



**ethnic
communities'
council of
victoria**

MEANT TO CARE **about** **culturally relevant** **dementia care**

Empowering
Informing
Resourcing

eccv Discussion Paper
Volume 1, Number 2

Ethnic Communities' Council of Victoria (eccv) Inc. was established in 1974 as a voluntary community based organisation.

35 years later, eccv is a non-partisan, broadly based, statewide, peak advocacy body representing ethnic and multicultural communities in Victoria.

Eccv's role includes supporting, consulting, liaising with and providing information to Victoria's ethnic communities.

Eccv delivers policy projects for key partners in areas like multicultural policy, aged care programs and skilled migration strategies.

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Abbreviations

AAV	Alzheimer's Australia Vic
ABS	Australian Bureau of Statistics
BPSD	Behavioural and psychological symptoms of dementia
CACPs	Community Aged Care Packages
CALD	Culturally and linguistically diverse
DoH	Department of Health
EACH	Extended Aged Care Package
EACH-D	Extended Aged Care Package – Dementia
eccv	Ethnic Communities' Council of Victoria
EMR	Eastern Metropolitan Region
HACC	Home and Community Care
LOTE	Languages other than English
NESB	Non-English speaking background
PAG	Planned Activity Group
RDNS	Royal District Nursing Service
RMIT	Royal Melbourne Institute of Technology
RUDAS	Rowland Universal Dementia Assessment Scale
TIS	Telephone Interpreting Service
UNSW	University of New South Wales

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- Filipino Community Council of Victoria
- Jewish Care
- J. Lawrence & Associates
- Migrant Information Centre (Eastern Melbourne)
- Royal Melbourne Hospital Interpreter Services
- Serbian Community Association of Victoria



Foreword

Dementia care is our biggest challenge in the 21st century. Our Prime Minister said in 2011 that we can expect to live 20 years longer. The Productivity Commission's final report *Caring for Older Australians* (2011) favours a person-centred approach that demands respect for the person's values, preferences and expressed needs.

With dementia expected to increase six-fold in the next four decades amongst Australians who speak a language other than English, policy makers and planners need to have strategies in place to respond to our community's changing needs. As Victoria's multicultural population is ageing proportionately faster than the average population, this discussion paper *Meant to Care about Culturally Relevant Dementia Care: Empowering, Informing, Resourcing* is a timely resource for service providers and public policy makers who aim to meet the needs of culturally diverse people living with dementia.

eccv has brought together a team of committed experts from ethnic and multicultural community based organisations and peak bodies with an interest in culturally responsive dementia care. Special thanks go to the members of the eccv Dementia Working Group, and in particular Alzheimer's Australia Vic, for their dedicated work in preparing this report. Based on their experience and knowledge of dementia community education, the clinical symptoms of the disease, and practical program delivery to a range of ethnic communities, they have provided valuable models and strategies to empower and better inform non-English speaking people living with dementia. Help in recognising dementia, insightful ways of improving language services, working sensitively with interpreters and understanding the relationship between ethnicity and dementia are some of the pertinent issues raised in this paper.

We applaud the Victorian Government's commitment to quality dementia care pathways for older people living with dementia. eccv and its partners encourage the Australian and Victorian Governments and service providers to take action and give serious consideration to implementing the recommendations in this paper so that people from culturally diverse backgrounds receive the culturally relevant care they are meant to have.

It is with pleasure and a sense of urgency that I commend this report to you.

A handwritten signature in blue ink that reads "Sam Afra JP". The signature is fluid and cursive, with a long horizontal stroke at the end.

Sam Afra JP
Chairperson eccv

Executive Summary

“The dementia revolution has begun quietly but we can expect to see momentous consequences”
(Julie Gross McAdam 2009)

Victoria has an ageing multicultural population which is an undeniable reality. That dementia is not understood well by people from culturally and linguistically diverse communities is challenging for aged care policy makers and service providers. Many non-English speaking people do not recognise the early signs of dementia. When people with diverse backgrounds do not access support services until they reach the point of crisis, the challenge for governments becomes more apparent.

The Victorian and Australian Governments have taken the initiative to develop a number of policies that provide effective dementia care pathways and related aged care services for Victorians. People from culturally diverse backgrounds who are living with dementia are at risk of missing out on quality dementia care if they do not understand the concept of dementia and the nature of dementia care.

eccv and its stakeholders have examined the factors that prevent non-English speaking Victorians with dementia from living quality lives. This discussion paper focuses on the role policy makers can play in empowering, informing and resourcing dementia care programs in the ethnic and multicultural community sector. It highlights best practice initiatives and multicultural resources that have already been trialled and developed by ethnic agencies, multicultural centres and peak bodies such as Alzheimer’s Australia Vic (AAV). It is important that governments recognise the multicultural community sector is overstretched and needs additional resources to strengthen and expand these valuable programs.

The title emphasises that we are ‘meant to care, about culturally relevant dementia care.’ Whilst this paper offers insights and suggested solutions for improving culturally responsive dementia care, it also provides a wealth of multilingual resources and tips that can be accessed by service providers.

Where decision makers and service providers remain complacent, or overwhelmed with the task at hand eccv, AAV and their partners in the multicultural sector are committed to improving the wellbeing of Victorians living with dementia. The key to policies that empower stakeholders and culturally diverse individuals are effective communication strategies to inform people about dementia, as well as adequate resources to further develop culturally relevant dementia care policies and practice in Victoria.

We encourage governing bodies to take meaningful action to improve the day-to-day lives of non-English speaking people with dementia by implementing the recommendations in this report which include:

- **Empowering** the sector through community engagement, training and strengthening programs;
- **Informing** culturally diverse people about what it means to live with dementia and how to get help;
- **Resourcing** multilingual initiatives and culturally inclusive research into dementia issues.

Recommendations

The recommendations are presented in three categories:

- Empowering
- Informing
- Resourcing

Empowering

1. That the Australian and Victorian Governments fully consider the needs of people from culturally diverse backgrounds in relation to the implementation of the proposed aged care reforms and recommendations of the Productivity Commission's report *Caring for Older Australians*.
2. That the Victorian Government includes a cultural diversity strategy in its Dementia Pathways Framework.
3. That the Australian and Victorian Governments ensure specific cultural diversity and dementia care strategies are included in Home and Community Care (HACC) agency Diversity Plans.
4. That the Australian and Victorian Governments strengthen partnerships with ethnic communities and existing culturally responsive dementia support programs in the community.
5. That the Victorian Governments encourage the use of the Rowland Universal Dementia Assessment Scale (RUDAS) as a culturally competent dementia screening instrument in assessment guides.
6. That the Victorian Government provides dementia awareness and dementia care training for staff in ethnic and multicultural community organisations.

Informing

7. That the Victorian Government facilitates a communication and promotion campaign on understanding dementia targeted at people from non-English backgrounds.
8. That the Victorian Government builds on existing culturally competent dementia communication strategies in alternative media such as ethnic radio and translated DVDs.
9. That the Victorian Government adopts the Royal District Nursing Service (RDNS) Translation Standards for community languages translations of materials related to dementia promotion.

10. That the Australian Government funds radio Community Service Announcements on dementia in a range of languages other than English.
11. That the Australian and Victorian Governments promote existing Commonwealth funded Alzheimer's Australia Dementia Help Sheets produced in 27 languages.

Resourcing

12. That governments adequately resource the translation of the *Eight Things You Need to Know About Dementia* produced by Alzheimer's Australia into the top 25 community languages spoken in Victoria.
13. That the Victorian government provides support for the development of an interactive training model for dementia and aged care workers based on existing La Trobe University research on *Caring for Older Survivors of Mass Trauma and Genocide*.
14. That government provides incentives for the training, recruitment and retention of bilingual dementia care workers.
15. That the Victorian Government facilitates research into effective dementia care in ethnic communities.
16. That the Victorian Government facilitates research into the further validation of the RUDAS as a multicultural dementia diagnostic tool across a range of culturally diverse groups in different settings such as with general practice.

