CONTINUING THE CONVERSATION:
ADDRESSING DEMENTIA IN ABORIGINAL AND
TORRES STRAIT ISLANDER COMMUNITIES

ALZHEIMER’S AUSTRALIA AND THE NATIONAL ABORIGINAL AND
TORRES STRAIT ISLANDER DEMENTIA ADVISORY GROUP

2015 NATIONAL WORKSHOP COMMUNIQUE

UNDERSTAND ALZHEIMER’S
EDUCATE AUSTRALIA
FIGHTDEMENTIA.ORG.AU
“SOME SERVICES REALLY NEED TO HAVE PROPER TRAINING FOR CARE AND ADMINISTRATIVE STAFF; THEY DON’T KNOW ENOUGH ABOUT DEMENTIA. THE CARERS ARE LOVELY BUT THEY DON’T HAVE THE KNOWLEDGE THEY NEED”
CARER – 2015 NATIONAL WORKSHOP

Alzheimer’s Australia together with the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) held a national workshop on 19 May 2015 bringing together consumers, service providers, health workers and health professionals to discuss how Aboriginal and Torres Strait Islander people living with dementia can be better supported.

A number of recommendations were made by workshop participants on: increasing awareness and knowledge of dementia in Aboriginal and Torres Strait Islander communities; how risk reduction strategies should be employed to lower the risk of developing dementia; and ways to address service gaps in Aboriginal and Torres Strait Islander communities.
The care and support of people with dementia is one of the largest health care challenges facing Australia. It is estimated that there are more than 340,000 Australians living with dementia and more than one million people involved in their care. By 2050 there will be nearly 900,000 people with dementia\(^1\). Each week there are 1,800 new cases of dementia in Australia and this is expected to increase to 7,400 new cases each week by 2050\(^2\).

Research indicates that Aboriginal and Torres Strait Islander people experience dementia at a rate three to five times higher than the general Australian population. Despite the higher rate of dementia in Aboriginal and Torres Strait Islander people, dementia is still largely unrecognised in communities and by Aboriginal and Torres Strait Islander health workers and service providers.

Aboriginal and Torres Strait Islander communities face particular challenges in relation to responding to dementia. The impact of dementia on individuals, families and communities occurs within a unique cultural context for Aboriginal and Torres Strait Islander people due to the compounded effects of a significant gap in life expectancy between Aboriginal and Torres Strait Islander people and non-Indigenous Australians, and with the knowledge of the additional health challenges faced by many first Australians.

In 2006, Alzheimer’s Australia held a National Indigenous Dementia Workshop, *Beginning the Conversation*, which brought together over 30 participants to discuss whether the issue of dementia was a sufficient priority for Aboriginal and Torres Strait Islander people to take action on and to determine what that action might be. The attendees agreed that dementia needed to be addressed to enhance community Elders capacity to age successfully into the future. A wellness approach was seen to be necessary to address the issue of dementia with other health conditions that compromise Aboriginal and Torres Strait Islander people’s reaching the age of 75.

A National Framework for Action was developed as a result of the 2006 workshop to address dementia in Aboriginal and Torres Strait Islander communities. The following key priority areas were identified:

2. Care and Support.
3. Research.
4. Diagnosis, Referral and Treatment.
5. Workforce Issues.
6. Partnerships and Collaborations.

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"The opportunity to bring together a diverse group of people who have intimate knowledge and understanding of the dementia issues facing Aboriginal and Torres Strait Islander people provides a great platform for mapping out the specific level of holistic care and support required to close the gap between Australia’s first people and the general Australian population.”
Fred Tanner, Chairperson, NATSIDAG

Alzheimer’s Australia held a national workshop, *Continuing the Conversation*, on 19 May 2015 which built on the initial workshop *Beginning the Conversation*.

This workshop had the aims of:
- Enabling a better understanding of the issues associated with dementia and how it impacts on Aboriginal and Torres Strait Islander communities.
- Identifying innovative practices to support Aboriginal and Torres Strait Islander communities.
- Identifying gaps in service delivery and propose solutions of how to better support Aboriginal and Torres Strait Islander people, families and communities in managing a diagnosis of dementia.

This Communique provides a summary of the workshop outcomes and outlines the recommended actions required to develop better responses to meet the needs of Aboriginal and Torres Strait Islander people with dementia, their carers, families and communities.

