

House of Representatives Standing Committee on Health and Ageing

Inquiry into Dementia: Early Diagnosis and Intervention

Submission by Woy Woy Community Aged Care

September 2012

About Woy Woy Community Aged Care

Our facility is a not for profit residential aged care facility owned by the community providing high and low care accommodation for the frail and aged.

The facility has operated in the local community of Woy Woy for 23 years.

It consists of 94 frail aged residents: 54 in high care and 40 in a low care

This includes an 11 bed low care dementia wing as well as a 15 bed high care dementia area.

We have a total of 37 residents with a diagnosis of Dementia and many more with a diagnosis of Cognitive impairment.

How early diagnosis and intervention can improve quality of life and assist people with dementia to remain as independent as long as possible:

The inevitable loss of independence and sense of control over their life begins even before formal diagnosis is made for a person with dementia.

Their quality of life will depend on the care provided by the carers, family members, local doctor and other services.

Families, friends and carers require much more support and education in caring for the person with dementia. Behaviour management strategies are crucial for the carer to assist the person with all aspects of their activities of daily living. This will improve the quality of life for the person with dementia and their carer/family and help to maintain independence.

We frequently see admissions to our facility in both low and high care with extremely stressed, anxious carers who themselves exhibit symptoms of depression and ill health and who are chronically sleep deprived and socially isolated. This does not make for quality of care for their loved one with dementia. There are many occasions where staff recommend to the relative to seek medical treatment and or counseling via their local doctor for the sake of their own health. In aged care we frequently provide care and great support not only to our residents but also to spouses/family members.

The carer/families lack of knowledge about dementia and the terminal nature of the disease also lead to unrealistic expectations of care and outcomes that can be provided by an aged care facility. Doctors appear unwilling to make a diagnosis of dementia and carers are unaccepting of a dementia diagnosis because of the social stigma of mental health. Carers often feel they have failed their loved one when they have to concede defeat and place them in residential aged care. The carer may become an aggressive advocate for the resident which is stressful to care staff who are trying to deliver quality services and meet the families expectations often well outside funded care.

For the person with dementia who lives alone and is supported only by the care provided by community care services, Community Aged Care Packages, EACH (Extended at home package) and EACHD (Extended at home Dementia Care) far too little time is allocated to each person due to funding restrictions to meet their physical, emotional, nutritional and psychological care needs.

Dementia is a 24 hour /7 day a week disease, more resources are needed for special circumstances such as when the client is unwell and requires more services on a casual basis or ad hoc basis.

To increase opportunities for continued social engagement and community participation for people with dementia.

Currently the main focus for social interaction for people with dementia in the community involves day care Centre's which also provide important respite for the carer, at least for a few hours.

The social stigma that exists surrounding dementia and the potential inappropriate behaviour prevents the person with dementia and their family/carer accessing the usual opportunities that are available for social interaction. Earlier diagnosis and intervention will assist the person with dementia and their family/carer to continue their usual involvement in the community and maintain their dignity as strategies and medications can be introduced at an earlier stage. The lack of knowledge and understanding in the general community eventually leads to a drop off in social engagement for both the person with dementia and their carer.

More extensive public education as happens for other disease: diabetes, stroke and cancer will reduce the stigma, promote understanding and aid in maintaining social engagement. It may also help promote more support for the carers.

Early diagnosis will allow the person with dementia to retain some dignity and have some input into these important decisions before their dementia progresses and they no longer have the legal capacity. Doctors also need to ensure that they have an honest dialogue with families regarding the progressive terminal nature of dementia.

To promote and assist the transition to residential care, we would like to see funding for residential aged care facilities to provide weekend and day respite on an hourly basis. This would allow us to begin the transition process into residential care, support the family/carer and provide information or appropriate referral as needed for the carer if they are having difficulties at home. It will also provide a much needed emotional and physical time out for the carer and assist in reducing their feelings of guilt and failure that can accompany them when they are admitting their loved one into permanent residential care.

Funding allocations needs to recognize the important role residential aged care facilities can play in supporting family/carers as well as the resident with dementia.

Woy Woy Community Aged Care is looking to provide cluster housing on the fringe of the residential aged care facility that would allow people living alone with dementia, the opportunity to remain in the community but with support on a needs basis from the aged care facility, this would also provide a transition into residential aged care. This concept fits between community living including retirement living and residential aged care. It is not yet known how this concept and service would be funded.

Help people with dementia and their carers to plan for their futures, including organizing financial and legal affairs and preparing for long term or more intensive care requirements.

Adding to the burden of caring for a person with dementia is the difficulty of organizing financial and medical affairs. It is very complicated and time consuming for the person with dementia and their family/carer to know the difference between Power of Attorney, Enduring Guardianship, ACAT assessment, bonds/accommodation fees as well as Advance Care Plans.

Specialist government funded advisory service needs to be available to talk to the person with dementia and their carer /family step by step through the process without any vested interest. Currently various advice and information is given sporadically by LMOs, discharge planners, ACAT assessors and Aged Care facility staff and other community groups.

How best to deliver awareness and communication on dementia and dementia related services into the community

Education is a must and needs to be ongoing, widespread public education campaigns are required to help reduce the stigma associated with dementia. It needs to encourage people to seek diagnosis and support early, often the person themselves is acutely aware of their declining cognitive ability but hides it as best they can, whereas with other diseases people are more willing to seek help earlier.

Education needs to acknowledge that the person with dementia has been an intelligent active and contributing member of the community that now needs our support and understanding. We need to maintain the dignity of the person with dementia. An awareness campaign needs to reach out to all ages in our community as the children at high school will be the carers in the near future, particularly with younger onset dementia and early diagnosis of the disease.

Medical professionals also need to have ongoing education and increased awareness so they can make early and accurate diagnoses of dementia so that early support and interventions can begin. Local medical officers should be encouraged to refer their patients to a specialist for diagnosis if they lack the skills or are unsure of the diagnosis of dementia. Often admissions to residential aged care have diagnosis of cognitive impairment and/ or short term memory loss without the vital connection of a correct diagnosis of dementia being made.

Social media may be a way of raising awareness and educating all areas of the community about dementia. Have the conversation; in preparing this submission, discussions with staff have identified ways to further enhance our own carer support through our in-house support group bringing carers together to support each other and develop social contacts.

Woy Woy Community Aged Care would be willing to partner with the federal government in trialing service opportunities identified by this inquiry in a residential aged care setting.

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