1. Introduction

About eccv

Ethnic Communities' Council of Victoria (eccv) is a statewide peak advocacy body that lobbies all levels of government on behalf of multicultural communities in a range of areas such as aged care. eccv has a long established track record of consulting key community organisations. In 2011 the eccv Aged Care Policy Committee established the Dementia Working Group to examine key issues and make recommendations to government to improve the quality of care for non-English speaking Victorians with dementia, their families and carers.

Dementia and Ethnic Communities

Dementia is a major issue of concern to Australia's ageing multicultural population. People with dementia experience difficulties with social, occupational and day-to-day care activities. International studies indicate that people with dementia represent one of the most marginalised groups of older people (Graham in Downs et al 2008). Research in the United Kingdom (Boise in Downs et al 2008) points out that ethnicity and cultural beliefs play an important role in how people experience dementia, how families respond to it and how they approach support services.

Victoria has the largest multicultural ageing population in Australia. Many older Victorians, their families and carers from non-English speaking and culturally diverse backgrounds find difficulties in understanding dementia and its implications for care, and are more likely to seek help from family and friends. They are at risk of poor health outcomes as they tend to underutilise health services for dementia (LoGiudice et al 2001; Low et al 2011 and Mukadam et al 2011). For example, a Melbourne-based study in a memory clinic indicated that non-English speaking patients presented at a later stage of dementia when symptoms were more severe and harder to manage. Culturally diverse people underutilise dementia services due to poor English proficiency; lack of knowledge; cultural perceptions and stigma; experiences of discrimination with health services; and lack of culturally relevant services (Low et al 2011). Misdiagnosis resulting from limited use of culturally valid dementia assessment tools exacerbates early access to support services.

In Victoria there have been various culturally responsive initiatives to increase dementia education by organisations including Alzheimer's Australia Vic, ethno-specific agencies and multicultural centres. Dementia awareness programs have been most effective when conducted in partnerships with ethnic and multicultural organisations in response to the range of different cultural groups. Sustainability of those programs is fraught due to limited and sporadic funding. The question arises: Who is meant to care about culturally relevant dementia care for people from non-English speaking backgrounds living with dementia? This discussion paper provides insights into the barriers to access and sets out suggested strategies for inclusive dementia care within a cultural diversity framework.

1.1 Stakeholder Engagement Process

Stakeholder engagement is an important aspect for high performing governments in the development of person-centred policy and practice in the 21st century. This discussion paper is the joint work of a group of

not-for-profit stakeholders with an interest in ethnic aged care and excellence in dementia care. Their common goal in the eccv Dementia Working Group was to improve dementia care for non-English speaking Victorians. Each stakeholder represented an area of expertise on dementia issues as well as the views of culturally and linguistically diverse Victorians living with dementia.

The purpose of this paper is to inform policy makers and service providers in aged care of the pertinent issues and strategies in providing effective dementia care for people from culturally diverse backgrounds. The findings of this paper have been informed by:

- Practical experience in ethnic and multicultural organisations in Victoria
- Expert input from Alzheimer's Australia Vic
- Australian literature, research and best practice
- International studies on dementia care

Extensive consultations via the Dementia Working Group examined the challenges, opportunities, and service gaps in relation to dementia care and older Victorians from non-English speaking backgrounds. Detailed questions addressed by the Working Group are in Appendix 1.

1.2 Population Trends

In Australia the prevalence of dementia by languages other than English spoken at home is predicted to increase six-fold by 2050 (Access Economic 2006). Risk factors that affect the uptake of mainstream dementia support services for people in ethnic communities are: lack of English, social isolation, insensitivity to their cultural needs, transport, loss of acquired languages and lack of understanding of the concept of dementia (Access Economics 2006).

Victoria's multicultural population is ageing proportionately faster than the average population. This trend will continue for a number of decades. Associated with this ageing of the population will be a significant increase in the number of people living with dementia. To assist the planning of support services it is useful to have an estimate of how many people are currently living with dementia, and how this is expected to change over the coming decades.

Prevalence estimates

A report from Access Economics (2010) provides estimates of the numbers of people with dementia living in metropolitan Melbourne and in rural and regional Victoria. It also provides projected estimates to 2050. For the numbers of people with dementia living in metropolitan and regional Department of Health Regions see Appendix 2.

	2011	2020	2030	2040	2050
Metro Melbourne	47,203	67,295	97,087	134,348	167,902
Rural & Regional	21,673	31,037	44,702	61,923	78,487
Total	68,876	98,332	141,788	196,271	246,389

Table 1: Estimated numbers of people with dementia in Victoria, 2011 – 2050

Source: Access Economics (2010)

Fig. 1: Population trends – Victorians Living with Dementia

In **Victoria** in 2011, there is an estimated 68,876 people living with dementia. By 2020, this number is expected to rise to 98,332. By 2050, the number of Victorians with dementia is projected to be 246,389, nearly 4 times as many as in 2011. One in four Australians with dementia is Victorian. There will be an estimated 20,339 new cases of dementia in Victoria in 2011.

In **metropolitan Melbourne** in 2011, there are an estimated 47,203 people living with dementia. By 2020, this number is expected to rise to 67,295. By 2050, the number of people in Melbourne with dementia is projected to be 167,902, 3.6 times as many as in 2011.

In **rural and regional Victoria** in 2011, there are an estimated 21,673 people living with dementia. By 2020, this number is expected to rise to 31,037. By 2050, the number of people in rural and regional Victoria with dementia is projected to be 78,487, 3.6 times as many as in 2011.

Multicultural ageing population

According to the Access Economics report (2006) one-sixth (16%) of people aged over 60 years spoke a language other than English at home, while just over one-third (33%) of people aged over 60 years were born in a country other than Australia. Around one in eight (12.4%) of Australians with dementia do not speak English at home.

Fig. 2: Victorian Diversity Statistics

- Victorians come from over 200 countries
- Victorians follow more than 120 religious faiths
- 20% of the population speaks a language other than English at home
- 44% were born overseas or have one parent born overseas

Source: Victorian Multicultural Commission (2011)

Overall in the period 2001 to 2050 there is projected to be a greater proportion speaking Asian (6.0% to 8.3%) and Middle Eastern (1.8% to 2.3%) languages and a fall in the proportion of Australians speaking English (83.8% to 82.4%) and other European languages (7.6% to 6.0%) (Access Economics 2006). Growing cultural diversity in Victoria's ageing population is a reality that will persist into the coming decades. In 2011, 40% of Victorians over 65 are from culturally diverse backgrounds (Howe 2006). The older culturally diverse population will grow by 44% in the next 15 years from 2011 to 2026. The proportion of older Australians from culturally diverse backgrounds has been growing more rapidly than the Australian-born population (Gibson AIHW 2001). They are more likely to be under-referred to aged care services, look to their families and friends first for support, and in particular have limited access to services in rural areas (Australia's Welfare 2007).

Fig. 3: Fast Facts

- From 1996 to 2010 the proportion of over 80s in the culturally diverse population increased from 16.3% to 25.9% compared with 22.9% to 27.5% for the Australian-born.
- From 2011 to 2026 ethnic people over 80 will increase by 59% compared with 29% in the Australian-born population.
- By 2026 one in every four people aged over 80 will be from culturally and linguistically diverse backgrounds.

Source: Gibson AIHW (2001)

1.3 About Dementia

Dementia involves brain damage. People with dementia experience day-to-day difficulties. Different types of dementia can affect people in different ways. Alzheimer's Australia Vic provides the following biological and clinical description.

Fig. 4: Dementia explained

Dementia describes a set of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. The hallmark of dementia is the inability to carry out everyday activities as a consequence of diminished cognitive ability.

Dementia may be diagnosed if two or more cognitive functions are significantly impaired. The cognitive functions affected can include: memory, language skills, planning, spatial skills, judgement and attention.

People with dementia may have difficulty solving problems and controlling their emotions. They may experience personality changes, agitation, delusions or hallucinations.

The exact symptoms experienced by a person with dementia depend on the areas of the brain that are damaged. With many types of dementia, some of the nerve cells in the brain stop functioning, lose connections with other cells, and die. Dementia is usually progressive and fatal, and is incurable.

There are over 100 diseases that can cause dementia, the most common being Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Mixed dementia, where more than one disease affects the brain, is also very common.

