Alzheimer’s Australia Dementia Awareness Week
16-22 September 2013

Alzheimer’s Australia ACT CALD celebration and information sharing day

Wednesday 18 September 2013

Theo Notaras Multicultural Centre
North Building, 118 London Circuit, Canberra

Dementia Awareness from a CALD Perspective

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Introduction

I would like to acknowledge that we are meeting on the land of the Ngunnawal and Ngambri peoples. I pay my respects to their elders past and present. Just as, for a century, this city has been a place where Australia’s political and community leaders have come to meet, so it has been a meeting place for many Aboriginal nations for thousands of years.

Thank you for your invitation to open today the Dementia Awareness Week CALD event.

For those who may not be familiar with the Federation of Ethnic Communities’ Councils of Australia (FECCA), we are the peak national body representing Australians from culturally and linguistically diverse (CALD) backgrounds. We promote multiculturalism as a core value that defines what it means to be Australian in the 21st century.

FECCA is a not-for-profit, independent, community-based organisation. Its role is to advocate and promote issues on behalf of its constituency to government, business and the broader community. We work to ensure that the needs and aspirations of CALD Australians are given proper recognition in public policy. We work to promote fairness and responsiveness to our constituency in the delivery and design of Government policies and programs.

The Australian community today is made up of people from more than 200 countries. Among us, Australians identify around 300 ancestries. More than 300 languages are spoken in Australian homes.1 As one of the most diverse and culturally rich nations in the world, multiculturalism is embraced as a core value that defines what it means to be Australian in the 21st century. I am pleased therefore for this opportunity as part of Dementia Awareness Week to talk about some crucial issues that affect health outcomes for people from CALD communities.

Alzheimer’s Australia and FECCA working together

I also would like to mention Alzheimer’s Australia’s alignment with FECCA and commend Alzheimer’s Australia’s inclusive approach to people from CALD backgrounds, including meeting the linguistic needs of many members of the community.2

Alzheimer’s Australia provides dementia-related information in many languages other than English. There are translations in Arabic, Armenian, Assyrian, Chinese, Croatian, Dutch, Finnish, German, Greek, Hindi, Hungarian, Indonesian, Italian, Japanese, Khmer, Korean, Laotian, Latvian, Macedonian, Malay, Maltese, Polish, Portuguese, Romanian, Russian, Serbian, Spanish, Tagalog, Tamil, Turkish, Ukrainian and Vietnamese.

It is commendable that Alzheimer’s Australia’s National Dementia Helpline offers access to the Translating and Interpreting Services (TIS), a real time translation service run by the Department of Immigration and Citizenship.

Last year, Alzheimer’s Australia conducted workshops for healthcare workers and students to

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2 http://www.fightdementia.or.au/understanding-dementia/cultural-diversity.aspx
raise awareness of dementia in CALD communities.

FECCA Chair Pino Migliorino also chairs the National Cross Cultural Dementia Network. This is a knowledge network that provides information provision, resource development and service delivery to culturally and linguistically diverse communities. The Network feeds advocacy and advice to Alzheimer’s Australia, government and non-government organisations across a broad range of issues that relate to people from CALD backgrounds.

AA has now formally invited FECCA to formally join the National Cross Cultural Dementia Network. I will be attending the next meeting in Melbourne.

Alzheimer’s Australia has invited FECCA to participate in the Start2talk project on planning ahead for dementia and other health related conditions.

Yesterday, I attended as part of Alzheimer’s Australia ACT’s Dementia Awareness Week a wonderful presentation by Dr Kristine Yaffe about maximising cognitive health.

As an informative and useful resource, FECCA has drawn on Alzheimer’s Victoria Project Perceptions of dementia in ethnic communities.

**Dementia Awareness Week from a CALD Perspective**

The theme for Dementia Awareness Week 2013 is *Brain Health: Making the Connections.* Key messages are:

- Keeping your brain active matters: Keeping your brain challenged and being socially active
- Being fit and healthy matters: Eating healthily and participating in regular physical activity are important for a healthy body and a healthy brain
- Looking after your heart matters: What’s good for the heart is good for the brain by avoiding smoking, managing your blood pressure, cholesterol, blood sugar and body weight.

So what do these important messages mean for people from CALD backgrounds and how can they effectively be conveyed and reinforced when it is estimated that 12.4% of Australians with dementia do not speak English at home?

Where low grasp of the health system, low language proficiency in a second language or the inability to communicate even in their first language combines with illnesses like dementia and behavioural and psychological symptoms of dementia (BPSD), people from CALD backgrounds are put at great risk and disadvantage compared to other Australians and as their illness progresses, it may be assumed that they will become further marginalised and...

