

# ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE AND DEMENTIA: A REVIEW OF THE RESEARCH

A REPORT FOR ALZHEIMER'S AUSTRALIA  
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TALKING ABOUT ALZHEIMER'S  
ACROSS AUSTRALIA  
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# CONTENTS

Foreword	4
Acknowledgements	5
Executive summary	6
Recommendations	7
Introduction	8
Background information on dementia	9
What is dementia?	9
How is dementia diagnosed?	9
What are the risk factors for developing dementia?	10
Cultural understanding of dementia	11
The health of Aboriginal and Torres Strait Islander people	11
Aboriginal and Torres Strait Islander population by state	11
What are the rates of risk factors for dementia in the Aboriginal and Torres Strait Islander communities?	13
Smoking	13
Physical Activity	13
Diet	13
Healthy weight	14
Alcohol consumption	14
Education	14
Heart disease and diabetes	14
Prevalence of dementia in Aboriginal and Torres Strait Islander communities	15
What is the prevalence of dementia in Aboriginal and Torres Strait Islander people?	15
Why is it important to receive a timely diagnosis and use culturally appropriate screening tools?	16
Policy and service implications	17
Preventative health	17
Service issues – remote and non-remote areas	17
Awareness and education	18
Aged care/community services	19
End of life care	21
Appendix 1	22
References	23

A full copy of the report including appendices and references  
can be found at [www.fightdementia.org.au](http://www.fightdementia.org.au)

# FOREWORD

Over the last two decades, a number of studies have been conducted across the country into the prevalence of dementia in Aboriginal and Torres Strait Islander people. The results have revealed that Aboriginal and Torres Strait Islander people experience dementia at a rate 3 to 5 times higher than the general Australian population. Despite the fact that higher rates of the disease have been reported in Aboriginal and Torres Strait Islander people, it still goes largely unrecognised in communities and by health workers and service providers

In 2006, the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) was formed to work with Alzheimer's Australia to raise the profile of dementia in Aboriginal and Torres Strait Islander communities and ensure the availability of culturally appropriate information and services. Since 2006, the NATSIDAG has focused on a number of key areas including:

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

We have achieved some headway in getting dementia recognised as a health issue in Aboriginal and Torres Strait Islander communities but more work is needed. It is essential that we target education and training to Aboriginal health workers to raise awareness of dementia and how to recognise the disease.

It is also essential that we address the allocation of resources and funding to take action on the lifestyle risk factors associated with dementia, as well as access to culturally appropriate services and supports. All too often, dementia takes a 'back seat' to other health issues in the community which results in a delay in the person receiving a diagnosis and accessing much needed information and support. In many cases, it is not until a crisis emerges that people seek help.

The aim of this publication is to:

- discuss the health and lifestyle risk factors associated with dementia
- provide a comprehensive overview of research into the prevalence of dementia in Aboriginal and Torres Strait Islander people and communities
- make policy recommendations to work towards tackling dementia in Aboriginal and Torres Strait Islander communities

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**Fred Tanner**  
**Chairperson**

**National Aboriginal and Torres Strait Islander  
Dementia Advisory Group**

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# EXECUTIVE SUMMARY

Aboriginal and Torres Strait Islander people view health and wellbeing in a holistic manner. The connections with mind, body, spirit, culture and country assist in the provision of health and wellbeing for Aboriginal and Torres Strait Islander people including individuals, families and communities experiencing dementia.

The high rate of dementia in Aboriginal and Torres Strait Islander communities requires urgent attention. Aboriginal and Torres Strait Islander people experience dementia at an earlier age than the general population and this, combined with the steadily growing number of older Aboriginal and Torres Strait Islander people, will result in the number of people effected by dementia growing significantly in the coming years.

Although higher rates of dementia have been reported in Aboriginal and Torres Strait Islander people, the disease is often overlooked by Aboriginal and Torres Strait Islander communities, health workers and service providers. Geographical constraints in the provision of services, a lack of education and awareness in communities and by health workers and the prevalence of other chronic diseases have all posed considerable barriers to the recognition of dementia as an emerging health issue.

If we are to continue to close the gap in health outcomes between the general population and Aboriginal and Torres Strait Islander people then a better understanding of dementia by Aboriginal and Torres Strait Islander people, communities, health workers and service providers will be essential. It will be necessary to work with communities and service providers to identify gaps in knowledge and services and build capacity to ensure that those living with dementia can access the services and supports they need to remain an active member in their community.

Dementia should be incorporated into pre-existing preventive health strategies to ensure that Aboriginal and Torres Strait Islander people are aware of the modifiable risk factors associated with dementia and adequately address them. This will be an important first step in getting dementia recognised by family members, communities and health professionals. The timely diagnosis of dementia is critical and the use of culturally appropriate assessment tools will assist in identifying those with a cognitive impairment and dementia and facilitate earlier access to services.

Mainstream aged care and community services should work closely with Aboriginal Community Controlled Health organisations where possible to ensure that the services they are providing meet individual and community needs. This will assist in the uptake of services by members of the community and assist in ensuring the cultural appropriateness of the services provided.

This paper includes the following recommendations to ensure that Aboriginal and Torres Strait Islander people, family members and communities have access to awareness, information, and appropriate support services for people with dementia.