Alzheimer's disease

is the most common form of dementia, and accounts for around two-thirds of cases. It causes a gradual decline in cognitive abilities, usually beginning with memory loss.

Vascular dementia

is cognitive impairment caused by damage to the blood vessels in the brain. It can be caused by a single stroke, or by several mini-strokes occurring over time. The symptoms of vascular dementia vary depending on the location and size of brain damage.

Dementia with Lewy bodies

is characterised by the presence of Lewy bodies in the cortex of the brain. Typical symptoms can include attention problems, reduced spatial skills, visual hallucinations, and balance and walking difficulties.

Frontotemporal dementia

involves damage to the frontal and/or temporal lobes of the brain. There are two main presentations – frontal (involving behavioural symptoms) and temporal (involving language impairments). However, the two often overlap.

Source: Alzheimer's Australia Vic (2011)

1.4 Policy context – Government Initiatives and Risks

Several Australian and Victorian Government initiatives focus on dementia care as a health and aged care priority. These include the development of a HACC Assessment Dementia Pathways Guide, Dementia Community Support Grants and some living at home dementia care support via aged care packages. Whilst these government initiatives respond to the cultural diversity needs and preferences of Victorians with dementia in a variety of ways, their cultural relevance leaves room for improvement as non-English speaking people living with dementia are at risk of missing out.

HACC Assessment Dementia Pathways Guide

The Victorian Department of Health in collaboration with the Royal District Nursing Service (RDNS) is conducting a HACC Dementia Pathways Project which is looking for appropriate ways to support access and assessment of people with dementia into the HACC program. Person-centred care is a key focus of the project which is being undertaken with broad-based community consultation. eccv and AAV are representatives on the Project's Reference Group. Early intervention strategies and ethno-specific support

will be listed in the guide. This discussion paper provides important input into that project in the form of resources and insights that focus on quality dementia care for people from non-English speaking backgrounds, their families and carers.

HACC Diversity Planning and Practice

The recommendations in this paper support the move towards a broader Diversity Framework in the Victorian HACC Program that encompasses the diversity of the Victorian community and acknowledges the barriers to accessing services of marginalised and disadvantaged groups. In this paper the focus is on improving policy and practice for those people living with dementia who do not fully understand the early signs and who are doubly disadvantaged by their culturally and linguistically diverse backgrounds.

Dementia Community Support Grants Program

Since 2006, the Australian Government offered the Dementia Community Support Grants Program for local community projects to improve dementia literacy, encourage innovation, bridge social gaps and encourage the social participation of people with dementia, their families and carers. The first three grant rounds funded over 150 projects at a cost of \$6.3 million.

Funded projects in the ethnic aged care sector generated some local best practice projects that provided opportunities for awareness raising, understanding dementia and empowering communities. Despite widespread application from the ethnic and multicultural community sector, the impact of culturally relevant dementia care was limited due to:

- A declining trend of funding for ethnic and multicultural agencies in Victoria from eight in 2007 to only two in round four in 2011.
- Short term nature of the programs (12 months).
- Unsuccessful applications of many ethnic and multicultural agencies to continue and expand the good work that commenced.
- No reports or reviews published to evaluate the successes and learnings of the programs.
- Insufficient promotion and distribution of resources developed by successful applicants.

Fig. 5: Number of Dementia Community Support Grants allocated to ethnic and multicultural agencies in Victoria by the Australian Department of Health and Ageing

Round 1, 2007 funded 8 ethnic and multicultural organisations

- Australian Polish Community Services – Addressing Dementia in the Polish Community
- Spanish Latin American Welfare Association – Dementia Awareness and Support for the Spanish-Speaking Community
- Dutchcare – Dementia Awareness and Understanding

- Australian Vietnamese Women's Welfare Association – Dementia Awareness Raising for the Vietnamese Community
- Migrant Information Centre, (Eastern Melbourne) – Dementia and CALD Communities Project
- Migrant Information Centre, (Eastern Melbourne) – Dementia and Culture Education Project
- Centre for Philippine Concerns Australia Victoria – Understanding Dementia

Round 2, 2008 funded 3 ethnic and multicultural organisations

- Australian Greek Welfare Society – The Greek Dementia Care Buddy Project
- Australian Multicultural Foundation – Understanding Dementia: Empowering the Community Through Peer Education
- Spectrum Migrant Resource Centre – The Intergenerational Project

Round 3, 2009 funded 5 ethnic and multicultural organisations

- Co As It Italian Australian Welfare Association – Dementia, Today is Yesterday
- Chinese Community Social Service Centre – Day Care Music Program for Chinese with Dementia
- Migrant Information Centre, (Eastern Melbourne) – Dementia Awareness in CALD Communities across the Generations
- Centre for Philippine Concerns Australia – Living in Dementia: You are not alone
- Serbian Community Association of Australia – Increasing Dementia Awareness among the Serbian Community in Victoria

Round 4 in 2010 funded 2 ethnic and multicultural organisations

- Australian Multicultural Foundation – A National Radio Awareness Program in Community Languages
- Spectrum Migrant Resource Centre – Cultural Connection – Gardening Across the Seasons

Ethno-specific Community Aged Care Packages

The Australian Government funds a range of community aged care packages to assist frail, older people to live at home longer. These include the higher care type CACPS (Community Aged Care Packages), EACH (Extended Aged Care Packages) and EACH-D (Extended Aged Care Packages – dementia specific) as well as the National Respite for Carers Program. There is a high demand for ethno-specific CACPs and EACH packages as people from non-English speaking backgrounds tend to access services later or when they reach a crisis point. In that situation they bypass early intervention programs and require care packages. The number of ethno-specific aged care packages allocated fall far short of the demand for them especially in the northern and western metropolitan areas of Melbourne.

2. Empowering

Empowerment in public policy is about public engagement with clients and community groups where both the government and the clients have a responsibility for the wellbeing. This discussion paper proposes an approach to dementia care that involves empowering, informing, and resourcing ethnic and multicultural agencies and individuals from culturally diverse backgrounds.

The person-centred practice in service delivery in the 21st century shifts power from the service providers to those who use the services. It describes the process of asking people what they want, planning the support they need and showing them how they can get it (Morley et al 2010). Front line managers need to understand 'dementia care and ethnicity' as well as person-centred tools in order to coach their staff in effectively delivering self-directed support along the lines of the Active Service Model.

International studies indicate that there is a variation of education levels, literacy and health literacy among people from diverse ethnic groups (Boise in Downs et al 2008). Lack of English can impact on a family's ability to understand the nature of dementia and to engage in conversations about care needs. In fact low education and low levels of English proficiency had a multiplier effect on limiting access to information and on how satisfactory interactions with service providers were. Providing culturally competent dementia care has been recognised in the United Kingdom as an integral part of excellence in dementia care (Bois in Downs et al 2008).

People from non-English speaking backgrounds tend to underutilise dementia services and do not have a good understanding of pathways of care.

Fig. 6 Utilisation of Dementia Services by Non-English Speaking Communities

International and national research has reported the underutilisation of health services for dementia by people of non-English speaking backgrounds (NESB) (LoGiudice, Hassett, Cook, Flicker & Ames, 2001; Low, Anstey, Lackersteen & Camit, 2011; Mukadam, Cooper, Basit & Livingston, 2011).

A study by Low, Anstey, Lackersteen and Camit (2011) reported that people from non-English backgrounds were less likely to recognise dementia symptoms from the vignette, in comparison to their Australian counterparts, suggesting that information disseminated through various initiatives may have been ineffective in reaching CALD communities. Their study found significant discrepancies in help-seeking preferences and acceptability of services between ethnic groups and their Australian counterparts. Ethnic group representatives were more likely to seek help from family and friends and were less likely to use and have access to services including residential respite and residential aged care.

There are several reasons why people of NESB backgrounds underutilise services for dementia care, or present at a much later, and more severe, stage of their disorder. Mukadam, Cooper and Livingston (2010) provided a review of 13 academic papers which sought to evaluate studies which assessed the reasons why people present at a much later stage of dementia. The following factors influenced dementia help-seeking behaviour:

- Differing aetiological beliefs about dementia in comparison to the Western medical model, in terms of psychological, spiritual and social causes, and therefore believed that dementia was not a disease warranting medical help.

