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**ECCV Submission to the
Inquiry into Dementia: Early Diagnosis and
Intervention
to the
House of Representatives Standing
Committee
on Health and Ageing
May 2012**

On behalf of Ethnic Communities' Council of Victoria (ECCV) I am pleased to present this submission and the attached ECCV Discussion Paper *Meant to Care* to the Australian Department of Health and Ageing.

ECCV is a peak advocacy body that lobbies all levels of government on behalf of multicultural communities within Victoria and welcomes the opportunity to contribute to the Inquiry into Dementia.

For over 30 years ECCV has remained the principal liaison point between ethnic communities, government and the wider community and has been a key player in building Victoria as a successful, harmonious and multicultural society.

Our ageing and multicultural society requires the careful implementation of culturally responsive strategies to enable people from a non-English speaking background to stay living at home longer and with the quality of life they deserve. I commend this submission for your serious consideration,
Sincerely

Joe Caputo OAM, JP
Chairperson

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Summary

1. Victoria has an ageing multicultural population. The incidence of dementia is increasing amongst people from culturally and linguistically diverse backgrounds.

2. ECCV feedback indicates that people from culturally diverse backgrounds living with dementia are at risk of missing out on quality dementia care.

3. ECCV consulted widely with Victoria's ethnic and multicultural aged care service providers on dementia related issues and produced the report *Meant to Care about Culturally Relevant Dementia Care 2011* (attached). The experience in the sector indicates that people from non-English speaking backgrounds who are challenged by dementia tend to access services later when they reach a crisis. The focus of the recommendations in the report was on:

- Empowering the ethnic and multicultural sector to engage in awareness raising on dementia issues
- Informing culturally diverse people about accessing dementia related support services
- Resourcing multilingual dementia related initiatives

ECCV commends the recommendations in the attached report to the Inquiry Committee.

4. Additional ECCV ethnic community stakeholder consultations in 2012 indicated that further issues to be addressed are:

- Culturally responsive diagnosis of dementia amongst people from non-English speaking backgrounds and providing them with timely support for living at home longer
- Culturally responsive information for health providers
- More effective dementia support referral pathways, including assessment and reassessment of people from non-English speaking backgrounds

Summary of key recommendations

5. That dementia early diagnosis and intervention initiatives:

- a) Provide culturally responsive dementia awareness and education targeted at individuals and families from non-English speaking backgrounds.
- b) Build partnerships with Victoria's extensive network of ethnic and multicultural aged care agencies
- c) Utilise culturally responsive dementia diagnostic tools
- d) Resource multilingual and culturally responsive initiatives about planning for quality living in one's advanced years.

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- e) Strengthen existing dementia initiatives targeted at culturally diverse communities
- f) Improve referral and assessment pathways for aged care support for culturally diverse people challenged by dementia

ECCV response the inquiry terms of reference

Improve quality of life and assist people with dementia to remain independent for as long as possible

6. ECCV's anecdotal evidence suggests that fear of dementia is quite pronounced amongst older people from non-English speaking backgrounds. Some cultural beliefs perpetuate the notion that dementia is an unavoidable part of ageing or even a form of madness rather than a disease. Stigma is therefore a major barrier to people from culturally diverse backgrounds seeking early diagnosis for dementia.

7. ECCV feedback indicates that discussing dementia in ethnic families is often considered inappropriate. As a result they are less likely to access dementia services and early intervention support.

8. ECCV advocates for sustainable ground work to equip both aged care and dementia service providers and ethnic organisations to work more closely with together to enable people from culturally diverse backgrounds to better access dementia support.

9. ECCV community consultation indicates that there were some incidents where a diagnosis of a patient from a non-English speaking background did not clearly differentiate between Parkinson's disease and dementia with Lewy bodies, whilst culturally responsive diagnostic tools would lead to more accurate assessment and diagnosis.

Recommendations 1

1.1 That government funded agencies provide culturally responsive dementia awareness and education targeted at individuals and families from non-English speaking backgrounds.

1.2 That government funded service providers form partnerships with ethnic and multicultural agencies to work on community engagement initiatives for people from culturally diverse backgrounds.

1.3 That awareness raising about dementia for culturally diverse people focusses in particular on stigma reduction.

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1.4 That culturally responsive dementia diagnostic tools be utilised by assessment services and General Practitioners.

Increase opportunities for continued social engagement and community participation for people with dementia

10. ECCV community feedback indicates that older people from non-English speaking backgrounds challenged by dementia, and without support, withdraw from their social contacts. They are then at risk of increased social isolation.

11. ECCV notes that in Victoria about 50 ethno-specific HACC Planned Activity Groups (PAGs) provide effective social engagement opportunities for older people from non-English speaking backgrounds.

Recommendation 2

2.1 The HACC resources are refocused to provide more ethno-specific PAG groups.

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

12. ECCV notes that a change in circumstances for older carers from non-English speaking backgrounds can leave them unsupported where they fall through the cracks in the aged care system. The following case is a typical example: A frail older non-English speaking woman loses her partner who had dementia. Her packaged care respite support ceases. She needs a new Home and Community Care (HACC) assessment. Soon after, she requires a packaged aged care assessment as her own health deteriorates. Feeling overwhelmed by too many different workers, and not really understanding the service system, she eventually rejects all forms of support but cannot cope on her own. She reaches a state of crisis and requires hospitalisation.

13. ECCV notes that many older people from non-English speaking backgrounds are traditionally dependent on their families and lack an understanding of aged care, dementia and respite support services.

14. ECCV believes that older people from non-English speaking backgrounds would benefit from a consistent relationship with a single person who is an aged care case worker with culturally responsive skills. Such a case worker would provide a consistent link with support pathways between HACC programs, PAGs, CACPs (Community Aged Care Packages) and relevant dementia respite services.

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Recommendation 3

3.1 That a single aged care case worker is assigned to people from non-English speaking backgrounds with changing circumstances to provide reassurance and continuity.

3.2 That government funded agencies retain face-to-face aged care assessments to maximise personal engagement with people from non-English speaking backgrounds.

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

15. ECCV believes it is vital to identify dementia early and to provide the right referrals and access to support services such as HACC programs and PAGs.

16. Individuals and families from new and emerging communities challenged by dementia find themselves in a system where many services are completely unfamiliar to them. Dementia support services therefore need to be presented in an easily identifiable way.

17. Planning for future ageing issues is a new concept for many people from culturally diverse backgrounds who are accustomed to relying on family support. How to plan when people lack capacity needs to be presented in a culturally sensitive way as well in community languages. ECCV believes if such concepts are culturally sensitive then non-English speaking people will be more open to them, for example talking about a will could be perceived as bad luck.

Recommendation 4

4.1 That more creative approaches are explored, in collaboration with ethnic agencies, on how to educate older people from non-English speaking backgrounds about the health, financial and aged care planning for the future.

Attachment: ECCV Discussion Paper *Meant to Care about Culturally Relevant Dementia Care 2011*

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