

# Perceptions of dementia in ethnic communities



Alzheimer's  
Australia Vic  
Living with dementia

## Project Report



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# Perceptions of Dementia in Ethnic Communities

## Executive summary

Alzheimer's Australia Vic was funded by Allens Arthur Robinson to conduct consultations with 12 culturally and linguistically diverse (CALD) communities to develop a resource kit detailing dementia perceptions in these communities. In addition to the kit, this report provides an overview of some of the key issues that were raised across these communities. This report covers a range of issues which were common across all communities as well as some additional issues that were raised but not included in the resource kit. The information has been compiled following consultation with ethnic and generalist community organisations and community members. Where available, other research has been used to support or reflect different opinions gathered through the community consultations. The report outlines project background, methodology, findings and discussion and conclusion. Tables of relevant information and data are provided at the end of the report.

Available research and anecdotal evidence suggest that there is much diversity in perceptions of dementia across different CALD communities. In some communities dementia is related to mental illness or a form of 'craziness' while in others it may be meaningless or regarded as a normal part of ageing. The word 'dementia' may be difficult to understand in some communities as there is no word to describe dementia in their language. As CALD populations are ageing rapidly, and in turn may be increasingly affected by dementia, it is important to understand how these communities view dementia and how much they know about the illness so that appropriate services can be offered. Differing perceptions of dementia may also help identify why certain cultures are not accessing current services.

While different issues affect different individuals and different communities in regards to dementia, there are some common issues that were identified by members and workers of CALD communities who participated in this project. These 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.
- 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.
- Communication problems caused by many people from CALD backgrounds having low literacy levels in English language and also in their own language. With the onset of dementia they may lose what skills they have in English and revert to their native language.
- 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 type of services that are available.
- The misconception that most people from CALD communities are cared for by family members. This is not always the case.

These issues are discussed in more detail in the report.

## CALD ageing population

People from culturally and linguistically diverse (CALD) backgrounds constitute a significant proportion of the older Australian population and they are ageing rapidly. In 2005, 16% of people over the age of 60 spoke a language other than English at home and approximately 33% were born overseas. Victoria has the highest proportion of CALD communities (see Tables 1 and 2). In Victoria, 26% of seniors are born in a non-English speaking country and this number is projected to increase to 31% by 2011. The needs of these communities need to be taken into consideration when planning and delivering services to elderly Australians.

**Table 1: Victoria:  
Language other than English spoken at home, 2006 Census**

Rank 2006	Language other than English (LOTE)	Persons	As % of Total LOTE
1	Italian	133,327	13.2
2	Greek	117,874	11.7
3	Vietnamese	72,161	7.2
4	Cantonese	66,853	6.6
5	Mandarin	64,374	6.4
6	Arabic	55,931	5.6
7	Macedonian	30,771	3.1
8	Turkish	29,748	3.0
9	Spanish	24,501	2.4
10	Croatian	22,961	2.3
11	German	19,608	1.9
12	Maltese	19,020	1.9
13	Hindi	18,181	1.8
14	Polish	17,787	1.8
15	Sinhalese	16,920	1.7
16	Serbian	16,865	1.7
17	Russian	14,339	1.4
18	French	11,864	1.2
19	Tagalog	11,284	1.1
20	Tamil	11,096	1.1

**Table 2: Victoria:  
Language other than English Speakers with Low English Proficiency by Age, 2006 Census**

Rank 2006	Language other than English (LOTE)	Persons
1	Vietnamese	25,518
2	Italian	22,640
3	Greek	22,606
4	Cantonese	16,606
5	Mandarin	14,066
6	Arabic	9,442
7	Turkish	6,551
8	Macedonian	5,791
9	Croatian	3,853
10	Language not stated	3,628
11	Khmer	3,604
12	Non verbal, so described	3,568
13	Serbian	3,478
14	Spanish	3,447
15	Russian	3,203
16	Other language	2,484
17	Polish	2,341
18	Assyrian	1,972
19	Korean	1,935
20	Maltese	1,823

## **Prevalence of dementia**

People from CALD backgrounds make up a significant part of the older Australian population and will be increasingly represented as our multicultural population ages rapidly. According to the Australian Institute of Health and Welfare (AIHW 2001), 30.8% of Victoria's older population will be from CALD backgrounds by 2011.