This workshop is timely as Australia is currently undergoing significant reform in both the aged care and disability sectors. While there is a continued focus on Closing the Gap, it is imperative that the unique and specific dementia issues facing Aboriginal and Torres Strait Islander people are addressed within these reforms. Failure to address the dementia-specific needs of Aboriginal and Torres Strait Islander people will place them at risk of being further marginalised with less access to services and support.
There was an overwhelming view of workshop participants that Aboriginal and Torres Strait Islander communities require specific service responses which address structural disadvantage and marginalisation in a culturally appropriate way.

The intersection of the complex needs that flow from a dementia diagnosis and other health issues faced by many in Aboriginal and Torres Strait Islander communities mean that they cannot be solely supported through mainstream health and care services. There is a need to fund more dementia-specific services that are culturally appropriate and can provide the care, support, social interactions and cultural connection that Aboriginal and Torres Strait Islander people with dementia and their families need. As part of this, organisations controlled and managed by Aboriginal and Torres Strait Islander people need to be supported to provide services, and Aboriginal and Torres Strait Islander health workers need to be empowered to provide dementia care and support.

With appropriate resourcing and support, Aboriginal and Torres Strait Islander people with dementia, and their families will have better outcomes and opportunities to live in the community for longer. The important role of Elders in communities, as well as the importance of individual and community connection to country need to be central in the design and delivery of dementia services for Aboriginal and Torres Strait Islander communities. The lack of services in local communities needs to be reversed.

The challenge is for the Government, mainstream service providers and health professionals to work in partnership with Aboriginal and Torres Strait Islander consumers, health workers and health organisations to ensure that the current reforms lead to better access to appropriate care and support from detection, to diagnosis and beyond. The workshop highlighted the importance of ensuring that Aboriginal and Torres Strait Islander consumers, communities, health workers and policy makers are central to the planning and delivering dementia services to Aboriginal and Torres Strait Islander communities.

KEY MESSAGES
Participants at the workshop identified the need for priority action across four main issues, including the need to increase:

1. Education and awareness of dementia in Aboriginal and Torres Strait Islander communities

2. Risk reduction strategies for dementia in Aboriginal and Torres Strait Islander communities.

3. Accessible, culturally appropriate, affordable, well located and responsive dementia and aged care services and supports in the community for Aboriginal and Torres Strait Islander peoples with dementia - from diagnosis to end of life care.

4. High quality and culturally appropriate residential aged care options for Aboriginal and Torres Strait Islander peoples with dementia.

“I find it really frustrating that services don’t talk to one another – I have been left on my own to find out how things match up.”
Carer – 2015 National Workshop
The workshop participants explored why, despite the higher rate of dementia in Aboriginal and Torres Strait Islander people, dementia is still largely unrecognised as a key issue in Aboriginal and Torres Strait Islander communities, and by Aboriginal and Torres Strait Islander health workers and mainstream service providers and health professionals.

The workshop participants recognised that awareness and education play an important role in assisting Aboriginal and Torres Strait Islander health workers, families and communities to recognise the signs and symptoms of dementia, and in providing appropriate care and support to the person living with dementia and their families.

Workshop participants acknowledged that dementia is usually perceived and experienced differently in Aboriginal and Torres Strait Islander communities, with it often being unrecognised as a medical condition or viewed as a normal part of ageing.

Workshop participants identified the following challenges:

- There are limited resources available that are targeted at Aboriginal and Torres Strait Islander health workers and mainstream service providers and health professionals regarding dementia and its impact on Aboriginal and Torres Strait Islander communities.
- Culturally-specific resources on dementia targeted at Aboriginal and Torres Strait Islander communities are scarce.
- Mainstream organisations delivering dementia services have a limited understanding of the impact of dementia in Aboriginal and Torres Strait Islander communities or how to work with communities in culturally appropriate ways.
- Mainstream organisations delivering dementia services have a limited understanding of the importance of using a strengths-based approach to ensure that Aboriginal and Torres Strait Islander people not only have the resources but are empowered to use them.
- Workforce development is limited and there are few educational opportunities for Aboriginal and Torres Strait Islander health workers and mainstream service providers working in communities to develop skills around how best to support Aboriginal and Torres Strait Islander people and communities impacted by dementia.
- There is a diminished availability and accessibility of resources due to limited and short-term funding to support the development, distribution and use of these resources.
**RECOMMENDATIONS**

