing a clinically significant level of depression, a finding which suggests that a 'substantial proportion of the depressed people in Australia are carers'.[13]

Caring can have many rewards, such as companionship, the strengthening of friendship, fulfilment and a stronger sense of meaning in life. But it is wrong that a disproportionate share of the responsibility and strain of caring, with its deleterious consequences for carer health and wellbeing, should be borne by a relatively small group in the community. This is especially the case when we know that there are things that can be done to support carers and offer them a better quality of life. For

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[10] *Dementia: A Public Health Priority*, p73.

[11] *The Wellbeing of Australians – Carer Health and Wellbeing*, October 2007.

[12] These included health, personal relationships, safety, standard of living, achieving in life, community connectedness and future security.

[13] Ibid. p5.

dementia carers, early diagnosis and intervention should be the first means by which support is provided.

The international literature is somewhat equivocal about the evidence that early diagnosis (as opposed to early intervention) is associated with better outcomes for people with dementia and their carers.[14] We expect though that this is for want of adequate investigation. For families and carers it is almost self-evident that early diagnosis holds advantages. It means that families and carers know what they are dealing with and are in a better position to seek support services, to make changes in domestic and living arrangements that mitigate safety risks and to optimise outcomes for all concerned. Early diagnosis helps families to negotiate amongst themselves the distribution of care and other responsibilities and to plan for the future, including about life’s priorities – caring, career and other goals. There is a much better chance that life will be manageable.

There is robust evidence that people with early stage dementia can benefit from drug treatments, for cognitive function, and from participation in peer support groups and individual behavioural therapy for depression.[15] To the extent they are effective, early intervention of this type, directed at the person with dementia, can also benefit carers. This is because it may alleviate the strains carers experience in dealing with a person whose behaviour has altered and cognitive function diminished and in the increased intensity of support and supervision required.

The other important element of early intervention is the intervention directed at the carer.

(iii) Some early intervention should be directed at the carer

It is natural to think of interventions for people in the early stage of dementia as being directed at the person with dementia. But there is also strong evidence of the benefits of interventions directed at the carer.[16] Such interventions include provision of information, advice and education, support groups, counselling, training in caring

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[14] *The Benefits of Early Diagnosis and Intervention*, p66.

[15] Ibid. p66

[16] *The Benefits of Early Diagnosis and Intervention*, p47, 66; and *Dementia: A Public Health Priority*, p75.

skills, training in self-management and coping skills, psychotherapy and respite. The benefits include reduced depression and carer strain and increased subjective wellbeing. A qualification is that much, though not all, of the current evidence seems to relate to established carers rather than to carers of people in the early stages of dementia.

As well as benefiting carers, interventions directed at the carer can also benefit the person with dementia. This is because the lives of people with dementia and their carers, who are generally family members, are closely interconnected. These relationships become even closer as the disease advances causing normal social interaction outside the home to diminish. Strong interdependence means that the wellbeing of the person with dementia typically hinges on the capacity of the carer. People with dementia prefer to stay at home for as long as possible but often the move to residential care is precipitated by carer stress. If carer stress could be avoided or better managed the wellbeing of both carer and the person cared for could benefit. And there is quite strong evidence that the earlier carers are supported the longer the person with dementia stays at home.[17]

The effectiveness of carer interventions is strongly attested by the evaluation of the outcomes of the National Carer Counselling Program (NCCP) recently conducted by Carers Australia in conjunction with Carers Victoria and Deakin University.[18] The aim of the evaluation was to determine the effectiveness of a six session counselling intervention offered by the NCCP. The wellbeing of carers was surveyed before and after counselling and again three months later. The methodology of the evaluation was consistent with that employed in the 2007 *Carer Health and Wellbeing* study mentioned earlier. Carers of people with dementia were included in the survey but it has not been possible to separately analyse their responses.[19]

The results of the evaluation were striking. Prior to counselling, the overall wellbeing measure for the carers surveyed was ‘the lowest value in the history of the Wellbeing

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[17] *The Benefits of Early Diagnosis and Intervention,* p63.

[18] *Carers Counselling Intervention Study 2011*, Deakin University, Carers Australia and Carers Victoria, July 2011.

[19] In 2010 about 13% of persons who received counselling under the NCCP were carers of people with dementia.

Index … [signalling] the desperate situation these people are in and the certainty of high levels of depression.'[20] After counselling the survey indicated a significant improvement in wellbeing though still at levels well below the community average. We believe that these results are significant and justify the expansion in the National Carer Counselling Program recently announced in *Living Longer, Living Better*. It should be noted, however, that a little over 5000 carers annually receive counselling at current funding levels for this program. Even with the announced increases, the program will be reaching only a very small proportion of carers likely to be in need of counselling.

(iv) Early diagnosis and intervention can be cost effective

The Committee's Terms of Reference focus on the improvements in people's quality of life that may stem from early diagnosis and intervention. Naturally, for the person with dementia and their family and carers, this is the key consideration. For society as a whole, however, another important consideration is whether early diagnosis and intervention can be cost effective. Again there is a considerable international literature that provides strong evidence that this can be the case.[21] In most of this literature the scope of the 'cost effectiveness' calculation tends to be quite narrowly focussed on financial considerations. The cost element of the calculation is the additional public expenditure on early diagnosis and intervention. The benefit is the savings made from delayed admission to residential care. The conclusion that there is significant net financial benefit seems robust. With the prospect of ever increasing strains on health budgets this is an important consideration and one which the Committee ought consider.

