



**Alzheimer's
Australia**
Living with dementia

Beginning the Conversation:

**Addressing Dementia in Aboriginal and Torres
Strait Islander Communities**



**Workshop Report
8-9 November 2006
Adelaide**

Mr. Eric Deeral, Chairperson, Elders Justice Group, Hopevale Community, Queensland.

“The causes of Aboriginal dementia in Gugu Yimithurr culture is part of a natural process. The body, mind and spirit naturally get older including the brain... It may not need to get fixed as long as the individual is safe and the family and the community is safe there may not be any need to do anything at all.

Dementia is a sick spirit, a lost spirit looking for help we call this WAWU WARRA – a sick spirit.

Other causes of a sick spirit in Hopevale is the past history of the stolen generation, dispossession, physical, social and emotional trauma, child abuse, drug and alcohol abuse, poor diet, a lack of spiritual practice and ancestral connection and a lack of traditional healers and herbal medicine being understood and used.

Hopelessness and despair, violence and aggression and lack of understanding of customary lore and kinship structures and finally traditional healing gone bad can all present like dementia.

We have to bring back the concepts that were stolen: Respect, Lore, Culture, Language, Connection to Land and take the best of mainstream modern concepts of healthy spirit and use both to live in the 21st century”

We can have a healthy spirit, a WAWU DAPPARR, and this is what we should be working towards.

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Glossary of Terms

AA	Alzheimer's Australia
ACATS	Aged Care Assessment Teams
CALD	Culturally and Linguistically Diverse
CCRE	Centre for Clinical Research Excellence
GP's	General Practitioners
HACC	Home and Community Services
KICA	Kimberley Indigenous Cognitive Assessment (Project)
NIDAN	National Indigenous Dementia Advisory Network

Executive Summary

The Australian Government made a commitment in the 2005 Federal Budget of \$320.6 million over five years to make dementia a National Health Priority with the aim of improving the quality of care for people with dementia and their families and carers.

In addition in April 2006 Australian Health Ministers endorsed a National Framework for Action on Dementia, providing a mechanism through which Governments at all levels can formally share ideas and develop a national vision for action. This Framework has five priority areas, and Aboriginal and Torres Strait Islander issues are specifically addressed under Priority 3, Access and Equity.

A two day National Indigenous Dementia Workshop was held in November 2006 with over thirty participants to discuss whether the issue of dementia is a sufficient priority for Aboriginal and Torres Strait Islander people to take action and to determine what that action might be. Workshop participants agreed that dementia needed to be addressed to enhance community Elder's capacity to 'successfully age' 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 seventy five.¹

It is well known that Aboriginal and Torres Strait Islander people experience poorer health status and access to appropriate health and aged care. Evidence indicates that younger Indigenous people are at a higher risk of traumatic dementia (from head injuries), vascular dementia, alcohol dementia, and drug related dementia. People who have these problems have high needs that can cause an extra burden on families, carers and services.

Recommendations from the Workshop Participants include:

Workshop participants agreed that a National Framework of Action was needed to address dementia as part of a national approach to successful ageing for Indigenous Australians. Recommendations from the workshop include:

1. Alzheimer's Australia to employ a National Indigenous Coordinator at an AO6 or EL1 position to progress the outcomes of the Workshop.
2. That a National Indigenous Advisory Network be funded and supported.
3. The National Executive Director of Alzheimer's Australia provide a draft of the National Dementia Training Manual to the reference group in December 2006.

¹. Over the age of seventy five there is evidence that states Aboriginal and Torres Strait Islander elders have a similar lifespan to non-Indigenous older people. The common causes of death and disability in this age group relate to various forms of dementia. As Aboriginal and Torres Strait Islander people grow older they will also be at risk of higher rates of dementia.

4. Parliamentary Friends of Dementia be requested to meet with the Indigenous Dementia Advisory Network in 2007 to showcase Aboriginal and Torres Strait Islander initiatives across the country, launching the National Dementia Training Manual and this report from participants at this workshop.
5. The Kimberley Older Indigenous Health Project put a proposal to Alzheimer's Australia and the Department of Health and Ageing to fund the development of resources (DVD, CD, and training kit) to accompany the Kimberley Indigenous Cognitive Assessment (KICA) Tool and support the roll out of the program to other States and Territories in May 2007.
6. Alzheimer's Australia include in their 2007 Budget Submission a request for funding Indigenous staff to work with Indigenous organisations in the provision of information on dementia and dementia care.
7. A National Framework of Action to address dementia and Alzheimer's be developed in the context of a National Strategy of Successful Ageing for Indigenous Australians and that the National Framework of Action be progressed in the 2007-2008 financial year.

A National Framework of Action to address dementia

The participants nominated six key action areas to be included in a National Framework of Action to address dementia.

Action Point 1: Community Awareness and Prevention

Assist Alzheimer's Australia develop and deliver community awareness raising and prevention programs targeting Aboriginal and Torres Strait Islander people. Increase people's awareness of the 'Successful Ageing' concept in Aboriginal and Torres Strait Islander people.

- Ascertain what Indigenous people understand dementia to be; giving greater cultural understanding to the development and use of resources to address dementia.
- Develop community awareness raising resources and campaigns to inform people of the health transition to older age in Aboriginal and Torres Strait Islander people and the resultant risk factors for dementia.
- Focus interventions with young people to improve brain growth and reduce the lifestyles that increase people's chances of acquiring dementia.
- Establish a national 'clearinghouse' with the Aboriginal Health Infonet to help service providers, governments and other agencies to disseminate resources and to share experiences of working in the field.

Action Point 2: 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 settings.

- Adopt person centred care approaches.
- Implement service standards through accreditation to meet the needs of Aboriginal and Torres Strait Islander people with dementia.
- Develop cultural protocols for implementation across service settings including hospital, primary healthcare, outpatients, emergency, geriatric, psychiatric and drug and alcohol relief.
- Develop strategies to better support carers who support people at home, in acute care and other service settings as well as for those who live alone and cannot access respite care.
- Where possible implement innovative solutions to improve accessibility to services. These innovations may include mobile services (a travelling information bus), delivering health messages to people living in rural and remote locations (computer animation); and activities that support localised action (carers support meetings).
- Ensure culturally appropriate information, advice and counselling services for Aboriginal and Torres Strait Islander people with dementia and those who care for them.
- Ensure Aged Care Assessment Teams (ACATS) can access culturally appropriate information and resources.

Action Point 3: Research

Aboriginal and Torres Strait Islander people implement a research agenda in partnership with existing organisations to determine the prevalence of dementia in communities; potentially determine modifiable risk factors; address the unmet needs of people with dementia and their carers and improve dementia services for Aboriginal and Torres Strait Islander people.

- Understand the prevalence of dementia and its risk factors (including drug and alcohol use, brain growth, separation) in urban and rural/remote Aboriginal and Torres Strait Islander communities.
- Research the benefits of an Indigenous workforce in the dementia field.
- Develop and validate cognitive screening tools for Aboriginal and Torres Strait Islander people living in urban, rural and remote locations.
- Identify how all types of Dementia are related to issues such as chronic disease, abuse of Elders and social cohesion.
- Social research is required to understand how Aboriginal and Torres Strait Islander people learn about dementia, determine culturally appropriate interventions and how dementia impacts on the different generations in the community.
- Establish a link between national and international literature and the health and well being of Indigenous people over the age of 75.

Action Point 4: Diagnosis, Referral and Treatment

Provide flexibility in responses to the needs of Indigenous peoples, their families and the services involved in the diagnosis, referral and treatment of people with dementia.

- Ensure the roll out of the Kimberley Indigenous Cognitive Assessment project (KICA) across the country in places where there is a high population of Aboriginal and Torres Strait Islander people in rural and remote locations.
- Ensure that all modes of service delivery and accommodation are flexible and reliable, provided by skilled and trained staff, and appropriate to individual needs.
- Develop culturally appropriate assessment tools for cognitive impairment and dementia for Aboriginal and Torres Strait Islander people in urban and rural/urban locations.
- Develop a range of in-home care options for Aboriginal and Torres Strait Islander people with dementia.
- Identify quality referral pathways for people with young onset of dementia and for those who are living alone.
- Reduce the vulnerability of Aboriginal and Torres Strait Islander people with dementia both financially and legally by improving access to information from Centrelink, Aboriginal legal rights services, and other social welfare agencies and that individual people are aware of, and can enact their rights, responsibilities and obligations

Action Point 5: 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, counselling and other services in a manner consistent with the needs of a community.

- Workers in Aboriginal and Torres Strait Islander people focused services access education and training in dementia awareness; and non-Indigenous people are supported by their workplace to access cultural awareness workshops.
- Alzheimer's Australia are resourced to undertake an Indigenous program of activity including the recruitment and training of Indigenous workers and the development of resources, community partnerships, visits to communities, counselling and support to families, engagement of traditional healers and a capacity to support other agencies with mentoring, training and delivering services to target groups.
- Best practice care models are identified and implemented across the country in a range of settings, and adapted to local and regional need.
- Early intervention approaches be promoted and adopted.

- That a specific stream in Aboriginal Health Worker Training be directed toward aged care and assisting our Elders age successfully.
- That the Indigenous workforce has opportunities to showcase their work, share information and ideas (electronically), and access information about programs that work.
- Where possible, person centred care is adopted as a practice through multidisciplinary teams in a range of settings.

Action Point 6: Partnerships and Collaborations

That Alzheimer's Australia and the National Indigenous Dementia Advisory Network oversee the development of strategic, operational and training partnership with appropriate organisations.

- Engage organisations who are involved in dementia programs already.
- Establish relationships with people who could champion successful ageing in the community.
- Establish partnerships with other agencies whose client groups are often stigmatised but who also experience dementia (People living with HIV/AIDS, people who have been long time alcohol and drug users)
- Meet regularly with partner agencies to progress tasks, advise on strategic developments, share resources and create opportunities to provide education and training into the future.
- Disseminate the outcomes of this approach.

Conclusion

These priority areas then are an articulation of a vision for successful ageing in Aboriginal and Torres Strait Islander communities with a primary focus on better understanding the prevalence and incidence of dementia among Indigenous people and providing better access to care. The vision will need to be underpinned by principles that not only promote equal rights for Aboriginal and Torres Strait Islander people but also equal outcomes in health and ageing.

Alzheimer's Australia
December 2006

Introduction

At the invitation of Alzheimer's Australia and the Australian Government Department of Health and Aging, over thirty participants met for two days to discuss whether the issue of Dementia is a sufficient priority for Aboriginal and Torres Strait Islander people to take action and to determine what that action might be.

The '*Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander communities*' workshop was funded by the Australian Government. It is part of the commitment made in the 2005 Federal Budget of \$320.6 million over five years to make dementia a National Health Priority with the aim of improving the quality of care for people with dementia and their families and carers. This is the first step to promote and coordinate activities to address the issues of Alzheimer's disease and Dementia in Aboriginal and Torres Strait Islander communities.

