CULTURAL NEWS

APRIL 2014 (VOLUME 9, ISSUE 1)

IN THIS ISSUE

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>From the CEO</td>
<td>2</td>
</tr>
<tr>
<td>Spanish Speaking Community says ‘Bienvenido’ to BrainyApp</td>
<td>5</td>
</tr>
<tr>
<td>New Website to Help People Plan Ahead</td>
<td>6</td>
</tr>
<tr>
<td>The Network</td>
<td>6</td>
</tr>
<tr>
<td>Talking About Alzheimer’s Across Australia</td>
<td>7</td>
</tr>
<tr>
<td>Cultural Diversity in Ageing 2014 Conference</td>
<td>8</td>
</tr>
<tr>
<td>The 3rd International Conference on Ageing in a Foreign Land</td>
<td>9</td>
</tr>
<tr>
<td>Incontinence Outreach in CALD Communities</td>
<td>10</td>
</tr>
<tr>
<td>The M Training is Coming... Get on Board</td>
<td>12</td>
</tr>
<tr>
<td>Global Perspective</td>
<td>13</td>
</tr>
<tr>
<td>Weblinks</td>
<td>13</td>
</tr>
<tr>
<td>Ageing Well in a Culturally Diverse Australia</td>
<td>14</td>
</tr>
<tr>
<td>Contact</td>
<td>14</td>
</tr>
</tbody>
</table>

UNDERSTAND ALZHEIMER’S EDUCATE AUSTRALIA
FIGHTDEMENTIA.ORG.AU

CULTURAL NEWS IS AN INITIATIVE OF THE AUSTRALIAN GOVERNMENT
2014 has been a very busy year so far, beginning with launch of the next phase of Alzheimer’s Australia’s Fight Dementia Campaign – Creating a Dementia-Friendly Australia. This latest campaign presents a vision for what the Government could achieve in tackling dementia over the next three years, including development of a national program of dementia advisors. This program would focus initially on supporting people from special groups, including those from Culturally and Linguistically Diverse backgrounds, providing dementia-specific respite care, improving quality of residential aged care, and supporting the development of dementia-friendly communities. The latest Fight Dementia Campaign document can be found here.

End of Life Care
On 12 February, Alzheimer’s Australia and Palliative Care Australia co-sponsored a Parliamentary Friends Meeting about dementia and palliative care. Kevin Andrews, Minister for Social Services, opened the event where Ita Buttrose, National President of Alzheimer’s Australia, and Professor Rod MacLeod, Conjoint Professor in Palliative Care at the University of Sydney, spoke to nearly 100 attendees about the importance of appropriate end-of-life care access for people with dementia.

At this event we launched the results of a national survey report, End-of-Life Care for People with Dementia, commissioned by Alzheimer’s Australia, from Piazza Research with support from the Bupa Health Foundation. The report explored the experiences of both consumers and health workers and identified a number of barriers to quality end-of-life care for people with dementia. These included a lack of advance care plans, poor understanding of legal options, inadequate pain management, and lack of access to hospices, palliative care specialists or community palliative support.

The survey found that for people from CALD backgrounds access to appropriate end of life care was even more difficult. The survey found:
- 43% of CALD family carers were dissatisfied with the care at end of life (compared to 26% of all carers)
- Nearly a third (30%) of CALD family carers were dissatisfied with adherence to end of life care wishes of the person with dementia (compared to 20% of all carers)

Less than half (46%) of care professionals had specific training in providing end of life care for people from CALD backgrounds.

Find out more about the survey results here.

Making Australia Dementia Friendly
Supporting the development of dementia friendly communities and organisations will be a key focus for Alzheimer’s Australia over the coming year. We will be encouraging and supporting key organisations such as banks and retail chains to provide dementia training to their frontline staff to ensure they know how to communicate effectively with a person who has a cognitive impairment. Additionally, we will be supporting communities to promote and encourage engagement of people with dementia in the local community including through voluntary and part time work, as well as in social activities such as choirs, walking groups and memory cafes. We will be working with the National Cross Cultural Dementia Network to look for opportunities to develop this approach in multicultural communities.
At the start of April we hosted Rachael Litherland, an expert on dementia friendly communities from the UK who presented to audiences across Australia about the importance of involving people with dementia from the start of establishing dementia-friendly communities and organisations. Rachael shared the lessons learnt to date from the UK experiences and explored what dementia-friendly means to people living with dementia in the Australian context.

