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**Submission No. 029**  
(Dementia)  
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1 May 2012

Clerk Assistant  
The Standing Committee on Health and Ageing  
House of Representatives  
PO Box 6021  
Parliament House  
CANBERRA ACT 2600

To Whom It May Concern

**RE: Inquiry into Dementia: Early diagnosis and Intervention Submission**

Please find enclosed Life Care's submission addressing the terms of reference set out by The Standing Committee on Health and Ageing to assist with the inquiry into Dementia: Early diagnosis and Intervention.

I can be contacted on 08 8239 9800 in regards to Life Care's Submission.

Allen Candy

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## **Life Care's Submission to The Standing Committee on Health and Ageing Inquiry into Dementia: Early diagnosis and Intervention.**

Life Care is a South Australian aged care provider that delivers services in residential care, retirement living and community care programs. 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' as a fundamental belief. Our 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 terms of reference and the organisation believes 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 who we support.

Early intervention is a key to maintaining wellbeing for individuals with dementia, as well as their families for as long as possible. As our population ages, there will not only be an increased demand on services, there will also be a change in what services are requested. Organisations such as Life Care are committed to meet the changing and increased needs and hope that this inquiry will enable us to voice our concerns and suggestions to House of Representatives Inquiry on Dementia

In response to the terms of reference for the inquiry Life Care would like to make the following observations and suggestions

a) *Improve quality of life and assist people with dementia to remain independent for as long as possible:*

- Individuals can be more independent, where they have choice and support. The health system needs to expand the current proactive approach to dementia care with improved access to community care packages. Early diagnosis and intervention enables relationships to be developed with individuals who have a diagnosis of dementia while their cognitive ability allows, as well as their families. People should be encouraged to seek early support from service providers, which will in turn provide support throughout the disease process.

For the individual with dementia, community care packages allow them to stay living at home for longer, provide a network to monitor and promote physical and cognitive wellbeing, and also provide a means of social connection. Packages allow individuals if they wish, to live alone in the community without the fear of social isolation. Life Care is pleased to see the increase in community packages that were announced in Living Longer. Living Better. Aged Care Reform Package. However, we believe that some minor adaptation's would greatly enhance outcomes. With the current system, there are a limited range of packages that are delegated depending on the determined need of the individual. A streamlined incremental approach to package hours would enable individuals to be treated as individuals, and maintain their quality of life and independence.

With early intervention, service providers could be introduced sooner to develop a relationship and support system and thereby assist individuals to maintain independence. The providers should be able to assist the individual throughout the journey and changes that will occur with dementia, increasing support as needed to meet their needs. If community packages were allocated at early diagnosis, and the provider was able to adjust service provision as needed for the individual, better outcomes would be achieved.

Community care packages also have a positive impact on the family carer and unit. With support, carers can continue to stay active in the community, and will in turn be able to continue the caring role, and reduce the demand on the residential care facilities.

- Respite programs promote independence and quality of life for both carers and individuals with dementia, and are another example of positive and proactive initiatives. Outcomes from respite programs are noted to be better when individuals are introduced to programs earlier in the disease process. Early diagnosis and intervention with respite programs provides the opportunity to promote physical and cognitive well being for the individual with dementia, as well as to provide an avenue for social interaction. At the earlier stages of dementia, individuals are more likely to have the cognition to accept changes to routine and separation from family members, and therefore will maintain an active lifestyle, but only if appropriate programs are available.

For individuals with dementia, respite programs provide an environment that is non threatening where they can participate in activities and programs promoting physical and cognitive wellbeing, quality of life and independence. With a diagnosis of dementia, individuals feel disempowered as they lose the ability to undertake activities that the community take for granted. Respite program guidelines need to be expanded to give greater flexibility for these individuals, as well as appropriate services for their individual needs.

Service providers should provide respite programs that are individually focused; to be able to meet the needs of individuals with dementia who are physically active as well as those who may be frail, to meet the needs of individuals who are at the early stages of dementia, to those with more severe dementia. Early intervention and diagnosis will assist with improved quality of life and independence.

Carers need support in their caring role, and better access to respite options will enable them to continue being involved within the community and finding a balance between their caring role and being an individual. Respite enhances quality of life for the individual with dementia as well as for their carer's and family. Our current NRCP program has waiting lists for day and overnight stays, and expansion of these programs would enable greater flexibility for carers as well as increased service provision. Increased funding is required if we are aiming to offer respite earlier to more carers in the community.

- Community based respite programs give carers flexible choices compared to residential options. The system needs to offer individuals greater flexibility and choice in the duration and access to respite options. For example, extending current NRCP programs to 7 nights a week would allow carers to access from 1 night to 2 weeks respite rather than being locked into longer blocks through the residential respite options. Flexibility will give carers and individuals with dementia independence and quality of life, and if introduced earlier in the disease process independence for both carer and care recipient will be promoted.
- Individuals who are diagnosed with younger onset dementia have a very complex disease path and require intense service provision and support for them as well as their families. To

optimise support and individual well being, early diagnosis is essential and appropriate programs for individuals with younger onset dementia should be established and maintained separately to traditional aged care programs. For example, Life Cares Side by Side program demonstrates how service providers can be innovative and develop appropriate programs to support a specific target group and promote independence, self esteem and a feeling of community connection for individuals.

