

Committee Secretary
Standing Committee on Health and Ageing
House of Representatives
PO Box 6021
Parliament House
CANBERRA ACT 2600
AUSTRALIA

Re: Parliamentary Inquiry into Dementia Early Diagnosis and Intervention

The National Cross Cultural Dementia Network (NCCDN) is pleased to provide a submission to the Inquiry into Dementia Early Diagnosis and Intervention. The NCCDN is a key advisory group which supports Alzheimer's Australia in meeting its commitments with respect to the needs of people with dementia and their family carers from culturally and linguistically diverse backgrounds (CALD).

Members of the NCCDN come from a wide range of professions such as geriatrics, clinical psychology, nursing, residential, aged care, education, social work, community work, knowledge and information management and research. Members come from organisations across the health and care sector, as well as Alzheimer's Australia.

It is a well-known fact that people from a culturally and linguistically diverse background constitute a large portion of the Australian population and that they are ageing rapidly. Currently one in eight Australians with dementia do not speak English at home (Access Economics, *Dementia prevalence and incidence among Australians who do not speak English at home* 2006)¹.

The NCCDN for the past ten years has advocated strongly to improve access to timely diagnosis for dementia for people from culturally and linguistically diverse backgrounds. A report undertaken by Alzheimer's Australia Victoria on the Perceptions of Dementia in Ethnic Communities (2008)² highlighted that whilst different issues affect different individuals and different communities in regards to dementia, there are some common themes which include:

- Lack of knowledge about dementia and its symptoms, as well as a lack of knowledge of what causes dementia.
- Variations in perceptions of dementia ranging from being: an illness, a normal part of ageing, a mental illness or having no meaning at all in some communities.
- Stigma associated with dementia or lack of understanding of dementia, resulting in people being marginalised and isolated from their own communities and sometimes even from family members.

Strategies to assist to raise community awareness of dementia

- Efforts and resources need to be placed into raising awareness of dementia amongst ethnic communities, not only those from established groups but also those from the emerging communities.
 - Strategies that could be utilised are the use of community development models; the use of key workers and the use of ethnic media campaigns utilising all forms of information dissemination, print, radio and television. Recently, the Australian Multicultural Foundation undertook a community awareness campaign on dementia for a number of ethnic communities using ethnic radio and print media and found the project to be extremely successful in raising community awareness.
 - Community awareness strategies need to be ongoing if they are to be effective and sustainable and not on an ad hoc basis.
- Late diagnosis of dementia often at crisis point, due to lack of knowledge about the early symptoms of dementia, where to go for help or being ashamed of being labelled.

Strategies to assist in timely and accurate diagnosis

- Often people from a CALD background are either diagnosed later from the onset of dementia or misdiagnosed due to the lack of culturally and linguistically appropriate screening tools and skilled clinicians.
- Some cognitive screening tools such as the Mini Mental State Examination (MMSE) have been translated into a range of languages and are successfully used in some instances, however many of these instruments can be biased due to education and cultural background. The Rowland Universal Dementia Assessment Scale (RUDAS) cognitive screening tool has been developed to take into account the education level, cultural background and language; however this is only one instrument. Additional research and resources need to be directed into this area to ensure that other diagnostic tools are developed which consider the needs of CALD communities.
- The use of bilingual, bicultural clinicians in undertaking a dementia assessment of CALD people
- Additional training of interpreters in the requirements of supporting a dementia assessment.
- Up skilling of clinicians in the needs of CALD clients is imperative. Clinicians must always consider the linguistic and cultural validity of any psychometric tests used for assessments and the cultural appropriateness of therapeutic approaches to be used in the first/best language³.
- Where feasible, CALD specialist diagnostic centres should be established to assist in the early diagnosis of dementia and to formulate dementia care management plans in collaboration with appropriate ethnic community groups.

- Communication problems caused by many people from CALD backgrounds having low literacy levels in English language and also in their own language.

Strategies to assist in communication

- Ensuring culturally and linguistically appropriate programs are established to support people with dementia from a CALD background.
 - Ensuring that mainstream services are meeting the needs of all Australians in their program delivery either in their own right or in partnership with ethnic communities.
- Lack of knowledge or acceptance of the service system by members of CALD communities who are often unfamiliar with dementia services and aged care services in general and how to access them. This is often due to language barriers or lack of culturally appropriate services or even strong preconceived ideas of the types of services that are available.

Strategies to assist in raising awareness of service availability

- Agencies need to ensure that information on their services reaches all Australians; dissemination should not only be via translated information but through direct contact with communities.
- Where possible specific Access and Equity workers should be employed to assist in improving agency accessibility.

All Australians regardless of race, cultural and linguistic background, location and ethnicity have an equal right to access affordable, quality dementia assessment and care services. These can only be made available for them if resources are better developed to meet their needs and are more widely known throughout the communities.

Pino Migliorino

Chairperson

National Cross Cultural Dementia Network

References

All references can be accessed on the Alzheimer's Australia website:

<http://www.fightdementia.org.au/>

1. Access Economics, *Dementia prevalence and incidence among Australians who do not speak English at home*, 2006.
2. Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008
3. South Australian Psychological Board, **Guidelines For Psychologists The Provision Of Psychological Services To Persons Whose First Or Best Language Is Other Than English**