Alzheimer's Australia commissioned Access Economics to estimate the prevalence and incidence of dementia for people from CALD backgrounds in Australia. Prevalence of dementia refers to the number of people with dementia in a population at a given point and incidence refers to the number of new cases of dementia arising over a particular period.

According to the 'Dementia prevalence and incidence among Australians who do not speak English at home' report (Access Economics 2006), around 1 in 8 Australians with dementia do not speak English at home. In Victoria, the proportions are even higher with 1 in 6 Victorians with dementia not speaking English at home. The study assumes that prevalence and incidence rates for the CALD communities are comparable to those for the Australian population as a whole.

## **Project background**

Alzheimer's Australia Vic was funded by Allens Arthur Robinson to consult culturally and linguistically diverse (CALD) communities on their perceptions of dementia in order to develop a resource kit. The resource kit, which would also include dementia information, is intended to assist those working with people from CALD backgrounds who have dementia. The project was initiated by Alzheimer's Australia Vic in response to the lack of research on the subject and anecdotal evidence which suggested that understanding of dementia varies significantly across different ethnic communities.

The project included consultations with members of twelve CALD communities and ethno-specific and generalist bilingual workers. A small number of questionnaires were distributed to ethno-specific organisations where consultations were not possible. There were a total of 35 consultations conducted across twelve ethnic communities. These consultations provided a greater understanding of CALD communities, their knowledge about dementia and their perceptions of dementia. Consultations were conducted with interpreters where required.

As well as providing an insight into the perceptions of dementia within ethnic communities, the project raised a number of key issues which are the subject of this report. It is important to note that these findings are based on the opinions of the individuals or groups consulted and should not be generalised to whole communities.

## **Project aims and objectives**

The aim of the project was to investigate the level of understanding of dementia within different ethnic communities and provide a summary for each community of their perceptions and understanding of dementia.

Project aims were:

- To increase awareness and understanding of dementia perceptions in CALD communities.
- To provide service providers with resources to assist in understanding the support needs of people with dementia from CALD communities.
- To disseminate information about dementia within different CALD communities.
- Identify possible barriers to effective communication with people with dementia from CALD backgrounds.
- To identify common issues in respect to dementia that may arise within different communities and raise awareness of these issues among service providers.
- To encourage sensitivity regarding people's cultural differences.

## **Project methodology**

The project “Perceptions of dementia in ethnic communities” funded by Allens Arthur Robinson was intended to provide some basic information about dementia perceptions in twelve CALD communities. The target communities were chosen for their relative size, the size of the 65+ age group and those that are projected to age in the near future. All target communities fall in the top twenty languages spoken at home according to 2006 Census. These groups also have the highest proportion of people with low English language proficiency.

## **Focus groups**

Focus group sessions were held with twelve CALD communities: Arabic, Croatian, Chinese, Greek, Italian, Macedonian, Polish, Russian, Spanish, Serbian, Turkish and Vietnamese. For most community groups there was at least one session conducted with community members and one session conducted with ethno-specific or bilingual generalist workers. Some communities had more consultations depending on the number of willing participants and the responses that were given during focus group sessions. The number of participants in each session varied between 5 and 55. The assistance of an interpreter was utilised for consultations with the community members. In total, 35 focus group sessions were held with a total number of 383 participants across twelve communities (see Attachment 1). Consultations were held across metropolitan regions of Victoria between January and June 2008.

