On 20th April 2012, the Federal Government released its aged care reform package “Living Longer. Living Better”. The package aims to create a more equitable and reliable aged care system nationally. The reforms also outline the Government’s plan to provide $268.4 million over this period to tackle dementia. The incidence of dementia is increasing with figures indicating that 280,000 people are currently living with dementia with the rate expected to grow to nearly 1 million by 2050.

As a part of the package, the Government has outlined its intention to expand its support of Australians from diverse backgrounds with $192.0 million to be spent in order to provide people from diverse backgrounds with better access to aged care services.

For Aboriginal and Torres Strait Islander people, the reform package will provide $43.1 million to create an extra 200 aged care places in the National Aboriginal and Torres Strait Islander Flexible Aged Care program, in addition to the 675 currently available, to allow more Aboriginal and Torres Strait Islander people with complex high care needs to stay close to their family and country in culturally appropriate care. This funding is in addition to the projected $112.5 million for existing Aboriginal and Torres Strait Islander Flexible Aged Care program.

A number of other key areas relevant to Aboriginal and Torres Strait Islander communities will also receive additional funding including:

• Sustainable aged care services in regional, rural and remote areas ($108 million) – as the delivery of aged care services is typically more expensive in these areas, eligible providers can receive a viability supplement on top of existing funding. Providers offering care to specific groups who may be vulnerable including Aboriginal and Torres Strait Islander people and older people who may be at risk of or are homeless will also be paid a viability supplement.

• Better support for those with younger onset dementia ($23.6 million) – further develop the National Dementia Support Program to enhance access to services with a single point of contact to assist those with younger onset dementia, their family and carers.

Effective Consumer Engagement in the Aged Care Process, released on 9th April 2012, by the Minister for Mental Health and Ageing, The Hon Mark Butler, outlines a host of failings in dementia care. The DoHA (Department of Health and Ageing) commissioned Alzheimer’s Australia to carry out a number of community consultations, sixteen in total, nationwide. The resounding message was that the aged care system is not working for people with dementia and especially for those from diverse communities.

An Indigenous consultation was held in Alice Springs with a number of themes emerging including:

- **Education/Awareness**: many people in Indigenous communities have a different understanding of dementia than the broader community with dementia sometimes equated with ‘madness’,
- **Access to services**: lack of services in remote areas and the necessity for mobile medical services,
- **Younger Onset Dementia**: concerns regarding the higher prevalence of YOD in Indigenous communities,
- **Indigenous culture**: health care systems not fitting in with Indigenous culture and the need for remote area nurses so Indigenous people do not have to leave their community to access services,
- **Workforce**: more care staff needed, especially Indigenous workers, and more incentive to join the health workforce,
- **Residential care**: issues surrounding the quality of residential aged care.


‘When Aboriginal people leave their community there is a huge void. Country heals people, it is their medicine. When they are back there their whole being, and essence of what makes them Aboriginal is healed. People desire to get back as soon as possible’. (Effective Consumer Engagement in the Aged Care Process, 2011, p.155).

Elder Abuse – A Cause for Action

The Australian Association of Gerontology NT will be holding a one day Elder Abuse conference in both Alice Springs and Darwin. The conferences, to be held in September, aim to bring together practitioners and experts in the field of aged services with the hope of improving service delivery in the NT, particularly for Aboriginal people. It is hoped the conferences will provide participants with an opportunity to learn and share knowledge of issues involving Elder abuse as well as provide a chance to establish new relationships and links. All health practitioners, advocates, students and stakeholders across the NT are encouraged to attend. The details are yet to be finalised, however, it is anticipated that some key speakers will include the Hon. Susan Ryan AO, the Federal Age Discrimination Commissioner (TBC) and Assoc. Prof Dale Bagshaw from UniSA (TBC). Please note the venue information below:

**ALICE SPRINGS**
Wednesday 5th of September 2012
(8.00 a.m. – 4.00 p.m.)
Venue: Witchetty Room, Araluen Arts Centre
Opening: Hon Warren Snowdon (Invitation extended) Federal Minister for Indigenous Health
Welcome to Country: Dr Patricia Miller AO