- Carers own interpretation of cognitive and memory impairments, including normalisation of symptoms as being normal part of ageing, denial that there is a problem and adaptation to the changing circumstance due to familial responsibility of caring for their elderly.
- Belief and experiences in the health care system including the experience of racism/discrimination, lack of clarity about referral pathways and beliefs that nothing could be done.
- Lack of dementia literacy, in terms of symptoms, prognosis and treatment and service options, as well as the personal and social stigma prevalent in their own community groups.
- Carers generally accessed help when they could no longer cope and take care of the individual and their symptoms.

Source: Anja Copelj, Masters candidate Clinical Psychology, University of Ballarat (2011)

2.1 Best Practice Ethno-specific Initiatives

A range of ethno-specific and multicultural dementia programs provide best practice models for people from non-English speaking backgrounds.

Early intervention

Social support and respite programs such as ethno-specific Planned Activity Groups (PAGs) under the Victorian HACC Program play an important role in empowering people from culturally diverse backgrounds. In the pathway of dementia care they provide early intervention support for people living with dementia.

She's not coming any more

Increased training and support is required for PAG Coordinators and more effective diagnosis and support pathways for PAG participants with early onset dementia. An individual's changes in behaviour such as confusion, aggression or inability to attend the weekly groups are sometimes perceived by other PAG members who speak the same language as leading to the 'dropping-out syndrome' with no ongoing support. Stigma and culture based perceptions of dementia result in inadequate understanding about identifying people with dementia and how best to support them. Training and dementia awareness education are required for staff in ethnic communities as well as individuals from culturally diverse backgrounds, as well as more effective support pathways for non-English speaking people challenged by dementia.

Better access and culturally competent pathways – building on best practice

Best practice ethno-specific dementia care projects provide excellent opportunities for service providers to build trust, understanding and to develop culturally responsive services that enable better access for people living with dementia from culturally diverse backgrounds. These programs provide effective culturally relevant dementia care however funding is sporadic and short-term leading to fragmented programs which lack strengthening opportunities.

In Victoria ethno-specific and multicultural agencies have played an important role since 2006 in strengthening the capacity of aged care providers to work with non-English speaking people with dementia

and their families. They also have considerable cultural competency in conducting information and awareness programs for intergenerational groups of people from culturally diverse backgrounds. Three culturally competent case studies are listed below.

Fig. 7: Examples of Best Practice Multicultural Dementia Projects

Case 1 – Dementia and Culture Education Project (Round 1)

The *Dementia and Culture Education Project* was part of the Community Support Grants funded through the Dementia Community Grants Program of the Department of Health and Ageing. It was a joint initiative of the Migrant Information Centre, (Eastern Melbourne) and Alzheimer's Australia Vic. It commenced in July 2006 and continued until the end of March 2007. The objectives of the project were to strengthen the capacity and skills of aged care service providers in the eastern metropolitan region (EMR) of Melbourne to work successfully with people with dementia from CALD backgrounds and their family members.

The project's target groups were aged care service providers including CACPs, EACH, and HACC and residential care facilities' workers in the EMR. Over the project period, eight training sessions were delivered to aged care service providers and staff from residential care facilities and over 185 people attended the training. The training focused on how to care for people with dementia from CALD backgrounds and how cultural factors may impact on the individual's and their family's response to dementia.

An information sheet was developed with practical suggestions on how to incorporate cultural factors when planning services for people with dementia from CALD backgrounds. The information sheet has been distributed widely in the region to over 7000 workers and clients.

Case 2 – Dementia and CALD Communities Project (Round 1)

The *Dementia and CALD Communities Project* was part of the Community Support Grants funded through the Dementia Community Grants Program of the Department of Health and Ageing. It commenced in October 2006 and was completed in June 2007. The objective of the project was to increase awareness of CALD communities (including people living with dementia and family members) in the EMR of early intervention, prevention, diagnosis and treatment of dementia. The targeted communities were the Chinese, Hungarian, Indian and Sri Lankan communities. Over the project period, seventeen forums and expos were delivered to CALD communities and over 1100 people attended. Material was widely distributed on prevention, diagnosis and treatment of dementia. As there was no dementia information available in Tamil an information sheet was translated into this language.

Case 3 – Dementia Awareness in CALD Communities across the Generations Project (Round 3)

The *Dementia Awareness in CALD Communities across the Generations Project* successfully raised awareness amongst young people from CALD backgrounds about dementia and how it affects older people in the community. Over 95 students were involved in a range of activities including information and activity sessions about dementia, excursions to dementia PAGs and the opportunity for younger people to share

their knowledge with over 255 older people from different CALD backgrounds at various multicultural intergeneration events.

2.2 Collaborative Initiatives – Alzheimer’s Australia Vic

Collaborative initiatives and partnerships across organisations lead to excellence in dementia care, more effective culturally relevant services and increased wellbeing of people from culturally diverse backgrounds that are living with dementia.

Dementia care and awareness programs that empower people come from the person-centred perspective and employ a proactive approach to community education (Lenihan and Briggs 2011). Alzheimer’s Australia Vic has worked in collaboration with smaller ethnic communities in the areas of mentoring, capacity building and increasing trust with a view to improve the uptake of dementia related services amongst people from non-English speaking backgrounds.

Fig. 8: Empowering People with Dementia

The *Empowering Small Ageing Ethnic Communities in Victoria Project* is a capacity building and mentoring project targeted at four small and ageing communities in Victoria: Laotian, Romanian, Finnish and Russian Jewish. These small communities have limited resources and infrastructure within their own communities to assist elderly members of the community living with dementia, their families and carers to access aged care services. The purpose of the project was to enable them to identify their aged care needs through a process of informing, empowering and resourcing. It also sought to develop specific culturally appropriate resources that will improve the communities’ access to support and understanding of the aged care service systems in Australia. The project aimed to:

- Develop culturally specific resources that would be delivered in a manner that is determined by each community.
- Provide project leadership, in partnership with the community leaders and in association with the Centre for Cultural Diversity and Ageing.
- Build the capacity of the communities by paying workers to work alongside Alzheimer’s Australia Vic for the duration of the project, and thereafter have the skills to provide ongoing support.

In order to improve access to information and resources developed, Alzheimer’s Australia Vic staff will continue to work with representatives from the four communities to ensure that older members of the community are well supported. This will be achieved through:

- Education
- Delivery of dementia information sessions to the four community groups

- Delivery of cultural briefings to mainstream services to better understand the needs of community groups and improve the provision of culturally appropriate aged care
- Mentoring – encourage members from the four communities to participate in educational opportunities offered by Alzheimer's Australia Vic and other relevant organisations
- Networking opportunities – Alzheimer's Australia Vic to link communities with suitable networks
- Ongoing partnerships
- Cultural briefings sessions will also be delivered to the generalist aged care service providers to assist them in supporting clients from these communities.

The project produced a range of resources including community profiles, a bilingual guide to aged care services in each language, bilingual dementia tip sheets and bilingual dementia Help Sheets, and in some cases pre-recorded bilingual community service announcements.

These resources are available at www.alzheimers.org.au or by calling the National Dementia Helpline on 1800 100 500. For language assistance people can call the Telephone Interpreting Service (TIS) 131 450 to connect to the helpline.

Source: An Alzheimer's Australia Vic project funded under the Community Partners Program, Australian Government Department of Health and Ageing (2011)

2.3 Culturally Appropriate Assessment Tools – RUDAS

Misdiagnosis of dementia amongst seniors from non-English speaking backgrounds has been reported by aged care workers in ethnic and multicultural agencies. Limited English language proficiency and literacy may affect the diagnosis and misdiagnosis of dementia (Bois in Downs et al 2008). The development of better culturally appropriate diagnostic tools for ethnic groups is fraught as assessors and general medical practitioners may be accustomed to using generic diagnostic tools. The RUDAS (Rowland Universal Dementia Assessment Scale) is a culture-neutral diagnostic tool. Service providers that use RUDAS consider it to be a 'multicultural mini mental' assessment scale. It is considered by many as a significant improvement on the existing culture-laden assessment tools.