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

Workshop participants agreed that dementia was a priority for Aboriginal and Torres Strait Islander people. Dementia needed to be addressed to enhance community Elder's capacity to 'successfully age' into the future. This wellness framework was seen as the most appropriate vehicle in which to prioritise dementia, and other health related conditions that compromised Aboriginal and Torres Strait Islander people's reaching the age of seventy five.²

1.1 What is Dementia?

Dementia is a term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning.³ Dementia is a broad term used to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions. Most people get dementia when they are older, occurring mostly in people who are over the age of 65. There are many different forms of dementia and each has its own causes. Some of the most common causes are Alzheimer's disease (a progressive degenerative disease that affects the

² Over the age of seventy five there is evidence that states Aboriginal and Torres Strait Islander elders have a similar lifespan to non-Indigenous older people. The common causes of death and disability in this age group relate to various forms of dementia. As Aboriginal and Torres Strait Islander people grow older they will also be at risk of higher rates of dementia.

³ Alzheimer's Australia Fact Sheet 1.1 What is Dementia? 2005. Available from www.alzheimers.org.au

brain), vascular dementia (poor circulation of blood to the brain), and Alcohol related dementia (Too much alcohol and a diet deficient in thiamine).⁴

1.2 Incidence of Dementia

It is estimated that dementia currently affects more than 190,000 people in Australia with the figure expected to reach over 730,000 by 2050 (2.8% of the projected population) (source Alzheimer's Australia).

During the next forty years the incidence of dementia is predicted to increase by 254%* in Australia.⁵

For Aboriginal and Torres Strait Islander peoples, the current numbers of people who have been diagnosed with dementia are relatively few. This number is likely to increase over the next few years as people live longer and more strategic approaches to diagnosing dementia are implemented in communities that promote information sharing, treatment and care for people with dementia.

Some preliminary information from the KICA projects based in the Kimberley region of Western Australia shows that Dementia education and management are limited as the prevalence of dementia and its subtypes in Indigenous Australians is unknown.

In 2006, 363 older Kimberly Indigenous Australians aged 45 years and above were assessed to discover the prevalence and types of dementia affecting Indigenous Australians. The initial data indicates as many as 13% of the 363 people have a form of dementia. (See Box 4) While these findings are preliminary, the high rates of dementia have implications for individuals, families, carers and communities.

1.3 Successful Ageing

As for other Australians, it is the desire of Aboriginal and Torres Strait Islander people to age successfully. For many Elders, Aboriginal and Torres Strait Islander communities their cultural roles and responsibilities will be compromised if they are unable to function in a way that allows them to be the elder statesperson in their community. These roles and responsibilities require Elders to provide guidance and support to the community, participate in decision making, cultural activities or ceremonial events; share stories, proffer advice, and pass on key information about their heritage. Often, people in the community look to Elders to provide information for Native Title Claims, teach the children in schools, and to 'look after country'.

⁴ Alcohol related dementia is called Korsakoff's syndrome. Taking Thiamine (Vitamin B1) appears to help.

⁵ *Estimates were taken from the Australian Bureau of Statistics population projection series report as shown in the "Aged and Community Service Development and Evaluation Reports", Number 35, January 1998.

<http://www.tsaofoundation.org/articles/society.html> as at 20 November 2006.

For many Elders, the desire to age successfully is curtailed by the onset of chronic disease, through removal to institutions (aged care or renal dialysis units away from country) and a lack of understanding by mainstream agencies about the functions of Elders in communities. Sometimes, an Elder's capacity to age successfully is compromised from within their own family. Sadly, Elder abuse (physical, financial and emotional) is not an isolated incident, nor an unfamiliar concept in many communities.

Ageing is one of the major achievements and challenges of the 20th century.⁶ Recognising this as far back as 1982, the United Nations convened the World Assembly on Ageing to promote the translation of the following principles into policy, practical programs and actions. The workshop participants agreed that further work is required to develop the following principles for Aboriginal and Torres Strait Islander communities:

1. Independence Principles - older persons need access to basic services and care, opportunities to work or make income, ability to influence the pace of their withdrawal from the labour force, access to education and training opportunities, safe living environments and support to reside at home for as long as possible.
2. Participating Principles - these address decision-making, dissemination of knowledge, community service and the formation of movements and associations of older persons.
3. Care Principles - encompass issues of family and community care, access to health, social and legal services, and matters pertaining to institutional care.
4. Self-Fulfilment Principles - call for older persons to have opportunities for full development of their potential and access to the educational, cultural, spiritual and recreational resources of the society.
5. Dignity principles - address issues of exploitation and physical or mental abuse, fair treatment and older persons being valued independently of economic contribution.

The realisation of these principles requires both initiative by older persons and the establishment of an enabling environment in Aboriginal and Torres Strait Islander communities and by the rest of society.

⁶ <http://www.tsaofoundation.org/articles/society.html> as at 20 November 2006.

For participants, successful ageing involves activity and an 'engagement with life'. It is this forward-looking, active engagement with life and with other human beings that is so critical to growing old well. However, participants believed that further work was required to more fully describe, seek endorsement for then communicate a 'successful ageing wellness framework' in Aboriginal and Torres Strait Islander communities.

There are many imperatives for developing this framework. The most compelling is the current *Health Transition* suggesting that in the next 40-50 years, Aboriginal and Torres Strait Islander communities will age in a manner consistent with the current non-Indigenous population. In this way, 'Ageing' is an emergent public health issue for Indigenous communities.

1.4 The Health Transition

A *Health Transition* to a longer life and 'Ageing' is now occurring in Aboriginal and Torres Strait Islander communities some fifty years after the same *Health Transition* occurred in non-Indigenous Australian populations.⁷

Box 2: Health Transition - Presentation at the workshop.

...If the Health Transition continues for older Aboriginal people i.e. a transition from lower rates of acute infectious diseases in children and young people – to later death from chronic heart and lung diseases in adults – this will result in longer adult life, with better health, for Aboriginal people in the coming decades... evidence shows this is happening some 40 years after the same health Transition in non-Indigenous Australians....

*Professor Tony Broe, Adelaide,
2006*

Box 1: Successful Ageing

The workshop participants agreed that 'successful ageing' was the ability to sustain well-being by maintaining three key behaviours or characteristics:

1. *Low risk of disease and disease-related disability* - reducing the risk and burden of disease that impacts on our ability to age well.
2. *High mental and physical function* – lifetime learning, stimulation and mobility
3. *Active 'engagement with life'* – living within a safe and cultural context.

While many agencies are heavily invested in stating that the life expectancy of Aboriginal and Torres Strait Islander people is on average 20 years less than non-Indigenous people, evidence suggests that despite this, the health and lifespan of Indigenous peoples is improving. Recent Northern Territory figures show improving health, with a reduction in early death rates, slowing of the rise in heart disease, renal disease, diabetes and cancer and an absolute fall in Chronic Lung Disease.⁸

⁷ Professor Tony Broe PowerPoint presentation Health, Ageing and Dementia in Aboriginal People presented to participants at the workshop.

⁸ D. P. Thomas et al, 2006 'Long-term trends in Indigenous deaths from chronic diseases in the Northern Territory: a foot on the brake, a foot on the accelerator.' Medical Journal of Australia, www.mja.com.au as at 1st December 2006.

More Aboriginal and Torres Strait Islander adults are surviving to mid-life, with significant numbers reaching 75 years of age. Over 75 Aboriginal and Torres Strait Islander elders have a similar lifespan to non-Indigenous older people.⁹

The most common disorders causing disability and death in those reaching 75 years and over are various forms of degenerative dementia. As many more Aboriginal and Torres Strait Islander people age, they will be more 'at risk' of and also experience higher rates of dementia.

It is well known that Aboriginal and Torres Strait Islander people experience poorer health status and access to appropriate health and aged care. Evidence indicates that younger people are at a higher risk of traumatic dementia (from head injuries), vascular dementia, alcohol dementia, and drug related dementia. People who have these problems have high needs that can cause an extra burden on families, carers and services.

1.5 Increase in Dementia in Aboriginal and Torres Strait Islander populations

Dementia will increase in the older Aboriginal and Torres Strait Islander population due to:

- The *Health Transition* which will rapidly increase the numbers of older and elderly Aboriginal and Torres Strait Islander peoples and will also increase the risk and rate of dementia.
- The older Aboriginal and Torres Strait Islander people as a population group are more likely to have experienced higher rates of imprisonment, head trauma and brain injury; higher alcohol and drug use rates and poorer nutrition than non-Indigenous people. This is due to the current literature about the experiences of the current 0 - 45 year old age group in Indigenous communities.
- Many older people will have been exposed to lifestyles that are likely to result in higher rates of adult diseases that may affect brain function including diabetes, hypertension, renal disease, vascular disease and stroke.

Early risk factors for late life dementia also exist in the younger populations of Aboriginal and Torres Strait Islander people:

- Younger Aboriginal people in 2006 have suffered childhood separations, family trauma, low birth weight socio-economic inequality, childhood malnutrition, chronic childhood infections (otitis media) and high ADHD rates.

⁹ Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2003. ABS Canberra Report no. 4707 pp. 179 - 202.

- Less early childhood school and tertiary education funding and opportunities; lower family expectations for books and reading; less access to good jobs; more mental and psychological stress and alcohol and drug use.

Therefore, as with all Australians, risk factors for Aboriginal and Torres Strait Islander people acquiring dementia occur across the lifetime. In 2004, US Professor Zaven Khachaturian worked with Australian experts to develop a vision in which the numbers of people diagnosed with dementia in coming years would be drastically reduced. Professor Khachaturian said that:

“...delaying the onset of dementia or slowing its progression will lessen the average number of years that people will spend living with the disease, improving quality of life for older Australians and their families. Importantly, the impact on health costs will also be dramatic, as people living with dementia for shorter periods will need less health care and community services.”¹⁰

The severity of the current and future health impacts of dementia for Aboriginal and Torres Strait Islander communities provide significant reasons for developing a framework of action to prevent the onset of dementia, provide support for carers of people with dementia and address problems that compromise people’s ability to age successfully.



Figure 1 Mrs. Bess Yarram and Mr. Eric Deeral, Workshop Participants, Adelaide November 2006

¹⁰ <http://www.alzheimers.org.au/content>.

2. Developing a Framework of Action

This section of the paper details the considerations of participants in the development of a Framework of Action to address dementia in Aboriginal and Torres Strait Islander communities.

2.5 *Survey Findings*

Twelve people were contacted prior to the workshop and interviews were conducted lasting between 20 minutes and 1.5 hours. These interviews were representative of the people present and consisted of managers, community workers, professionals, researchers, academics, carers, long time workers in the field and people just entering the field.

The surveys were to elicit information from people that asked people to consider how dementia affected their roles and responsibilities in a community, the approaches that best described what the workforce is doing; the issues for the workforce, and access to services. Finally people were asked to nominate priorities to address dementia and Alzheimer's in Aboriginal and Torres Strait Islander communities.