The main aim of these focus groups was to:

- Gauge people’s understanding of dementia
- Determine the perceptions of dementia among the target groups
- Explore people’s perceptions regarding different dementia services and care options as well as the role of family members

## **Questionnaires**

Due to time restraints and the availability of workers, questionnaires were sent to the Greek, Russian and Vietnamese ethno-specific agencies. Ethno-specific workers were invited to send in their individual questionnaires but most agencies decided to collate information through one worker and then forward information collected from their work colleagues. There were a total of seven questionnaires received from community workers. A sample of the questionnaire is included in Attachment 2.

## **Limitations**

Before outlining the key issues, there are some specific limitations relating to the project that need mentioning. Firstly, it is important to note that the information in this report, as well as in the resource kit, is mainly based on consultations with the target CALD communities. Due to the scope of the project and time constraints, the number of consultations, and therefore number of people consulted, is limited. Even though many of the issues raised in the report are supported by research on the topic and other publications it is important that this information is not generalised across all members of CALD communities. More in-depth research should be conducted in order to gain further information on dementia perceptions in CALD communities.

Further issues concern the process of consultation with CALD communities. Most of the consultations were conducted with established ethno-specific organisations and contact with community members was also made through these organisations. Ethno-specific providers have limited staff and resources to provide ongoing assistance and therefore it was sometimes difficult to organise a time that suited everyone. Also, most of the community members that were consulted belonged to an established group and were therefore more likely to have better access to information.

The method of running consultations with ethnic groups also proved difficult. Due to the need for an interpreter, consultations took longer and this sometimes resulted in loss of interest. This in turn means that some questions may not be answered. Questionnaires that were sent to some ethno-specific organisations were not utilised with community members, as they were not translated and most community members that were consulted had limited English. Where questionnaires in English were used, they had a low return rate.

In terms of consultations it was also difficult to control the number of participants. Even though the average number was specified, sometimes more and sometimes fewer people turned up. Groups ranged from 5 participants to a largest of 55.

Finally, an important issue to note is regarding consent to be recorded. Most groups did not sign the consent form, which was provided in English, due to lack of understanding why they need to sign and also due to fear and mistrust, even though information was explained through an interpreter.



## **Understanding of dementia/perceptions of dementia:**

The main finding from the consultations with twelve CALD groups is that dementia understanding varies across different communities and perceptions of dementia depend on the level of understanding of dementia within a specific community. Although ethno-specific workers and generalist workers have promoted dementia awareness and available support services, there is still a need for further education and services.

Despite variations in the understanding of dementia across and within the twelve communities, there was a significant lack of overall understanding of dementia. Few people had a clear understanding of what dementia is, or its symptoms and causes. Most communities were familiar with the term 'dementia' but were unable to provide any information about what the illness actually is.

Dementia was usually described in terms of its symptoms, such as memory loss. At the same time memory loss was well accepted as a normal process of ageing. Among these communities, dementia is often considered a part of normal ageing and something that happens only to old people. There is therefore significant confusion about the difference between memory loss due to age and memory loss associated with dementia.

Other members of CALD communities considered dementia as mental illness or 'craziness'. This is again due to lack of understanding of the illness, but also stems from the apparent lack of physical symptoms as most symptoms are seen to be psychological. This link to mental illness resulted in stigma being attached to having dementia.

Very few people identified that dementia is an illness related to changes in the brain. There was very little knowledge about other symptoms of dementia or about what causes dementia. Commonly dementia was attributed to stress and family problems, depression and other physical illnesses such as diabetes, headaches and heart disease.

Consultations also revealed that there was also lack of understanding of the relationship between dementia and Alzheimer's disease. In some communities dementia is seen as the beginning of the illness and Alzheimer's disease as the final stage of the illness. In other communities, dementia and Alzheimer's disease were seen as two separate illnesses.