RUDAS is used by Alzheimer's Australia Vic, the Royal District Nursing Service and some aged care assessment services in Victoria. AAV supplies a DVD that provides an easy to follow guide to RUDAS utilisation with interpreters. Further evidence-based research is required to validate the use of the RUDAS as an effective multicultural assessment scale to facilitate more widespread acceptance amongst General Practitioners and dementia assessment personnel.

2.4 Caring for Older Survivors of Torture and Trauma

Traumatic memories are linked to Behavioural and Psychological Symptoms of Dementia (BPSD) amongst culturally diverse older people who experienced pre-migration mass trauma and torture. Residential care facilities are potential reminders of such trauma. This results in barriers to accessing aged care services.

Research conducted at La Trobe University into *Caring for Survivors of Mass Trauma and Genocide* (Teshuva and Wells 2010) highlights the need for appropriate care and support for older survivors of torture and trauma as well as additional training for dementia and aged care workers. That research has been completed and successfully trialled at a professional development seminar held at eccv with Supported Access Workers. Funding support is required for that important project to develop interactive training modules for aged care staff to improve dementia care for older war and genocide survivors from culturally diverse backgrounds.

2.5 Transition to Residential Care

Empowerment is about both government and potential clients understanding pathways of dementia care and support. Non-English speaking people confronted with dementia issues are at risk of dropping out of, or not accessing, early intervention support. Lack of English and social isolation often cause culturally diverse people to discount residential care as an acceptable option. They tend to access services later in situations of crisis which may result in difficult transitions to residential care.

In a climate of increasing aged care and health costs policy makers and aged care service providers need to take advantage of collaborative culturally responsive support possibilities. The number of ethno-specific aged care facilities in Victoria is limited to about a dozen. It is important that policy makers acknowledge that families and carers would provide regular visits to non-English speaking relatives with dementia in aged care facilities. Many people from culturally diverse backgrounds do not have a driver's license. Policy makers need to ensure that aged care facilities as part of their cultural competency accreditation standards recognise and foster same-language family support and friendly visiting programs.

The transition to residential care has an enormous impact on the emotional and social wellbeing of non-English speaking seniors with dementia, their families and carers. Aged care policies need to recognise diverse cultural values and the dependency world view. Consequently they need to support three aspects of a culturally responsive dementia care pathway for prospective non-English speaking residents and their families with regard to:

- Choosing a facility linked to transport or within walking distance
- Maintaining the relationship with the prospective resident's carers and family
- Developing a relationship with the staff that respects their cultural values

In addition residential facilities need to provide culturally appropriate activity programs. There is a need to address the aged care sector's lack of awareness of best practice examples for culturally diverse residents with dementia. For example, culturally meaningful activities are needed that are in community languages, are intergenerational and cater for a broad range of interests.

2.6 Culturally Inclusive Research

Existing university research does not always reflect Victoria's diverse communities. Significant reasons are that ethnic and multicultural organisations have insufficient resources to become funded industry partners

with universities and also many research projects do not include allocations for interpreters and translations. Dementia research is needed that specifically targets culturally and linguistically diverse communities.

RUDAS

Additional evidence-based research is required in the areas of ethnic perceptions of dementia and attitudes to service support as well as on validating more appropriate culturally competent dementia diagnostic tools such as the RUDAS.

Fig. 9: Literature review on the shortcomings of research on dementia in Victoria's ethnic communities

The Alzheimer's disease knowledge base has increased throughout the years, from a smaller number of papers published annually to hundreds. However, research on people with Alzheimer's from culturally and linguistically diverse backgrounds in both Australia and overseas has been insufficient (Low et al. 2009).

As a result there are very limited findings regarding ways in which culture influences the provision of care to people with Alzheimer's across CALD groups in Australia (Low et al. 2009) especially since according to the ABS (2006) about one in five Australians were born overseas (ABS, 2006).

Furthermore, there has been limited research on the development of screening tests used to diagnose dementia. According to Low et al (2009) at this stage appropriate tests to measure functional change and cognitive decline are not available and even though RUDAS has been developed to be language and culture fair it still needs to be validated across different cultural groups and in different settings.

The importance of research that includes adequate numbers of CALD subjects becomes obvious as the Australian elderly population becomes more ethnically diverse. There is a pressing need to understand the unique challenges and opportunities this presents for research and service delivery (ABS, 2006).

Source: Eugenia Georgopoulos, PhD candidate RMIT, 2011

Innovative Approaches – Arts and Dementia Care

Arts and dementia care have the potential to improve the quality of life of people with dementia through music and art therapy. Ethnic residential aged care facilities and multicultural community organisations in Victoria have explored creative ways to care using multilingual resources, for example the Doutra Galla Health Centre project using music with Chinese speakers. All people with dementia, including those from culturally and linguistically diverse backgrounds, should have access to good practice models of arts and music programs (Lawrence 2011a).

Academics such as Julie Gross McAdam, Victoria University, incorporate the person-centred design concept with creative art therapy to empower and engage people living with dementia. She focuses on the place of reminiscence, storytelling and memory painting to improve individual wellbeing and advocates

exploring much stronger links between art and dementia. Innovative approaches need to be explored and trialled based on research into the effects of culturally relevant art therapy and dementia care.

Fig. 10: Arts and Dementia

For both formal and informal carers, the experience of caring for someone progressing along this 'dementia journey', (and therefore providing the vital 'frontline' psychosocial support), also contains profound challenges, among which may be:

- a sense of powerlessness in the face of a relentlessly advancing, unpredictable, disease monster;
- a corrosive guilt, that somehow they have not provided the effort or proficiency of care with which to enable healing or at least a palliative wellbeing;
- an increasingly difficult process of communication, connection and negotiation with the person 'enthralled' by this monster;
- confrontation with an image of their own possible future experience as an ageing person with dementia;
- a resultant, exhausted demoralisation or alternatively a self-protective distancing from the care recipient(s).

People from CALD backgrounds can face a cascade of additional problems including:

- Limited knowledge and understanding of dementia, which may be seen as either a normal part of ageing or similar to madness and thereby associated with stigma, shame and denial. As a consequence dementia is often diagnosed at a more advanced stage and there is significant dementia service underutilisation relative to the non-CALD population;
- A 'double loss' of linguistic capacity – the skills and preferred use of languages other than one's 'mother tongue' (such as English) are often lost even for those without dementia while aphasia frequently progresses in more advanced stages of this group of syndromes. Together, they conspire to make negotiation with others in one's social environment increasingly difficult. This is especially the case in contexts without access to a speaker of one's 'mother tongue' and specific dialect such as a close family carer;
- Increasing risk of conflicts and confusion arising from differences between the cultural values and beliefs of a person with dementia and their carers;
- For those from more 'traditional' CALD backgrounds, challenging adjustments accompanying major life transitions (eg loss of authority, increased dependency, moving from home into residential facilities);
- A lack of access to culturally and linguistically appropriate aged care services which could ameliorate the impact of many of these issues. Mainstream services usually lack 'cultural competence', a responsiveness to the cultural and linguistic needs of their CALD clients.

Culturally appropriate art and music programs offer the potential to address each of these issues. Along with a range of other psychosocial interventions, they are gaining popularity in dementia care for their achievements. A wealth of anecdotal clinical evidence supports this effectiveness and while rigorous confirmatory, empirical evidence is still somewhat limited, it too is being steadily addressed over recent years.

Source: (J. Lawrence 2011a)

3. Informing

“The dementia revolution has begun quietly but we can expect to see momentous consequences” (Julie Gross McAdam 2009). Whilst empowerment is about community engagement, it goes hand in hand with informing and resourcing as key aspects of excellence in dementia care. It is crucial to establish a meaningful dialogue between service providers and their clients through a proactive dementia communication and education program targeted at people from non-English speaking backgrounds with dementia, their families and carers.