# RECOMMENDATIONS

- 1.** Dementia should be incorporated into pre-existing preventative health strategies and programs aimed at lowering the risks associated with diabetes and cardiovascular disease.
- 2.** The Your Story Matters resources should be widely disseminated by Alzheimer's Australia trainers, Service Access Liaison Officers and key workers to Aboriginal and Torres Strait Islander health workers and communities to target the modifiable risk factors associated with dementia.
- 3.** Access to support services for Aboriginal and Torres Strait Islander people with dementia and their carers needs to be improved particularly for those residing in remote areas.
- 4.** Awareness and education programs should be delivered to Aboriginal and Torres Strait Islander communities to raise the profile of dementia including through the increased funding of Alzheimer's Australia education and training programs.
- 5.** Training packages targeting dementia awareness and the use of the Kimberley Indigenous Cognitive Assessment be promoted to mainstream health professionals and Aboriginal and Torres Strait Islander health workers through Aboriginal Community Controlled Health Organisations to support access to timely diagnosis.
- 6.** Alzheimer's Australia key workers should be funded to work alongside Aboriginal and Torres Strait Islander health workers to increase awareness, and provide information and support in accessing services.
- 7.** Mainstream aged care and community care services should work with Aboriginal Community Controlled Health organisations where possible when providing services for Aboriginal and Torres Strait Islander clients.
- 8.** Education and awareness of palliative care be provided to Aboriginal and Torres Strait Islander health workers and communities to ensure a greater understanding of the services provided.
- 9.** Further research should be conducted to gain a greater understanding of the palliative care needs of Aboriginal and Torres Strait Islander people and communities.

# INTRODUCTION

Australia's population is ageing with 14% or 3.2 million of the estimated 23 million people living in the country aged 65 years and over (AIHW, 2013). These numbers are expected to increase dramatically and by 2056, it is expected that between 23%-25% of people will be aged 65 years and over (ABS, 2008). The ageing population will result in a growth in the total numbers of people living with dementia with the risk of dementia doubling every five years after the age of 65 (Alzheimer's Disease International, 2009). Although older age is a risk factor for developing dementia, dementia is not a normal part of ageing and can affect people even in their 30s (WHO, 2012; AIHW, 2012). National estimates indicate there were 322,000 people living with dementia in Australia in 2013 with these numbers projected to increase to 400,000 by 2020 and over 900,000 by 2050 (AIHW, 2012).

Research to date indicates that Aboriginal and Torres Strait Islander people experience dementia at a rate 3 to 5 times higher than the general Australian population. The reasons for higher rates of dementia in the Aboriginal and Torres Strait Islander population are still being explored, however, higher rates of chronic diseases such as cerebrovascular disease and diabetes and exposure to modifiable risk factors may account for these differences.

The purpose of this paper is to provide a comprehensive overview of the cultural understanding of dementia in Aboriginal and Torres Strait Islander communities, explore the health of Aboriginal and Torres Strait Islander people, review the research into the prevalence of dementia, discuss modifiable risk factors associated with dementia, and consider the policy and service implications of dementia in Aboriginal and Torres Strait Islander communities.



# BACKGROUND INFORMATION ON DEMENTIA

## What is dementia?

Dementia is a syndrome that results in the gradual deterioration of cortical functioning including language, judgment, comprehension, memory, thinking and learning (WHO, 2006). The course of dementia varies from person to person and is dependent upon a range of factors including the type of dementia diagnosed, physical health, lifestyle factors and the social supports of the person with the disease (Alzheimer's Disease International, 2009; AIHW, 2012; Lipton & Marshall, 2012). As dementia advances, the person's ability to carry out activities of daily living such as shopping or managing finances declines eventually resulting in the person with dementia needing assistance to undertake even simple activities (AIHW, 2012; Alzheimer's Disease International, 2009).

There are a number of diseases that cause dementia with the most common types including Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with lewy body disease (AIHW, 2012; Draper, 2011). Other less common causes include Parkinson's disease, Huntington's disease, alcohol-related dementia and traumatic brain injury (AIHW, 2012; Jensen, Bell, Flicker et al., 2012).

## How is dementia diagnosed?

Dementia is a complex health condition and there is no single diagnostic assessment that provides a definitive diagnosis. In the broader Australian population, there is difficulty in getting access to a timely diagnosis with the average time between first noticing symptoms and receiving a diagnosis being approximately 3.1 years (Speechly, Bridges-Webb & Passmore, 2008). Aboriginal and Torres Strait Islander people may experience even longer delays due to cultural understanding of dementia in Aboriginal and Torres Strait Islander communities as well as difficulties in getting access to appropriate health professionals.

The pathway for diagnosis of dementia usually starts with a person or family member noticing symptoms of cognitive impairment and contacting a health professional (often a GP). In response to concerns about cognition, health professionals usually undertake a comprehensive investigation to rule out other potential causes of cognitive impairment including depression, vitamin deficiency, thyroid dysfunction and other health conditions. The assessment often includes medical history, a physical examination, interviews with family members and the use of cognitive screening tools (AIHW, 2012; Seeher, Withall & Brodaty, 2011).

## What are the risk factors for developing dementia?

There are various risk factors associated with dementia with many of these factors acting in combination to increase the person's overall risk of developing dementia (AIHW, 2012). The most significant risk factor for dementia is advancing age with the risk of dementia doubling every five years after the age of 65 (Alzheimer's Disease International, 2009; AIHW, 2012; Jensen et al., 2012). Genetic risk factors have also been identified with those with a family history of the disease at an increased risk of developing dementia (Alzheimer's Disease International, 2009; AIHW, 2012; Jensen et al., 2012). A range of chronic diseases have similar risk factors as dementia including cardiovascular risk factors such as diabetes, hypertension, obesity and physical inactivity all of which have a high prevalence in Aboriginal and Torres Strait Islander communities (Seeher et al., 2011). Table 1 provides information on the modifiable risk factors associated with dementia and other chronic diseases.