As part of this work, we are conducting a survey on the experiences of people with dementia in their local communities to support our dementia-friendly work. I would encourage anyone with dementia to take part. The survey can be accessed at survey or hard copies can be obtained from Kylie Watkins (Kylie.Watkins@alzheimers.org.au) or (02) 6278 8934.

The Voice of People with Dementia
The Alzheimer’s Australia Dementia Advisory Committee continues to develop and identify priorities from the perspective of people living with dementia. The group has recently produced a simple guide on how to best communicate with a person with dementia called “Talk to Me” (available here).

Members of our groups are also involved internationally in advocating for the needs of people with dementia and Kate Swaffer, the Chair of the Alzheimer’s Australia Dementia Advisory Committee, was recently involved in setting up the Dementia Alliance International, a non-profit group of people with dementia from the USA, Canada, Australia and other countries that seek to represent, support, and educate others living with the disease.

We are also establishing a broader network of people with dementia and carers across Australia to support the work of our advisory committees. If you know anyone who would be interested in participating in one of our networks please contact Samantha Blake at Samantha.Blake@alzheimers.org.au or (08) 6271 1007 for more information.

Senate Report on the Care of People with Behavioural Symptoms of Dementia
The Senate Committee on Community Affairs released a report last week on their Inquiry into the Care and Support of People with Dementia and Behavioural and Psychiatric Symptoms. The comprehensive report provides a road-map for improving the quality of dementia care in Australia. The report’s recommendations focus on the need to improve access to dementia-specific respite, primary care, quality of residential aged care services, and to reduce the use of restraint in aged care services.

The Senate Committee’s recommendations on the use of restraints are consistent with those in the Alzheimer’s Australia report launched on the 10th April, The Use of Restraint and Psychotropic Medication in People with Dementia, including the need for training and education for GPs and the aged care workforce on appropriate care for people with behavioral symptoms of dementia, and mandatory reporting on the rate of use of psychotropic medications and physical restraints within aged care facilities. Both reports recognised that for people from CALD backgrounds, difficulty communicating their needs and getting access to translation services and culturally appropriate care may exacerbate behavioural symptoms or make it difficult for staff to understand the cause of the behaviour. This highlights the importance in ensuring access to culturally and linguistically appropriate care and support for all people with dementia.
I recently spoke with the ABC program Lateline about the use of psychotropic medications in aged care facilities and alternative methods to manage behavioural symptoms of dementia. Alternative methods of care include providing purposeful activities for the person, understanding the person’s tendencies and personality, as well as adapting the environment to be less confusing. Link to the Lateline episode outcome for people with dementia. For the full details of the campaign visit our website here.

It is pleasing that the main recommendations of the report support the focus areas of our most recent Fight Dementia Campaign document. Alzheimer’s Australia will continue to lobby for changes in these areas to achieve a better outcome for people with dementia. For the full details of the campaign visit our website here.

Future Priorities
The rest of the year will be very busy as well, with forums planned on dementia and hospitals, our response to the Federal Budget, preparations for Dementia Awareness Month and a second international speaker on dementia friendly communities, and our continued involvement in the implementation of the 2012 Aged Care Reforms.

Glenn Rees AM
Chief Executive Officer
Alzheimer’s Australia
Spanish-Australian comedian and actor Simon Palomares recently launched the Spanish language version of the award-winning **BrainyApp**. Developed by Alzheimer’s Australia in partnership with the Bupa Health Foundation, the original **BrainyApp** was launched in late 2011 as the world’s first risk reduction app in the global fight against dementia.

The new Spanish version, **BrainyApp español**, is the first non-English translation of **BrainyApp**, which helps users to monitor and improve the physical, mental, dietary and social aspects of their lifestyle. “As a Spanish speaker myself, I am delighted that this innovative and vital resource has been made accessible to the Spanish-speaking community,” Simon said.

Based on scientific research that links brain health to a reduced risk of developing dementia, **BrainyApp español** assists people in monitoring and improving their Brain-Heart health. “**BrainyApp español** is a convenient tool to help the Spanish speaking community rate and track their brain health’, said Alzheimer’s Australia’s National Dementia Risk Reduction Manager, Suha Ali.