Many people were able to state that a range of myths existed in communities, that a range of experiences could present like dementia and that there were a range of activities that could enhance community perception of dementia.

Finally and most significantly, the importance of Elders in our communities was stated over and over again, with many people saying that it was an honour and a privilege to work with our Elders and that they found their jobs rewarding.

2.6 *Myths about Dementia*

At this workshop, Aboriginal and Torres Strait Islander people's discussions concluded that currently, dementia is not often considered a medical issue, and is more often thought of as a natural part of the cycle of life and death. Alzheimer's and Dementia were illnesses that respondents thought would make people vulnerable (removal, abuse, exploitation) if they were not living in strong caring families. These vulnerabilities highlighted that there are many times throughout an Indigenous person's lifetime where removal is deemed a necessity (birth, schooling, aged). This process of removal has major implications for people's relationship with country, their dreaming, their totems, and their capacity to care for country and fulfil cultural rights, responsibilities and obligations.

Most respondents to the survey felt that not many Aboriginal or Torres Strait Islander people knew about dementia unless they were caring for a family member who had dementia. It was a widely held view that Aboriginal and Torres Strait Islander people did not know what dementia was and had little understanding of how the potential risk of dementia might be reduced. Many

myths exist in the communities about dementia. These myths could be addressed with factual information delivered by appropriate people.

Some myths people shared included:

Myth 1: “It would be nice if people lived long enough to get dementia or Alzheimer’s!”

Rebuttal: People are ageing and there are a significant number of Aboriginal and Torres Strait Islander people surviving healthily up to the age of 75. More information is required about risk factors that contribute to dementia across the lifetime, including information about the health transition occurring in the Aboriginal and Torres Strait Islander communities to old age. This is an emerging public health issue that will compromise our capacity to age successfully into the future.

Myth 2: “Dementia is too hard for people in communities to prioritise because they have too many other things to worry about!”

Rebuttal: This is often stated by service providers who have a role to play in assisting communities deal with dementia but do not know how to intervene. There are many competing issues and priorities in a community. However, many carers and family members are already overburdened by caring for people in highly stressful environments and Elders may be vulnerable to exploitation. If dementia is considered in a wellness framework, then successful ageing is the goal of any intervention. Having fully functioning Elders is critical to holding the fabric of Indigenous societies together. From this view, there is a multitude of opportunities to work together to address any health issues that compromises people’s ability to age successfully.

Myth 3: “There are plenty of easily accessible resources to help people and their families cope with dementia and Alzheimer’s across Australia.”

Rebuttal: The truth of the matter is that many resources are not specifically targeting Aboriginal and Torres Strait Islander people. Factual information needs to be provided to people to develop local information specific to their community, region, circumstance and language group. More indigenous specific information and training could be provided to workers in aged care and other facilities to better cater for the needs and aspirations of Elders and their families. Information can also be provided to Carer’s agencies. Whilst this is difficult, it is not impossible. Collaboration, information sharing and a clearinghouse of resources should be established which is easily accessible for people across the country. Information also needs to be provided at a local community level.

There are many myths about dementia in communities. Dementia will become a feature of communities as more people age successfully, and

experience the full effects of chronic diseases, vascular disease and illnesses related to long term alcohol abuse.

2.2.1 Recommended Actions to reduce the myths regarding dementia in communities:

1. Implement strategies to improve the diagnosis of dementia in communities.
2. Provide correct information to community people and health professionals about dementia.
3. Implement the Dementia Training Program in regional areas across Australia.

Box 3: Noela Baigrie: Cultural Safety and Holistic Care

I am a registered nurse and a strong advocate for cultural safety and holistic care for our people particularly our old people and those with dementia. I believe they are and have been exponentially disadvantaged on every human and social level possible. I want to ensure that we as a nation give back and continue to honour and respect their status and to ensure that we have the collective capacity and the resources to heal the sick spirits of our old people and that in their last journey the “whole person” will know a full measure of wellness. My hope is that this may continue for generations to come.

This is the reason why I have just commenced a Master of Philosophy at Griffith University and will be looking at “Aboriginal families living with Dementia” which will include those living with dementia in the home and the capacity of families to care for them, and the interaction and communication of health professionals, and are current resources meeting the cultural and care needs of Aboriginal people with dementia.

2.3 Differing world views about ageing, assessment and care

Respondents indicated that there were differing world views about the process of ageing between Indigenous peoples and the mainstream service providers. Consideration will need to be given to the different socio-cultural factors that define age. For example: biological verses chronological ageing was seen as an important distinction for Aboriginal and Torres Strait Islander community people. Risk factors including exposure to illness, consumption of tobacco and alcohol, lack of access to fresh fruit and vegetables as well as living in stressful environments will age a person significantly. A person with dementia therefore may only be 40 years old, but biologically that person may be comparable to a 65 year old non-Indigenous person. Research is needed to refine the views and experiences of Aboriginal and Torres Strait Islander people and the processes of ageing in the 21st century.

The need for culturally sensitive assessment tools were mentioned by many of the respondents as being critical in developing any type of response to issues relation to dementia in communities. The development of these assessment tools will need to be cognisant of underlying values and principles of individuals, families and communities and delivered in partnership with people

from the community. A number of projects around the country have developed assessment tools that have been found effective by those who implement them, and those with whom the tool is being used. Respondents thought these tools can be replicated across the country with emphasis on local and regional distinctions.

Best practice models were required to guide interventions and programs across the country. People were concerned that current practice models were based on a premise of 'risk assessment and reduction', rather than an Indigenous principle of 'keeping people safe'. It was thought that programs developed and delivered across the country would need to learn different strategies to manage difficult behaviours. Some attention was required from an advisory group to think about the range of behaviours that needed to be managed in a National Framework of Action.

2.3.1 The behaviours that need to be managed in a National Framework of Action include:

Respondents to the workshop felt that cultural safety and respect for Elders was the most important consideration for the development of a Framework of Action. In order for this to occur, there were four clusters of behaviours that were identified as needing to be managed in a Framework of Action.

1. Preventative Behaviours:

(Lifestyle changes) – Change of behaviours to reduce the likelihood of acquiring dementia: - diet, exercise, education, stimulation, consumption of alcohol and tobacco

2. Difficult behaviours of clients

Behaviour is often managed in the family home or institution: Attention seeking (reversion), Sexual Aggression, Separation, Loss, Grief, Re-activated trauma)

3. Isolating behaviours

Loneliness of Elders and others (long term substance abusers) who are disconnected from family supports, those who are not visited by families once institutionalised other behaviours people use to overcome loneliness. For example 'doctor shopping' – dementia induced from high toxicity from over medicating is increased due to isolation and people seeking connection from people in the medical profession.

4. Cross cultural behaviours

Without good cross cultural skills people can cause problems because of insensitivity and the imposition of world views between mainstream agencies and their Indigenous clients.



Figure 2 Ms. Kerry Markoulli, Mrs. Maxine Turner, Ms. Anna Dwyer and Ms. Kate Smith, Workshop Participants, Adelaide November 2006

2.3.2 Conclusion and Recommended Actions to address differing world views about Ageing, Assessment and Care

It was also acknowledged by all respondents that the majority of their Elders preferred to be cared for at home, or in a place where people could readily access their families. In some situations this is difficult to manage, particularly in places where the Elder is vulnerable and not able to be kept safe. Also acknowledges in the survey were the needs of family members, carers and the need for respite care. Actions include:

1. Undertake research to refine the views and experiences of Aboriginal and Torres Strait Islander people and the processes of ageing.
2. Develop culturally appropriate assessment tools for use in diverse settings.

3. Assess best practice models of care and adapt for implementation across the country. These models scope home care practices, respite care, keeping people close to or on country and institutional care.



Figure 3 Final deliberations at the Adelaide Workshop, Adelaide 2006

Box 4: The Kimberley Indigenous Cognitive Assessment (KICA) Projects

Dementia has a major impact on the lives of those with the condition, their family and community. However diagnosing dementia in Kimberley Indigenous Australians has been difficult without a valid cognitive assessment tool.

Kimberley Region

The KICA projects are based in the Kimberley region of Western Australia. The region covers an area of 421,451 square kilometres. It has a diverse and widely spread Indigenous population with approximately 30 Indigenous languages still spoken today.

KICA development

The Kimberley Indigenous Cognitive Assessment (KICA) was developed in conjunction with communities, Indigenous health and aged care organisations, language centres and older people in the region. It is comprised of client and carer reports of 1.medical history 2.alcohol and smoking history 3.cognition 4.depression 5.carer report of daily function. The tool is presented in simple English, enabling it to be translated directly by an interpreter when required. The Kimberley Language Resource Centre translated the KICA to Walmajarri (a language from the desert area of the Kimberley) and successfully back translated it to English.

KICA validity study

To test for KICA validity and reliability 84 participants aged 45 yrs and above and their carers were assessed with the tool. 80% of those tested were from remote Indigenous communities.

Community consultation, education, and regular feedback to the council and clinic were essential to the studies success. Links were already established in many remote communities by Kimberley staff. Following an assessment with the KICA the geriatrician, blinded to the KICA result, completed a medical assessment. With the clients permission a medical report was sent to local doctors and referrals were made to other services if required. Interpreters were used and greatly assisted in the successful delivery of the tool. Specialist clinicians blinded to the KICA results reviewed the geriatrician report and diagnosed participants using DSM-IV and ICD-10 criteria. Their diagnoses were then compared to the KICA results to determine the validity of the tool.

Validity results include an internal consistency (alpha) of 0.87, sensitivity of 91% and specificity of 93%. The area under the ROC curve is 94% with a cut off score of 31-32/39.

The Northern Territory KICA validity study was completed in 2006. The area under the ROC was 0.95 with sensitivity of 82.3% and specificity of 87.5%, with a cut off score of 31-32/39.

The KICA is a valid and reliable assessment tool for cognitive impairment in the older Indigenous population of the Kimberly and Northern Territory.

Dementia Prevalence Study

Dementia education and management are limited as the prevalence of dementia and its subtypes in Indigenous Australians is unknown.

363 older Kimberly Indigenous Australians aged 45 years and above have been assessed to discover the prevalence and types of dementia affecting Indigenous Australians.

Community council permission was gained prior to the study taking place. As recommended by councils, male and female Indigenous workers were employed in each community to assist with the project. Interpreters from each community were also employed. These workers are given training to improve community knowledge of dementia and other health conditions affecting the older population.

Feedback was given to the community councils and health summaries were completed on all consenting participants for their clinic records. All councils are currently being revisited to discuss the results. Initial results suggest dementia prevalence in the Indigenous population aged 45 yrs and above of ~13%. More detailed results will be published once all community councils have been revisited for final approval.