**Table 1:** Modifiable Risk Factors for the major chronic diseases (Alzheimer's Australia, 2010).

Chronic Disease	Modifiable Risk Factors							
	Diet	Weight	Physical Inactivity	Blood pressure	Blood cholesterol	Blood sugar	Smoking	Alcohol Consumption
Dementia	✓	✓	✓	✓	✓	✓	✓	✓
Heart disease	✓	✓	✓	✓	✓	✓	✓	✓
Type 2 diabetes	✓	✓	✓	✓	✓	✓	✓	✓
Stroke	✓	✓	✓	✓	✓	✓	✓	✓
Chronic kidney disease	✓	✓	✓	✓	✓	✓	✓	✓

# CULTURAL UNDERSTANDING OF DEMENTIA

Dementia is viewed and experienced differently by Aboriginal and Torres Strait Islander people and communities and often goes unrecognised as a medical condition (Arkles, Jackson Pulver, Robertson et al., 2010). The behavioural changes associated with dementia may be viewed as “childlike” or “sickness” or “madness” with many people only seeking assistance when the behaviour breaks cultural norms (Arkles et al., 2010 p. 2). Research conducted by Smith, Flicker, Shadforth et al. (2011) in the Kimberley region of Western Australia highlighted the various perspectives of Aboriginal people regarding the causes of dementia including old age, head injury, lack of family visits and brain changes. Similarly, research conducted by Garvey, Simmonds, Clements et al. (2011) revealed a number of differences in understanding Alzheimer’s disease in life expectancy, memory and the roles of aluminium and nutrition, prevalence, management of wandering and personality changes. To ensure that Aboriginal and Torres Strait Islander people are adequately supported throughout the dementia journey, greater awareness and education is necessary for communities and their health service providers.

# THE HEALTH OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

## **Aboriginal and Torres Strait Islander population by state**

The Australian Aboriginal and Torres Strait Islander population is diverse and subject to considerable distribution across Australia (AIHW, 2011). In the 2011 Census of Population and Housing, 548,370 people identified as being of Aboriginal and/or Torres Strait Islander origin (ABS, 2011). A jurisdictional breakdown of the Aboriginal and Torres Strait Islander population can be seen in Table 2 taken from the 2011 census count.

The Aboriginal and Torres Strait Islander population has a younger age distribution than the non-Indigenous population due to higher fertility and lower life expectancy (ABS, 2011). Nationally, nearly 4 per cent of Aboriginal and Torres Strait Islander people fell into the 65 years and over age bracket (ABS, 2011). The number of older Aboriginal and Torres Strait Islander people (55 years and over) is expected to more than double over the period from 40,000 in 2006 to between 82,000 and 86,600 in 2021 which will result in an increase in the total numbers of Aboriginal and Torres Strait Islander people living with dementia (ABS, 2009).

**Table 2:** 2011 ABS Census Counts(a) – Indigenous Status by State and Territory

Aboriginal and Torres Strait Islander Status						Proportion of total population	Age by state and territory
	Aboriginal and Torres Strait Islander peoples		Non-Indigenous	Status not stated	Total	Aboriginal and Torres Strait Islander peoples	Aboriginal and Torres Strait Islander peoples over 65
State / Territory	No.	%	No.	No.	No.	%	%
NSW	172,624	31.5	6,402,111	342,923	6,917,658	2.5	4.2
VIC	37,991	6.9	5,069,156	246,893	5,354,040	0.7	4.3
QLD	155,825	28.4	3,952,706	224,206	4,332,737	3.6	3.4
SA	30,431	5.5	1,503,205	62,934	1,596,570	1.9	4.1
WA	69,665	12.7	2,038,786	130,719	2,239,170	3.1	3.3
TAS	19,625	3.6	456,345	19,380	495,350	4.0	4.5
NT	56,779	10.4	137,774	17,391	211,944	26.8	3.4
ACT	5,184	0.9	338,030	14,005	357,219	1.5	2.1
<b>Australia</b>	<b>548,370</b>	<b>100.00</b>	<b>19,900,764</b>	<b>1,058,586</b>	<b>21,507,719</b>	<b>2.5</b>	<b>3.8</b>

## **What are the rates of risk factors for dementia in the Aboriginal and Torres Strait Islander Communities?**

Aboriginal and Torres Strait Islander people experience worse health outcomes than the non-Indigenous population resulting in substantial gaps in life expectancy (Aspin, Brown, Jowsey et al., 2012). The burden of chronic diseases in Aboriginal and Torres Strait Islander populations is two-and-a-half times greater than the general Australian population with cardiovascular disease, diabetes, kidney disease, cancer and respiratory diseases significantly contributing to the morbidity and mortality of Aboriginal and Torres Strait Islander people (AIHW, 2011). Aboriginal and Torres Strait Islander populations have higher rates of health risk factors including ones which have been found to be related to dementia.

### **Smoking**

Smoking is a known risk factor for dementia. Two recent meta-analyses reported an increased risk of dementia including Alzheimer's disease, vascular dementia and cognitive decline in current smokers compared to non-smokers (Anstey, Sanden, Salim et al., 2007; Peters, Poulter, Warner et al., 2008). Data from the 2008 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) suggests that after adjusting for age, the proportion of Aboriginal and Torres Strait Islander people aged 15 years or over who were current smokers was 2.3 times higher than the general population (ABS, 2008; MacRae, Thomson, Burns et al., 2012). Nearly half (47%) of Aboriginal and Torres Strait Islander people aged 15 years and over were current smokers and nearly 20% were ex-smokers. Aboriginal and Torres Strait Islander people residing in remote areas were more likely to be current smokers than those living in major cities (53% and 42% respectively) (ABS, 2008). According to Vos et al. (2009), tobacco smoking was a leading cause of disease burden (17% of the total health gap) in Aboriginal and Torres Strait Islander people.

### **Physical activity**

There is significant evidence that physical activity may protect against cognitive decline or dementia in older age. Physical activity is also integral in improving mental and physical health and in reducing the risk of being overweight or obese (ABS, 2008). In the 2004-2005 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS), an estimated three quarters of Aboriginal and Torres Strait Islander adults aged 15 years and over living in non-remote areas reported low to very low levels of physical activity in the 2 weeks preceding the survey (AIHW, 2011). For both males and females, levels of participation in physical activity declined with age with nearly 47% of those aged 15-24 engaging in physical activity which decreased to around 4% for people aged 55 years and over (ABS, 2008 cited in MacRae et al., 2012). An analysis by Vos et al. (2009) on 2003 data revealed that physical inactivity accounted for 12% of the total health gap in Aboriginal and Torres Strait Islander people.