Being brain healthy is important at any age, particularly as changes in the brain that lead to dementia can start when people are in their 20s, 30s and 40s. **BrainyApp español** has a range of different activities to help guide people on what they can do to improve their brain health. While many people may be aware of what they need to do to reduce their risk of heart disease and diabetes, many are not aware that these same lifestyle choices may also lower their risk of developing dementia.

**BrainyApp** and **BrainyApp español** allows users to take a Brain-Heart Health Survey about their diet, exercise patterns and lifestyle. It then provides suggestions and ideas about how to improve on these, and includes brain games that encourage users to build Brain-Heart points.

The content of the original **BrainyApp** was translated into Spanish, in collaboration with Sanitas (affiliated with Bupa in Spain ). **BrainyApp español** is available as a free download from the App Store for users of iPhone, iPod and iPad devices as well as for Android phones and tablets from the Google Play Store. Simply search ‘BrainyApp’ in either store. **BrainyApp** is based on the scientific evidence presented in Alzheimer’s Australia’s **Your Brain Matters: The Power of Prevention**. For more information, go to [yourbrainmatters.org.au](http://yourbrainmatters.org.au)
NEW WEBSITE TO HELP PEOPLE PLAN AHEAD

Alzheimer’s Australia has launched a new program and website – called Start2Talk – that helps people plan ahead for their future healthcare, lifestyle and financial decisions. It also helps carers who are making decisions with, or for, someone else. The website is designed from the consumer point of view, and has information and links for all States and Territories. The site includes a number of practical worksheets that help a person work through the process of planning ahead. The worksheets can be completed and stored online or printed out and done by hand. The website is available at www.start2talk.org.au

The developer of the website – Dr Chris Shanley – consulted with the National Cross Cultural Dementia Network to try to make it as culturally accessible as possible. As the site requires a level of English language proficiency, it was acknowledged that it will not be directly relevant to many people from CALD communities. However, the approach taken has been to include a section for multicultural workers to encourage and assist them to spread the word about planning ahead within their communities.

The website also includes translated material in 30 languages. A DL-size brochure and an Emergency Contact card for wallet or purse are available as promotional resources. Contact Chris Shanley on 0423 842 781 or info@start2talk.org.au to get copies of these resources or to make any enquiries about the Start2Talk website.

Chris Shanley
Manager, Aged Care Research Unit, Liverpool Hospital

‘Most of us would prefer not to think about becoming unwell or developing dementia, but it is important to have plans in place in case we do. Start2Talk has been developed by Alzheimer’s Australia and our partners to help all Australians start the conversations involved in planning ahead.’ - Ita Buttrose AO OBE
UPCOMING CONFERENCES

Cultural Diversity in Ageing 2014 Conference: Shaping Inclusive Services  
MELBOURNE 12-13 June 2014  
For more information click

Risky Business 2  
SYDNEY 26-27 June 2014  
For more information click

Dementia and Recreation National Conference 2014  
MELBOURNE 20-21 August 2014  
For more information click

Dementia and Community Care  
MELBOURNE 30-31 October 2014  
For more information click

47th Australian Association of Gerontology National Conference  
ADELAIDE 26-28 November 2014  
For more information click

Dementia Congress  
MELBOURNE 20-21 February 2015  
For more information click

International Conference on Ageing in a Foreign Land  
ADELAIDE 24-25 June 2015  
For more information click

The event will inspire organisational leaders, direct care service providers, policy makers, researchers and advocates to embrace culturally inclusive initiatives and ensure that their work meets the needs of older Australians from culturally and linguistically diverse backgrounds. The broad range of themes will include research informing practice, consumer directed care, policy development and implementation, community engagement, innovative service models and much more.

This year’s conference theme Shaping Inclusive Services will showcase culturally inclusive measures and models designed to ensure quality outcomes for older Australians from culturally and linguistically diverse backgrounds.