**DARWIN**
Friday 7th September 2012
(8.00 a.m. – 4.00 p.m.)
Venue: Mal Nairn Auditorium, CDU
Opening: Hon Rob Knight (Invitation extended) NT Minister for Senior Territorians and Attorney General
Welcome to Country: Bilawara Lee

If you wish to attend or require further information, please contact the Event Manager Natalie Bell at events@associatedadvertising.com.au

National Dementia Helpline 1800 100 500
www.fightdementia.org.au
NATSIDAG: LOOKING TO THE FUTURE.
BY KERRY ARABENA
CHAIRPERSON

In April 2006, Australian Health Ministers endorsed a National Framework for Action on Dementia, providing a system through which Governments at all levels could formally share ideas and develop a national vision for action. This framework identified five priority areas, and Aboriginal and Torres Strait Islander issues were specifically addressed under Priority 3: Access and Equity.

A two-day National Indigenous Dementia Workshop was held in November 2006 with over 30 participants in attendance to discuss whether the issue of dementia was a sufficient priority for Aboriginal and Torres Strait Islander people to take action and to establish what that action might be. The attendees agreed that dementia needed to be addressed to enhance community Elder’s capacity to age successfully into the future. A wellness approach was seen to be necessary to address the issue of dementia along with other health conditions that compromise Aboriginal and Torres Strait Islander people’s reaching the age of 75.

One of the key recommendations from the 2006 workshop was the founding of the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) which would provide advice to Alzheimer’s Australia in the development and delivery of a National Framework for Action to address dementia in Aboriginal and Torres Strait Islander communities and incorporated six priority areas: 1) community awareness and prevention, 2) care and support, 3) research, 4) diagnosis, referral and treatment, 5) workforce issues, and 6) partnerships and collaborations.

We have come a long way since 2006 and through the hard work of our dedicated members, the NATSIDAG has steadily worked towards addressing the six priority areas with a focus on community awareness and prevention, research, and partnerships and collaborations. It is now time for us to look to the future and what areas the NATSIDAG can progress further in order to ensure equity and access to culturally safe services for Aboriginal and Torres Strait Islander people with dementia, their carers and families, and the community. We have identified the following areas which we will be targeting in the near future:

- Diagnosis, referral and treatment – provide flexibility in response to the needs of Aboriginal and Torres Strait Islander people, their families and the services involved in the diagnosis, referral and treatment of people with dementia.
- Care and support – ensure Aboriginal and Torres Strait Islander people with dementia and their carers have access to care and support in a range of service setting
- Workforce issues – that funding is allocated to developing a workforce that is localised, able to work in a manner consistent with community values, aspirations and cultural frameworks and is able to provide information, advice, counseling and other services in a manner consistent with the needs of the community.

In keeping with our view to the future, the NATSIDAG is also undertaking an internal review of our governance including our membership processes and positions. The terms of office of all members will finish on 30 June 2013 and membership terms are for a maximum period of 1 year. If you are interested in becoming a member of the NATSIDAG, please contact our Secretariat Kristen Holdsworth at kholdsworth@alzvic.asn.au or 03 9816 5715 in order to obtain an Expression of Interest form.

Thank you for your time.

The NATSIDAG Team

Kerry Arabena
(Chair person)
NSW
Professor Tony Broe
Neuroscience Research Australia
Garry Morris
Booroongen-Djugen Aboriginal Corporation (BDAC)
QLD
Venessa Curnow
(Member - of Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN)
Noela Baigrie
Nurse Educator (Indigenous Health)
SA
Mark Elliott
Adelaide Hills Community Health Service
Jenny Hayes
Alzheimer’s Australia SA Inc
WA
Lester Coyne
Western Australian Community Health Service
Leon Harp
Burnna Yurrul Aboriginal Corporation – BYAC Contractors
NT
Djapirri Mununggirritj
Yirkala Women’s Resource Centre

AUSTRALIAN GOVERNMENT
Mark Gaukroger
ALZHEIMER’S AUSTRALIA
Glenn Rees
Barbara Fenemore
SECRETARIAT
Kristen Holdsworth
NATSIDAG UPDATE

The NATSIDAG (National Aboriginal and Torres Strait Islander Dementia Advisory Group) has been working hard to raise awareness about dementia in Aboriginal and Torres Strait Islander communities.

