



Submission to
House of Representatives Standing Committee on
Health and Ageing
inquiry into
Dementia: Early diagnosis and Intervention

May 2012

Introduction

ECH Inc., Eldercare Inc. and Resthaven Inc. are three of South Australia's largest and most experienced providers of residential and community aged care and housing options for older people.

Our combined operations offer a comprehensive range of services and support to frail, older South Australians, including independent retirement living, Home and Community Care (HACC) services, community aged care packages, Transition Care, health and well-being services, respite and residential aged care. In all, we employ close to 4,000 staff and provide assistance to many thousands of residents and clients each year.

We thank the Committee for the opportunity to make a submission to this important inquiry and offer comments below against the Terms of Reference.

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

We firstly need to respect and appreciate that people with dementia usually continue to have the capacity to be independent and functioning individuals and do not become dependent immediately upon diagnosis. Early diagnosis means that the family can be educated and upskilled about the implications of dementia but also what capacity the person has despite the diagnosis. The actual diagnosis needs to consider the type of dementia and its implications for possible symptoms and progress, and to carefully explain this to the individual and family.

Early screening can lead to more accurate and timely diagnosis, using a graduated approach ranging from less invasive screening tools (e.g. clock drawing) through to Minimal Mental State Examination (MMSE) and Frontal Assessment Battery (FAB). Early screening can therefore avoid potentially heartbreaking situations for people believing they have dementia when they don't or families wrongly treating a person as though they have dementia. Early intervention can also lead to use of medications that can at least have temporary or modest effects or delay decline in cognitive function.

Families relate stories of not being listened to by some service providers and of staff (albeit well-meaning) speaking only to the carer and not to the person with dementia. They also tell of feeling overwhelmed by the information given during the first contact with the service system and of not being in control of decisions about the individual's care and activities.

Service providers and their staff therefore need to support people living with dementia, through:

- improving staff knowledge and skills in optimising each person's independence through a wellness rather than illness approach: 'doing with' rather than 'doing for'; identifying the risks or barriers to independence and addressing these each time they are identified; supporting people to continue to be valued contributors to their family, friends and the community (e.g. continuing in employment if they are able, volunteering in the community, and continuing to advocate for other people with dementia¹;

¹ [Christine Bryden](#) and [Kate Swaffer](#)

- facilitating referral to the person's GP: the diagnosis of dementia and identifying dementia as a chronic condition attracts MBS benefits associated with chronic conditions (health assessment, preparation and review of a management plan, team care arrangements. GPs can then be paid for the time spent to develop strategies/plans with each person around their diagnosis. Similarly, Nurse Practitioners (NPs) can offer significant input to the care of people with dementia and who need access to suitable MBS items that reflect the basis of diagnosis and ongoing treatment plans, including detailed structured assessment. GPs and specialists often partner with NPs as part of a multidisciplinary approach.
- not forgetting the other health aspects of the person beyond dementia (emotional support, depression, mobility, nutrition, continence) and ensuring there are sufficient resources to provide the necessary services;
- providing opportunities for activities for people to exercise their mind and body:

*'There is a growing body of research that has examined the links between physical activity and cognitive impairment and dementia in older people. Overwhelmingly, the results have shown an association between the two. Studies have linked sedentary behaviour (which includes slow walking, daily household activities, and limited leisure-time activity) with increased risk of dementia. Other studies have demonstrated the positive effect of exercise on measures of mild cognitive impairment and executive function and the Mini-Mental State Examination (MMSE). Regular physical activity in mid and late life has been associated with lower risk of developing dementia.'*² ;

- promoting the value of home to people with dementia and providing support to families/carers who strive to keep the person with dementia at home: more intensive case management; subsidies for living costs; increased respite that meets the carer's needs (usually community based rather than residential). To highlight the situation faced by many families, one client told us:

"My last electricity bill with Dad at home was \$1200 for three months. We would never have done it any other way but I don't think people realise the cost of running a washing machine four or five times a day because of the wet clothes, the bedding. Power's on almost all day, heating, cooling, lighting, TV. My water bill would have been what you'd expect for having eight people in the home."

- providing support to carers to maintain them in their caring role (health services, respite, information, networking, skills). This includes access to out-of-hours services and support for working family members and particular support for grandchildren and male children who seem to have more difficulties in understanding and coping with the circumstances of the person with dementia.

² Alzheimer's Australia: *Towards a National Dementia Preventative Health Strategy*, Paper 21, August 2010

Increase opportunities for continued social engagement and community participation for people with dementia

We need to continue to reinforce and promote the person-centred model in aged care and the wider community (schools, businesses and community groups):

- ongoing education of aged care staff and community members;
- funding for small group and individualised support for people with dementia to assist them to engage with their community (e.g. providing additional support via paid or voluntary workers to assist the person to connect with a community group). Providing funding incentives for community groups to become dementia friendly - education for members, buddy programs etc. People with dementia can be excluded from aged care therapy programs despite there being potential benefits for them. Staff need to understand that people with early stage dementia are still able to develop new memories;
- train staff and carers in, for example, the Montessori strengths-based approach: identify with the individual as to what they can do, and optimise their ability and their value. There are many research examples of people with dementia being able to continue to undertake activities that involve skills developed in the past. An example offered by a carer of a person with advanced dementia and wandering behaviour was keeping them engaged by having them sit and 'read' a newspaper. Even though they had actually lost the ability to read, they could still turn the pages and look at the images. Another example was developing a book with art work depicting a person's life experiences and sharing anecdotes with family members.

