

Inquiry 4th March 2013

Submission No. 110

(Dementia)

Date: 04/03/2013

My name is Jacinta Robertson, and I am the Manager Respite Programs for Life Care and I manage a day and overnight NRCP program as well as other day respite options and a unique work place engagement program, Side by Side that provides respite for carers of individuals with younger onset dementia. I have worked in this role for approximately 5 years.

I would like to start by thanking the committee for providing the opportunity for our carer group to be heard today. As a representative from the industry I also value this opportunity which has allowed me to act as an advocate for the group and work towards our aim of supporting and improving outcomes for carers and care recipients.

Life Care is a South Australian aged care provider that delivers services in residential care, retirement living and community care programs including packages, wellness centre and cottage respite. A significant number of our clients have a diagnosis of dementia, and we proudly run programs that target support for these individuals. Life Care believes that as an organisation our success comes from adopting the philosophy of 'Live every day'. The mission statement reflects this and is expressed as 'Our purpose is to partner with people to embrace life and live every day'. This belief is consistent with the Inquiries focus and we believe that with our expertise and dedication to support for individuals with dementia, that we are in a position to provide some insight into how early diagnosis and intervention can have positive outcomes for the individuals we support.

Representatives from our carer group have a number of issues that they would like to present today and these include

- The carer allowance and bonus payment
- Early diagnosis and GP education
- Early intervention and a lack of centralised information
- ACAT system
- CDRC
- Standard of workforce
- Respite funding
- Entry to residential care

Today I would also like to briefly highlight a number of issues that are apparent as a service provider that relate to the diagnosis and intervention of dementia care.

Diagnosis of dementia

A large number of carers describe a very frustrating and stressful path towards diagnosis of dementia, especially individuals with YOD. Stories of GP's who are dismissive of symptoms and concerns is common. There is antidotal evidence of the need to improve the awareness and understanding of dementia within our medical and health professions, especially for individuals with YOD.

Community Care Packages for individuals with dementia

A number of carers often raise the concern of their inability to access a community care package and they have reported that ACAT assessors have told them to expect a 12 – 24 month wait for an EACH D package to be available. With CDC's there are changes expected in the near future but until there is an increase in the available funding these concerns will continue. Community packages can improve the health, independence and general wellbeing of both the carer and care recipient and the need to reduce these long waiting times for support is obvious. Without support in the community through packages or flexible respite, carers are often forced to seek support in residential care at a much earlier stage, which increases the financial burden on the health system

NRCP funding

Our programs are aimed at supporting carers and providing a flexible model of care that promotes physical and cognitive well being for the carer and care recipient. Our NRCP program is funded for day and overnight options; however the current funding only provides 4 nights per week respite. With this model we do not provide flexible choices for carers as we dictate nights that can be accessed due to the funding limitations. Our program is currently achieving 110% occupancy due to high demand so we have worked with external providers to provide 7 nights/ week respite options. Within the first month of the increased hours we achieved greater than 90% occupancy. We are proud to have achieved increased options and flexibility however the funding is only for a limited 12 month period, and due to the ongoing high demand for our programs we have 3 month waiting lists for overnight stays.

These outcomes demonstrate a successful program that provides respite options that are supportive to carers. Our waiting lists demonstrate a need to expand our model of care and with our extended model only having confirmed funding until August there is a need to urgently review our funding and the demand for extending the current model if we are to aim to provide appropriate support and intervention in dementia care

Identified target groups

Individuals with Younger onset dementia have been highlighted within Living Longer Living Better as a group that have identified gaps in service delivery. We support a number of individuals with this diagnosis and have identified a need for a specifically designed program of support and intervention for SA. The complex needs of this group from diagnosis to support programs have not been appropriately addressed within our state and with the anticipated increase in diagnostic rates, appropriate interventions and planning are urgently required. Traditional respite options for older individuals are not appropriate or appealing to individuals with YOD. Individuals with YOD do not often meet the criteria for traditional community programs and access to residential care is extremely difficult due to funding being aimed at individuals over 65 years of age.

Appropriate intervention

An individual with dementia has a very individual path as they move from early diagnosis to moderate and advanced stages. Irrespective of age, there needs to be flexible models of support in both community and residential settings to meet their needs. For example, an 80 year old with some early signs of cognitive decline, will not find a program for individuals with advanced dementia

stimulating or appropriate. Service providers must have flexible management of programs and the skills to identify and address each individuals needs. Their models of care are often restricted due to funding and staffing constraints, rather than individual care needs.

Recommendations

- An increase in funding for community packages will assist carers and provide appropriate intervention that is aimed at the promotion of independence and well being. A public health approach to dementia care will have benefits for the individual, their families, the community and the health system.
- Increased funding to allow expansion of successful respite programs that have evidence that they are meeting individual needs, and that are providing appropriate intervention and support for individuals with dementia and their families.
- SA needs a specific YOD program to provide the appropriate support and intervention for this identified target group. Funding for a stand alone community day and overnight unit as well as funding for residential support for individuals under 65 years of age is essential if we are to address the identified gaps in service provision
- An education program for GP's with the aim of improving diagnosis and management of dementia, specifically YOD should be explored and the Medicare local networks may provide a forum for such programs

In closing I would like to once again thank the committee for the opportunity to raise our concerns and I hope that by forums such as this we will be able to achieve better outcomes for carers and individuals with a diagnosis of dementia.