**Recommendations:**

- 1. To expand the number of community care packages for individuals with dementia, allowing service providers to work with individuals with dementia from early diagnosis.**
- 2. To provide incremental increases in community care service provision so that transition from low to high care packages is no longer required. Early allocation as well as flexibility with community care packages will enable providers to meet determine individual needs.**
- 3. To expand current NRCP programs to 7 nights per week, and offer increased community based respite options that are individually focused**
- 4. Expansion of community respite programs allowing individuals to stay in the community sector, rather than the necessity for residential respite options giving greater support and options to those individuals who are in the early stages of the disease process**
- 5. Development and funding of programs that meet the identified needs of target groups such as those with younger onset dementia, where early diagnosis is essential for the individual and their family to achieve the aim of promotion of independence**

*b) increase opportunities for continued social engagement and community participation for people with dementia*

- Day respite options currently offer social engagement options for individuals with dementia , however are primarily for individuals with well established signs and symptoms of Dementia and provide activity programs designed for this level of need. With early diagnosis and intervention, appropriate programs that meet the needs of individuals with early stages of dementia should be developed and expanded to meet the growing need within our community. These will provide the initial contact to service provision in an appropriate forum that will meet individual needs.
- Organisations need to be encouraged to ‘think outside the square’ and to develop new models of care that promote engagement interaction and community engagement. Our Side by Side program is an example of how with a new approach to respite care we can achieve exceptional outcomes and social engagement for individuals with dementia

**Recommendations:**

- 1. To develop appropriate respite options that meet the needs of individuals with early stages of dementia**
- 2. Service providers to have the ability to provide a range of respite models that will enable individuals with dementia to stay in a familiar environment as their needs change from initial diagnosis to advanced dementia. Models of respite care need to meet individual needs from the early to advanced stages of dementia**
- 3. Service providers to be encouraged to review their model of care and encouraged and supported to try new and innovative programs that will meet the needs of individuals at different stages of dementia**

c) *To help people with dementia and their carers to plan for their futures*

- Dementia care link workers provide a valuable resource for individuals with dementia and their families. This program should be enhanced to enable link workers to provide information to the community. An awareness campaign should be undertaken with general practitioners of the link worker role and the benefits of early referral. Referral to link workers provides a primary point of contact during the crucial time of diagnosis and coming to terms with the disease.

**Recommendations**

- 1. Link worker program to be expanded and promoted within the health sector and general public**
- 2. Education program regarding link work roles to be undertaken with general practitioners**
- 3. Education programs regarding early and differential diagnosis of dementia should be undertaken with general practitioners and the public**

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

- Respite is often referred to as having negative connotations. Awareness of what positive programs can achieve would be beneficial for the community. A community awareness campaign, designed to de stigmatise community support programs would assist the community to gain awareness of the benefits of support programs and the importance of community engagement, and would encourage contact at the time of early diagnosis, once again improving outcomes
- Campaigns that are able to reach members of the community in a non threatening or confrontational manner are important with dementia education and awareness. The Side by Side program provides community education and engagement within a hardware store. This provides opportunities for people not comfortable with accessing existing avenues for advice, and has proven to be easier for individuals to speak to staff there rather than asking a general practitioner. Community education programs that reach out to the community and provide a safe and non threatening environment for education and resources, should be explored, and will once again promote contact at the time of early diagnosis or concerns.
- A number of individuals with younger onset dementia have experienced a demoralising and complex process and journey to diagnosis. With improved understanding by general practitioners we may in time be able to cease the pattern of distress that comes with the process of diagnosis, as well as achieving early diagnosis.

**Recommendations:**

- 1. Community awareness programs related to carer support, community care and respite programs, that are delivered in non traditional environments**
- 2. Continuing education programs for general practitioners regarding diagnosis of younger onset dementia**

Life Care as a service provider of community packages and respite options has direct communication with carers who are living with family members with dementia, from early diagnosis to the advanced stages of dementia. We also support individuals with dementia in our residential facilities. Their experiences and our involvement with their journey have provided us with an insight into how the system can support them, and where we feel service provision can be adapted to improve outcomes. Changes to diagnostic and intervention processes will hopefully enhance outcomes for these individuals. The Live Longer. Live Better. Age Care Reform Package has demonstrated the governments' commitment to reviewing the system and improving outcomes. The Inquiry into Dementia: Early diagnosis and Intervention will enable the government to further review and implement changes promoting early diagnosis and implementation that will enhance better outcomes for individuals with dementia, their families and the community.