The terminology used for dementia contributes to the lack of understanding of dementia in some communities. For example, in Italian and Polish communities, dementia is still described and spoken of as senility or sclerosis. In the Arabic speaking communities 'kharaf', the word that is currently used for dementia, has very negative connotations and means that the person has lost their mind. This seems to further strengthen the negative perceptions in this community. A similar concern was also raised for the Serbian community where, even though there is a word for dementia, it is not always used and some people use 'izhlapeo', which translates as 'evaporated'. Some participants from the Turkish community have also suggested that the word 'bunama' used for dementia is not appropriate as it refers to "second childhood". It does not seem to have negative connotations but it does not describe the condition accurately.

Another important issue that communities identified was social isolation, which arises as a result of poor understanding of dementia and stigma associated with it. Many people are unwilling to discuss the illness openly in fear that they will be labelled as 'crazy'. As a result they tend to participate less in group activities or engage in social support groups. The community, including family members, may decrease contact with the person because they do not understand the illness but also because they do not know how to behave or what to do with the person who has dementia. This social isolation places additional stress on carers who spend most of their time caring for the person with dementia without any respite. Carers may also feel that they have to apologise to family

and friends for the person with dementia and justify why they need to utilise additional services. This is particularly difficult when the person with dementia looks physically 'normal'.

The lack of knowledge and understanding of dementia is illustrated by the number of questions asked by consultation participants, about what dementia is, what causes dementia, its symptoms, medications and prevention. The consultations addressed some of these issues by providing further information on dementia at the end of the consultation. In these instances this project also contributed to raising awareness of dementia in these communities.

The available research on dementia in CALD communities in Australia (e.g. LoGuidice et al. 2001, Smith et al. 2007) supports the results from our consultations, that dementia is poorly understood, identified late and may be poorly supported in many CALD communities. Research from the United States and the United Kingdom raises similar concerns. For example, a study of African-, Chinese- and Latino-American families found similarities in the reported lack of knowledge about early signs of Alzheimer's disease and attributed the early symptoms to normal ageing. Among African Americans, it was 'old timer's disease', whereas Latino's used the phrase *el loco* for craziness (also used by the Spanish community in Australia) and the Chinese used *hu tu* for becoming forgetful in old age. Similarly, studies of Asian elderly found that family members attribute dementia to normal process of ageing and something they would have to live with. Furthermore, the same study found that the American Chinese community saw dementia as a form of madness while Vietnamese community in the US perceives dementia as possession by the spirits (Mahoney et al. 2005).

### **Diagnosis**


In most communities the first point of contact for diagnosis is their family doctor. Anecdotal and published evidence suggests that people from CALD communities are diagnosed later after the onset of the illness compared to the rest of the population (LoGuidice et al. 2001). This is mainly due to lack of recognition of the early symptoms of dementia, particularly memory loss which is usually attributed to old age. Study of African-, Chinese- and Latino-American-carers' impressions of dementia and diagnosis also found that these communities attributed elderly relative's memory loss to normal ageing (Mahoney et al. 2005). Linked to this is also the tendency of some communities to ignore the early symptoms as there are no apparent physical symptoms.

It is common for members of CALD communities with low English proficiency to see a doctor who does not speak their language. This is due to either lack of availability of bilingual doctors or problems with accessing them. This may present a barrier when discussing the illness if an interpreter is not utilised. Due to the complex nature of the illness it may take longer to explain this process to a person who does not speak English. It is therefore important that the communities are informed about the availability of longer appointments and interpreter services.

Lack of culturally appropriate, validated diagnostic tests (e.g. Smith et al. 2007) may also impede the diagnosis of dementia in CALD communities in Australia, although validation of specific tests for minority groups is expanding overseas. As doctors are often the first, sometimes only, point of contact for people from CALD communities, they need to have access to appropriate information about the condition and the support services available, as well as the availability of translated resources.