### **Diet**

Good nutrition is important in maintaining health across the lifespan and is strongly linked to reducing the risk of chronic diseases (NHMRC, 2003a; NHMRC, 2003b). The change from traditional diet to refined carbohydrates and saturated fats has impacted upon the health of Aboriginal and Torres Strait Islander people (AIHW, 2011; O'Dea, 1991; NHMRC, 2000). For people living in remote areas, accessing fresh fruit and vegetables has been problematic due to the considerable costs associated with transporting and handling produce (AIHW, 2011). In the 2004-2005 NATSIHS, one in five (20%) of Aboriginal and Torres Strait Islander people residing in remote areas reported no usual daily intake of fruit compared with one in eight (12%) in non-remote areas (ABS, 2006). Nearly 42% of Aboriginal and Torres Strait Islander people living in non-remote areas reported eating the recommended daily intake of fruit and 10% the recommended daily intake of vegetables (ABS, 2006). Aboriginal and Torres Strait Islander people were twice as likely to report no usual daily fruit intake and 7 times more likely to report no daily vegetable intake than non-Indigenous Australians (AIHW, 2011). In the 2009 analysis conducted by Vos et al. low fruit and vegetable intake accounted for 5% of the total health gap.

## Healthy Weight

Obesity in midlife is associated with a higher risk of dementia as well as a range of other chronic diseases (Luchsinger & Gustafson, 2009). Body mass index information collected as a part of the 2004-2005 NATSIHS revealed that 57% of Aboriginal and Torres Strait Islander people 15 years and over were classified as either overweight or obese (AIHW, 2011; MacRae et al., 2012). Aboriginal and Torres Strait Islander males aged 18 years and over (34%) were more likely to be overweight than women (24%) (AIHW, 2011). Aboriginal and Torres Strait Islander women were nearly twice as likely to be obese than non-Indigenous women and Aboriginal and Torres Strait Islander men around 1.5 times more likely to be obese than non-Indigenous males (AIWH, 2011). High body mass accounted for 16% of the total health gap in Aboriginal and Torres Strait Islander people in 2003 (Vos et al., 2009).

## Alcohol Consumption

Excessive consumption of alcohol also poses a considerable risk to the health of Aboriginal and Torres Strait Islander people and is associated with a number of chronic diseases including dementia. Data collected as a part of the 2004-2005 NATSIHS revealed that nearly half of Aboriginal and Torres Strait Islander adults (49%) had consumed alcohol within a week of the interview with 16% consuming alcohol at risky/high risk levels (ABS, 2006). After adjusting for age, the proportion of Aboriginal and Torres Strait Islander adults who reported drinking at risky/high risk levels was similar to non-Indigenous adults (15% and 14% respectively) (ABS, 2006). The data revealed that males had their highest rate of alcohol consumption in the 35-44 age range while females were in the 25-34 age range (ABS, 2006). Similar results were also recorded in the 2008 NATSISS with around 37% of Aboriginal and Torres Strait Islander people aged 15 years and over reporting consuming alcohol at risky or high risk levels in the 2 weeks prior to the interview (AIHW, 2011). According to Vos et al. (2009) alcohol accounted for 4% of total health gap in Aboriginal and Torres Strait Islander people in 2003.

## Education

The relationship between education and cognitive decline and dementia has been explored by researchers. Results suggest that higher levels of education may be protective whilst fewer years of education have been associated with an increased risk of cognitive decline and dementia (Seeher et al., 2011; Smith, Flicker, Dwyer et al., 2010; Valenzuela & Sachdev, 2006; Meng & D'Arcy, 2012). Low levels of education are also commonly linked with unemployment, poverty, poor quality housing and diminished ability to access health services (AIHW, 2011). The gap in retention rates between Aboriginal and Torres Strait Islander students and the general Australian population widens with each additional year of schooling. In 2010, the Year 10 retention rate for Aboriginal and Torres Strait Islander students was 96% compared with 100% for non-Indigenous students. For Year 11, the rates were 72% and 93%, respectively (ABS 2011b). The results of the 2008 NATSISS showed a positive association between higher levels of schooling and reported health status. Aboriginal and Torres Strait Islander people aged 15-34 years who had completed Year 12 were more likely to rate their health as excellent or very good compared to those who had left school at Year 9 (59% and 49% respectively) (AIHW, 2011).

## Heart Disease and Diabetes

Diabetes and heart disease are associated with an increased risk of dementia. First results from the 2012-2013 Australian Aboriginal and Torres Strait Islander Health Survey released in November 2013 highlighted that nearly 1 in 8 or 12% of Aboriginal and Torres Strait Islander people had heart disease and around 1 in 12 or 8.2% had diabetes mellitus. These rates were significantly higher than the general Australian population across all age groups (ABS, 2013). High blood pressure was also a considerable issue for Aboriginal and Torres Strait Islander people with 1 in 5 or 20.3% of Aboriginal and Torres Strait Islander adults having measured high blood pressure (systolic or diastolic blood pressure equal to or greater than 140/90 mmHg) (ABS, 2013).

*The historical context of Aboriginal and Torres Strait Islander health can be viewed in Appendix 1.*

# PREVALENCE OF DEMENTIA IN ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

## What is the prevalence of dementia in Aboriginal and Torres Strait Islander people?

Research into the prevalence of dementia in Aboriginal and Torres Strait Islander people has revealed higher rates of the condition than the general Australian population. Dementia prevalence in the Northern Territory (NT) was explored by Li, Guthridge, Aratchige et al. (2014) from 2008 to 2011 based on data sources including hospital admissions, aged care services, primary care and death registration. Results from the study revealed that in 2011, the estimated prevalence of dementia in the Aboriginal population 45 years of age and older was 3.7 per 100 and 1.1 for non-Indigenous people in the NT. Aboriginal people were often younger at the time of diagnosis with Alzheimer's disease the most common sub-type at 15.1% followed by vascular dementia (Li et al., 2014). The results represented a marked increase (threefold) from a previous study based on the same data sources (Cotter et al., 2012) and are probably a result of a combination of better detection in routine care and the modelling employed to account for the missing cases. Routine care in the Northern Territory had improved with the advent of the KICA.