Here are just some of the things we have been doing:

• In 2012, the NATSIDAG contributed to a report jointly developed by the World Health Organisation (WHO) and Alzheimer’s Disease International. The report aims to raise awareness of dementia as a public health priority and advocates for action at both an international and national level. The NATSIDAG outlined and discussed barriers that may prevent Aboriginal and Torres Strait Islander people accessing health and social services and the importance of flexibility in care pathways and policies. To view the report, please go to http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html

• NATSIDAG has been liaising with Alzheimer’s Australia on the Aboriginal and Torres Strait Islander Identification Project. Aboriginal and Torres Strait Islander people are often under-identified in many health-related data collections. The project involves training staff to ask the question “Are you of Aboriginal or Torres Strait Islander origin?”. Through identification, Aboriginal and Torres Strait Islander people can gain access to programs specifically designed for Aboriginal and Torres Strait Islander people, improve health outcomes and close the gap.

• We are updating our information - over the coming months, changes to the Alzheimer’s Australia website will be occurring. This will include member profiles, new and updated links, and information about our meetings. This is aimed at providing everyone with a more comprehensive overview of what we at the NATSIDAG do and ensure that we are supplying the latest and most relevant information.

VALIDATION OF THE KICA IN VICTORIA

Dementia is a significant public health issue in Australia and results in considerable social and financial strain for those living with dementia and their family members. In Indigenous communities, the extent of dementia is still largely unknown, however, past research has indicated a higher prevalence in some instances at a rate around 4 to 5 times higher amongst Indigenous than non-Indigenous peoples over the age of 65, however, the rates in the Indigenous communities for people less than 65 could be significantly higher. Determining the prevalence of dementia and its subtypes is important in our bid to tackle dementia and to close the gap between Indigenous and non-Indigenous health.

An important step in establishing dementia prevalence in Indigenous communities is to ensure that culturally appropriate cognitive screening tools are used. The KICA (Kimberly Indigenous Cognitive Assessment) was developed in order to address the lack of culturally suitable screening tools and has since been validated in parts of Western Australia, the Northern Territory, and Queensland. Currently in New South Wales there is the Koori Growing Old Well Study which is underway with preliminary results expected by the end of 2012.

In Victoria, a study will be undertaken in the coming months in order to validate a modified version of the KICA in Indigenous people aged 50 years and over residing in a regional (Mildura) or urban (Brunswick) area. The project is being conducted by Dr Dina LoGiudice, Professor Stephen Gibson, and John Price from Alzheimer’s Australia Vic. The study has ethics approval from Monash University, Melbourne and phase one of the project which will involve two focus groups, will commence once the key expert panel have discussed the project. Alzheimer’s Australia Vic has formal agreements with the Mildura Aboriginal Corporation and ACES (Aboriginal Elders Community Service, Melbourne) to participate and collaborate on the study as well as agreement to collaborate with NARI (National Ageing Research Institute, Melbourne).

National Aboriginal and Torres Strait Islander Dementia Advisory Group

Our aim is to assist Alzheimer’s Australia and its member organisations develop a capacity to ensure dementia related information, programs and services are accessible, appropriate and well regarded by Aboriginal and Torres Strait Islander people, communities and representative agencies.

For more information about the NATSIDAG please refer to the following site: http://www.fightdementia.org.au/understanding-dementia/aboriginal--torres-strait-islander-groups.aspx
DEMENTIA – A PUBLIC HEALTH PRIORITY

The ‘Dementia – A Public Health Priority’ Report was launched on the 11th April 2012 by the World Health Organisation and Alzheimer’s Disease International and outlines the devastating impact dementia is having at a global level. The purpose of the report is to raise awareness of dementia as a public health priority, convey a public health approach, and to advocate for action at international and national levels based on the principles of inclusion, integration, equity and evidence.

The key messages from the report included:

• Dementia is not a normal part of ageing.
• 35.6 million people were estimated to be living with dementia in 2010. There are 7.7 million new cases of dementia each year, implying that there is a new case of dementia somewhere in the world every four seconds. The accelerating rates of dementia are cause for immediate action, especially in low- and middle-income countries where resources are few.
• The huge cost of the disease will challenge health systems to deal with the predicted future increase of prevalence. The costs are estimated at US$604 billion per year at present and are set to increase even more quickly than the prevalence.
• People live for many years after the onset of symptoms of dementia. With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life.
• Dementia is overwhelming for the caregivers and adequate support is required for them from the health, social, financial and legal systems.
• Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders – at international, national, regional and local levels.
• People with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them.