- Develop a national dementia information directory or website to increase the accessibility of dementia resources to Aboriginal and Torres Strait Islander people, communities and health workers.
- Increase the number of up to date, accessible and culturally appropriate resources that respond to the specific issues of dementia in Aboriginal and Torres Strait Islander communities. Resources should be delivered in a range of mediums, target different age groups, and use methods such as the use of personal stories.
- Distribute current resources in culturally appropriate and meaningful ways, including accessing Aboriginal and Torres Strait Islander community and cultural events, using mediums such as music and dance to convey messages, and by using Aboriginal and Torres Strait Islander dementia ambassadors and Elders.
- Further develop links and partnerships between existing networks including Aboriginal Community Controlled Health Organisations, Aboriginal and Torres Strait Islander health workers and Alzheimer’s Australia to ensure that culturally appropriate information is developed for communities with community members.
- Increase the focus on ensuring regular and ongoing communication between Aboriginal and Torres Strait Islander health workers, health organisations and Alzheimer’s Australia, with the aim to both create new relationships, and to nurture and sustain current relationships.
- Develop culturally appropriate training and education regarding dementia that targets Aboriginal and Torres Strait Islander health workers and health organisations. The development of this training should involve Alzheimer’s Australia, Aboriginal and Torres Strait Islander health workers and Aboriginal Medical Services to ensure that these sessions are designed and delivered in a culturally appropriate manner.
- Develop new resources to train mainstream service providers regarding the impact of dementia in Aboriginal and Torres Strait Islander people and communities as well as training on how to ensure the provision of culturally appropriate care and services.
- When working with Aboriginal and Torres Strait Islander communities, promote a whole of community approach to education about dementia that includes children, parents and grandparent to ensure intergenerational knowledge and support.
- Promote and develop corporate and business partnerships to increase funding for the development of information and resources around dementia in Aboriginal and Torres Strait communities.
The workshop participants recognised that Aboriginal and Torres Strait Islander people experience potentially preventable chronic diseases at a rate two and half times greater than the general Australian population. Cardiovascular disease, diabetes, kidney disease, cancer and respiratory disease contribute to higher rates of poor health and disability and lower life expectancy. The workshop participants explored the links between risk reduction strategies for chronic health conditions and risk reduction strategies for dementia, and how Aboriginal and Torres Strait Islander communities may benefit from greater exposure to these.

Workshop participants identified the following challenges:

- A lack of recognition of the importance of the social determinants of health and their role in dementia in Aboriginal and Torres Strait Islander people and communities by mainstream service providers, policy makers and Government.
- Little acknowledgement of the existing capacity and strengths within Aboriginal and Torres Strait Islander communities to respond to the issue of dementia in their own communities.
- Little attention given to providing dementia risk reduction information in ways that are culturally appropriate and accessible.
- Ineffective health prevention and health promotion strategies due to short term funding of dementia risk reduction for Aboriginal and Torres Strait Islander communities.

Recommendations:

- Encourage the involvement of dementia related organisations to partner with organisations working to reduce the poor health outcomes of Aboriginal and Torres Strait Islander peoples. In particular, Alzheimer’s Australia should consider joining the National Close the Gap Coalition to help address the social determinants of health and advocate for social change.
- Identify new opportunities to promote fostering safe Aboriginal and Torres Strait Islander communities across the country where communities are supported to look after community members impacted by dementia.
- Establish yarning groups to promote discussion of dementia and how people and communities can lower their risk of dementia.
- Identify ways in which Aboriginal and Torres Strait Islander health workers and Aboriginal Community Controlled Health Organisations can be supported to deliver dementia risk reduction information to local communities.
- Undertake further work to foster stronger connections between Alzheimer’s Australia support groups in each state and territory and Aboriginal and Torres Strait Islander health workers and communities, with the aim of providing additional education and support to Aboriginal and Torres Strait Islander communities.
- Introduce more health prevention and health promotion strategies that assist Aboriginal and Torres Strait Islander communities to better understand and support their community members who are dealing with dementia.