Through a KICA implementation project to begin in 2007 these results will assist in the planning of dementia policy and services aimed at prevention, carer support and education, and management for Indigenous Australians.

Kate Smith (PhD student) and Anna Dwyer (Project officer) are supervised by Dr Dina LoGiudice, Prof Leon Flicker and Dr David Atkinson, with the assistance of community workers, councils, interpreters and specialist clinicians.

Contact details:

For a copy of the KICA tool: www.healthykimberley.com.au/chronicdisease.html

2.4 *Issues for the Workforce*

There is a real perception from many of the workers in the area that dementia is not considered by funding agencies as an area 'worth investing in'. Respondents were able to qualify these perceptions with the following experiences:

- It is really difficult to get people to do research in the area (small numbers of people – emerging issue)
- Indigenous people working in the area have to deal with institutional racism, are undervalued, underpaid and not resourced to come together;
- There is often a high turnover of Indigenous staff due to organisations having money, but not having a commitment to their Indigenous employees (Inadequate contracts of employment, professionally marginalised, no funds allocated to work with Indigenous communities in these organisation – no available funds to develop resources for the community);
- Efforts of Indigenous people to work together at a national level have been thwarted in the past, and workplaces are unprepared to commit staff time and salary for joining together at national forums to develop resources for the community;
- There is not enough information provided to members of the workforce who focus on vascular diseases to expand their role to manage dementia in a workplace or service environment;
- An experience of people across the sector is that of isolated practice – people felt supported in a peer network rather than from managers within their organisations. In places where there was support for these initiatives people belonged to a Community Controlled Organisation;
- In many instances, families of people who entered residential facilities were also considered members of the workforce because mainstream agencies needed their assistance to manage their Indigenous clients. These agencies were utilising the cultural skills and understandings of family members and relatives at a time when families were grieving about being separated from their loved ones. The imperatives are for the aged care facilities to access cross cultural training or develop meaningful relationships with communities they provide services for so families can work through their issues of grief rather than focus their attention on the needs of non-indigenous workers;

Respondents felt that these issues inhibited the potential of any strategy. There was a perception that these situations could well be remedied if political, strategic and training partnerships were developed and investments in the area were not ad hoc. Thus, there was a lot of support for a National Framework of Action to sustain efforts people are making in the area.

2.4.1 Recommended Actions to address issues for the workforce:

1. Identify the roles and responsibilities of the Indigenous workforce across the country, and undertake a survey to ascertain the obstacles to their practice.
2. Develop a national cross cultural training and awareness program for workers in the aged care and other sectors relating to Aboriginal and Torres Strait Islander people and Successful Ageing.
3. Enhance access to professional development regarding dementia.
4. Implement a specialist training stream addressing issues associated with Successful Ageing and Aged Care in the Aboriginal Health Worker Training Programs across the country.
5. Implement strategies to reduce practitioner's experience of isolation including access to debriefing and counselling services, improving networking capacities and establishing appropriate partnerships.

Box 5: What respondents said they are doing in their work place

Setting up Elder support groups and focusing on social activities

Avoiding being 'set up to fail'

Promoting opportunities for people to express and experience that culture as a method of enhancing well being

Taking what mainstream has to offer and making it 'fit' traditional value systems

Forging partnerships – some of these recognised, formal and informal (and subversive!)

Facilitating and participation in training

Providing debriefing and support to carer's, families and friends

Researching issues for people who live in urban areas

Setting up auditing and recall systems in PHC agencies

Box 6: Ms. Audrey Deemal – Dementia and the Centre for Clinical Research Excellence

The Centre for Clinical Research Excellence (CCRE) at the Queensland Aboriginal and Islander Health Council, Brisbane aims to support research to improve health outcomes in the community, through supporting training for Aboriginal and Torres Strait Islander Health Workers and health professionals by increasing the opportunities for Aboriginal and Torres Strait Islander researchers. It is envisaged that the research findings will assist in improving health service practices.

Currently the CCRE is focusing on the prevention and management of circulatory and associated conditions, such as heart, kidney disease, diabetes, respiratory disease and depression as a co-morbidity. These diseases come under the umbrella of Chronic Disease and were chosen as it is one of the major causes of excess morbidity and mortality among Aboriginal and Torres Strait Islander peoples. The focus is also on the urban population because there is limited information about their health needs, health issues and health outcomes.

The Queensland Aboriginal and Islander Health Council leads the CCRE in partnership with a number of Universities, such as Queensland University of Technology (QUT), University of Queensland (UQ), James Cook University (JCU) and the National Heart Foundation of Australia (NHF).

Currently we are looking into whether to include Dementia and Alzheimer's as part of the chronic disease research questions. What we need to find out is:

What is the prevalence and incidence of dementia and Alzheimer's disease among indigenous people?

Is it a concern among urban Aboriginal and Torres Strait Islanders?

Is it a co-morbidity of chronic disease such as heart diseases, diabetes etc?

Is there enough information out there to assist our communities in dealing with the diseases and supporting carers?

3. Carriage of the National Aboriginal and Torres Strait Islander Framework of Action to address Dementia and the Strategy for ‘Successful Ageing’

Workshop participants felt that Alzheimer’s Australia was best positioned to improve services for Aboriginal and Torres Strait Islander people with dementia. This is because the agency is credible, has expertise and experience to assist Indigenous peoples better understand the public and personal dimensions of dementia. Alzheimer’s Australia in their National Consumer Communiqué has also developed a set of principles that underpin their priority actions:

1. Indigenous peoples with dementia and carers need support that will help them maintain their quality of life
2. Indigenous peoples need to be supported in their homes;
3. Indigenous peoples with dementia and carers need to be recognised as partners in decision making about care options;
4. Indigenous peoples with dementia and carers need access to contemporary quality care provided by trained, accredited and appropriately remunerated Indigenous workers;
5. Indigenous peoples with dementia and carers need to see a national symbol for cognitive impairment so that people with dementia are treated appropriately particularly in the delivery of service.¹¹

3.1 Ensuring Aboriginal and Torres Strait Islander Peoples input to the National Framework for Successful Ageing

The participants recommended that a National Indigenous Dementia Advisory Network (NIDAN) be established to enact these principles on behalf of Alzheimer’s Australia. The workshop participants agreed that the NIDAN undertake to provide strategic advice in the development and delivery of a National Framework of Action to address dementia including community awareness and prevention, care and support, research, diagnosis, referral and treatment; workforce issues and partnerships and collaborations. This would be made possible by identifying Aboriginal and Torres Strait Islander people who could advise Alzheimer’s Australia in the following manner:

¹¹ Alzheimer’s Australia have developed a Communiqué from the National Consumer Summit on Dementia from the 5-6 October 2005. On the first page of the communiqué they identified a seven point action plan to improve services to people with dementia that is underpinned by these principles whom they say applies equally to all people living with dementia including people from Indigenous backgrounds. The word ‘Indigenous’ has been inserted in front of the word “people” in this report.

1. Devise appropriate reporting, feedback and input from regions to the Strategy;
2. Work with Alzheimer's Australia to increase the Indigenous workforce;
3. Advise on the development, adaptation and dissemination of key resources;
4. Identify working models and promote the replication of these across States and Territories;
5. Identify key partnerships at the national level (Carers Associations, Australian Association of Gerontology, HACC Reference Groups, and the CALD Network), State level (State Affiliates of AA, service agencies focusing on drugs and alcohol), regional levels (program areas, researchers, families, clan/kinship groups) and within the current AA driven and Indigenous specific networks across regional Australia.

(See Draft Terms of Reference for the NIDAN in Appendix 1)

3.2 How respondents proposed to address Priority 3 in the National Framework of Action: Access and Equity

There were a number of proposals made by the respondents to assist Aboriginal and Torres Strait Islander people access community and mainstream services. Many of these related to improved coordination between Commonwealth and State jurisdictions with an aim to 'link up' services to create a safety net around individuals and families.

A policy focus was advocated for, as were systematic approaches to care, resource development and integrating services across large geographical areas. Respondents acknowledged the importance of establishing a research agenda that could feed into programmatic development in primary healthcare and other essential services. Developing a capacity to develop diverse referral pathways for clients was considered vital. Other proposals included:

1. Improving access to carers and respite care services;
2. Increasing the number of Gerontologists in the field;
3. Reducing the competition for funding in the area by creating opportunities to work together;
4. Creating specific information in the community;
5. Adopting best practice referral networks that include counselling and support to family members and supporting workers in the field;
6. Managing community care packages
7. Developing awareness raising and health promoting campaigns;
8. Creating multidisciplinary teams and adopting case management approaches; as well as
9. Working in the community to develop cultural definitions of dementia and share ideas about how to keep people safe.

A number of professional development and workforce issues were also advocated for. Strategies to improve access to services through the workforce included:

1. Reducing the discrimination in institutions (the examples used was if people are Aboriginal or Torres Strait Islander, obese, as well as having a form of dementia then they were more acutely discriminated against in institutional settings)
2. Offer workers stable employment in reputable organisations that had investments in implementing an Indigenous program.
3. Support the Carers workforce on the principles of shared care, shared responsibility
4. Create an aged care specific AHW stream in Health Worker training.

All of these improvements have been considered in the development of the National Framework for Action.

3.3 Priorities to Address Dementia in Aboriginal and Torres Strait Islander Communities

When asked to identify priorities for Alzheimer's Australia and the Australian Government Department of Health and Ageing in the development of a National Framework for Action to address dementia, workshop respondents included the following:

1. The creation of a research agenda for remote, rural and urban populations;
2. Invest in an Indigenous Steering Committee to guide these initiatives;
3. Invest in a national Indigenous referral unit to respond to calls from families by Indigenous Counsellors and that this referral unit have the capacity to provide face to face support. (This referral unit was thought of as a national hub; with Indigenous people out posted to States and Territories across the country)
4. Have a clearinghouse for Indigenous specific information
5. Work with a national data collection agency to get statistical information to underpin strategies;
6. Provide information to promote early intervention and prevention across the lifespan;
7. Assist institution gain their accreditation; and
8. Develop local and regional models of working collaboratively.

3.4 *Recommended Actions to improve access and equity for Aboriginal and Torres Strait Islander people:*

1. The Australian Government acknowledges supports and funds Alzheimer's Australia to have primary carriage of the Aboriginal and Torres Strait Islander People's Strategy for Successful Ageing.
2. Alzheimer's Australia invests in a National Aboriginal and Torres Strait Islander Peoples Advisory Group.
3. That a National Framework of Action be presented to AHMAC for endorsement to engender appropriate collegial relationships between the Commonwealth and the States and Territories.

Box 7: TUMAKE YANDE - ABORIGINAL AGED CARE PROGRAM by Joanna Diasinas (Hills Mallee Southern Region - South Australia)

Tumake Yande is a HACC funded program which covers the Hills Mallee Southern Region of South Australia. Our client base can be found in Murray Bridge, Tailem Bend, Victor Harbor, Goolwa, Meningie, Raukkan and Mannum - this is some 35 000 square kilometres - lots of travelling.