Dementia is most common in those over 80 (Downs et al 2010). People who migrated to Australia from predominantly non-English speaking countries during the mass migration years in the 1950s and 60s are reaching their frail, advanced years. Refugees from African backgrounds are starting to reach an age where they can no longer support themselves within the community (Ahmed 2010). For cultural reasons, many are unprepared for concepts such as aged care services, dementia care and aged care facilities. Alzheimer’s Australia Vic has been working on a culturally responsive community education approach on understanding dementia.

Dementia is a new word

Many older people from culturally diverse backgrounds experience dementia as a new word and concept. They may not access dementia support programs if they lack an understanding of what it means to live with dementia.

Alzheimer’s Australia Vic has identified *Eight Things You Need to Know about Dementia* in a study involving culturally diverse communities. The eight themes are currently translated into Greek and Italian. Service providers and non-English speaking people living with dementia would benefit from a concerted government approach to develop translated resources in 25 community languages in Victoria.

Fig. 11: Eight things you need to know about dementia – CALD Community Education

Alzheimer’s Australia Vic conducted a study with 35 focus groups involving 383 participants from 12 different cultural communities to determine what people from CALD backgrounds wish to know about dementia.

The study found that common to these groups was a lack of knowledge of dementia, its symptoms and causes, people with dementia were being marginalised and isolated, and they tended to have a late diagnosis – often at crisis point.

Families living with dementia are less likely to know about dementia and use general health facilities and are likely to experience great stress as they are reluctant to seek help.

There is a need to ensure clients from other cultures have access to tailored and timely support and education services, through building sustainable relationships with key CALD communities and by further developing the capacity of aged care professionals.

The investigations resulted in the production of the presentation *Eight Things You Need to Know about Dementia*.

The eight themes (in English and Greek or Italian) are:

1. What is dementia
2. Important facts about dementia
3. Who gets dementia
4. Signs and symptoms of dementia
5. How dementia is diagnosed
6. Living with dementia
7. Caring for someone with dementia
8. Getting help

Each of the eight themes is accompanied with eight messages. Community organisations may choose to receive a presentation on any one of the eight themes, or all eight themes over an extended period. Teaching notes are incorporated into the kit in standard and low literacy formats.

Source: Alzheimer's Australia Vic

3.1 Community Education

As governments are moving towards a person-centred approach to service delivery it is becoming important to develop community education programs that make clients more aware of their own situation and needs. We need to find ways to articulate issues related to living with dementia in new and enlightening ways. Communication strategies and information support for non-English speaking people living with dementia need to incorporate ethnic radio, translated DVDs and role plays.

The way people from diverse cultures understand dementia impacts on service use. Many people in ethnic communities combine a 'folk model' of thinking with a 'biomedical thinking' about dementia (Boise in Downs et al 2008:58). Current ways of communicating are not generally culturally appropriate. Different cultural groups have different needs. Some prefer written communication; others have high levels of illiteracy in English and in their first language so a number of methods of communicating are necessary. An effective form of communication is to link into cultural events and use talking to communicate the message. The community as a whole needs to understand the concept of dementia. Peer education models are important. These would involve training people from within the community to educate the community. There are not enough volunteers from CALD communities in the area of dementia education. Those that volunteer are often older and do not drive.

In Victoria Alzheimer's Australia Vic, and several ethnic and multicultural aged care providers, lead the way in proactive and alternative communication strategies targeted at people from culturally diverse backgrounds. These organisations provide useful models for other service providers.

Fig. 12: Dementia Communication Strategies – Alzheimer's Australia Vic Ethnic Radio

Alzheimer's Australia Vic has developed and implemented an ethnic radio campaign (community announcements audio recordings) to raise the awareness of dementia in 6 ethnic community languages: Chinese (both Cantonese and Mandarin speaking), Greek, Vietnamese, Laotian, Romanian and Russian.

The audio materials were developed in partnership with the following ethno-specific services: Chinese Community Social Services Centre, Australian Greek Welfare Society, the Australian Vietnamese Women's Welfare Association, the Lao Elderly Association, Australian Romanian Community Welfare, Health & Services Association of Victoria and the Shalom Association.

The announcements cover topics around memory changes, dementia, services and dementia risk reduction. These announcements vary slightly for each community depending on their specific needs as well as ensuring that information is conveyed in a culturally appropriate manner. The material will continue to be aired on ethnic radio stations whenever there is an opportunity.

We are hopeful that ethno-specific agencies and service providers with access to community radio will use these recordings as a tool to raise awareness about dementia and access to support services.

Source: Dementia Ethnic Radio Campaign – CALD community services announcements, Alzheimer's Australia Vic project funded by Department of Health (2009)

3.2 Carers as People 'Living with Dementia'

A Victorian study commissioned by eccv (Radermacher 2008 and 2010), points out that older people from culturally diverse backgrounds choose to stay at home longer than the average population. Joint eccv and Carers Victoria community consultations (2009) highlighted groups of 'hidden ethnic carers' that do not access support as they do not identify as carers whilst providing support for older, frail people in ethnic communities. It is important to understand the vital caring role that families play in ethnic communities and to provide intergenerational information and community education on living with dementia.

The report *Strategic Directions in CALD Dementia Research in Australia* (UNSW 2009) identified the key issues that impact on culturally diverse carers as poor English and low literacy in their own language; unfamiliarity with services and how to access them; feelings of shame and guilt if seeking outside services; cultural stigma about dementia and mental illness; and perceptions that service providers and health practitioners are not empathetic to their ethnicity related issues such as identity, dislocation and racism. The report states that there have been no Australian studies on the efficacy of caregiver support programs for culturally diverse groups.

Spirituality and Dementia

It is important to explore how we can care for people's spiritual needs at various stages of dementia. A literature review of spirituality and dementia care (Lawrence 2011) indicates that 'spirituality extends beyond religion to include a person's values or beliefs'.

Fig 13: Spirituality and Dementia

Spirituality, as a key contributor to health and wellbeing in the lives of most older people, is an experience which is radically changed by the ravages of progressive memory loss. It may also provide a remarkable resource for readjustment, reassurance and healing including those on the 'dementia journey'. Consideration of spirituality broadens our understanding of the existential dimension of this dementia journey and the elements of care which might address the personal challenges associated with this dimension.

For many, dementia is an experience of progressive, demoralising loss: of memory, identity, communicative competence, control over one's life circumstances and self-confidence, leading to anger, frustration and fear. For the 25% of Australian elders born overseas, the existence of 'foreign' childhood reference points, language, culture and religious issues can further complicate this 'loss' experience.

In relation to spiritual needs a recent U.S. review for example identified three themes relating to residents with dementia in long term care:

- Preserving meaningful connections with the world around them;
- Maintaining a sense of meaning, purpose and the will to live;
- Having a relationship with God.

A care model focussing instead on 'personhood' and 'making spaces' and which incorporates spirituality may enable a person with dementia to enjoy '... a process of growth that can still flourish when all other growth has stopped and our physical and mental powers begin to decline.' (King 1998). This response emphasises 'being' with a person with dementia more than 'doing' things to them or for them.

One experienced aged care chaplain has suggested that implementing this model will include:

- Listening and responding, with or without words and always with patience and respect;
- Welcoming and affirming the contribution which people with dementia can make to others;
- Taking time to discover a person's spirituality;
- Giving and receiving affection;
- Respecting the need for space, privacy and dignity;
- Encouraging participation and meaningful activity;

- Using simple repetitive rituals;
- Providing special occasions ... and making every day special.' (Hall 2008)

Source: J. Lawrence (2011b)

3.3 Interpreting and Language Services

The perennial issue is communication in appropriate languages. Currently the language services system in Victoria is fragmented. Language services need to be developed in both the areas of interpreting approaches and translating services.