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3 Access Economics (2006), *Dementia prevalence and incidence among Australians who do not speak English at home*, Alzheimer’s Australia, Canberra. piii

4FECCA draft submission to the Senate Community Affairs Committee Inquiry into Care and Management of Younger and Older Australians Living with Dementia and Behavioural and Psychological Symptoms of Dementia (BPSD) September 2013. The point to be made is, as Runci states “when the resident and staff member do not speak a common language … it is possible that the distress of non-English speaking residents cannot be effectively...
Their incapacity becomes yet another barrier to receiving support and appropriate health care services that is after all, the right of all Australians.

It is important to remember that everyone is an individual and just because you may come from a particular ethnic group does not necessarily mean you will hold the same views or opinions about illnesses like dementia, or have the same amount of knowledge about the condition.

That said, in some CALD communities, the messages about dementia may not be heeded because of preconceptions about the illness and displayed behaviours associated with dementia. The existing research on people from CALD backgrounds in Australia tells us that it is “poorly understood, identified late and may be poorly supported in many CALD communities.”

Contrary to stereotypical assumptions that family members will assume the role of the carer, this is not always the case. For example, an older person from a CALD background may find that the expectation to be cared for at home and by family may not eventuate into actual support.

Weakened family ties, ‘acculturation’ of the next generation, the children of immigrants who see themselves as ‘Australian’ in all senses, move away. Their interests, commitments and responsibilities now lie outside the nuclear family.

**Perceptions of illness**

*Poor knowledge cannot be confidently attributed to culture or race*.

People from CALD backgrounds, first generation or newly settled immigrants are no different from other Australians when it comes to stigma or fear that is associated with dementia. We cannot assume that everyone is health literate nor can the possession of knowledge displace long held or traditional beliefs or deep-seated superstition.

Feng shui, imbalance of yin and yang, retribution for individual or family sins, possession of evil spirits, for example, can all be attributed to traditional beliefs that may fuel denial and prevent a person from seeking medical attention even if they become aware of symptoms of dementia.

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7 Ibid p5.

As well, as found by the 2009 Access Economics report for Alzehiemer’s Australia Making Choices, among some CALD people with dementia, “there may be cultural sensitivities regarding institutionalisation with consequent over-representation of CALD groups in formal community care programs.”

It is interesting to note that the research cites over-representation of CALD people with dementia in formal community care programs, although CALD people tend to access services later. On the other hand, there is “under-utilisation of all types of mainstream non-government services by people from CALD groups in Australia.”

What assumptions can be drawn from this?

According to Cheng et al in Report on Strategic Directions in CALD Research in Australia, differing perceptions, lack of knowledge, lack of understanding about dementia that is only diagnosed at the point of crisis, linguistic and social isolation and even the word ‘dementia’ itself are contributory assumptions as to whether someone will access help.

Language

Research results indicate that persons with dementia and minimal English language proficiency may derive special benefit from language-specific services.

I have referred to the importance of Alzheimer’s Australia tremendous service to CALD Australians by offering translated resources and links to the Translating and Interpreting Service. Studies undertaken indicate the importance of providing language relevant resources. Navigating the health system, let alone understanding medical jargon can be difficult if not confronting for anyone.

It is not enough to be literate and have English as a first language. Imagine what many first generation immigrants, newly settled or minority groups (who may also be illiterate even in their first language) have to face.

The ability to recognise or understand symptoms of dementia or BPSD then falls to others. If the person is not a family member or carer, there may be the issue of stigma or feelings of

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12 Susannah J Runci and Daniel W O’Connor, Department of Psychological Medicine, Monash University, Melbourne, Victoria, Australia. Jennifer R Redman, Department of Psychology, Monash University, Melbourne, Victoria, Australia. Language use of older Italian-background persons with dementia in mainstream and ethno-specific residential care. P706.
distrust in going outside the home to speak to a stranger about the illness. The barriers to appropriate health care then become compounded.

Language and communication are important factors in service delivery. For older persons with lower levels of English proficiency and dementia, interaction between staff in a mainstream facility as opposed to one that is ethno-specific\(^\text{13}\), will depend on adequate staff training that is culturally sensitive and linguistically matched to the person who is being cared for.

Inability to communicate may lead to confusion, distress for the resident and misinterpretation of their needs by staff and perhaps over prescription of medication as a recourse. Is sufficient specialist training in the workforce available for younger or older CALD people with dementia and BPSD?

**Models of care**

*Beyond the rhetoric: what do we mean by a ‘model of care’?\(^\text{14}\)*

Conceptual and theoretical perspectives, a person-centred approach, carer participation, easily navigable access to community-based, mainstream and ethno-specific services with referral to real person contact for people from CALD backgrounds, clear aims around services and structures and specialist services, all inform pragmatic models of care delivery.\(^\text{15}\)

As well, and to meet the increasing demand and expectations of younger and older people living with dementia and BPSD including CALD persons, strategies to enhance models of care should include planning ratios for adaptive environments.

FECCA found useful the following reports that address the special needs of culturally appropriate care and management for people with dementia.