Carers report stories of losing their social engagement with a partner in residential care as a result of not being able to drive and having to rely on difficult public transport arrangements. Transport becomes a very real issue in maintaining relationships and actual contact.

Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements

We continue to hear from people with dementia and their carers that they experience difficulty in finding information, navigating systems, advocating for themselves, and knowing what their options are (including the effects on finances). Testamentary capacity becomes a critical issue and early expert advice is important.

Some suggestions include:

- mandatory care planning following a diagnosis of dementia as an MBS item so that the person with dementia and their carer do not leave the GP with a diagnosis but without any identified pathway forward;
- increased access to counseling and advisory services specialising in understanding and supporting people with dementia and their families;

- increased access to a dementia link worker/key person who can support people with dementia and their families in navigating the pathway of dementia, understanding that no “journey” is the same;
- increased access to financial planning provided by independent, accredited aged care specialists;
- promotion of Advance Care Planning as a concept for all people at all ages. Make it clear and transparent that planning with and for the person with dementia does not stop when the person has been diagnosed. Refer below for additional comments regarding testamentary capacity.

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

Some suggestions for increasing awareness of dementia are:

- Government funded media campaigns along the lines of Beyond Blue but including that dementia is not an inevitable part of ageing. Many people are not aware of, for example, the differences between dementia and normal age-related changes to the brain;
- Providing opportunities (including formal mechanisms) for people with early stage dementia to express their views and influence policy and practices in government agencies and government-funded services;
- Promoting the very positive lives that can still be led by people who do have a diagnosis of dementia;
- Sharing the stories of people with dementia who have been able to stay at home until they died;
- Incentives to community members/businesses to be age and dementia friendly environments; and
- Making the subject of dementia part of the “Society and Environment” curriculum at schools.

General Comment

In addition to the comments above, some general observations are that people with dementia and their families are often stigmatised by a diagnosis of dementia and have great difficulty coming to terms with what may lay ahead. They can have feelings of embarrassment and shame that need to be overcome through the help of health professionals and other care and support staff. Any intervention provided for people with dementia needs to consider these issues, which relate to staff training about effective communication, to their skill sets, and to service systems taking these issues into consideration for initial assessment and subsequent processes.

It is also important to ensure that there is continuity in access to and the nature of services available to people aged less than 65 who develop dementia. Care needs to be exercised so that COAG policy and funding decisions related to age and jurisdictional responsibility do not create adverse effects.

The Australian Government has recently announced a package of important initiatives for 'Tackling Dementia'³. The measures include support for primary health care providers to undertake more timely dementia diagnosis; expansion of the Dementia Behaviour Management Advisory Services; a new funding supplement; and staff training initiatives in residential, home and acute care. While we welcome the announcement, the measures fall short of what Alzheimer's Australia has called for⁴ and as aged care providers, we will need to gauge their impact over time against the National Aged Care Alliance *Blueprint for Aged Care Reform*⁵. The reform package is largely being funded by the redirection of aged care funds in the Forward Estimates and through means testing measures. There is very little new money being made available (only \$576.9m over five years).

Nevertheless, the announcement is an important step forward in improving the quality of life for people living with dementia.

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³ Australian Government, *Living Longer. Living Better*, April 2012

⁴ [Alzheimer's Australia: Fight Dementia Action Plan](#) 2012

⁵ [NACA: Age Well - preparing for our future now](#) February 2012

**A CARER'S EXPERIENCE
in her words**

I (not her real name) cared for both her parents who had dementia for many years before they died. Neither went into residential care and towards the end both came to live with I. Her mother also had Parkinson's Disease and received one of the first EACH packages that were released in South Australia.

I believe that people need to start accessing the available medication as soon as possible, as the first resort. With my Mum the medication provided 'windows of opportunity' where she was relatively 'normal'. Doctors need to be more aware of the medication that is available for early signs of dementia.

I wish that I'd known about the signs earlier rather than later because I would have gone and looked up information to find out how to help Mum and how to handle things differently. The education of people is key. Families and carers also need to understand that they're still a person even when they're frustrating to be with.

You get to know who your friends are. A lot of family and friends dropped out like 'hot cakes'. They didn't know how to have a conversation with Mum and when she really needed people (after being there for others for years); it was too hard for them. It relates to ignorance and the people around them being educated.

This was a while ago, but staff and other people need to be more educated in how to work with someone with dementia, the trigger points and how to handle them.

Everyone forgot that people with dementia can still do things. I tried to keep things as normal for as long as possible. I would sit Mum at the sink, put a tea towel in her hand so that she could dry the dishes (even if it took an hour). She didn't get so stressed when she had things to do. In the initial stages, the care worker asked Mum to write down her story about her younger life and parts of this were put into a book about what life was like in Tintinara. That was a real help. She also put together a picture book with all the family and when Mum couldn't remember what had happened to people, they would sit down and talk about it which seemed to be calming for her.

Dad's dementia started after Mum died (the shock of it seemed to trigger it). He was always interested in horse racing, cricket, football etc so I helped him keep up with that - I installed Foxtel so that he could watch everything.

It's important that people stay in their own home, in their familiar surroundings for as long as possible with the people around them being educated, informed about how to manage and respond. My parents were better when they were stimulated and had more people around them.

A day program would be good as long as people do things that they're interested in and the person can cope with the new environment.

The EACH package was very important in helping to support my parents.