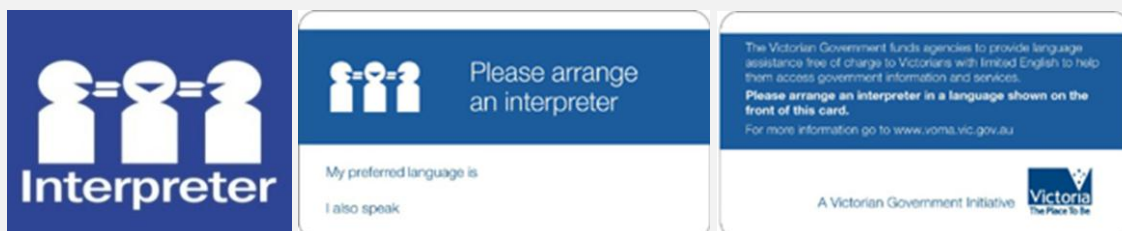
Interpreter Services

There is a need to train interpreters in how to work with people that have dementia. The use of accredited interpreters is a fundamental principle for effective communication with non-English speaking people. Interpreting for people living with dementia requires pre-briefing of the interpreters as they may not know the client has dementia until the actual meeting.

Additional training is needed for clinical, aged care and language services professionals (i.e. interpreters) in how to improve current services and improve cooperation between the professional roles. Non-English speaking people can become tense with doctors present so there needs to be some flexibility from the doctor in how to respond to this. Interpreters who have experience in dementia care and aged care bring an insightful understanding and are able to recommend appropriate approaches if the doctor is flexible, whilst staying within the boundary of the interpreter's professional role.

Fig. 14: Alzheimer's Australia Vic engages interpreters

It is important that people from non-English speaking backgrounds understand that interpreting services are available and services should ensure that they have access to services and that this is promoted through the following symbol. It is also appropriate to have an interpreter request card available for clients.



Interpreter symbol

Interpreter card

Source: Alzheimer's Australia Vic

Bilingual Staff

There is also an inverse issue here related to an assumption that because a bilingual aged care worker has the language, they will be able to build an effective relationship. This is not necessarily so. It is important to value human capacity to engage and communicate at a non-verbal level alongside language ability. Fundamentally this is about quality relationships, particularly in residential care. Workforce issues associated with how to use bilingual staff need to be considered.

Translating Standards

There should be a cultural translation of resources, not just a direct translation from English. The Royal District Nursing Service has produced a set of Translation Standards to guide the consistency and quality of translations. The standards define a clear process for the development of information for LOTE and ensure that the final material is acceptable to ethnic communities. Resources that meet the standard are given an 'electronic tick'. The system requires users to enter a Licence Agreement with the RDNS which holds copyright to the 'translation standards tick' trademark on its nationally translated publications.

Caution needs to be exercised in translated documents as some academic translations use a style of language that is not well understood by community members including community aged care workers. It is important to create translations in consultation with the ethnic community groups and not to rely solely on professional language services for example because the term 'carers' does not easily translate. Carers Victoria worked closely with the community to create a DVD that conveyed the meaning of the concept clearly. A similar approach could be applied to dementia related terminology.

4. Resourcing

Government departments are moving away from the model inherited from the post-war years to a more sustainable one in the early 21st century where clients move out of their traditional role as passive recipients to engaged consumers (Lenihan and Briggs 2011). Empowering, informing and resourcing are key ingredients for successful community engagement. A successful action plan requires governments, service providers and people from culturally diverse backgrounds to learn how to work together in the areas of health, ageing and caring. A plan of action that assigns responsibility for quality dementia care needs to build on what is already there and also to build real partnerships so they can work together with mutual trust.

4.1 Service Providers are Meant to Care

If service providers are meant to provide culturally relevant dementia care they need culturally relevant tools and resources. Staff working in dementia care, aged care and social support need communication cards and recipe books to help accommodate non-English speaking client needs. There are non-English speaking residents with dementia living in many aged care facilities around Melbourne. For example there are isolated older people of Serbian background in at least 20 residential care facilities. They cannot relate to the generic music and activities. Resources such as culture specific music DVDs and improved

partnerships between ethnic community organisations and residential care facilities would help address their social isolation.

4.2 Perceptions of Dementia in Ethnic Communities

Service providers in community aged care as well as residential aged care need information that will assist them to work with culturally diverse communities. An invaluable resource for service providers dealing with people from diverse backgrounds living with dementia has been the Alzheimer's Australia Vic *Perceptions of Dementia in Ethnic Communities* resource kit. Such resources require widespread promotion in the aged care sector.

Fig. 15: *Perceptions of Dementia in Ethnic Communities* resource kit – Alzheimer's Australia

The primary aim of the *Perceptions of Dementia in Ethnic Communities* project was to collect information around dementia perceptions in 12 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.

Source: Alzheimer's Australia Vic

4.3 Clearinghouse for Culturally Relevant Dementia Resources

Ethno-specific agencies and peak bodies such as Alzheimer's Australia Vic have produced a wide range of useful culturally relevant dementia care resources. To avoid duplication and maximise access to such resources a clearinghouse or central collection point of culturally relevant dementia care resources would be beneficial to service providers, volunteers and carers.

Alzheimer's Australia has produced a wide range of resources to support people with dementia, their families and carers. These are listed in Appendix 3 and include:

- Bilingual help sheets
- Perceptions of Dementia Kit
- *Understanding Dementia* DVD in nine languages
- DVD of RUDAS guide to administration and scoring

The DVD in nine languages is an important alternative medium for communicating with non-English speaking people with limited literacy. The *Understanding Dementia* DVD provides a good model for communicating the message to older people and their families however its content lacks culturally diverse situations that would make it meaningful to diverse cultural groups.

4.4 Diversity Workforce Development

Dementia care workers will be needed in increasing numbers throughout Australia and Victoria. International research indicates that the high turnover rates of health and aged care workers can be effectively addressed with improved training, better supervisor skills and more favourable working conditions. A workforce that is meant to care about culturally relevant dementia care requires adequate training in cultural competency as well as in understanding dementia. The recruitment and retention of bilingual and well qualified staff in the area of dementia care are essential to maintain a culturally responsive aged care workforce. There is a need for government incentives such as scholarships to encourage bilingual aged care staff.

The stakeholders in this consultation believe there is a lack of appropriately dementia trained staff in ethnic aged care services particularly in respite care. Ongoing training is needed for aged care workers to understand dementia issues in relation to culturally diverse clients as new immigrants are arriving from parts of the world where attitudes to ageing, health care and beliefs are quite different from those of earlier immigrants. Several ethno-specific residential care facilities in Victoria provide some best practice examples of culturally relevant dementia care programs and in residential and community care settings for example the *Host Home Program East* at Fronditha Care and staff training programs in dementia care at Jewish Care.

Victoria has a growing untapped market of culturally diverse people who are attracted to Aged Care Certificate training programs especially those delivered through certified Registered Training Organisations in ethnic and multicultural agencies. It is important that such bilingual workers with aged care qualifications also receive adequate training in dementia care.

Overseas qualified nurses and care staff from predominantly non-English speaking countries bring valuable diversity skills to the aged care industry. Cultural awareness training for local staff and newcomers would improve their workforce transition into the Australian system. Increasingly the residential care workforce is dominated by international students with short-term commitments. Essentially this is due to the chronic underfunding of sector awards. New ways need to be explored for developing systems that provide the possibility of direct recruitment from overseas of younger people from particular backgrounds with a commitment of five years minimum to work in the sector. Currently the balance of workforce from some communities is older and they struggle to manage the physicality of the job. Workforce development in Victoria is needed in the following areas:

- Training ethnic sector workers in dementia care
- Cultural competency training for the mainstream workforce
- Recruitment of bilingual people to work in dementia or residential aged care

5. Concluding Remarks

Quality dementia care is one of the biggest challenges faced by governments and service providers in the 21st century. They are meant to care about culturally relevant dementia care. Policy makers need to consider how they will go about empowering, informing and resourcing the health, aged care and dementia care sectors to respond to provide culturally responsive services to Victoria's ageing multicultural population.

The key to excellence in dementia care for non-English speaking people living with dementia, their families and carers is in increased community engagement. Developing partnerships of trust and mutual respect are crucial to providing cost effective and culturally responsive dementia care.

This discussion paper highlights some best practice examples in the ethnic and multicultural community aged care sector that could provide a model for other projects and community organisations. A priority is to ensure that perceptions of ethnic communities in relation to dementia and access to care are well understood by service in the aged care sector. The challenge is to provide adequate culturally relevant dementia care support for Victoria's ageing ethnic population. This paper highlights good culturally responsive dementia that is sporadic and has limitations.