### **Role of the family**

Despite popular belief that the elderly from CALD backgrounds are cared for by their extended families, in reality this is often not the case. There was overall consensus among



the individuals consulted that family members are still expected to care for the person with dementia. However, at the same time there is growing recognition that this is not always possible. Families themselves have increased responsibilities with work and children, while others admit to weaker family ties as a result of migration. Many believe that the blurring of the two cultures through migration experiences contributes to fewer people being cared for by family members and also to a lack of informal support networks. In other words, there was a strong belief that the younger generations have accepted 'the Australian way' and have no issue with putting their parents in residential care. Acculturation issues arose in other studies where participants expressed concerns that their children might forget their cultural traditions of caregiving (Mahoney et al. 2005).

In some communities there is a strong expectation that the family or the children will care for parents with dementia, however it was noted that, as the traditional values mix with newly acquired Australian values, the reality for many elderly is changing. Children have their own responsibilities and there is quite often a lot of stress and tension in the family when three generations live together. Overall, most of the CALD communities consulted agreed that they would care for the person with dementia for as long as possible and would consider other options if they were unable to cope. Most say that residential care would only be an option when dementia is well advanced and the person is unaware of anything. This is consistent with the overall findings of Australian Institute of Health and Welfare (AIHW 2006) that most people with mild dementia are living in households (96%) and most people with moderate or severe dementia are in cared accommodation (91%). According to AIHW (AIHW 2001), people from CALD backgrounds are also more likely to be living with children compared to those from English-speaking countries including Australia.

In some ethnic communities the elderly parents care for grandchildren while the parents work. In these cases, the expectation that the children will care for the parents is even greater. For example, members of the Turkish community stated that the parents provide their children with everything they need, they pay for their schooling and university, assist with weddings and house purchases and mind the grandchildren. In return they expect that their children will reciprocate by caring for them when they are frail and ill. Despite the expectations that family will take on the caring role, this role is overwhelmingly taken on by the spouse of the person with dementia.

### **Attitudes to residential care**

According to the opinion of participants in the consultations, residential care is still perceived negatively in CALD communities. There is a strong preference for people to stay in their own homes for as long as possible and residential care is only considered as the last option and usually at very late stages of the illness. This is also reflected in the report by Australian Institute of Health and Welfare which indicated that people from CALD backgrounds are still more likely to use home-based services than residential services. According to AIHW, despite the growth of people from CALD backgrounds from 7% to 15% in the last five years, a lower percentage are represented in Home and Community Care services, Community Aged Care Packages and Extended Aged Care at Home (EACH) and EACH Dementia services. It also indicates that those who are from a non-English background enter residential care at much higher dependency levels than English-speaking people born overseas and people born in Australia (AIHW, 2006).

Language and social isolation are some of the main reasons why people do not see residential care as an acceptable option. A recent study of CALD residents in mainstream facilities by Monash University found that people from CALD backgrounds were most commonly the sole resident with a particular language in the facility or had only one other resident speaking that language at their facility and this compromised their quality of life and care (Runci et al, 2005).

In our study, there was a widely held belief that those who are placed in residential care deteriorate more quickly. Sometimes residential care is seen as a place to go and die. The general consensus is that there is a preference for people to be cared for at home and there is strong resistance to residential care.

There were similar issues raised for respite services. If respite is accepted it is usually in-home respite or somewhere where both the carer and the person with dementia can attend. It may take some time for the carer to feel comfortable to send the person with dementia away for a respite break.

The stigma of placing a family member in residential care was also strong within CALD communities. It is considered shameful to place someone in residential care and there is a perception that you will be judged by the community if you do this. This leads to carers caring for the person with dementia well beyond their capabilities. Most spouses who care for someone either with dementia or another illness say that they would do so until they were physically incapable.

Some people felt that 'word of mouth' plays an important role in creating negative perceptions of residential care. People who have a family member in a nursing home or have visited someone in a nursing home have said that people have little stimulation and social interaction, especially if they do not speak English. This view spreads quickly when these issues are discussed within their communities.