The Program is staffed by our Manager, Darrell Sumner, me as Regional Coordinator, and the clients within the three geographic areas are supported by Laurie Rankine in Murray Bridge, by Nola Richardson in Tailem Bend, Meningie and Raukkan, and by Phyllis Williams in Victor Harbor and Goolwa.

All decisions made about the program are endorsed by the Elders Advisory Committee which meets on the first Monday of every month - the meeting is followed by a BBQ. We hold a Regional Elders BBQ on the third Friday of each month – this is in addition to the Elders Advisory Committee Meeting BBQ as we consider socialisation to be paramount within the Aboriginal Community.

We have recently developed a Strategic Plan which addresses concerns raised by Elders relating to the erosion of the Ngarrindjeri culture and are now looking at further possibilities for the inclusion of Youth in social programs in an attempt to reverse the trend of social erosion – craft workshops (feather flower making, basket weaving, wood carving), boat trips, swan egging and the like.

The supports we offer our clients include but are not limited to Transport, Home Help, Rubbish Removal, Respite and Advocacy. Transport is the biggest issue within the Aboriginal Community and the lack of personal transport often leads to social isolation - in fact, the main method of supporting our clients is through Transport. Transport is one of the major challenges faced by workers within Aboriginal services. This is not a regional issue - this is nation wide.

I am currently conducting assessment of each Aboriginal person over 45 years with a view of consolidating our client base. This commenced in February this year and continues. I have found that there are three possible outcomes from each assessment:

Firstly, the client can continue to attend social functions as scheduled (currently twice a month) and does not require additional supports apart from the occasional request for transport to and from medical appointments or shopping. Secondly, the client will accept minimal support in the form of Home Help - this is arranged through the Health Service as is generally around one hour per week. The third possibility is that the client presents with complex needs and would benefit from a Community Aged Care Package - with the client's consent, Joanna will submit a Service Request for Aged Care Assessment Team approval

with a view to offering a Package with Murray Mallee Aged Care Group whose CACP Program is an integral part of Tumake Yande.

The Aboriginal Aged Care Workers are strongly encouraged to visit clients or potential clients. They are not office based workers, but field workers - time spent in the office is mainly for the preparation of Progress Notes which is a departmental requirement, the reporting of Statistics which is a requirement of our funding body (HACC), or for contacting clients who may need transport to any of the social activities we schedule.

4. Key Action Areas for Inclusion to the National Framework for Successful Ageing

The respondents nominated six key areas of action be included in a National Framework for Successful Ageing. It was recommended that a National Advisory Group take a strategic view of the action needed. The Advisory Group would be supported by others at the operational level around specific identified issues in these key areas of action. The Areas respondents nominated include:

4.1 Community Awareness and Prevention

Across a life time there are interventions that make a difference to a person's capacity to successfully age. Efforts in this area should ensure better brain growth of young people and protect against, and remediate risk factors that make good brain growth possible. It is under this key action area that community focused campaigns, slogans, resources fact sheets, videos and other tools should be developed to raise the community's awareness of the issues involved with Alzheimer's and Dementia.

4.2 Care and Support

It was reiterated throughout the two days the importance of carers and the value that have in the community. Also discussed was the importance of assisting carer's access respite care. The Care and Support Action Area specifically targets the people who have dementia and their carers, families, relatives and loved ones who are looking after them.

4.3 Research

A nationally agreed research agenda targeting specific populations of Aboriginal and Torres Strait Islander people should be developed and support given to agencies to gain funding to implement these research programs. Where possible, Indigenous researchers should be encouraged to publish their findings in peer reviewed papers. Other initiatives could be the development of a scholarship scheme and a grants scheme specifically for Indigenous Australians to undertake further study in the area of Dementia. This area focuses on Indigenous researchers, research institutions and research partners.

4.4 Diagnosis, Referral and Treatment

This focus area would assist local groups and regions develop models of diagnosing dementia (including the development of appropriate assessment tools) developing diverse referral pathways and promoting treatment options for people in primary healthcare settings, GPs and other health facilities. This

area focuses on clinical workers and colleagues involved in the diagnosis, referral and treatment of people with dementia.

4.5 Workforce Issues

Capacity development of an Indigenous workforce in this field is an imperative, as is increasing the understanding, acceptance and enthusiasm for working with Aboriginal and Torres Strait Islander people in the mainstream agencies. This area focuses on professional development, capacity building, upskilling and meeting the needs of the workforce.

4.6 Partnerships and Collaborations

This key area identifies partners in political, strategic, operational and training agencies. This work can only be successful if placed within a credible organisation and Indigenous people are mentored and encouraged to support a range of partnerships and collaborations to implement each of the key action areas. To implement a comprehensive program of action requires support from a range of partners who are resourced to collaborate and implement strategies incorporated in the National Framework of Action.

These priority areas then are an articulation of a vision for successful ageing in Aboriginal and Torres Strait Islander communities with a primary focus on the reduction and management of dementia. The vision will need to be underpinned by principles that not only promote equal rights for Aboriginal and Torres Strait Islander people but also equal outcomes.



Figure 4 Mrs. Elida Kuno-Hutchins with Ms. Venessa Curnow, Adelaide Workshop, November 2006

Box 8: Sharing the Caring - Venessa Curnow, November 2006

I have a passion for working with older Indigenous people, they're our living link to past stories and traditional culture. There are many disadvantages facing Indigenous people in Australia today, poor outcomes in: health; socio-economics; culture; finance; and education. But there is one way of overcoming these poor outcomes, by learning from the past and embracing our older people and people with disabilities. When I first started my career, I worked in a mainstream, private, for profit nursing home. The building structure for the dementia wing was at that time institutional; long corridors with rooms off either side; on the second storey; two communal areas; and completely secure from the remainder of the nursing home.

Residents had good quality care, and challenging behaviours were well managed by dedicated staff. Many advances have been made in building design and outlays, nowadays there more home like. Whereas, Indigenous communities had non-institutional style buildings for decades prior to this 'new' revolution in mainstream aged care industry. I see great potential here for building a two ways, functional, equitable relationship between Indigenous and non-Indigenous peoples, based on mutual respect when establishing national Indigenous dementia strategy. Indigenous population can benefit from gaining much valuable resources from Non-Indigenous population such as knowledge of western methodology of management; funding; access to training and qualifications; infrastructure.

In return Indigenous population can offer knowledges about many social sciences, our perceptions of health and well being, and inform people of the uses of out botanical assets that have been learnt over many ten of thousands of years. There is much to learn from Indigenous perception of dementia and ageing process. With a different perception, alternate methods of caring and assisting people with dementia may appropriate for Indigenous people and offer alternatives and assistance to people suffering from dementia and their carers with other cultural backgrounds. Just as mainstream dementia wings now have gardens, and overall residential aged care facilities are becoming more home like, and de-institutionised. Indigenous residential aged care facilities had made these changes decades previous, through their different perception of ageing.

Box 9: Mr. Brett McKay, Co-ordinator, Aboriginal Social Support Program (HACC), Coffs Harbour Aboriginal Family Community Care Centre – NSW.

“I am no health expert! – But surely all areas of Aboriginal and Torres Strait Islander health need urgent resources and support to tackle the historical effects of past social injustices that have so clearly, so blatantly, altered and obliterated the average life expectancy and most importantly – the quality of life – of us as First Nation Peoples.”

“The need to address Dementia and improve access for Aboriginal and Torres Strait Islander peoples to culturally appropriate / respectful service provision has been identified and resources are available.”

Additional funding of \$31.4 million, announced on the 25th October 2006, will help frail older people, younger people with disabilities and their carers to continue living independently in their own homes and communities. The Australian Government Minister for Ageing, Senator Santo Santoro, and the New South Wales Government Minister for Ageing and Disability Services, Mr John Della Bosca, said their governments would provide the funding through the Home and Community Care (HACC) Program, a joint Australian Government-NSW Government initiative.

Mr Della Bosca said: "HACC is important because of the care and support services it provides. They range from social support, centre-based day care and respite care to community transport, domestic assistance, home modifications and maintenance, as well as food services. "Services for people with dementia and their carers will receive a significant boost. There are also specific initiatives to improve access for Aboriginal and Torres Strait Islander peoples and people from different cultural backgrounds.

“The critical importance of first contact and cultural considerations that services must be aware of and implement when dealing with Aboriginal and Torres Strait Islander health issues such as Dementia must be a key priority for the National Indigenous Dementia Advisory Network (NIDAN). Ongoing thought and consultation is integral in ensuring that what is actually presented as culturally appropriate is indeed acceptable to Aboriginal Elderly, Young Disabled and their Carers.”

“It is imperative that a strong recommendation be put forward to develop a skilled aged care workforce trained in Dementia specific cultural awareness, with a concentrated emphasis on strengthening and bolstering the participation of the Aboriginal aged care workforce in the rapidly increasing field of Dementia within Aboriginal Communities of both urban and regional / remote Aboriginal communities throughout Australia. “

“I believe the mind and body are one – they belong to and rely on one another the same as we as Indigenous People belong and interact / connect with Country or Land/Sea/Sky. If this link is damaged or severed in any form – then one’s inner wellbeing or *spirit* is compromised and this “sickness of spirit” – (Hopevale Elder, Mr Eric Deeral) should be healed (early intervention) – through sharing of knowledge (traditional & modern), kinship support, love, care and compassion. Healing also refers to the nurturing of the spirit along its natural journey to the ‘other side – that beautiful dreaming place with our ancestors.’ Dementia and Alzheimer’s disease to me is the mind or spirit moving back and forth between these realms and the body being not ready or reluctant in following.”

