



House of Representatives Standing Committee on Health and Ageing

Inquiry into Dementia: Early Diagnosis and Intervention

Submission from Alzheimer's Australia NSW

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The focus of this submission from Alzheimer's Australia NSW is on community based diagnosis, intervention and support. It is acknowledged that a large proportion of the population with dementia have been diagnosed following entry into a residential aged care facility. The issues around early diagnosis and intervention practices around the four themes of the Committee inquiry will be very different for a population living in residential aged care, to those who remain independent and living in their own home.

There are many benefits of a timely diagnosis for people with dementia and their carers. These include:

- understanding the cause of the symptoms;
- assessment and possible treatment of reversible causes;
- timely access to services and support networks, and to potentially beneficial medications;
- opportunities to exercise choice by planning ahead for legal and financial matters, and for future medical care;
- the opportunity to implement important choices and life changes relating to family, employment, accommodation and social relationships before the dementia progresses to advanced stages, or before a crisis point is reached that forces hasty decisions; and
- the opportunity to optimise quality of life and remain independent, with appropriate support, for as long as possible

Timely diagnosis therefore has an important role in influencing the three major focus areas of the Committee. The question around community awareness raising is important from the perspective of improving knowledge of dementia, particularly encouraging the 'worried well' to see their GP.

The Committee is focussed on the early diagnosis of dementia and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

1. improve quality of life and assist people with dementia to remain independent for as long as possible;

Access to early diagnosis can result in interventions such as those listed below which can improve the quality of life of a person with dementia, as well as their carers. These intervention practices support independence:

- Safely Home Program (Alzheimer's Australia and NSW Police initiative)
- Safe 2 Walk assistive technology which enables people with dementia to walk around their neighbourhood independently and safely
- Provision of assistive technologies for people with dementia
- Provision of social support, respite and activities which improve the quality of life of the person with dementia, but also the carer. Thereby contributing

- to the caring relationship being maintained and the person with dementia being able to remain living at home.
 - Community health, equitable access to community continence nurses.
2. increase opportunities for continued social engagement and community participation for people with dementia;

Access to early diagnosis can result in interventions such as those listed below which can increase the opportunities for social engagement and community participation:

- Community-based social support programs for people with dementia which provide one-on-one mentoring/buddy support or group social events/activities e.g. UnitingCare YOD program, Alzheimer's Australia NSW programs with Men's Sheds, dementia cafes, visits to local art galleries.
- Carer support groups
- Individualised support for people with dementia to participate in/be included in mainstream community activities eg. To be a volunteer, a member of a bowling club, a member of an art class or gym
- AlzNSW community dementia awareness and education programs that de-stigmatise dementia
- Mentoring and buddy type social support programs
- Social inclusion initiatives for people with dementia including volunteer opportunities and support to participate in local community activities
- Community-based social support options rather than traditional day care centre/program models
- Provision of individualised packages of care and support services.
- Therapeutic social and creative activities for people with dementia e.g. music, art, drama, dance etc
- Dementia risk reduction campaigns such as the AlzNSW 'Mind Your Mind' program as part of healthy ageing initiatives.
- Lifelong learning opportunities to the whole NSW population as learning new skills is a dementia risk reduction strategy
- Support for working carers of people with dementia through a holistic assessment process for respite and other support services which includes both the person with dementia and their family carer/s. This is particularly pertinent for people with younger onset dementia (YOD) and their families given the different life-stage issues (e.g. mortgage repayments, dependent children, difficult access to superannuation and Centrelink payments etc).
- Access to transport, either through community transport services through the HACC Program, accessible public transport (elevators at train stations and height adjusting buses), subsidised taxi schemes and clear guidelines around driving and dementia.

3. 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

Access to early diagnosis can result in people with dementia and their carers being able to plan for their futures, in the context of declining capacity and function as a result of the disease. Initiatives such as those listed below can assist: the broader population prepare for a diagnosis of dementia (which hopefully doesn't occur), people with dementia, and their carers.

- AlzNSW Planning Ahead community forums which improve community awareness of their need to complete and the value of future legal and health plans.
- There is a single access point for resources and information about legal and health planning.
- A public awareness campaign to reduce the stigma surrounding dementia, this should include ongoing funding of Dementia Awareness Week activities coordinated by AlzNSW.
- It needs to become standard practice for GPs, community service providers and other health professionals to provide information about planning ahead. It should be commonplace for everyone to have a will, an advance care directive, an enduring power of attorney and an enduring guardian. AlzNSW holds locally based community events about planning ahead which attract up to 100 people per event.
- Government led initiatives to prevent financial abuse of people with dementia rather than reactive measures which respond to incidences of abuse.
- Support services to assist people with dementia to manage their money/finances.
- Policy changes are needed in the banking sector to prevent financial abuse and provide safeguards for people with dementia. This could include clearer criteria/processes for assessing capacity for financial decision making.
- Health professionals (e.g. GPs, neurologists, psychiatrists, geriatricians) must work together to ensure a timely diagnosis of dementia and provide referral pathways to appropriate support services.
- The experience of people with younger onset dementia and their families must be recognised and they must be well supported in their use of aged care services and in the bureaucratic transition from services for people under 65 years to aged services.

4. how best to deliver awareness and communication on dementia and dementia-related services into the community.

A national dementia awareness campaign is required to de-stigmatise dementia, and to raise understanding and awareness of the condition amongst the general

community and within the primary care sector. Such a campaign would have the objective of making all Australians aware of the symptoms of dementia, and the importance of seeking medical help. Alzheimer's Australia and the various State organisations, including AlzNSW, have been making significant inroads in raising awareness of dementia in the community through mainstream and social media.

Other awareness and information that support people with a diagnosis of dementia and their carers to remain independent include:

- At Home with Dementia resource for carers of people with dementia (ADHC publication)
- Early intervention education programs and support services meet the needs of people living with dementia, their families and carers
- Government investment in community awareness raising about dementia in CALD and Aboriginal communities.
- AlzNSW professional, volunteer and carer education programs that build knowledge and skills for supporting community participation of people with dementia
- There is a pressing need for GPs to receive more effective education and training to be better able to address the needs of people seeking help with memory loss and the symptoms of dementia.
- AlzNSW community dementia awareness and education programs that de-stigmatise dementia