In contrast a previous study performed in Western Australia in 2006-2008 utilised direct and careful assessment of 363 Aboriginal people (55% female) residing in communities in the Kimberley region. This study looked at formal assessment of cognitive impairment and dementia. Participants were aged between 45 to 96 years and were assessed using the Kimberley Indigenous Cognitive Assessment (KICA) and reviewed by a geriatrician or geriatric psychiatrist. The prevalence of dementia reported in the study was 12.4% for those over 45 years and 26.8% for those aged over 65 years. The prevalence of cognitive impairment not dementia (CIND) was 8.0% in those over 45 years and 13.4% in those over 65 (Smith, Flicker, Lautenschlager et al., 2008). These rates were 5.2 times greater than the overall Australian population rate of 2.4% when age standardised (Smith et al., 2008). The study indicated that dementia rates were higher among males (62%), those who had no formal education (80%), those who had previously sustained a head injury (69%), and those who had diabetes and hypertension (40% and 44% respectively).

Similar results were obtained in research conducted by Zann (1994) in far North Queensland. Six study sites were selected to represent urban, rural and isolated Aboriginal and Torres Strait Islander communities in the Northern Regional Health Authority area. The results of the study revealed that 20% of participants aged 65 years and over had dementia. The study identified an additional 15 participants who were displaying symptoms consistent with the onset of dementia, however, a formal medical diagnosis was needed to confirm these cases (Zann, 1994). The health profiles of the participants revealed substantial chronic health issues including diabetes, stroke, hypertension, syphilis, head injury and alcohol abuse (Zann, 1994). The majority of those who had previously been diagnosed had Korsakoff's dementia or alcohol related dementia (Zann, 1994) in their notes the validity of which is uncertain. Consultations which occurred as a part of the study highlighted that the word dementia in Aboriginal and Torres Strait Islander culture had no meaning and that many people in communities had serious concerns about dementia (frequently referred to as 'back to childhood') (Zann, 1994 p. 4). As the study did not utilise validated cognitive assessment tools, the results should be viewed with caution.

The Koori Growing Old Well Study (KGOWS) was recently undertaken in five city and regional New South Wales Aboriginal communities (La Perouse, Campbelltown, Kempsey, Nambucca and Coffs Harbour) with Aboriginal and Torres Strait Islander people aged 60 years and over. 336 participants were screened for cognitive impairment. Results from the study revealed similar rates of dementia: the age-adjusted rate was 21% or three times the general Australian rate of 6.8%. Alzheimer's disease was the most common form of dementia (44% of cases), followed by vascular dementia identified in 17% of cases, dementia due to head trauma was found in 7% of cases and mixed dementia diagnosis in 29% of cases (Radford et al., 2014a; Radford et al., 2014b). The study also noted a high prevalence of mild cognitive impairment. The screening tools utilised in the study included a modified version of the Kimberley Indigenous Cognitive Assessment (mKICA), Mini Mental State Exam (MMSE) and the Rowland Universal Dementia Assessment Scale (RUDAS) (Radford & Mack, 2012) with the tests performing similarly. KGOWS is examining not only the well-known

mid-life risk factors, but also the importance of early life events affecting brain growth and development; such as education, job opportunities, parenting, early life trauma and stress.

A pilot study has also been conducted in the Torres Strait in order to identify the prevalence of dementia and cognitive impairment in communities. The study also utilised the KICA with a review conducted by a geriatrician. A total of twenty residents living on Hammond Island aged between 45 and 85 years participated in the study with results indicating an increased rate of dementia at 5% with another 20% of the sample having some cognitive impairment (Strivens & Flicker, 2013). A total of 80% of the participants including those with cognitive impairment had at least one vascular risk factor including diabetes, hypertension, heart problems, currently smoking and high cholesterol (Strivens & Flicker, 2013). Further research is needed in the Torres Strait in order to obtain a more comprehensive view of the prevalence of dementia in communities.

### **Why is it important to receive a timely diagnosis and use culturally appropriate screening tools?**

The timely diagnosis of dementia is essential to ensure that the person living with dementia and their family members can access appropriate information and support services, put in place legal and financial plans, consider future living arrangements and care services, and ensure the appropriate medical management of the disease (AIHW, 2012). For non-Indigenous people, the time between family members noticing the symptoms of dementia and a firm diagnosis averaged 3.1 years and although no data is currently available it is reasonable to assume these delays may be even longer in Aboriginal and Torres Strait Islander communities (Speechly, Bridges-Webb & Passmore, 2008; Phillips, Pond & Goode, 2011).

To ensure that Aboriginal and Torres Strait Islander people obtain a timely diagnosis, the use of culturally appropriate validated cognitive assessment tools is critical (Alzheimer's Australia, 2006). The commonly used cognitive assessment tools including the Mini Mental State Exam (MMSE) may have limited applicability in remote communities due to inherent cultural and educational biases (Pollitt, 1997; Smith, LoGuidice, Dwyer et al., 2007).

The KICA is a culturally sensitive assessment tool developed for older Aboriginal people living in rural and remote areas. The tool was developed in 2003 in Western Australia and has been validated in the Kimberley region of Western Australia (Smith, Flicker, Dwyer et al., 2009). The tool was developed with the support of local Aboriginal community members, Aboriginal councils, health services and clinicians (Smith et al., 2009). The KICA comprises a number of subsections including a cognitive assessment, carer cognitive report, questions relating to medical, smoking and alcohol history, emotional wellbeing, carer report of behavioural and psychological symptoms of dementia and activities of daily living (Smith et al., 2009). These subsections of the KICA provide key information and aid in determining the severity of cognitive impairment, differential diagnosis, the subtype of dementia and the appropriate management of the disease (Smith et al., 2009). Validation of the tool has occurred outside of Western Australia including the Northern Territory, Queensland and New South Wales with a modified version of the tool currently being assessed in Victoria. Little is known regarding the utilisation of the KICA by health professionals in the screening of dementia with Lindeman & Smith (2010) recommending further research to establish the uptake of the tool and whether it has resulted in an increase in the identification of dementia in Aboriginal and Torres Strait Islander people as is suggested by the Northern Territory data.