5. National Framework of Action

<h3>Action Point 1</h3>	<h3>Community Awareness and Prevention</h3>
<p>Assist Alzheimer's Australia develop and deliver community awareness raising and prevention programs targeting Aboriginal and Torres Strait Islander people. Increase people's awareness of the 'Successful Ageing' concept in Aboriginal and Torres Strait Islander people.</p>	<ul style="list-style-type: none"> • Ascertain what Indigenous people understand dementia to be; giving greater cultural understanding to the development and use of resources to address dementia. • Develop community awareness raising resources and campaigns to inform people of the health transition to older age in Aboriginal and Torres Strait Islander people and the resultant risk factors for dementia. • Focus interventions with young people to improve brain growth and reduce the lifestyles that increase people's chances of acquiring dementia. • Establish a national 'clearinghouse' with the Aboriginal Health Infonet to help service providers, governments and other agencies to disseminate resources and to share experiences of working in the field.
<h3>Action Point 2</h3>	<h3>Care and Support</h3>
<p>Ensure Aboriginal and Torres Strait Islander people with dementia and their carers have access to care and support in a range of service settings.</p>	<ul style="list-style-type: none"> • Adopt person centred care approaches. • Implement service standards through accreditation to meet the needs of Aboriginal and Torres Strait Islander people with dementia. • Develop cultural protocols for implementation across service settings including hospital, primary healthcare, outpatients, emergency, geriatric, psychiatric and drug and alcohol relief. • Develop strategies to better support carers who support people at home, in acute care and other service settings as well as for those who live alone and cannot access respite care. • Where possible implement innovative solutions to improve accessibility to services. These innovations may include mobile services (a travelling information bus), delivering health messages to

	<p>people living in rural and remote locations (computer animation); and activities that support localised action (carers support meetings).</p> <ul style="list-style-type: none"> • Ensure culturally appropriate information, advice and counselling services for Aboriginal and Torres Strait Islander people with dementia and those who care for them. • Ensure Aged Care Assessment Teams (ACATS) can access culturally appropriate information and resources.
Action Point 3	Research
<p>Aboriginal and Torres Strait Islander people implement a research agenda in partnership with existing organisations to determine the prevalence of dementia in communities; potentially determine modifiable risk factors; address the unmet needs of people with dementia and their carers and improve dementia services for Aboriginal and Torres Strait Islander people.</p>	<ul style="list-style-type: none"> • Understand the prevalence of dementia and its risk factors (including drug and alcohol use, brain growth, separation) in urban and rural/remote Aboriginal and Torres Strait Islander communities. • Research the benefits of an Indigenous workforce in the dementia field. • Develop and validate cognitive screening tools for Aboriginal and Torres Strait Islander people living in urban, rural and remote locations. • Identify how all types of Dementia are related to issues such as chronic disease, abuse of Elders and social cohesion. • Social research is required to understand how Aboriginal and Torres Strait Islander people learn about dementia, determine culturally appropriate interventions and how dementia impacts on the different generations in the community. • Establish a link between national and international literature and the health and well being of Indigenous people over the age of 75.
Action Point 4	Diagnosis, Referral and Treatment
<p>Provide flexibility in responses to the needs of Indigenous peoples, their families and the services involved in the diagnosis, referral and treatment of people with dementia.</p>	<ul style="list-style-type: none"> • Ensure the roll out of the Kimberley Indigenous Cognitive Assessment project (KICA) across the country in places where there is a high population of Aboriginal and Torres Strait Islander people in rural and remote locations. • Ensure that all modes of service delivery and accommodation are flexible and

	<p>reliable, provided by skilled and trained staff, and appropriate to individual needs.</p> <ul style="list-style-type: none"> • Develop culturally appropriate assessment tools for cognitive impairment and dementia for Aboriginal and Torres Strait Islander people in urban and rural/urban locations. • Develop a range of in-home care options for Aboriginal and Torres Strait Islander people with dementia. • Identify quality referral pathways for people with young onset of dementia and for those who are living alone. • Reduce the vulnerability of Aboriginal and Torres Strait Islander people with dementia both financially and legally by improving access to information from Centrelink, Aboriginal legal rights services, and other social welfare agencies and that individual people are aware of, and can enact their rights, responsibilities and obligations.
<p>Action Point 5</p>	<p>Workforce Issues</p>
<p>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, counselling and other services in a manner consistent with the needs of a community.</p>	<ul style="list-style-type: none"> • Workers in Aboriginal and Torres Strait Islander people focused services access education and training in dementia awareness; and non-Indigenous people are supported by their workplace to access cultural awareness workshops. • Alzheimer’s Australia are resourced to undertake an Indigenous program of activity including the recruitment and training of Indigenous workers and the development of resources, community partnerships, visits to communities, counselling and support to families, engagement of traditional healers and a capacity to support other agencies with mentoring, training and delivering services to target groups. • Best practice care models are identified and implemented across the country in a range of settings, and adapted to local and regional need. • Early intervention approaches be promoted and adopted. • That a specific stream in Aboriginal Health Worker Training be directed toward aged care and assisting our Elders age

	<p>successfully.</p> <ul style="list-style-type: none"> • That the Indigenous workforce has opportunities to showcase their work, share information and ideas (electronically), and access information about programs that work. • Where possible, person centred care is adopted as a practice through multidisciplinary teams in a range of settings.
<p>Action Point 6</p>	<p>Partnerships and Collaborations</p>
<p>That Alzheimer’s Australia and the National Indigenous Dementia Advisory Network oversee the development of strategic, operational and training partnership with appropriate organisations.</p>	<ul style="list-style-type: none"> • Engage organisations who are involved in dementia programs already. • Establish relationships with people who could champion successful ageing in the community • Establish partnerships with other agencies whose client groups are often stigmatised but who also experience dementia (People living with HIV/AIDS, people who have been long time alcohol and drug users) • Meet regularly with partner agencies to progress tasks, advise on strategic developments, share resources and create opportunities to provide education and training into the future. • Disseminate the outcomes of this approach.

6. Workshop Conclusions

All the participants at the workshop were able to identify that dementia is a priority for Aboriginal and Torres Strait Islander populations. There will be some challenges to bringing this National Framework of Action to fruition. Some obstacles to be overcome include the developing relationship between the Australian, State and Territory Governments and a shift in the research agenda by the National Health and Medical Research Council. Also, Alzheimer's Australia will need to develop a capacity to address the issues presented by Aboriginal and Torres Strait Islander people in this workshop.

In following up the Workshop it was agreed

- a. The workshop participants operate as a virtual reference group and share information, stories, achievements and resources between each other as required. The Contact List is finalised and sent to everyone for their information in November 2006.
- b. A final copy of the report, photos from this workshop to be put up on the Alzheimer's Australia Website
- c. The Report from the Workshop is circulated to participants in December 2006 for consultation.
- d. To set up a National Indigenous Dementia Advisory Network on the basis proposed in Appendix 1.

6.1 *The 2006 – 2007 Recommendations from the workshop:*

Workshop participants agreed that a National Framework of Action was needed to address dementia as part of a national approach to successful ageing for Indigenous Australians. Recommendations from the workshop include:

1. Alzheimer's Australia to employ a National Indigenous Coordinator at an AO6 or EL1 position to progress the outcomes of the Workshop.
2. That a National Indigenous Advisory Network be funded and supported.
3. The National Executive Director of Alzheimer's Australia provide a draft of the National Dementia Training Manual to the reference group in December 2006.
4. Parliamentary Friends of Dementia be requested to meet with the Indigenous Dementia Advisory Network in 2007 to showcase Aboriginal and Torres Strait Islander initiatives across the country, launching the National Dementia Training Manual and this report from participants at this workshop.
5. The Kimberley Older Indigenous Health Project put a proposal to Alzheimer's Australia and the Department of Health and Ageing to fund the development of resources (DVD, CD, and training kit) to

accompany the Kimberley Indigenous Cognitive Assessment (KICA) Tool and support the roll out of the program to other States and Territories in May 2007.

6. Alzheimer's Australia include in their 2007 Budget Submission a request for funding Indigenous staff to work with Indigenous organisations in the provision of information on dementia and dementia care.
7. A National Framework of Action to address dementia and Alzheimer's be developed in the context of a National Strategy of Successful Ageing for Indigenous Australians and that the National Framework of Action be progressed in the 2007-2008 financial year.



Figure 5 Audrey Deemal and Coralie Ober, Queensland Representatives, Adelaide Workshop, November 2006



Figure 6 Mr. Eric Deeral, Ms. Kerry Arabena and Mr. Leon Harp, Adelaide November 2006



Figure 7 Professor Don Gorman and Mrs. Di Barker, Adelaide November 2006

Appendix One:

Draft Terms of Reference for the National Indigenous Dementia Advisory Network (NIDAN)

Objective:

To Assist Alzheimer's Australia and its member organisations develop a capacity to ensure information; programs and services are accessible, appropriate and well regarded by Aboriginal and Torres Strait Islander people and our representative agencies. To achieve this goal, the NIDAN will:

Terms of Reference:

1. Provide advice and guidance to Alzheimer's Australia and its member organisations to consult with, develop partnerships and implement programs in a manner consistent with the cultural requirements of the communities in which they are delivered.
2. Promote and advocate for research to address the social and cultural requirements of diverse Aboriginal and Torres Strait Islander individuals, groups and communities.
3. Develop principles to underpin practice, training and care in the area.
4. Work with and support Indigenous workers in the organisation; providing mentoring and advice, supporting these and other workers develop, implement and evaluate programs and resources to raise community awareness and reduce the risks of dementia.
5. Promote the work of Alzheimer's Australia with the Aboriginal and Torres Strait Islander community through developing partnerships and supporting the Indigenous workers to advocate the efforts of the organisation in the field.

Membership:

An Advisory Group Convener:	An External Chairperson
Secretariat Person:	The Indigenous Worker in Alzheimer's Australia
Membership:	The CEO of Alzheimer's Australia Australian Government Department of Health and Ageing Mr. Cyril Oliver Mrs. Noela Baigrie Mrs. Sheree Freeburn Ms. Amanda Bosworth
Additional Members:	The expansion of this membership must include other Aboriginal and Torres Strait Islander employees of Alzheimer's Australia as they are recruited to positions within the organisation. The participation on the NIDAN should be part of the duty statements of new staff.

The Advisory Network's membership is small; others can be invited for particular meetings to discuss the implementation of specific programs. For example the KICA program workers can be invited from Western Australia to establish how the program can be rolled out across regional Australia. Upon completion of the National Dementia Training, others who were on the reference group can meet with the Advisory Group and discuss the implementation of the Package.