Some ethno-specific organisations have attempted to break down the negative perceptions of residential care facilities by taking groups of community members for visits to residential care facilities in order to cultivate a better understanding of residential care. However, at the same time there are still reports about poor treatment of CALD clients in residential care. A recent report by Australian Polish Community Services (2008) on people from ethnic backgrounds in residential care indicated that ethno-specific service providers are still reporting incidents of poor care or insensitive treatment of their client groups in residential aged care facilities funded by the Australian Government.


### **Attitudes to counselling services**

According to the members of CALD communities consulted in this project, counselling services are often not acceptable as a form of support. There is a prevailing attitude that this type of service is for people who are mentally ill. In some communities there were no correct translations for the word 'counselling'. In other communities counselling was only acceptable for those who were diagnosed with depression or needed assistance with dealing with war trauma or family problems. In some CALD communities, counselling is often seen in terms of psychological or psychiatric counselling rather than as information provision and support service.

Counselling for dementia was not something that communities felt they would use. The reason most commonly cited for this was the fact that counselling was not offered in their preferred language. People felt that dementia was a sensitive issue and they felt uncomfortable speaking about it to 'strangers' especially through an interpreter. They emphasised the importance of building trust with the counsellor and also the importance of face to face contact. Most have indicated that any type of telephone service would not be highly utilised, especially if the service was provided through interpreters.

### **Language and communication**

Language was still considered one of the most significant issues for members of CALD communities. Most groups indicated that English literacy is quite low, which in turn prevents them having equitable access to services. There are low literacy levels in the elderly from CALD backgrounds even in their own language.



Literacy has significant implications for the way in which dementia information is provided and for dementia awareness models. According to the participants, information in the person's native language is preferred, but this information needs to be clear and simple. There were some disagreements about the format in which information is best presented, that is written or oral. Most people expressed concerns that, even if they spoke English well, the information about dementia would be too complex. It becomes even more complex when it is translated in another language as there is often no corresponding terminology in the other language. The same concerns were expressed by the ethno-specific workers. Currently available information is targeted at mid to high levels of literacy. The language used in translations is often that currently used in the country of origin, rather than the older forms of language which the CALD elderly speak and understand. Even though the elderly may technically speak the language, they may not understand the terminology used in translations currently. Finally, as many elderly from CALD backgrounds are illiterate in their own language, provision of written material was deemed inappropriate. When questioned about the use of interpreter services, most of those consulted indicated that they would find the process to access interpreters and then access dementia services too complex.

Two main suggestions were put forward by most communities to address this issue. The first was for mainstream service providers to start producing more non-written based materials and more specifically for a greater utilisation of the ethnic media. Most communities indicated that they listen to ethnic radio and watch ethnic television programs and that the information that is presented through these media tends to get further.

Information sessions were also suggested, but most communities indicated that they should be conducted in the first language of that community and that incentives such as food should be provided to maximise participation and attendance.

Another problem that people expressed is the difficulty of explaining dementia to young children and also feeling uncomfortable about children living with elderly grandparents with dementia. People felt that more education for children and younger people from CALD communities is required.

### **In Summary - Dementia and cultural diversity**

The primary aim of the 'Perceptions of dementia in ethnic communities' project was to collect information around dementia perceptions in twelve ethnic communities which would provide a basis for service providers when working with clients with dementia from CALD backgrounds. All this information was compiled in a resource kit. The secondary outcome was that some key issues were raised that were common to almost all communities consulted. Although information about dementia is readily available in a number of languages and disseminated among the CALD community and the service providers, there is still insufficient knowledge about the illness and acceptance of available services.

Information contained in this project is based on opinions of people who were consulted during this project. It is important to remember that each person is an individual and each individual within a specific ethnic group may not hold the same views or opinions about dementia or even have the same amount of knowledge about the condition. It is essential to consider the perceptions of ageing, memory changes and dementia and recognise the differences within and across cultures in order to engage CALD communities and provide culturally and linguistically appropriate services. The basic principles of the 'person-centred care' approach need to be taken when working with people with dementia from CALD backgrounds.