# POLICY AND SERVICE IMPLICATIONS

The higher prevalence of dementia in Aboriginal and Torres Strait Islander communities requires the implementation of policies and strategies to ensure that people living with dementia in communities are adequately cared for and supported. There is also an opportunity to build on and expand existing strategies tackling other chronic diseases prevalent in Aboriginal and Torres Strait Islander communities to incorporate dementia.

## Preventative Health

There is mounting evidence supporting the efficacy of preventative health strategies and early interventions which aim to identify and modify the risk factors associated with major chronic diseases. These strategies could potentially have a considerable impact on preventing or delaying the onset of dementia in Aboriginal and Torres Strait Islander communities (Alzheimer's Australia, 2010). Dementia could be incorporated into pre-existing preventative health strategies aimed at lowering the prevalence of diabetes, cardiovascular disease and stroke in communities in the short-term (Alzheimer's Australia, 2010).

In 2012, with funding from the Commonwealth, Alzheimer's Australia launched the 'Your Brain Matters' program which aims to raise awareness regarding the risk factors associated with dementia. The program promotes 'brain health' by looking after the heart, body and brain. The 'Your Story Matters' health resources for Aboriginal and Torres Strait Islander communities have been developed as a part of the program to promote the message of brain and body health. Ensuring dissemination of the resource to Aboriginal and Torres Strait Islander health workers is important not only to raise awareness of dementia but also in increasing knowledge regarding the modifiable risk factors associated with dementia. Copies of the resource can be obtained at: <http://www.yourbrainmatters.org.au/news/closing-gap-dementia>

**Recommendation:** Dementia should be incorporated into pre-existing preventative health strategies and programs aimed at lowering the risks associated with diabetes and cardiovascular disease.

**Recommendation:** The Your Story Matters resources should be widely disseminated by Alzheimer's Australia trainers, Service Access Liaison Officers and key workers to Aboriginal and Torres Strait Islander health workers and communities to target the modifiable risk factors associated with dementia.

## Service issues – remote and non-remote areas

The provision of services that meet the needs of Aboriginal and Torres Strait Islander people in a holistic manner is essential to ensure the uptake of services (Ware, 2013). Data collected as a part of the 2008 NATSISS revealed that 30% of Aboriginal and Torres Strait Islander people aged 15 years and over reported problems in accessing health services (AIHW, 2011). Participants indicated that the most significant barriers to accessing services included excessive waiting times or the unavailability of services at the time required (15%) (AIHW, 2011). Access to services in remote Australia is particularly problematic (Smith et al., 2011).

Aboriginal and Torres Strait Islander people residing in the Northern Territory reported the highest rate of difficulty in accessing services (40.4%), followed by Western Australia (32.4%) and New South Wales (30.3%) (AIHW, 2011). Those participants residing in remote areas had more difficulty accessing services (42.0%) compared to those residing in non-remote areas (25.9%). For those living in remote areas, barriers to accessing services included no service in area (23.7%), not enough services in area (20.5%), transport/distance (18.7%) followed by waiting time too long or not available at the time required (15.9%). The biggest barrier for those participants living in non-remote areas included waiting time too long or

not available at the time required (14.4%), cost of the service (9.6%) followed by not enough services in area (8.7%).

Participants in the 2008 NATSISS also reported differences in the types of services they had difficulty in accessing. These difficulties were more pronounced in remote areas and included accessing dentists (27.4%), hospitals (14.5%) and doctors (12.3%). For those in non-remote areas, participants reported difficulty in accessing services including dentists (16.9%), doctors (8.6%) and Aboriginal and Torres Strait Islander health workers (5.5%) (AIHW, 2011).

**Recommendation:** Access to support services for Aboriginal and Torres Strait Islander people with dementia and their carers needs to be improved particularly for those residing in remote areas.

## Awareness and Education

The recognition of dementia as a substantial health problem in Aboriginal and Torres Strait Islander communities is the first step in ensuring that people receive a timely diagnosis of the disease and are able to access the supports and services they need. The chronic diseases prevalent in Aboriginal and Torres Strait Islander communities often mandate high level care and consequently necessitate substantial funding and the allocation of human resources (Alzheimer's Australia, 2010). This has posed a considerable barrier to the recognition of dementia as a major health problem in Aboriginal and Torres Strait Islander communities with the priority of treating other chronic conditions (Alzheimer's Australia, 2010).

The increasing number of older Aboriginal and Torres Strait Islander people will result in an increase in the absolute number of people living with dementia. It is therefore crucial for dementia to be recognised as a chronic disease by both Aboriginal and Torres Strait Islander communities and service providers working with communities to ensure that the increasing need

for culturally appropriate support and care services will be met. General awareness and education packages about dementia will be necessary in order to raise the profile of dementia within Aboriginal and Torres Strait Islander communities.

Alzheimer's Australia Service Access Liaison Officers (SALOs) have undertaken projects around the country with Aboriginal and Torres Strait Islander communities to increase awareness of dementia. The SALOs have worked with communities to ensure the implementation of projects that meets the specific needs of communities. These projects included:

- The Storytelling Project (WA) - was undertaken to encourage Aboriginal and Torres Strait Islander people to record and share their life story in a culturally appropriate way.
- The Aboriginal and Torres Strait Islander Dementia Risk Reduction Project (NT) - aimed to increase awareness of what is dementia, provide education around the modifiable risk factors associated with dementia and the provision of education sessions. Resources developed as a part of the project are now available in four languages.
- The Aboriginal Access Program (Vic) - aimed to increase awareness, education and support in Aboriginal communities and build collaborative relationships with Aboriginal Health Services and communities. The considerable work done by the SALO resulted in a Memorandum of Understanding being signed between Alzheimer's Australia Vic and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO).

