

Submission No. 017

(Dementia)

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**House of Representatives Committees
House Standing Committee on Health and Ageing
Inquiry into Dementia: Early diagnosis and Intervention**

Submission by DutchCare Ltd (Vic)

DutchCare is making this submission in the context of the Aged Care Reforms (ACRs) which were announced on 20 April 2012 and the National Health and Hospital Reforms (NHHRs) which are gradually being rolled out. Its focus of interest is on people from a non-English speaking background (NESBs).

DutchCare contends that in the development of programs designed to encourage the early diagnosis of dementia and subsequent treatment, NESBs must be regarded as core business with human and financial resources allocated accordingly. This is in contrast to their current status as ‘add-ons’ in dementia initiatives and aged care services generally.

Assumptions

For the purposes of this submission, it is assumed that:

- Australia’s Multicultural Policy will be reinforced so that government funded services are responsive to cultural and linguistic diversity;
- DoHA will continue to have carriage for the policy development and funding of programs for dementia ranging from research to support for carers, and
- Alzheimer’s Australia will continue to be “committed to ensuring that the needs of people from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander communities are met in all aspects of service provision, information, support and education.”

Demographics

Far from being incidental consumers, ageing NESBs comprise a significant proportion of the population aged 65+.

In Victoria, for example, an average of 40% of the population aged 65+ in the 4 metropolitan planning regions is from a non-English speaking background. Close to 90% of the ethnic aged live in these areas. There are also high concentrations in several regional centres.

These figures are from the 2006 Census. When released, statistics from the 2011 Census are expected to add to these percentages.

Information

One of the planks of the NHHRs was that access to evidence-based, consumer friendly information would be made available to support people make better health choices and considered decisions about their use of health services. The intention was to encourage people to lead healthy lifestyles and seek early intervention in health concerns such as memory loss and behavioural changes.

Translating this initiative to the ACRs, the proposed Gateway will provide a centralised information and referral service. If it is to be of any use to NESBs, it will need to be advertised in the ethnic media such as newspapers and radio so that its existence is known and acted upon.

Information on disease prevention, health, aged care and support services needs to be developed in first languages and be posted on the proposed My Care website where it can be accessed by interpreters and staff working in the primary, allied health, acute and aged care sectors. Ideally, the national call centre would be manned by bilingual staff or have a subsidiary unit which specialises in the provision of information in languages other than English.

Translated material on dementia already held by Alzheimer's Australia will need to be transferred to the My Care website.

For NESBs, doctors may be the first practitioners to detect dementia even if the condition was not the reason for a consultation. They, too, need access to information on how a particular ethnic group views dementia so that a sensitive approach to early diagnosis can be made. This implies that research findings on attitudes to dementia and dementia care will also be posted on the My Care website.

Doctors also need to be aware of dementia assessment instruments such as RUDAS which are culturally unbiased. They need to guard against the danger of mistaking poor English language skills with dementia or confusion.

Extending the involvement of general practitioners in the early diagnosis of dementia, it is expected that Medicare Locals established under the NHHRs will identify, and act on, gaps in dementia diagnosis and dementia support in their geographical areas of interest.

Measuring NESBs' access to dementia services

Under the ACRs, the Government will increase the availability, accessibility and coordination of aged care data for the community by establishing a centralised data clearinghouse at the Australian Institute of Health and Welfare." This is intended to address the "lack of evidence in aged care".

The Government could start by ascertaining the degree to which NESBs are accessing aged care and **support services** compared to their non-NESB counterparts. From there, it would be possible to set uptake targets for NESBs as a whole, or specific ethnic groups, in each of the Department of Health and Ageing's (DoHA) planning regions. Access should be measured annually to ensure NESBs get their fair share of the services.

Despite Alzheimer's Australia being committed to ensuring that the needs of people from culturally and linguistically diverse backgrounds are met in all aspects of service provision, information, support and education, its State branches cannot provide statistics on how deeply they are penetrating NESB communities. Unlike packaged care and residential care providers, they do not submit data on NESBs' use of their

services to DoHA. Rather, they report to DoHA against increased numerical targets of Helpline users. This in itself is a disincentive to conduct outreach services to a more complex and time-consuming target group.

It is time to redress this situation by making the submission of data on the use of Alzheimer's Australia's services by NESBs and their carers a condition of funding.

NESB consumer advocacy and consultation

Once NESBs' uptake of aged care and support services is known, reasons for over or under use can be investigated.

To this end, consultative mechanisms involving NESB elders and, separately, ethno-specific and multicultural service providers, should be instituted so that culturally and linguistically appropriate alternatives to, say, dementia respite, counselling, and training programs can be developed.

Supporting carers

To help maintain people with dementia in the community, their carers will need all the help they can get in respect of information, training and socialisation. This includes NESBs.

Prior to the establishment of the Aged Care Service Improvement and Healthy Ageing Grants Fund by DoHA in 2011, ethnic providers applied for, and competed with, other agencies including Alzheimer's Australia itself for grants under DoHA's Dementia Community Support Grants which aimed to provide support and raise awareness for people with dementia and their families. (This is despite Alzheimer's Australia having similar aims and objectives which imply universal cover.)

Additionally, ethnic agencies obtained funding under DoHA's Community Partners Program (CPP) (also subsumed under the Healthy Ageing Grants Fund) for dementia training and support and then used that funding to engage Alzheimer's Australia to assist in the development and provision of a program.

For NESB communities, funding initiatives like this have ended up being fragmented and extremely limited because of short term funding, the absence of strategic targeting and the lack of follow-up support services. Sadly, these have been the only opportunities to assist NESB carers and those they care for. Worse, they have only captured the carers of successful agencies who have the resources and skill to write applications.

It is true that the State branches of Alzheimer's Australia have made the occasional foray into ethnic communities but their efforts thus far have been miniscule in the face of the size of the NESB target group.

The ACRs' *Living Longer. Living Better* document suggests there will be no change to this arrangement. Under the section dealing with culturally and linguistically diverse communities (p 25), agencies are pointed in the direction of Aged Care Service Improvement and Healthy Ageing Grants Fund as the means of developing

culturally and linguistically diverse (CALD) appropriate services. This continues to be “do-it-yourself” territory.

Support for carers also comes from respite provided through Carers’ Australia and their State offices. Again, NESBs are in exactly the same place as they are with Alzheimer’s Australia. Carers’ Australia also reports to DoHA on the number of its Helpline contacts. It, too, cannot provide statistics on how deeply it is penetrating CALD communities. Like Alzheimer’s Australia, it has developed some CALD appropriate services but nowhere near the number required for the size of the population.

Research

For some CALD communities, dementia is a taboo which is an impediment to early diagnosis. In others, there is no word in first languages which directly translates into ‘dementia’. This makes early diagnosis tricky. Research has already demonstrated this,

Under the ACRs, the clearing house recommended for research purposes might also be used to update literature searches on research conducted on CALD communities’ attitudes on dementia, dementia care, financial/legal planning and generational change with a view to developing information packages which make diagnosis of dementia and assistance with care more acceptable. Again, consumer consultation would accelerate this process.

Conclusion

Any discussion on the early diagnosis of dementia and intervention in respect of NESBs is academic until such time as NESBs are considered part of the target population and automatically included in policy and practice considerations. Until this occurs, they will continue to be treated as add-ons. Initiatives for this group will be piecemeal, uncoordinated and short-lived as they have been over the past 20 years.

The Aged Care Reforms offer an opportunity to rectify this situation.

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