Appendix Two:

Agencies participants nominated to partner with:

- Australian Government Department of Health and Ageing
- ARC/NHMRC Ageing Well Network
- Aboriginal Health Worker Groups
- Alzheimer's Australia and affiliate organisations
- National Health and Medical Research
- Parliamentary Friends of Dementia
- Dementia Working Group
- Aboriginal and Torres Strait Islander Social Justice Commissioner at the Human Rights and Equal Opportunity Commission
- Divisions of General Practice
- Aboriginal Hostels Limited
- Hazel Hawke Foundation
- Aged Care Services Australia
- Australian Association of Gerontology
- Australian Rural Nurses Association
- National Aged Care Alliance
- Australian Medical Association
- Australian Indigenous Doctors Association
- Congress of Aboriginal and Torres Strait Islander Nurses
- Council of Remote Area Nurses Association
- National Aboriginal Community Controlled Health Organisations and the agency's affiliates
- Aboriginal Drug and Alcohol Services
- Local Government Associations
- Aboriginal HACC Services
- Department of Transport (in States and Territories)
- Aboriginal Justice Association
- Ombudsman's Office
- Community media (CARMA, Black radio)
- ANZ Society for Geriatric Medicine
- National Respite Services
- Carers Groups
- Carelink
- Centrelink
- Queensland Aboriginal and Torres Strait Islander Aged Care Network
- Indigenous Domestic Violence Programs
- Substance Abuse and Alcohol Rehabilitation Programs
- Disability Services
- TAFE Colleges
- Bachelor College and other Indigenous RTOs
- NGOs and AMSs
- Elder Groups
- Local Groups (Women's Groups, HACC groups, Homecare, Community Councils)

Appendix Three:

Participants at the Workshop

Name and Contact details	Experience in the field
<p>Professor Tony Broe AM Clinical Program Director, Community Health & Aged Care, Prince of Wales Hospital</p>	<p>Professor Broe is a Conjoint Professor, Geriatric Medicine, UNSW and is a member of the Alzheimer's Australia virtual group who developed <i>Dementia Research: A Vision for Australia</i>. Professor Broe is one of Australia's eminent medical and scientific experts in the field of aging.</p>
<p>Ms. Bernadette Edwards Consulting Psychologist Townsville Hospital. Qld. 4810</p>	<p>Ms. Edwards has worked with Aboriginal peoples in rural and remote communities for many years and has supported allied and other health professionals in rural and remote area practice. Bernadette is a practicing geriatric psychologist at the Townsville hospital.</p>
<p>Mr. Eric Deeral Hopevale Community Cape York, Queensland COMMUNITY ELDER</p>	<p>Mr. Deeral is the Chairperson of the Elders Justice Group in Hopevale and is researching the local numbers of people in Hopevale suffering a form of Dementia. He has written a dictionary in his local language and been acknowledged for the contributions he makes to his community in a number of prestigious award ceremonies in Queensland.</p>
<p>Mr. Cyril Oliver Aged Care Health Worker Danila Dilba Health Service Darwin, NT CRCAH and AMS Representative</p>	<p>Mr. Oliver is an Aged Care Health Worker based at Danila Dilba Aboriginal Medical Service. He has established Aged Care centres in the NT and is working with men on Maningrida community on cultural issues about aging and illness. He is keen to encourage Health Workers to consider specialising in aged care. Cyril is a member of the Cooperative Research Centre on Aboriginal Health.</p>
<p>Ms. Geri Malone Executive Director Australian Association of Rural Nurses & Midwives AARNM</p>	<p>Ms. Malone supports and looks after the interests of nurses and midwives plus other allied health workers in rural and remote area practice. . Particularly interested in professional development and support for generic practitioners in isolated settings as their agency is a peak body that will need to address emerging health issues in Aboriginal and TSI communities in the future.</p>
<p>Professor Don Gorman Director, Centre for Rural & Remote Area Health University of Southern Queensland Toowoomba Qld 4350</p>	<p>Professor Gorman's areas of study/research are in Indigenous and mental health issues and he has strong links with the local Aboriginal community and their representative agencies. Is interested in collaborative research programs with Indigenous people and other agencies.</p>
<p>Mrs. Vanessa Curnow Specialist Aged Care Nurse Bamaga Hospital Northern Peninsula Area Torres Strait Health Care Services</p>	<p>Ms. Curnow is currently working at Bamaga Hospital. She has worked in aged care for the past 7 years within Aboriginal and Torres Strait Islander Communities throughout Queensland (ranging from Eagleby in Metropolitan to remote communities such as Doomadgee).</p>

<p>Mrs. Noela Baigrie Lecturer, Griffith University Faculty of Nursing Brisbane, QLD CATSIN</p>	<p>Mrs. Baigrie is a key person in the Congress of Aboriginal and Torres Strait Islander Nurses and is currently lecturing in the Faculty of Nursing at Griffith University. She is interested in doing her Masters degree in Kornekoffs Disease – alcohol induced amnesia. She is the only Indigenous aged care quality assessor in Australia. She will be representing CATSIN.</p>
<p>Mrs. May Turner Aboriginal Liaison Officer Metropolitan Domiciliary Care Adelaide, South Australia</p>	<p>Mrs. May Turner is involved in the various dementia projects with Alzheimer's over the years and is currently working in Domiciliary Care in Adelaide. Her focus is on ensuring Aboriginal people access appropriate services.</p>
<p>Ms. Audrey Deemal Queensland Aboriginal and Islander Health Council Centre for Clinical Research Excellence Brisbane, Queensland 4000</p>	<p>Ms. Deemal has specific experience and expertise from a range of rural, remote and urban health related projects. She is developing policy and practice outcomes for Aboriginal Medical Services and is focusing primarily on urban issues. QAIHC is involved due to the co-morbidity factors affecting people with Chronic Diseases. QAIHC has a Centre Clinical Research Excellence and is interested sharing information and developing partnerships in this area.</p>
<p>Mr. Tim Agius Adjunct Senior Research Fellow, School of Social Work and Social Policy, University of South Australia</p>	<p>Mr. Agius is the Director, Aboriginal Health Branch, New South Wales Health, and Indigenous health consultant who wrote has worked on the development of a number of National Aboriginal and Torres Strait Islander Strategies. He is also an Adjunct Senior Research Fellow at the School of Social Work and Social Policy, with the University of South Australia</p>
<p>Mrs. Maxine Turner Department for Families and Communities South Australia</p>	<p>Mrs. Turner has been involved in the various dementia projects with Alzheimer's over the years in government and non government settings and has made contributions at a State and National level, particularly in the development of resources.</p>
<p>Ms. Amanda Bosworth Aboriginal Community Care Aged Care Package Coordinator 2 Oldford Road Davoren Park 5113</p>	<p>Ms. Bosworth has knowledge, networks and has conducted the dementia training in the past number of years. She has extensive networks throughout the local community and ahs also been a major contributor to the development of national resources and training packages. She now manages over twenty community aged care packages and was the previous Aboriginal Liaison Officer with Dementia SA.</p>
<p>Ms. Coralie Ober Visiting Research Fellow School of Public Health University of Queensland</p>	<p>Ms. Ober is a Visiting Research Fellow at the University of Queensland and also a Director of a major Indigenous Research Institution. Coralie is focusing on Drug and Alcohol issues and has participated in the development of the Alzheimer's Training Package for Aboriginal people.</p>
<p>Mrs. Bess Yarram PO Box 878 Sale Victoria 3850 Ph: 03 5144 6529</p>	<p>Mrs. Bess Yarram was the previous Chair of the National Aboriginal and Torres Strait Islander HACC Reference Group. Mrs. Yarram has made significant contributions to this area both within her State and at the National Level.</p>
<p>Mr. Leon Harp Aboriginal Training Officer HACC Training and Transport Brokerage WA 6026</p>	<p>Mr. Harp has just been awarded a position at the HACC Training and Brokerage Organisation and is the Aboriginal Training Officer. His role is to coordinate training and other professional development services for HACC service providers throughout the State. He has over 25 years experience in the Community</p>

	Sector
<p>Ms. Joanna Diasinas. Regional Coordinator Tumake Yande - Aboriginal Aged Care Program Hills Mallee Southern Region</p>	<p>Ms. Diasinas is the Regional Coordinator of the Aboriginal Aged Care Program and is closely associated with program implementation in urban and rural areas. Joanne will be attending. Joanne works with a range of programs including an Elders program. She has spent over ten years in 'mainstreamed' aged care and brings this experience to her current position.</p>
<p>Mrs. Vicki Cummings Coordinator - Tumpinyeri Murray Mallee Aged Care Group MURRAY BRIDGE SA 5253</p>	<p>Ms. Cummings is the Coordinator of Tumpinyeri - Community Aged Care Package Program for Aboriginal Elders within the Hills Mallee Southern Region. Vicki has successfully run her program since its inception 5 years ago</p>
<p>Mrs. Elida Kuno-Hutchins Manager Fred Leftwich Resthome Shanty Creek Road Emerald Creek Via Mareeba Queensland 4880</p>	<p>Mrs. Elida Kuno-Hutchins is the manager of an alcohol relief agency that has just invested in high care facilities for dementia patients. She and her agency provide care for people with no where else to go. She has a large client base in region. Up to 40 beds are available and there is an increasing focus on care for dementia patients.</p>
<p>Ms. Leonie Lippitt Twin Cities Aboriginal and Torres Strait Islander Corporation, 1 Charters Towers Road, TOWNSVILLE QLD 4810</p>	<p>Mrs. Lippitt is the program manager at the Twin Cities Aboriginal and TSI Corporation Aged Care facility. She is also a community advocate who is doing a course in Indigenous Mental Health and a representative of the Network of Aged Care Services in Queensland</p>
<p>Mrs. Faye Kingston C/- Ms. Leonie Leppert Twin Cities Aboriginal and Torres Strait Islander Corporation, 1 Charters Towers Road, TOWNSVILLE QLD 4810</p>	<p>Mrs. Kingston is a 72 year old carer of her husband who is Stage 2 dementia. She is his sole carer and has been doing a lot of public speaking about her role as a carer of her husband. She will be speaking at this workshop about her personal story about providing this care, and the lack of services available for elderly carers.</p>
<p>Mr. Brett McKay Aboriginal Social Support Coordinator Coffs Harbour Aboriginal Family Community Care Centre</p>	<p>Mr. McKay is a young Wiradjuri man who is committed to adopting knowledge and teachings (Lore) bestowed upon him by Community Leaders / Elders and applying these philosophies in a modern Community Development environment. Brett's forte' is designing and implementing positive service delivery models that embrace culturally respectful / competent service provision, particularly in the key area of Aboriginal and Mainstream Partnerships.</p>
<p>Ms. Kate Smith and Ms. Anna Dwyer Project Officers Kimberly Elderly Peoples Project Derby WA</p>	<p>Ms. Kate Smith and Ms. Anna Dwyer are Project Officers in Derby for the Kimberley Older Person's Project. They have been working on the NH&MRC funded project that is due to wind up at the end of November. They will be presenting information from their research particularly on the prevalence of dementia in the Indigenous population, the prevalence of risk factors, how to assess it and the current service issues for community people.</p>
<p>Ms. Di Barker Coordinator Minjerriba Aboriginal Corporation Stradbroke Island Queensland</p>	<p>Mrs. Di Barker is the Manager of the Minjerriba Aboriginal Corporation who has, with her staff developed community based dementia initiatives on a Island community. Their work networks with local supply agents, banking services, and community carers and can speak about their work for Aboriginal people on Stradbroke Island.</p>