As a result of the SALO program, ongoing relationships and connections with Aboriginal and Torres Strait Islander communities have been established. Further SALO projects aimed at raising awareness and utilising the Your Brain Matters resources would

be beneficial to ensure that health workers and community members are aware of the modifiable risk factors associated with dementia. This work must be accompanied by increased access to support services.

A training package for primary health care workers including nurses, doctors, Aboriginal health workers and all allied health professionals was established by the Centre for Remote Health into recognising and responding to dementia in Aboriginal and Torres Strait Islander communities. The two day workshop covers information including issues in assessing and diagnosing dementia, the use of the KICA, future research and evaluation needs in the area, models of care and collaborative care planning (Jensen & Lindeman, 2009). The expansion of training packages across the country is integral to ensure Aboriginal and Torres Strait Islander people attain a timely diagnosis of dementia. A training package about dementia and how to administer the KICA for Aboriginal health workers is currently under development by Alzheimer's Australia Victoria. The promotion of such training packages to Aboriginal health workers and Aboriginal Community Controlled Health Organisations (ACCHOs) is particularly important given the significant role Aboriginal health workers have in the community, often being the first point of contact for many people in the community.

**Recommendation:** Awareness and education programs should be delivered to Aboriginal and Torres Strait Islander communities to raise the profile of dementia including through the increased funding of Alzheimer's Australia education and training programs.

**Recommendation:** Training packages targeting dementia awareness and the use of the KICA be promoted to mainstream health professionals and Aboriginal and Torres Strait Islander health workers through Aboriginal Community Controlled Health Organisations to support access to timely diagnosis.

## Aged care/community services

Accessing services and supports that meet the individual needs of the person living with dementia is integral to ensure that the person maintains their independence and autonomy as long as possible, makes informed decisions in relation to their care and receives much needed emotional and social support. Aboriginal and Torres Strait Islander people invariably face additional barriers to accessing supports and services for variety of reasons.

A research project conducted in the Kimberley region of Western Australia looked at unmet care needs of people with dementia and their carers and trialled a community care model to meet those needs. Interviews with service providers, caregivers of Aboriginal people with dementia and remote Aboriginal community-based aged care workers identified the following issues to accessing services (Carrol, Smith, Flicker et al., 2010):

- High turnover and shortages of staff due to low pay, undervalued positions, lack of housing in the region and accommodation allowance only provided to higher paid staff
- Lack of cultural awareness and education for community care staff – service providers, caregivers and community workers would benefit from training around dementia, elder abuse, the KICA, and service availability for people with dementia
- High living costs for food and transport and competing priorities of need
- Better communication and coordination of services and greater flexibility in service provision

A number of other important issues were also identified in the uptake of services in remote areas (Carrol et al., 2010). The community care model was

trialled in order to meet the needs of frail aged, people of all ages with disabilities and those with a mental illness in remote communities. The project focused on strengthening capacity in community through consultation, employment, ongoing training and development and the provision of one access point in the community to services (Carrol et al., 2010).

In 2011, Alzheimer's Australia conducted a consultation on behalf of the Department of Health and Ageing with Aboriginal and Torres Strait Islander consumers identifying a range of issues with dementia and aged care service provision. This included a lack of services in remote areas and the need for mobile medical services to ensure people can stay in the community. A lack of understanding of Aboriginal and Torres Strait Islander culture by health professionals was also a considerable concern and was a significant barrier to the uptake of health services.

The 2012 Aged Care Reforms aims to create a more equitable and reliable aged care system nationally and has the potential to have a substantial positive impact in Aboriginal and Torres Strait Islander communities. The reforms have a focus on increased consumer choice and access to community care while creating a sustainable system. The increase in community care could mean that Aboriginal and Torres Strait Islander people living with dementia could continue to live in their communities, however, this will be dependent upon the individual's ability to access services. It is therefore integral that Aboriginal and Torres Strait Islander health workers are informed and educated regarding what services and supports are available and how clients can access aged care places and home care packages. As a part of the reforms, a key worker program was established in order to support younger people living with dementia.

A key worker approach for people with dementia in Aboriginal and Torres Strait Islander communities could be critical to ensuring people get access to the services and supports they need. In 2013,

the National Younger Onset Dementia Key Worker program was rolled out in order to provide people living with younger onset dementia and their family members and carers the support they need from the early stages of diagnosis. The key workers establish an ongoing relationship with the person living with dementia and their family members and carers and provides information, support and advocacy services. Alzheimer's Australia is advocating that this program be extended to people with dementia of all ages, starting with support for people from vulnerable groups including Aboriginal and Torres Strait Islander people.

The introduction of Consumer Directed Care (CDC) will provide people with greater input into the types of care services they receive and how those services will be delivered. This will provide Aboriginal and Torres Strait Islander people with greater flexibility and ability to access services which respond to their needs. This may also empower consumers to take greater control of decisions relating to their care.

**Recommendation:** Alzheimer's Australia key workers should be funded to work alongside Aboriginal and Torres Strait Islander health workers to increase awareness, and provide information and support in accessing services.

**Recommendation:** Mainstream aged care and community care services should work with Aboriginal Community Controlled Health organisations where possible when providing services for Aboriginal and Torres Strait Islander clients.

## End of life care

The provision of quality end of life care is important in order to lessen the burden to the individual, their families and carers and to ensure that the range of care needs including the physical, emotional, psychological and spiritual are met (Shahid et al., 2013). The uptake of palliative care services by Aboriginal and Torres Strait Islander people remains largely unknown mainly due to a lack of data (Sullivan, Johnston, Colyer et al., 2003). To date, only a handful of studies have been conducted into the end of life care needs of Aboriginal and Torres Strait Islander communities.