It is important to acknowledge that some of the views expressed in this document about the term 'dementia' and about perceptions held about dementia are not confined to people from culturally and linguistically diverse backgrounds. It is also to be noted that some issues identified by people from particular communities may also exist in other communities. Looking across the twelve community profiles, it is often the commonality of perceptions that is noteworthy and it demonstrates the need for information and support to all people, irrespective of our cultural or linguistic backgrounds.

The key themes around dementia perceptions and diagnosis raised in this report were also supported by other available research. While these themes indicate that there is an ongoing need for culturally and linguistically appropriate information and services to be available, they also suggest that further research needs to be done around these issues in order to ensure equitable access for CALD communities. When working with people with dementia from CALD backgrounds there are a number of things that service providers need to take into consideration. These include:

- Poor understanding of dementia
- Stigma associated with dementia
- Diversity within and across cultures
- Responsibility of care
- Reversion to primary language
- Knowledge of the service system
- Communication and cultural barriers
- Expectations and reliance on children
- Under utilisation of services
- Acceptance of heavy burdens/stress levels on the second generation

It is also particularly important to take into consideration the migration experiences of a particular community and also individuals within that community. The following aspects need to be considered:

- assimilation pressures
- loss of authority
- prejudice and discrimination
- role reversal parent/child
- communication problems
- cultural/linguistic/social isolation
- loss of support systems
- loss of physical environment



### **Tips and strategies for working with people with dementia from CALD backgrounds**

1. Consider each person as an individual – they are influenced by the culture and experiences of their country of birth, migration experiences, religion, ethnic background, language and family system.
2. Understand barriers to access – linguistic, economic and social barriers that individuals from different cultures face, preventing access to healthcare and social services. Try to provide services in a person's preferred language.
3. Understand that families may use alternative models of care and use alternatives to western philosophy and practice.
4. Do not place everyone in a particular ethnic group into the same category, assuming that there is one approach for every person in that group.
5. Respect cultural differences regarding physical contact, appropriate eye contact and voice volume.
6. Cultivate relationships with families over time, not expecting immediate trust in and understanding of dementia services.
7. Consider the family's background and experience in determining what services are appropriate.
8. Consider the culture's common perceptions of ageing, caring for elderly family members and memory impairment.
9. Understand that the family's culture impacts on choices regarding ethical issues such as artificial nutrition, life support and autopsies.
10. Regard the religious community for various cultures as a critical support system.

# References

Access Economics, *Dementia prevalence and incidence among Australians who do not speak English at home*, 2006, pp9-22.

Australian Institute of Health and Welfare, *Projections of Older Immigrants*, 2001

Australian Institute of Health and Welfare, *Older Australia at a glance: 4th edition*, 2006

Australian Polish Community Services, *People from Ethnic Backgrounds in Commonwealth Funded Residential Care – Victoria*, 2008

Dilworth Anderson, P. and Gibson, B, 'The cultural influence of values, norms, meanings and perceptions in understanding dementia in ethnic communities', *Alzheimer's Disease and Associated Disorders: an International Journal*, 2002, 16: S56-S63.

LoGiudice D, Hassett A, Cook R, Flicker L, Ames D. 'Equity of access to a memory clinic in Melbourne? Non-English speaking background attenders are more severely demented and have increased rates of psychiatric disorders', *International Journal of Geriatric Psychiatry*, 2001, 16: 327-334

Mahoney, F.D, Cloutterbuck J., Neary S., and Zhan L., 'African American, Chinese, and Latino Family Caregivers' Impressions of the Onset and Diagnosis of Dementia: Cross-Cultural Similarities and Differences', *The Gerontologist*, 2005, 45: 783-792

Sundaram, V. "Madness, Demons, or 'Loss of Soul': Dementia in Asian Elders", *New America Media*, News Report, 2007

