**Submission No. 059**
**(Dementia)**
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NATIONAL AGEING RESEARCH INSTITUTE

# Submission from National Ageing Research Institute to the House Standing Committee on Health and Ageing,

# Inquiry into Dementia: Early diagnosis and Intervention

Terms of reference:

The Committee will inquire into and report on the dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

- improve quality of life and assist people with dementia to remain independent for as long as possible;
- increase opportunities for continued social engagement and community participation for people with dementia;
- 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; and
- how best to deliver awareness and communication on dementia and dementia-related services into the community.

**Summary of NARI's response**

- There needs to be further research into the effectiveness of early intervention models for people with mild dementia or mild cognitive decline in order to build the evidence base
- More research is needed into ways to promote early detection in primary care, including for people from culturally diverse backgrounds
- Our research provides examples of the benefits of social engagement and community participation. Further research is required into the determinants of social engagement and community participation
- Advanced care planning is beneficial. Further research is required into the best methods for preparing people with dementia and their carers to plan for their futures. NARI conducts

research investigating the rights of people with dementia who are negotiating the health care system.

- The media is a powerful way to communicate awareness of dementia and services available. An independent body that monitors the quality of news stories about dementia and supports the translation of latest research findings from researchers to the general public would assist in raising awareness of dementia and reducing stigma.

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

When undertaking the evaluation of the federal government Extended Aged Care at Home Dementia program, it was evident that clients accessing the services provided were able to maintain or improve their quality of life. Family carers and health service providers both indicated that earlier access to the services provided would have been more beneficial. There is substantial research evidence that people who access support services earlier have better outcomes than those who first seek and access service supports when they are further advanced in their dementia. The general community needs to understand that small amounts of supports provided sooner rather than later will lead to better outcomes than if they delay seeking support. The Fitness for the Ageing Brain (FABS) study also demonstrated the benefit of physical activity for people with mild cognitive decline. This research is now being extended to people with mild dementia to see if physical activity can be beneficial at a later stage through the FABS 2 study, being conducted at NARI. There needs to be further research into the effectiveness of early intervention models for people with mild dementia or mild cognitive decline in order to build the evidence base about models of cognitive stimulation and health promotion for people with dementia or mild cognitive decline.

### How working with people from culturally diverse communities can increase awareness of dementia and enable culturally appropriate responses that encourage earlier detection and referral to specialist care.

Early detection of dementia is important as it allows the person with dementia and their family to plan for the future and maximises the potential benefit of early intervention. However, people from culturally diverse backgrounds tend to present later for assessment and diagnosis and often at crisis point. Recent research at NARI involved working with people from the Vietnamese and Chinese communities in Melbourne to develop culturally appropriate education materials for people with dementia and their families, community workers and general medical practitioners. These materials were disseminated through a number of channels, including community meetings, tip sheets for community workers and GPs, and seminars for professional staff. During the study period, there was considerable increase in the number of referrals to Memory Clinics from these communities. More research is needed into mechanisms that support and encourage early detection and referral for people with dementia, including those from culturally diverse backgrounds.

## How early diagnosis and intervention can increase opportunities for continued social engagement and community participation for people with dementia

Research at NARI has shown that continued social engagement and community participation for people with dementia has benefits both for the person with dementia and for their family carers. A study of participation in a choir for people with dementia is showing some benefits. People with dementia are transported to the choir location, while their family carer uses the time for respite. Costs are carried by the Commonwealth carer Respite program. Early intervention for people with dementia to be involved in activities such as this can be of benefit by providing stimulation and social engagement, for both of which there is increasing evidence that they can be beneficial to maintaining functioning. Other innovative services such as the Memory Lane Cafe which was evaluated by NARI and found to be effective in maintaining social engagement and community participation need to be supported by the government and extended to more locations. Further research is required into the determinants of social engagement and community participation so that we can better understand how to achieve participation by people who are reluctant to engage.

## How early diagnosis and intervention can 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

Further research is required into the best methods for preparing people with dementia and their carers to plan for their futures. NARI conducts research investigating the rights of people with dementia who are negotiating the health care system. Advanced Care Planning (ACP) is the process for making and writing down future health care wishes in advance. ACP enables competent adults to record their treatment wishes in the event they should they lose capacity or be unable to communicate their wishes when it is required. Advanced planning of end-of-life care is considered best practice for all older people, including those living with terminal illness and whom it is expected will lose legal capacity. Even though the purpose and reasoning behind undertaking ACP are clear, because the trajectory of dementia is mostly on the order of years and includes impaired cognition, there are numerous potential confounding issues that can make the reality of ACP a complex process for dementia. Further research is required to ensure that people with dementia can use ACP at every stage of their dementia journey.

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

Dementia Behaviour Management Advisory Services in each state, Dementia Training Study Centres and Dementia Collaborative Research Centres are federally-funded services that communicate information about dementia to health professionals. Awareness and communication on dementia is being provided through Alzheimer’s Australia directly to family carers and people living with dementia. However the media is another direct source of information for the Australian community, that can be better prepared to communicate accurate information while at the same time reflecting appropriate attitudes and perceptions about the condition, including the benefits of early diagnosis and intervention. Recent research at the National Ageing Research Institute and The University of Melbourne provided evidence about the reporting of dementia-related stories in Australian media. The media – newspapers, television, radio, magazines and internet – is a powerful medium for translating knowledge about dementia for carers, people living with dementia and the general public. Yet many ageing-related stories in the media are negative eg nursing homes maltreating residents.

There is a substantial literature on quality of reporting health information in the media, especially with respect to stigma and mental illness but little attention has been paid to the reporting of dementia. The media is potentially a powerful tool to help spread health awareness and influence perceptions, beliefs and attitudes yet we have not fully developed the supports necessary for effective knowledge translation using the media. The media's role as disseminators of information on dementia is particularly important due to the potential to influence public perception of the risk reduction and early intervention. An independent body that monitors the quality of news stories about dementia and supports the translation of latest research findings from researchers to the general public would assist in raising awareness of the condition. As identified in the Productivity Commission’s report on ageing last year, a ‘one-stop shop’ to find out about ageing related services will assist people when seeking services. Educating health professionals, especially general practitioners, in how to access dementia services will assist in raising awareness about dementia.

Dr Colleen Doyle

Director

Service Development & Evaluation Division

National Ageing Research Institute

Ph

Email

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