The recommendations call for action in the areas of building on existing ethno-specific partnerships; well-coordinated and adequately resourced community education and information provision to non-English speaking people living with dementia. Culturally inclusive research is required in areas such as dementia diagnostic tools and new ways of empowering non-English speaking people with dementia. The ethnic and multicultural community organisations will be pivotal in any future research studies. The strategic directions of government policies and practice are paramount in ensuring that service providers develop sound culturally relevant dementia person-centred care plans. Empowerment is about a public engagement process where governments, service providers, culturally diverse clients and ethnic community organisations share the responsibility for quality dementia care in our ageing multicultural society.

Appendix 1

Questions addressed by the eccv Dementia Working Group

- What are pertinent issues regarding dementia support for people in ethnic communities from non-English speaking backgrounds from culturally and linguistically diverse backgrounds?
- What culturally appropriate support services, initiatives, projects and resources do you know of that are working well?
- What are current weaknesses, service gaps and concerns?
- What are some real-life stories that you know of?
- What opportunities can we build on e.g. policies, research, pilots, models?
- What are the threats, risks, barriers to improving support services, tools and resources?
- What actions can we suggest in any of these areas?
- What policy recommendations can we make?

Appendix 2

Prevalence estimates by Victorian Department of Health Regions

The Access Economics report also provides estimates of the numbers of people with dementia living in metropolitan and regional Department of Health Regions.

DoH Region	2011	2020	2030	2040	2050
Eastern Metropolitan	13,660	18,941	26,270	35,821	44,061
North & West Metropolitan	16,841	25,060	36,834	51,291	64,545
Southern Metropolitan	16,701	23,294	33,982	47,237	59,296
Barwon South-Western	5,794	8,137	11,589	16,030	20,294
Gippsland	4,050	5,947	8,703	12,157	15,468
Grampians	3,336	4,762	6,830	9,439	12,019
Hume	3,774	5,439	7,825	10,706	13,281
Loddon Mallee	4,718	6,752	9,754	13,592	17,425
Total Victoria	68,876	98,332	141,788	196,271	246,389

Table 2: Estimated numbers of people with dementia by Department of Health Regions, 2011 – 2050

Source: Access Economics (2010)

Appendix 3

Fig. 16: Useful Dementia Resources at Alzheimer's Australia

Alzheimer's Australia has a wide range of resources to support people with dementia, their families and carers. These are available at www.alzheimers.org.au and include:

Selected dementia help sheets in 27 languages: Arabic, Armenian, Chinese, Croatian, Dutch, Finnish, German, Greek, Hindi, Hungarian, Indonesian, Italian, Japanese, Khmer, Korean, Lao, Latvian, Macedonian, Malay, Maltese, Polish, Portuguese, Romanian, Russian, Serbian, Spanish, Tagalog, Turkish, Ukrainian and Vietnamese.

Alzheimer's Australia has also produced tip sheets on dementia risk reduction under its *Mind your Mind* program. Tip sheets are available for download in Arabic, Assyrian, Chinese, Croatian, Finnish, Greek, Italian, Lao, Macedonian, Romanian, Russian, Serbian, Spanish, Turkish and Vietnamese.

www.mindyourmind.org.au

Source: Alzheimer's Australia Vic

References

- Ahmed, B, 2010 in eccv Ageing and Cultural Diversity Strategy
- Australian Bureau of Statistics, 2007. *2006 Census of Population and Housing*. Canberra: Australian Bureau of Statistics
- Access Economics 2010 *Projections of dementia prevalence and incidence in Victoria 2010-2050: Department of Health Regions and Statistical Local Areas, Alzheimer's Australia Vic*
- Access Economics 2006 *Dementia prevalence and incidence among Australians who do not speak English at home* Commissioned by Alzheimer's Australia
www.alzheimers.org.au/common/files/NAT/20061124_Nat_AE_FullDemPrevAustDoNotSpkEngHome.pdf
- Downs, Myrna and Bowers, Barbara eds. 2008 *Excellence in Dementia Care*, McGraw Hill Open University Press
- Gibson, D, Braun P, Benham, C, and Mason, F. 2001, *Projections of Older Immigrants: people from culturally and linguistically diverse backgrounds, 1996-2026*, Australia AIHW cat. no. AGE 18
- Gross McAdam, Julie. 2009 *Chocolate works just as well as art anyway*, paper presented at the 4th International CECD Conference in Adelaide, SA Australia by PhD candidate, School of Education, Victoria University
- Hall, W, 2008 *Dementia and Spirituality: Seminar Notes*, Lifecare South Australia (Unpublished)
- King, U, *Spirituality, ageing and gender* in Jewell, A (Ed) 1998 *Spirituality and Ageing*, London: Jessica Kingsley Publishers.
- Lawrence, John, 2011a Paper on Arts and Dementia submitted for Masters in Health Promotion Victoria University (unpublished)
- Lawrence, John, 2011b Paper on Spirituality and Dementia submitted for Masters in Health Promotion Victoria University (unpublished)
- Leniha, D and Biggs, L, 2011 *Co-Design: Towards a New Service Vision for Australia*
www.humanservices.gov.au/spw/corporate/publications-and-resources/resources/co-design-toward-a-new-service-vision-for-australia.pdf
- Lister S, Benson C, 2006 *Comparative analysis of dementia and ethnicity in the New South Wales Aged Care Assessment Program: 1996 and 2001*. *Australasian Journal on Ageing* 25(1):24-3.
- LoGiudice, D, Hassett, A., Cook, R, Flicker, L. & Ames, D. 2001 *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*, 16, 327-334.
- Low, L F, & Anstey, K J, 2009 *Dementia Literacy: recognition and beliefs on dementia of the Australian public*. *Alzheimer's & Dementia*, 5, 43-49.
- Low, L.F, Kaarin, A, Lackersteen, S., & Camit, M. 2011 *Help-seeking and service use for dementia in Italian, Greek and Chinese Australians*. *Ageing and Mental Health*, 15(3), 397-404.
- Low, L.F, Draper, B, Cheng, A., Cruysmans, B., Hayward-Wright, N., Jeon, Y. H., Lo Giudice, D., Wu, H. Z. Y., Zogalis, G, and Brodaty, H. 2009 *Policy and Practices Updates: Future research on dementia relating to culturally and linguistically diverse communities*. *Australasian Journal on Ageing*, 28 (3), pp. 144-148

Morley, Alison; Redburn, Diane; Jennison, Wendy; Mascal, Jackie; Fryer, Jane; Sanderson, Helen and Bailey, Gill 2010 Using Person Centred Thinking to Implement Dementia Care Mapping UK www.helensandersonassociates.co.uk/media/38803/usingpcttoimplemendementiacaremapping%20%282%29.pdf

Mukadam, N, Cooper, C, Basit, B, & Livingston, G, 2011 Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, 23, 1070-1077.

Mukadam, N, Cooper, C, & Livingston, G, 2010 A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, 26, 12-20.

Radermacher, Harriet; Feldman, Susan; Browning Collette. 2008 *Review of Literature Concerning the Delivery of Community Aged Care Services to Ethnic Groups – Mainstream Services versus Ethno-specific: It's not an Either Or*, Healthy Ageing Research Unit, Monash University, report commissioned by Ethnic Communities' Council of Victoria

Radermacher et al 2010 *Practising Positive Partnerships in the Ethnic and Multicultural Community*, Healthy Ageing Research Unit, Monash University, report commissioned by Ethnic Communities' Council of Victoria

RDNS translation standards poster: *A process for developing culturally and linguistically appropriate health education materials*, accessed 8.8.2011 www.rdns.com.au/what_we_do/Initiatives/Documents/Translation%20Standards%20Poster.pdf

Teshuva, K and Wells Y. 2010 *Caring for Older Survivors of Genocide and Mass Trauma*, Lincoln Centre for Research on Ageing, AIPCA, La Trobe University www.latrobe.edu.au/aipca/aipc_pdf_docs/aged_care_older_survivors.pdf

UNSW and Dementia Collaborative Research Centres. 2009 *Strategic Directions in CALD Dementia Research in Australia – An Australian Government Initiative*



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