Smith K, LoGiudice D, Dwyer A, Thomas J, Flicker L, Lautenschlager NT, Almeida OP, Atkinson D. " 'Ngana minyarti? What is this?' Development of cognitive questions for the Kimberley Indigenous Cognitive Assessment", *Australasian Journal on Ageing*, 2007 26: 115-119

Runci, S., Speaking their language aids dementia patients, *Monash Newslines*, 2004

Runci SJ, Redman JR, O'Connor DW, Language use of older Italian-background persons with dementia in mainstream and ethno-specific residential care, *International Psychogeriatrics*, 2005,17: 699-708

Victorian Multicultural Commission *Population Diversity in Local Councils in Victoria: 2006 Census*, Melbourne, Victoria 2007.



## Attachment 1: Numbers of participants by language group

Language group	Number of participants
Arabic	28
Chinese	19
Croatian	9
Greek	80
Italian	59
Macedonian	17
Polish	12
Russian	24
Serbian	20
Spanish	39
Turkish	51
Vietnamese	28

## Attachment 2: Community workers questionnaire

1. Please provide some key characteristics of your community group that may be relevant to dementia and related services (e.g. migration history, literacy, barriers to service uptake, religion).
2. How does your community perceive dementia (e.g. as normal part of ageing, as mental illness etc.)?
3. What are some common ideas about the causes of dementia in your community (e.g. is it recognised that there are physical causes or is the illness attributed to something else such as stress)?
4. Are there any specific names or terminology in your language that is used for dementia?
5. What are some cultural behaviours/mannerisms etc that service providers need to be aware of when working with a person with dementia from your community?
6. Are members of your community likely to discuss dementia and memory problems openly?
7. If yes, who are they most likely to talk to (GP, family, community, priests etc.)?
8. From your experience, when are members of your community usually diagnosed?
9. Who would they most likely go to for diagnosis (e.g. GP, hospital, specialist etc.)?
10. What do you think would be the impact of diagnosis on the person?
11. What do you think would be the impact of the diagnosis on family members?
12. Who is the main person to take care of the elderly in their family (Expectations of the elderly vs reality for children/family to provide care, particularly at later stages)?
13. Who is the most likely person in the family to explore treatment options and services available that can assist in managing dementia?
14. What role does the community (ethnic agencies vs general community) play in supporting the person with dementia and their family?
15. Is there a preference for people to be taken care of at home or in a residential facility?
16. What is the attitude towards professionals like doctors/counsellors/community workers?
17. What are some other influences that are important in caring for people with dementia, e.g. priests, traditional medicine?

### **Attachment 3: Community questions**

#### Understanding and perceptions of dementia

1. What have you noticed about memory as you age?
2. If you noticed changes would you discussed them with your family/community/community workers/GP?
3. Have you heard of Alzheimer's disease or dementia?
4. If so, what do you think is Alzheimer's disease? What do you think is dementia?
5. What do you think causes dementia?
6. What words would you associate with dementia?
7. Do you know anyone who has the illness?

#### Diagnosis

1. If you were worried about your memory or someone close to you, where would you go for help?
2. Who would usually attend the appointment with the person?
3. Who receives the diagnosis?
4. Acceptance of diagnosis? How would a diagnosis of dementia be usually accepted?

#### Dementia Care

1. Who is the main person likely to take care of the elderly in their family?
2. Is there an expectation that children/family will provide care?
3. Who is the most likely person in the family to explore treatment options and services available that can assist in managing dementia?
4. What role does the community (ethnic agencies vs general community) play in supporting the person with dementia and their family?
5. Is there a preference for people to be taken care of at home or in a residential facility?
6. What is the attitude towards professionals like doctors/counsellors/community workers?

#### Other influences (religion, traditional medicines, culture and traditions)

1. What are some other influences that are important in caring for people with dementia?
2. What is the role of priests/spiritual advisers
3. Are there any traditional medicines that are used for treating people with dementia?