The time to act is now by:

• Promoting dementia friendly society globally.
• Making dementia a national public health and social care priority worldwide.
• Improving public and professional attitudes to, and understanding of, dementia.
• Investing in health and social systems to improve care and services for people with dementia and their caregivers.
• Increasing the priority given to dementia in the public health research agenda.

The report also features information contributed by the NATSIDAG on care pathways for Aboriginal and Torres Strait Islander people and a case study.


CONTACT NUMBERS

NATIONAL DEMENTIA HELPLINE
1800 100 500

ALZHEIMER’S AUSTRALIA
1800 100 500 OR www.fightdementia.org.au

DEMENTIA BEHAVIOUR MANAGEMENT ADVISORY SERVICE (DBMAS)
1800 699 799

COMMONWEALTH RESpite AND CARE-LINK CENTRE
1800 052 222

EMERGENCY RESpite (AFTER HOURS)
1800 059 059
KOORI DEMENTIA CARE PROJECT

22nd March 2012 saw the launch of the Koori Dementia Care Project (KDCP) by Professor Tony Broe from Neuroscience Research Australia and Project Manager, Sharon Wall.

What is the Koori Dementia Care Project?

The KDCP has been funded for two years by the Department of Ageing Disability and Home Care and will build on the Koori Growing Old Well Study (KGOWS) which focuses on healthy ageing and dementia in five Aboriginal communities in New South Wales. The KDCP not only aims to translate the knowledge gained from the KGOWS into meaningful care and practice for Aboriginal communities but also build capacity in urban and regional Aboriginal communities about the effects of dementia on older Aboriginal people and their families and community.

The project will involve collaborations between the KGOWS, the KDCP project team, specific community leaders and identified information leaders within the Aboriginal communities of La Perouse, Campbelltown, Kempsey, Nambucca, Coffs Harbour and Mount Druitt.

What do we know about dementia in Indigenous communities?

Most of what we have learnt to date about dementia in Indigenous communities has come from remote settings. Research has revealed that in the Kimberly, dementia affects Indigenous Australians at almost five times the rate than non-Indigenous Australians.

The KGOWS has continued dementia research in Indigenous communities in order to understand the prevalence of dementia in urban and rural settings within New South Wales. Through the KGOWS, much has been learnt about risk factors, protective factors and how to look after the brain which is important information to share with all communities.

How will the Koori Dementia Care Project make a difference in communities?

The dementia wants and needs of each community will be established and training and collaboration with the appropriate people within each community will be undertaken. Aboriginal Dementia Knowledge Holders (ADKH) will be recruited and supported as ongoing resources for their communities.

It is hoped that the information gained through the KDCP will drive the development of services for older Aboriginal people with dementia and their families. The project team will be working with local guidance groups in each of the communities to make sure that relationships with mutual respect are continued.

For further information about the KDCP, please visit the Neuroscience Research Australia website:


Or regarding the Koori Growing Old Well Study (KGOWS)


Alternatively, further information can be obtained from the Project Manager, Sharon Wall, on 0419 849 101 or email: sharon@ageingbycaring.com.au
This newsletter has been edited by Kristen Holdsworth.

Articles were contributed by Venessa Curnow, John Price and Kristen Holdsworth.

We can’t do it without you: please remember this newsletter belongs to you. If you would like to share a story, tell other people what’s happening in your community, or to make any other comments or suggestions, please contact:

Kristen Holdsworth  
National Aboriginal and Torres Strait Islander Liaison Officer,  
Learning and Development,  
Alzheimer’s Australia Vic.  

Email: kholdsworth@alzvic.asn.au  
Phone: 03 9816 5715

To download previous editions of this newsletter, go to our website:  

For further information about dementia, please go to our website:  

For the latest information about upcoming conferences, workshops and events look under the Dementia section on the Australian Indigenous Health InfoNet  
http://www.healthinfonet.ecu.edu.au

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