Keynote speakers and themes at the conference include:

- Dr Sally Goold OAM - Aboriginal and Torres Strait Islander ageing communities and services provision
- Dr Olga Kanitsaki AM – Excellence in culturally inclusive initiatives
- Associate Professor Debra King – Workforce diversity and implications for service provision
- Tony Briffa – Gender identity and community belonging
- Professor Graeme Hugo and Dr Loucas Nicolaou - Compiling evidence, identifying the gaps and making research accessible to providers of services to people from culturally and linguistically diverse backgrounds
- Dr Christina Ho – Diversity within diversity
- Jane Lewis – ‘Workforce diversity’ workshop facilitator

Nominations for the inaugural Centre for Cultural Diversity in Ageing Excellence Awards are also now open, with winners announced at the conference. This unique award honours the not-for-profit sector, aged care services and individual excellence in the delivery of services and support to older Australians from culturally and linguistically diverse backgrounds. All organisations and individuals are encouraged to nominate their service or project, or an individual who deserves recognition.

Register now to attend this much anticipated national event! For more information, visit www.culturaldiversity.com.au or call 03 8823 7979.
The 2015 conference will be hosted by LOGOS Australian Centre for Hellenic Language and Culture, Flinders University and The Foundation for Hellenic Studies and will include keynote speakers; Dr Alexander Kalache, President of the International Longevity Centre Brazil and Dr Briony Dow, President of the Australian Association of Gerontology, Mr Joseph Caputo OAM JP, Chair, Federation of Ethnic Communities Council of Australia and Professor Graeme Hugo, Director of the Australian Population and Migration Research Centre at the University of Adelaide.

The Ageing in a Foreign Land conference will address the needs of the migrant diaspora with regard to ageing and health, service provision, language and cultural identity, and issues of Greek and other Culturally and Linguistically Diverse communities in Australia and overseas.

We welcome attendance and participation from academics, researchers, practitioners, policy makers, service providers and aged care workers. It is an unique opportunity for institutions and individuals to be part of a very exciting event, extend their learning, share their experiences with others, promote their activities and create a dynamic and vibrant network to further advance their knowledge and careers.

The motto of our conference is: "Real people with real experiences".

A defined program will be dedicated to presentations on Ageing, we are particularly (but not exclusively) seeking papers and posters on:

| Are you crazy? Mental health wellbeing and lifelong education in the community | Being alert and check the facts: Anti-ageing rhetoric/industry and ageing realities | Claiming the territory: Connect, be active, keep learning, take notice, give back to the communities |
| Community oriented linguistic and cultural programs/activities. Positive ageing and culturally appropriate care | Cutting edge: Who is making decisions about CALD including medical and transitional options? | Families and ageing migrants: Intergenerational relationships and care in the community |
| Focus point: Experiences of ageing among the Hellenic and other Diasporas | Impact on CALD aged care in regard to the transfer of responsibility and changes in policy settings | Is someone out there to tell me what to do? Bureaucratic barriers and access to services for ageing migrants |
| New challenges for CALD people? Person/Consumer directed care | “Old” Stories: I can hear your voice because the children are listening | Supporting professional staff: challenges, positive experiences and leadership initiatives |
| Tangible realities: Demographics, transport and Housing | The Law is watching you: Human rights and issues of abuse | Work together: Education, training and re-training. Interdisciplinary engagement and research on migrant ageing |

For further information E: ageingconference@flinders.edu.au
INCONTINENCE OUTREACH IN CALD COMMUNITIES

Incontinence doesn’t discriminate; about one in four Australians (or 4.8 million) over the age of 15 experience bladder or bowel control problems, affecting men and women of all ages, creeds and races. Asking for help to manage incontinence can be difficult; in fact research shows the majority of people (70 per cent) affected by incontinence don’t discuss the issue with anyone.

So imagine how challenging it is for people from culturally and linguistically diverse (CALD) communities who have, not only the language barrier to overcome, but the embarrassment and associated cultural stigma.

The prospect becomes even more daunting if the person is further disadvantaged by conditions such as dementia or mental illness, which, like incontinence, don’t discriminate.

A 2011 report by the Victorian Continence Resource Centre found that the awareness of the prevention and management of incontinence in CALD communities was disturbingly low. It also revealed that many ethnic groups had false beliefs that it was a normal, untreatable part of ageing or having a baby.