- **Dementia Model of Care.** Department of Health, Western Australia. 11 July 2011
  
  *Quality Dementia Care Standards: A Guide to Practice for Managers in Residential Aged Care Facilities. February 2007*\(^\text{16}\)

FECCA believes that innovative models of care founded on ethical philosophy that integrate concepts and beliefs with intent, social stimulation and social interaction with other CALD people, including CALD dementia sufferers, should be championed. There are a number of service provider models which resonate with people from CALD backgrounds.

\(^{13}\) Ibid p705  
\(^{16}\) Alzheimer’s Australia (Accessed September 2013 at www.fightdementia.org.au)
NCAN (the National CALD Ageing Network) (slide 2)

FECCA has established NCAN as a web-based communication network for people and organisations in, and involved in, the CALD ageing sector through the FECCA website. The NCAN website can be accessed via the icon on the FECCA homepage (www.fecca.org.au) or directly at http://www.fecca.org.au/about-ncan. Communication is primarily via email but more and more information will continue to be made available on the NCAN website.

We are encouraging anyone and everyone, and all organisations, with an interest in CALD ageing and aged care, to join NCAN on line.

Creating a research evidence base (slides 3 and 4)

A FECCA project in collaboration with the Australian Population and Migration Research Centre at the University of Adelaide will undertake a systematic review of the existing research of older CALD people and create an accessible database of past and current research into older CALD people to provide and promote the translation of research into CALD aged care practices.

The outcomes of the review will also be a first step to identifying research needs and priorities in CALD ageing and aged care and preparing a means for pursuing a CALD ageing and aged care research agenda.

It will provide a basis for future CALD program development towards the goal of ensuring that Australians from CALD backgrounds have equal access to high quality, culturally appropriate aged care that is founded on a strong evidence base.

Most importantly, we are looking for your help in identifying any research, reports and/or references that may be relevant to this review. In particular we would like information or references you have to research or literature on:

- older people from CALD backgrounds in general;
- older people from CALD backgrounds with dementia;
- CALD carers and carers of CALD aged; and
- older people from CALD backgrounds with mental health conditions.

We would also welcome suggestions and comments on where you think there may be significant gaps in available literature and research relating to these topics.

All collated relevant information will become part of an accessible, searchable database that can be used to inform better practice and policy in the delivery of services to older people from CALD backgrounds.

If you have any relevant information, reports, and/or references, or would like to make a comment about the gaps in current research, please contact the project officer assisting FECCA on this project before the end of October 2013:
Dementia care at home

It is very important that the Government has improved the Extended Aged Care and Home Dementia (EACHD) packages. The additional supplements of the Dementia and Cognition Supplement in Home Care Packages and the Dementia and Severe Behaviours Supplement in Residential Care have been implemented in Home Care Packages and residential aged care since 1 August 2013. This can be very important for CALD dementia sufferers and their carers.

CALD Aged Care Strategy

In 2012, FECCA made a significant contribution to the Government’s National Ageing and Aged Care Strategy for People for Culturally and Linguistically Diverse (CALD) Backgrounds17 (the CALD Aged Care Strategy).

The Strategy will greatly assist inclusion, empowerment, access and equity, quality, and capacity building among CALD people and community organisations by ensuring that all future aged care policy is culturally, linguistically and spiritually inclusive.

Conclusion

In conclusion, FECCA suggests that there are challenges ahead in meeting the needs of both younger and older people from CALD backgrounds with dementia or BPSD.

Innovative tools need to be created towards a person-centred approach.

Caring for people from CALD backgrounds must be culturally sensitive, as with the assessment tools, resources for educative kits and resource material using different communication means and in languages. These will empower people from CALD backgrounds to learn about symptoms of dementia and BPSD, and breakdown the barriers of fear, superstition and stigma.

There also needs to be increased numbers of bilingual and bicultural dementia-trained staff in the workforce to work with persons from CALD backgrounds with dementia and BPSD.

There needs to be increased community engagement through concerted and collaborative partnerships between ethnic community groups to:

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• share information that might dispel negativity, fearful perceptions and myths about dementia and BPSD

• locate where help, counselling or services are located.

We need increased funding for qualitative research in relation to services specific to people from CALD backgrounds with dementia and BPSD. As well, there is a need for qualitative Australian research on education to improve awareness in CALD families where someone has dementia or BPSD.

FECCA congratulates Alzheimer’s Australia for the long list of events organised during Dementia Awareness Week from Singing from the Heart that is a yearlong project, morning teas, education and training workshops, to seminars. FECCA looks forward to continued collaboration with Alzheimer’s Australia and assisting you, including through the National CALD Ageing Network, to enhance awareness of dementia in CALD people.

Thank you for this opportunity to launch this Alzheimer’s Australia ACT CALD celebration and information sharing day as part of Dementia Awareness Week 2013, to talk with you and meet with you today.