We would make the additional point, however, that if a broader concept of benefit was included in these cost benefit calculations – to include the improved quality of life that interventions offer to people with dementia and to their carers, including the prevention and reduction of illness of carers - these calculations are likely to produce much higher measures of net benefit.

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[20] Ibid. p11.

[21] *The Benefits of Early Diagnosis and Intervention*, pp59-64; and *Improving Services and Support for People with Dementia*, p43.

(v) Early diagnosis and intervention – part of a broader array of supports and incentives for carers

Central to the public policy discussion of recent years about aged care is the ageing of Australia's population that is projected over the coming decades. The proportion of the population of more than 70 years of age is expected to increase from 9.4% in 2010 to 17.4% in 2050; the proportion older than 85 to rise from 1.6% to 5.1% over the same period.[22] It is this factor which is the main driver behind the large increase in the prevalence of dementia that is projected over the same period.

These trends have obvious implications for aged care and they loomed large in the Government's recently announced reforms of the aged care system *Living Longer, Living Better*.[23] A feature of the announced reform is a major expansion in home care packages, including the dementia supplement for these packages. This measure responds to the preference of older Australians to remain in their own homes as long as possible. It is also the case that the delivery of formal care services to the home is, in most instances, more cost effective for government compared with residential care.

As a strategy, ageing at home depends on the availability of carers. Even though formal services are brought into the home, in most cases ongoing support from a family member or friend will be highly desirable if not essential. This may be for the purpose of companionship, support and care not provided in the care package or for the back-up and coordination of formal services. Yet projections for the next few decades indicate that, increasingly, there are likely to be fewer carers compared with the expected numbers of older Australians.[24] This is largely driven by the ageing of the population but other factors include the increasing prevalence of single person households, higher female participation in the workforce and an apparent decline in the willingness of children to accept heavy responsibilities of care for their parents. In its report *Caring for Older Australians* the Productivity Commission cited work by NATSEM as indicative of research in the area. NATSEM projected an increase of

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[22] These are Treasury projections. They are cited in: Productivity Commission, *Caring for Older Australians*, Vol 1, June 2011, p39.

[23] Australian Government, *Living Longer. Living Better.* April 2012.

[24] See discussion on this subject in *Caring for Older Australians*, Vol 1, pp56-9.

60% in the supply of carers between 2001 and 2031 compared with an increase of 160% in the demand for carers over the same period.[25]

These projections suggest that a priority for social policy should be to help create an environment that enables or encourages family members and friends to take on and persist with the responsibilities of caring. For carers or potential carers of people with dementia an important aspect of such an environment would be early diagnosis and intervention. But this would just be the beginning. Also required would be a full range of carer support services, tailored according to the stage of the disease and the circumstances of the family. This would include information and advice, support and advocacy, counselling, therapy, education and training and respite.

Living Longer, Living Better foreshadows a ‘streamlining and expanding’ of carer services. But much more than what currently seems to be envisaged will be necessary over the longer term if ageing at home is to be a viable option for the large majority of those older Australians who seek it. In particular *Living Longer, Living Better* has little to say about helping people to combine caring with paid employment. For what many people will be seeking is not just support to help them in their caring, with an occasional break in the form of a few days respite each month, but arrangements which allow them to genuinely combine caring with paid work, even to the point of not sacrificing a career. It is likely that if such caring and work combinations are not possible many people will be discouraged from caring.

There would also be other advantages in encouraging more people to combine caring and paid work. Such an arrangement could be expected to reduce the strains, social isolation and financial penalties experienced by carers. There are important equity reasons why the community should seek to do this. Given, moreover, the close inter-dependencies within a family, improved carer wellbeing should flow on to benefit the person being cared for.

Carers Australia believes that government should encourage people to combine caring and paid work by boosting the availability of suitable respite and liberalising

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[25] The NATSEM work is cited in Caring for Older Australians, Vol 1, p58.

eligibility conditions for income support for carers. We also believe that the attitudes and practices of employers will need to change. If a person is to combine caring with paid work they will generally need flexible working arrangements that will allow them adequately to respond to the changing and not always predictable needs of the person they are caring for. Such flexible arrangements are not normally on offer from employers. Carers Australia has outlined some suggestions for introducing more flexible working arrangements for carers in its recent submission to the Fair Work Act Review.[26]

Conclusion

Most of the care and support for people with dementia is provided by carers, most of whom are family members. For many of these carers the demands of caring are enormous, with serious consequences for health and other aspects of their lives. Carers of people with dementia need more support including early diagnosis and intervention. In particular there is robust evidence that interventions directed at the carer can be effective in relieving strain and depression amongst carers. There are, in turn, likely to be beneficial effects for the person with dementia and for the affordability of the care system overall. Over the longer term much more support for carers will be needed, including measures which facilitate the combining of caring with paid work, if family members and friends are to care for people with dementia in numbers that the Government's strategy of ageing at home would appear to imply.

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[26] Carers Australia, *Submission to the Fair Work Act Review*, February 2012. http://www.carersaustralia.com.au/storage/Final%20Submission%20on%20Fair%20Work%20Act.pdf