Australian Institute of Health and Welfare. (2011). The health and welfare of Australia’s Aboriginal and Torres Strait Islander people, an overview 2011. Cat. no. AIHW 42. Canberra: AIHW.
The workshop participants explored some of the key gaps in dementia services for Aboriginal and Torres Strait Islander people. There was acknowledgement that receiving a diagnosis of dementia generally takes an average of three years for the general Australian population which due to service gaps and barriers in accessing services could be substantially longer for Aboriginal and Torres Strait Islander people. The workshop identified that there are few services located within communities and cultural connection was often not identified as a key part of mainstream service delivery within Aboriginal and Torres Strait Islander communities. This places Aboriginal and Torres Strait Islander people diagnosed with dementia at an increased risk of further social isolation. The workshop was presented with information that there are very limited support services such as housing and transport for Aboriginal and Torres Strait Islander families accessing dementia services. It also heard that there is often a lack of understanding and cultural competency by mainstream service providers working with Aboriginal and Torres Strait Islander people.

Workshop participants identified the following challenges:

- Limitations in the willingness of mainstream service providers, policy makers and Government to work with Aboriginal and Torres Strait Islander communities to identify the specific needs and challenges of communities, with a tendency to deliver ‘solutions’ that are not culturally or community based.
- Mainstream service providers frequently fail to respond to the particular needs of Aboriginal and Torres Strait Islander people and communities when delivering services. This often results in fragmentation in service delivery, particularly between community based and residential care services, and sees Aboriginal and Torres Strait Islander people fall through the gaps.
- The concentration of dementia services within urban areas results in Aboriginal and Torres Strait Islander people having to leave country in order to access services.
- Limited recognition that Aboriginal and Torres Strait Islander communities themselves are often best placed to offer appropriate care and respite services.
RECOMMENDATIONS

• Promote a community development approach to the provision of care and services for Aboriginal and Torres Strait Islander communities. In particular, build capacity for services that are locally driven, locally designed and locally owned in Aboriginal and Torres Strait Islander communities as the preferred service delivery approach.

• Promote and encourage more flexible care models such as respite services which offer culturally appropriate activities and care on country.

• Develop programs to enable health specialists visitations to rural and remote areas, supporting Aboriginal and Torres Strait Islander peoples and communities to remain on country while accessing appropriate dementia care.

• Create partnerships between Alzheimer’s Australia and Aboriginal Community Controlled Health Organisations, to improve knowledge about the support and services that are available for people with dementia.

• Develop better links between community and residential care to ensure clear care pathways and a smoother transition between services.
The workshop was presented with evidence regarding concerns regarding the provision of residential aged care to Aboriginal and Torres Strait Islander dementia patients. Little research has been conducted into the residential aged care needs of Aboriginal and Torres Strait Islander communities, however, a lack of clear information regarding the aged care system and the impersonal nature of mainstream services have been raised.

This was reiterated by workshop participants who voiced concerns regarding the provision of information to Aboriginal and Torres Strait Islander families and communities about how the aged care system works and what options are available in relation to residential and community care. Information was provided to the workshop regarding the very limited availability of residential aged care services specifically designed for Aboriginal and Torres Strait Islander people, with very few services taking into account the needs of Elders.

Once again, the workshop was provided evidence about the need for mainstream residential care providers to improve the cultural appropriateness of care for Aboriginal and Torres Strait Islander individuals and families.

Workshop participants identified the following challenges:

- A very low level of culturally appropriate residential care available for Aboriginal and Torres Strait Islander communities, with mainstream services rarely well positioned to provide culturally appropriate care.
- A very low level of Aboriginal and Torres Strait Islander specific residential aged care.
- A lack of recognition for existing Aboriginal and Torres Strait Islander specific residential care.

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RECOMMENDATIONS

- Improve the cultural competency of mainstream aged care services, in all areas of service provision in residential care (from the provision of recreational activities, physical design of facilities and menu planning). As part of this, encourage stronger relationships between mainstream aged care providers and local Aboriginal and Torres Strait Islander health workers and Aboriginal and Torres Strait Islander health organisations.
- Develop and implement culturally appropriate principles that build on the Dignity in Care principles to ensure that culturally appropriate residential aged care services are available.
- Promote the establishment of Aboriginal and Torres Strait Islander specific residential aged care services that are run by communities.
- Promote and showcase successful models of care that are being implemented in Aboriginal and Torres Strait Islander communities, with the aim of establishing similar services and models in other locations.
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