Shahid et al. (2013) explored the views of palliative care providers (PCP) in the provision of end of life care to Aboriginal and Torres Strait Islander people. A number of barriers to providing palliative care services were identified including many Aboriginal people having little knowledge or understanding of palliative care and the belief held by many that palliative care only relates to the 'last few days of life' (Shahid et al., 2013, p. 3).

Evidence collected during the study indicated that once the concepts of palliative care had been explained to families, patients and health professionals in rural and remote areas that services were positively embraced (Shahid et al., 2013, p. 3). Late referral to services was also deemed a considerable issue by service providers which ultimately resulted in insufficient time to establish relationships with patients and family members (Shahid et al., 2013). A number of other issues relating to communication and cultural differences in discussing death and dying, rituals associated with death and the need for cultural sensitivity and respect for grief and spiritual practices were also cited (Shahid et al., 2013). These results mirrored those collected by Sullivan et al. (2003) as outlined in the report National Indigenous Palliative Care Needs Study. The study highlighted geographical issues and the availability of palliative care services,

dislike of hospitals and hospices, and lack of referral or referral only in the latter stages of the disease. Education and adequate data collection will be essential in order to gain a clearer picture of the uptake of palliative care services by Aboriginal and Torres Strait Islander people as well as further research assessing the palliative care needs of Aboriginal and Torres Strait Islander people and communities.

**Recommendation:** Education and awareness of palliative care be provided to Aboriginal Torres Strait Islander health workers and communities to ensure a greater understanding of the services provided.

**Recommendation:** Further research should be conducted to gain a greater understanding of the palliative care needs of Aboriginal and Torres Strait Islander people and communities.

# APPENDIX I:

## Historical context of Aboriginal and Torres Strait Islander Health

Aboriginal and Torres Strait Islander people have resided in Australia for at least 50,000-60,000 years (Dudgeon et al., 2010; O’Dea, 1991). Aboriginal people lived as hunter-gatherers across the country in varying climatic conditions (O’Dea, 1991). There is limited data available, however, early reports indicate that Aboriginal people were physically fit and lean with little evidence of the chronic diseases prevalent in Aboriginal people residing in Western society today (O’Dea, 1991). Men and women equally contributed to securing food with women gathering certain types of plants, small animals and vegetables and men larger mammals such as kangaroos, fish or reptiles (O’Dea, 1991). The diet of Torres Strait Islander people varied from island to island, however, subsistence farming was augmented with fishing and hunting with turtle, dugong, fish and molluscs forming an essential part of the traditional diet (Beckett, 1990; NHMRC, 2000). The acquisition and preparation of food as a part of the hunter-gatherer lifestyle often necessitated continued physical activity including walking long distances, gathering wood for fires and digging pits in the search of food or for cooking expending large amounts of energy (O’Dea, 1991; NHMRC, 2000). Available evidence suggests that the traditional diet of Aboriginal and Torres Strait Islander people was low in sugars and energy density but high in nutrients and micronutrients, protein and complex carbohydrates with a low glycaemic index (NHRMC, 2000). Although animal fats were a feature in the traditional diet, it would have been low in total fat and in particular saturated fats (NHMRC, 2000).

At the time of colonisation, Aboriginal people had nearly 270 language groups and 500 dialects with each of these language groups characterised by its own culture and land (Dudgeon et al., 2010; Ranzijn, McConnochie & Nolan, 2006). Intricate kinship systems and social organisations meant that each person in the group had a clear understanding of what their role was, how they fit into the authority system, what could be expected from others in the group, and who they were related to and what these relationships signified (Dudgeon et al., 2010; Ranzijn et al., 2006). The Torres Strait Islander community was also diverse with their own creation stories, social organisations and kinship systems based around the principle of reciprocity which were well established prior to colonisation (Osborne, 2009).

Land is central to Aboriginal and Torres Strait Islander people both at a collective and individual level (Dudgeon et al., 2010). The Dreaming represented and explained creation in Aboriginal nations with Dreaming Stories an integral part of this (Campbell-McLeod, 2013). Dreaming stories or traditional stories were shared orally and formed but one component of a highly complex spiritual belief system (Campbell-McLeod, 2013). The Dreaming created structures for culture including how the universe was created and laws to live by (Ranzijn, 2006). Individuals and family groups belonged to particular territories and had spiritual ties to country; religion was therefore based upon the concept of connectedness or oneness with the land (Dudgeon et al., 2010). The notion and beliefs of land ownership held by Aboriginal and Torres Strait Islander people differed from the European legal system with Australia declared ‘terra nullius’ or ‘unoccupied land’ in order to establish a settlement (Dudgeon et al., 2010; Armitage, 2011).

Colonisation resulted in a considerable change in the traditional lifestyle of Aboriginal and Torres Strait Islander people. The arrival and settlement of Europeans on the land resulted in changes to the traditional diet of Aboriginal and Torres Strait Islander people and the introduction of European foods such as tea, flour, sugar and meat such as beef and lamb which was often given in the form of rations (O’Dea, 1991; NHMRC, 2000). These foods would become a staple for many Aboriginal and Torres Strait Islander people (O’Dea, 1991; NHMRC, 2000). European settlement also resulted in the introduction of disease such as small pox, chicken pox, measles and influenza which caused a significant decline in the numbers of Aboriginal people who had no exposure to the diseases previously (Dudgeon et al., 2010). Violence against Aboriginal people was also a common occurrence due to resistance from Aboriginal groups to the loss of land and many Aboriginal groups taking livestock from European flocks which often resulted in conflict (Dudgeon et al., 2010; Armitage, 2011). The removal of Aboriginal children from their families also had significant and resounding negative emotional and social consequences for many Aboriginal people across generations (Dudgeon et al., 2010).

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