



National Evaluation of the Dementia Initiative

1. Are you submitting a comment as a:

- Person living with dementia
 Carer, family member or friend of someone living with dementia
 Health professional or service provider. Please specify: _____
 Other: Please specify: **Peak body for carers in NSW**

2. Are you submitting a comment on behalf of an organisation? **Yes**
Please specify the name of the organisation: **Carers NSW**

3. Comment Summary – Please summarise your comments in less than 300 words.

Carers NSW is pleased to note the recognition and inclusion of carers in the National Dementia Initiative. The representation and participation of carers in the Stakeholder Reference Group is encouraging, but would be strengthened by more clarity around the roles of carer and consumer representatives.

The Extended Aged Care at Home Dementia (EACHD) packages are an important component of the Initiative, and Carers NSW would like to see this extended to ensure that people with dementia and their carers have access to these services, including people with younger onset dementia and people in the earlier stages of dementia.

The provision of training for carers through the Dementia Caring Pilot is a promising development, particularly in light of the model of training developed, which has the potential to enable training that meets the needs of carers, when they need it. However consideration needs to be given to the delivery of this training, and to the provision of respite for participants.

4. Background Information – Please include information that will provide the Minister and members of his Dementia Advisory Group background about the issues raised.

About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
 - Undertake research, policy development and advocacy
 - Provide carer services and programs
 - Provide education and training for carers and services providers
 - Build capacity in the sector.

Carers NSW' vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful. Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

5. Issues for consideration – Please include specific and succinct information about the aspects you want considered.

Importance of carer inclusion and recognition

Carers NSW congratulates the Dementia Initiative on the level of carer inclusion and recognition achieved to date. Although there is more that could be done, it is encouraging to see that the needs of carers have been considered alongside the needs of people with dementia, that there is recognition of the key role of informal care in the care of people with dementia, and that there is awareness that carers are also consumers of the dementia services delivered as part of this Initiative.

Carer representation

It is pleasing to see that ‘carer stakeholder representatives’ have been included in the Membership of the Stakeholder Reference Group. Carers NSW believes that carers should be represented and their perspective taken into account in decision making and service planning processes which will impact upon them as carers. Thus we were pleased to see that at least one of the consumer representatives has experience as a carer.

This Reference Group is a good example of the importance and benefits of carer representation. However, it needs to be made clearer which members represent people with dementia, and which members represent carers. Carers and people with dementia have independent perspectives and represent different interests. The unique nature of their experiences and perspectives needs to be recognised and respected. Although their interests may often interrelate, it is generally inappropriate for a consumer to represent the carer perspective, or vice versa. Giving carer representatives the title of consumer representative can undermine their role as representatives of carers and the unique expertise that they have as carers.

Extended Aged Care at Home Dementia

Carers NSW believes it is vital that dementia carers are supported by formal care services. The majority of people with dementia are cared for at home by a family member,ⁱ with 37 per cent of people with dementia receiving no formal care.ⁱⁱ Access Economics has estimated that the cost of replacing carers of people with dementia with formal care services at \$5.5

billion per annum.ⁱⁱⁱ It is unfair, and unrealistic, to expect that a significant number of carers can provide this support on their own.

The Evaluation indicates that there were several issues that arose in the implementation of the EACHD packages. While it is positive that these services are being made available to carers, Carers NSW is concerned at the doubts that exist over the amount of packages required, and hopes that the current number of 2,000 care packages will be increased to ensure that people with dementia and their carers can access these supports. Another concern relating to accessibility is the time lag between Aged Care Assessment Team (ACAT) approval for EACHD and the commencement of services. Feedback from carers to Carers NSW indicates that there is also a lag experienced between requesting an ACAT assessment and the assessment occurring. These issues are also experienced in relation to other packages. Carers NSW hopes that the inclusion of this issue in this Evaluation will lead to improvements in this area.

It is important that younger people with dementia are not excluded from services such as EACHD on the basis of their age. Carers NSW has advocated on behalf of carers of people with younger onset dementia in the past, and knows from experience that this group faces a general lack of appropriate services in addition to barriers such as age requirements. As the Evaluation states, it is particularly important that young people with dementia and their carers receive support to live in the community for as long as possible, and that they receive these services as early as possible.

Carer education

It is well established that carers need information, education and training to be able to sustain their caring role and maintain their own health and wellbeing. Carers NSW is very pleased that this need has been recognised in the Initiative, through the delivery of the Dementia Caring Pilot, and hopes that the Pilot will be continued.

The delivery model of this training is to be encouraged. The smaller group basis for training, delivered when required by the carer, and the capacity to target the training to the individual needs of the carer are features, which if properly implemented, can increase the usefulness and appropriateness of training to the carer, and ensure that their needs are met.

Carers NSW recommends that careful consideration is given to the implementation of this pilot, and how the principles such as delivering training when requested by the carer (instead of when it suits the provider) can be made reality. As the evaluation has demonstrated, this is a challenging task, with carers experiencing a wait time between recruitment and training.

Consideration should also be given as to whether the Commonwealth Respite and Carelink Centres (CRCCs) are the most appropriate providers of carer education. CRCCs have high levels of expertise in brokering and arranging respite services for carers, at times in very complicated circumstances. However, providing education and training is quite different. For the CRCCs to effectively deliver education and training, a considerable cultural shift would be required, and an increase in their capacity and skill base would be necessary, in addition to the changes to the bureaucratic structure already commented on in the Evaluation.

Feedback that Carers NSW has received from some CRCCs indicates that they have limited resources and capacity to provide carers with education and training, and that their focus is firmly on arranging and brokering respite, not directly providing emotional support, education and training or addressing other carer needs. Consideration should be given as to whether the Dementia Caring Pilot training should be delivered by organisations with greater expertise in delivering education and training, such as the national Network of Carers Associations. Carers NSW and the Network of Carers Associations have extensive

experience providing information and emotional support, counselling programs and developing and delivering education and training to carers (and service providers), and are well placed to deliver initiatives such as the Dementia Care Pilot.

The Dementia Care Pilot should also include the provision of additional respite to carers, so that they do not have to use their allocated respite in order to attend. CRCCs have indicated to Carers NSW that carers are often reluctant to use their allocated respite to attend training. This would be particularly true of carers of people with dementia. In the Carers NSW Carer 2010 Survey, 82 per cent of dementia carers said that time constraints were the most difficult part of being a carer. When asked what would make their caring role easier, 57 per cent selected more respite, which was more popular than better financial support and more support services. Respite must be provided to dementia carers to facilitate their participation in the Pilot, and to ensure they are not disadvantaged through their attendance.

OPTIONAL:

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ⁱ Department of Health 1992 cited in AIHW 2006 *Dementia in Australia: national data analysis and development*, Canberra.

ⁱⁱ Access Economics 2009 *Making Choices Future dementia care: projections, problems and preferences*, Canberra.