This information, combined with the Continence Foundation of Australia’s concern about the relatively small number of calls to the National Continence Helpline from CALD community members, gave rise to the Continence Foundation’s latest national program, Incontinence Outreach in CALD Communities, launched in June this year.

The Continence Foundation’s chief executive officer Barry Cahill said that reaching out to all Australians, including those from CALD communities, was critical because of the condition’s wide-reaching consequences. “Its impact is far-reaching and not limited to the inconvenience of managing bladder or bowel leakage. There are also deeper social effects, including psycho-social problems arising from lowered levels of employment, exercise, depression and social isolation,” Mr Cahill said.

Current research suggests that people who are incontinent are at a higher risk of suffering from a depressive illness. There is also research suggesting common biochemical factors that link depression and incontinence.

Recent studies at the University of Adelaide revealed that about 20 per cent of the population affected by incontinence suffer from depression, much higher than the general population at about six per cent. According to Jodie Avery at the University’s School of Population Health and School of Medicine, this is a particular problem amongst females, with approximately 35 per cent of incontinent women suffering from depression. Incontinence also lowers productivity and length of participation in the workforce. Its ramifications spread into people’s social and volunteer activity in the community.

Incontinence also lowers productivity and length of participation in the workforce. Its ramifications spread into people’s social and volunteer activity in the community.

The recently released Australian Institute of Health and Welfare’s (AIHW) report Incontinence in Australia, revealed that, in 2009-10, only 26 per cent of people with severe incontinence aged 15 to 64 participated in the workforce, compared with 56 per cent of the population without incontinence problems. “Severe incontinence can profoundly affect the quality of life of those who experience it,” AIHW spokesperson Dr Pamela Kinnear said.
A person becoming incontinent can often be the tipping point for their carer handing their care over to a nursing home. Faecal incontinence is one of three major causes (along with decreased mobility and dementia) for admittance to a residential aged care facility, with 25 per cent of nursing staff time spent directly with the dealing with the consequences of incontinence.

The Continence Foundation’s Incontinence Outreach in CALD Communities has introduced a range of initiatives to reach CALD communities, their carers and health professionals. Its message is simple and clear; that incontinence is not a normal part of life, it can be treated, better managed or cured in most cases, and help is available.

As part of the campaign, the Continence Foundation has introduced new web pages in 21 languages, soon to expand to 28 languages. Each page links to 17 bilingual fact sheets on topics such as bedwetting, pregnancy, pelvic floor muscles, prostate issues and incontinence products.

The pages, at www.continence.org.au/other-languages, also feature videos and audio translations of all fact sheets.

The Continence Foundation has also produced new interpreting guidelines for interpreters working in a continence assessment. They are:

- Guidelines for conducting presentations with an interpreter;
- Guidelines for health professionals – working with interpreters in a continence assessment; and
- Guidelines for interpreters – what to expect in a continence assessment.

These can be downloaded from the Resource section of the Continence Foundation’s website under the Professionals topic at www.continence.org.au/resources.php

“The Continence Foundation is hopeful these initiatives will support interpreters and health professionals as they go about their work in sensitive continence assessment settings,” Mr Cahill said.

As well as these initiatives, a recent extensive and targeted advertising campaign encouraging members of CALD communities to access the National Continence Helpline (1300 33 00 66) via the Telephone Interpreter Service (131 450) has been effective, with a sharp rise in the number of calls to the helpline from CALD community members.

By providing these resources, it is hoped the message about the prevention, management and treatment of incontinence will reach far and wide into the culturally and linguistically diverse Australian community.

For more information go to www.continence.org.au

Contact: Maria Whitmore
03 9347 2522
THE M-TRAIN IS COMING... GET ON BOARD!

**M-TRAIN**: A Multi-national Randomised Trial of Long-Term Brain Training in Daycare Centres for the Prevention of Dementia and related Disease Burden

**What is it?**
M-TRAIN is a clinical trial of long-term computerized cognitive training (so-called ‘brain training’) in daycare centres, targeting older frail clients who do not have dementia.

Our aim is to enrol 100 daycare centres, and over 2000 clients, from around the world. Daycare centres in Sydney, San Francisco (USA) and Hong Kong are already on board the M-TRAIN!

**Why are we doing it?**
Our lab-based research shows that brain training – when structured correctly and supervised by a skilled trainer – can improve overall cognitive function in older individuals. We therefore wish to determine whether such an approach can be deployed in the real world to delay the onset of dementia. Given that older frail are at high risk of dementia, they represent the ‘ideal’ target to test this idea. M-TRAIN will be a world-first.

**How will it work?**
We are currently in the planning and funding stage. Upon commencement, daycare centres will be “randomised” (like a flip of a coin) as being either a ‘business-as-usual’ or ‘brain training’ site. If a centre is selected as a brain training site, staff will be professionally trained on how to supervise and implement brain training with their clients. We will supply new computers and brain training software. Our staff will then carry out baseline cognitive testing of those clients who agree to participate, and training can then begin. The idea is to replace one current daycare centre activity with our brain training program. Our staff will be available to help support centre staff throughout the study. Finally, our staff will carry out repeat cognitive testing over the 4-year follow-up period to determine whether or not the intervention has been effective.

**How can a daycare centre be involved?**
For the moment we are seeking in-principle commitment from centre director/managers’. Over the coming months we will be carrying out information sessions and progressing to planning and logistical discussions.

**What’s in it for your daycare centre?**
We are passionate that our science is translated into the real world. This is a chance for daycare centres to put their centre at the ‘centre’ of a world-first trial. Also, centre staff will be up-skilled on how to deliver a scientifically-proven approach to brain training. Furthermore, if a centre is selected as a brain training site, it will receive new computers and brain training software to keep!

**More information?**
Centres interested in being involved in the M-TRAIN should contact the project’s principal investigator, Associate Professor Michael Valenzuela on Michael.valenzuela@sydney.edu.au or phone the M-TRAIN Coordinator, Amit Lampit on 0401 858 616.
The March 2014 issue of *Global Perspective* is now available.

**Read Global Perspective now**

This issue includes news:

- ADI and associations lead civil society response to G8 dementia summit
- A new report on nutrition and dementia
- Update on the rising impact of dementia worldwide

Alongside regular features including a carer's story, living with dementia, a research update and a profile of an ADI member association.

To subscribe to the *Global Perspective* mailing list click here.

---

**WEBLINKS**

Alzheimer’s Australia  
[www.alzheimers.org.au](http://www.alzheimers.org.au)

Alzheimer’s Disease International  
[www.alz.co.uk](http://www.alz.co.uk)

Australian Government  

Australian Multicultural Foundation  
[www.amf.net.au](http://www.amf.net.au)

Centre for Cultural Diversity in Ageing  

Federation of Ethnic Communities Council (FECCA)  
[www.fecca.org.au](http://www.fecca.org.au)
AGEING WELL IN A CULTURALLY DIVERSE AUSTRALIA

An Intergenerational Perspective

A new study by a team of researchers from the University of Adelaide and Flinders University aims to give voice to older Culturally and Linguistically Diverse (CALD) individuals along with the younger Australian-born generations, who provide care and assistance to the older members of their family, to understand what ‘ageing well’ means to them. The uniqueness of this study is the comparison across generations and cultures about the expectations of informal and formal aged care provision, and what is required to ensure that people from CALD backgrounds have opportunities to age well.

In late 2013 a pilot study was carried out across Adelaide, Brisbane and Darwin within the Greek community. Overall, 96 interviews were conducted across three generations, including 28 ‘complete families’ where one family member from each generation was interviewed. Preliminary results highlight the importance of family in provision of informal care, with formal services seen as a last resort. Low levels of education combined with limited English proficiency (spoken and written) hampered access to services. Strong emotional and cultural ties to Greece were evident but participants generally acknowledged that life in Australia has been good. Good health, financial security and close family ties were considered important aspects of ageing well.

The research group are intending to expand the scope of this project to cover a range of CALD population groups as well as gaining insights from aged care service providers from both culturally specific organisations and ‘mainstream’ service providers in the near future. For more information about this project please contact: Dr Helen Feist at helen.feist@adelaide.edu.au

CONTACT

Any questions or comments are welcome.

To subscribe/unsubscribe or if you have any information you would like to see included in future editions please contact:

E: nccdn@alzheimers.org.au
P: (08) 83722140

NATIONAL DEMENTIA HELPLINE
1800 100 500