<p>Ms. Sheree Freeburn Aboriginal Carer Program Coordinator Carers NSW World Square NSW 2002</p>	<p>Ms. Freeburn has worked for Carers NSW for the past seven years. She will be piloting a draft training package for dementia in the mid coast region of NSW, was a member of the State Dementia Network and was on the overseeing committee of the Dementia Program in the State. She is part of the Community Care Gathering Network for NSW a support for non-government agencies in the State.</p>
<p>Mr. Glenn Rees National Executive Director Alzheimers Australia</p>	<p>Mr. Glenn Rees has been National Executive Director of Alzheimer's Australia for 6 years. Before that he was deputy CEO of ATSIC and Deputy Secretary in the Department of Health and Community services.</p>
<p>Ms. Kerry Markoulli Director Dementia Policy and Programs Commonwealth Department of Health and Aging</p>	<p>Ms. Markoulli has been assisting Aboriginal and Torres Strait Islander people develop strategic advice and nationally utilised resources in the HACC, Aged Care and Dementia areas. She is keen to see national action to address Dementia in communities.</p>
<p>Mr. Alan Landford Director Dementia Policy and Programs Commonwealth Department of Health and Aging</p>	<p>Mr. Landford has replaced Ms. Markoulli as the Director in the Dementia Policy and Programs area. He has over a decades worth of experience in the Carers sector and will be a key person to negotiate the development of the National Framework of Action.</p>
<p>Ms. Helena Kyriazopoulos Access and Equity Unit Alzheimer's Australia SA Inc</p>	<p>Mrs. Kyriazopoulos is a key coordinator for the Culturally and Linguistically Diverse community, Chairing the CALD network with a brief to assist Alzheimer's Australia make their programs accessible across the country.</p>
<p>Mrs. Sam Moskwa Grants Manager AIATSIS Canberra ACT</p>	<p>Ms. Moskwa has extensive project development and a management background in health promotion and community development. She has managed programs and grants in both NGO and Government agencies in NSW and the ACT. Ms. Moskwa has a particular interest in inclusive programs and services and is currently the Grants Manager for the Australian Institute of Aboriginal and Torres Strait Islander Studies.</p>
<p>Ms. Kerry Arabena Visiting Research Fellow AIATSIS Canberra ACT</p>	<p>Ms. Arabena is a visiting research fellow at the Australian Institute of Aboriginal and Torres Strait Islander Studies and a PhD Candidate at the School of Resources, Environment and Society at the Australian National University.</p>

Appendix Four:

Mrs. Faye Kingston's Presentation

72 year old Aboriginal Elder

THROUGH THE EYES OF A CARER

I am a full time carer for my husband Peter and have been for the past 7 years.

We have been married 55 years this year. In 1999 Peter was a healthy man and could do anything and everything. He served 22 years in the RAAF as an engine fitter and later in charge of fuel quality control at the Amberley Airbase. He was discharged in Canberra where he joined the Australian Federal Police and served 24 years until he retired. It was 1987.

Peter, as a child, had the best education his parents could afford. He was also schooled in dancing and music. He also played piano and violin and passed his music exams with high honours. Also fitted into his days were Irish, Ballet and Tap dancing; he was a champion in Highland. In his 'spare time' he played tennis.

When we retired and moved to Queensland, we built our dream home on an island in Moreton Bay, where we lived for 17 years.

One night in 1999, after dinner, Peter became sick and we thought it was indigestion and treated it as such. The next morning, Peter was worse and I realised it was serious; he was taken to the Royal Brisbane Hospital by helicopter. The Doctor examined Peter and tests were done and the Doctor told me that Peter was seriously ill and had an aneurism of the aorta and needed an operation immediately. I was told he may not come through the operation and to prepare my family for the worst. In 1998 we had lost our eldest son, aged 44 years, and now I was about to loose my beloved Peter.

After the operation he was placed in intensive care, on life support, not expected to live. This was our second blow so soon after loosing our son.

I sat with Peter for two and a half weeks, with the help and support of my family to give me a rest from time to time. I was told once again by the Doctor that Peter was slipping away. I held his hand and gave him all my strength and love and told him of our life together and hoped he could hear me.

Peter did survive the operation with the help of the medical staff and our love and prayers. Peter left the hospital a month later, frail and thin and returned home with me to the Island. I noticed over a period of time Peter was not the same person. He could not do small tasks which he could do before and I would have to continually repeat myself before he understood.

I became concerned and took Peter to our doctor and explained how Peter was unable to do small tasks and I had to repeat myself over and over. The doctor ordered a series of tests, including a CAT scan of the brain. We had the CAT scan done and returned to the doctor with the results. The news was devastating; Peter's left front lobe was shrinking and he was diagnosed as being in the early stages of Alzheimer's. The doctor explained what to expect of this disease, as I had no idea what Alzheimer's was.

I went into denial and could not accept it and made excuses, like 'Could it have been the drugs? Was it being on life support? The medical trauma or the near death experience?' But no, it was Alzheimer's.

Peter was referred to the Princess Alexander Hospital dementia unit where he saw a specialist. He had 3 months of testing and put on medication, but it was too late. I still have trouble accepting Peter's Alzheimer's. He was referred to the Brisbane University where he had an MRI scan done and from those results my family and I were told by the specialists it definitely was Alzheimer's. My beloved Peter, husband of 48 years, had this terrible disease.

My world collapsed around me as this was not how our married life was supposed to end. Was I now to watch Peter slip away over a period of time, as I had only heard the word Alzheimer's in conversation and now it was on my doorstep.

In a couple of months I had to take the finance management role from my husband and found it very hard and had to learn very quickly how to cope. I sold our home on the Island and I did it on my own. We moved to Townsville to be with my family so I could get help. I wanted to give Peter the quality of life before it became worse, as he was slipping away before my eyes. I brought our homes here in Townsville and he was happy going out seeing different places.

I was put in contact with an organisation, which has helped me so much and has become my dear friends. I must admit I gave them a hard time at first, as I found it hard to accept help from other people. I was not going to let this disease beat me. I was not going to put Peter into respite. I told them it was my place to look after him.

I thought I was wonder woman.

I tried over the months to cope, but it beat me and I had to give in. I became very angry, frustrated and was again, in denial. But most of all I felt guilty as I did not understand that everyone was trying to help me while I was trying to understand the situation. I became confused, as I was trying to help Peter and understand him. Then I realised it was me who was fighting the disease.

One day I was sitting on my own crying trying to understand the books and leaflets which were given to me. They helped and showed a part of what to expect, but Peter was different to what I read. So I put the books away, for to

understand it you have to live and cope with it hands on 24 hours a day and 7 days a week, and that is what I am doing now. It is a full time live in course.

You sit alone; you cry alone and have very few close friends. No one to put their arms around you and say "How was your day?" No one for me to tell of my day, for no one understands.

Hospitals

Do you find it hard when they have to go to the hospital? I know from my experiences with Peter and the problem that you have come up against. For instance you explain to the medical officer Peter has severe Alzheimer's. I also tell them I have to speak for Peter. Some staff understand and will speak to Peter to reassure him it is all fine. Then they will speak to me and I give them all the information. To explain the problem I use body language to Peter and show them how I communicate to find out how much pain he is in and where it is located.

Tell the person with Alzheimer's what you are going to do by touching their hand to assure them they won't be hurt, speak softly at all times for they react to sharp voices and can be upsetting to them. If in doubt ask the carer to explain, that is what we there for. On one occasion I gave the medical staff all the information on Peter and when she asked him a question he couldn't answer, so I answered for him. I was told "I am speaking to your husband." I threw my hands up in disgust and said to the Doctor "Do you know what? I will wait outside and I will congratulate you if you can have a conversation with my husband who has severe Alzheimer's. If you can, I will be very impressive with the outcome. But if you can't I will be outside.

These people are arrogant through ignorance. They need to be shown or take time out to learn. Nor have they been shown how to deal with Alzheimer's patients. Not all the staff are the same some do understand.

I have had two encounters with the hospital and was very frustrated to how Peter was treated by hospital staff. For instance, when their meals are brought in it is put in front of them and put on the tray and they (the Alzheimer's patient) are left to defend for themselves. How can they when they don't know what is in front of them. So the meal is left and it gets cold. Some one may come in to see if they have eaten but by then the meal is cold. Would you eat cold food?

Peter was in pain and when I came in to see him (which was three times a day to feed him) I was told he was asleep. Peter wasn't asleep he was in quite a lot of pain with a distended stomach. I ran to the desk and told the staff and I was told "Well why didn't he press the bell?" How could he press the bell, how could he tell them when he cannot converse with anyone? Why wasn't he checked on more often? The Doctor was called and proceeded to ask Peter questions. Don't they read the charts to see that Peter could not answer? The questions. I was angry when I tried to talk to the Doctor to explain Peter had Alzheimer's and to direct his questions to me, he asked

Peter what was his level of pain, he couldn't tell him so I showed him how to find out. So I ask you how many patients go through the same problem, when we carers are not around. How are our loved ones cared for?

Learn from the carers, let us show you how to learn and understand the patients needs with Alzheimer's for we live and cope with it. We could teach others how to cope for we don't get it out of a book ours is hands on learning. Time does not allow me to mention for there is more as we all know.

My husband sits quietly watching TV, but he is not alone because I am with him always. I laugh when he laughs and cry when he cries. He cannot converse with me in a normal fashion but I have become good at reading his body language. We still go out and enjoy ourselves to lunch and dinner and sometimes to the club which he enjoys, but over the months it has become less as he is getting tired and just wants to stay at home where he feels safe.

How do I cope you ask? It is the most demanding and stressful position for us the carers, but you live and cope and take one day at a time for every day is different. Peter will shave his face with a comb and comb his hair with a razor, having a shower and dressing at all hours of the night, placing two cardboard boxes on top of each other to use as a ladder. Time does not allow me to mention what my days and nights are really like. I rest when he sleeps and I am up when he is up. It is a 24 hour a day, 365 days a year job.

I do get respite now and with it I manage to do small tasks like sleep while he is away for a short time as I do not know what my night will bring.

I still get depressed and upset and wish I could close my eyes and when I wake up and find it was all a bad dream, and everything will be back to normal, but it is not a bad dream it is very real.

It is very hard and lonely sometimes but you make the most of what you have and are thankful and get on with what life deals you. I do wish sometimes I had someone outside of my family to have a cuppa with and a laugh, as I do miss this form of companionship. To see other couples enjoying themselves, I tend to wish we could have the same quality of life we once had.

When you go home tonight having your family around you talking about your day, please spare a moment and think of me and other carers sitting alone in silence with their loved ones with little or no conversation.

A couple of weeks ago I fell and injured my shoulder tearing the ligaments. I was taken to hospital. Peter stayed home with family. He stood outside the front door and waited for me to come home. When I arrived he cried when he saw me and would not leave my side. He was trying to help me for I had been hurt. He sat on the bed beside me and wiped my tears away and kept asking are you ok. But not in words you could understand. He was upset and I could see it in his eyes.

My main concern was for Peter, not myself. Who would look after him now? I rang Blue Care the next day and told them I was unable to look after him as I needed time for my injury to heal. I told them of my concerns for Peter, and that same day, with their assistance, Peter was placed in respite for 5 weeks. He was confused as to why he had to leave me, but I really had no other choice.

My husband is not the man I once had; he is in flesh and body and I am still grateful I have him. To see his face light up when I put my arms around him, see the love in his eyes, his lovely broad smile when I tell him "I love you" and he says me to. To see him trapped in his body, happy but frustrated at times, for he is unable to express in words what he wants to say to me. I place my hands on his face to let him know that I am here to protect and care and give him the reassurance that everything is alright.

Peter is now unable to care for himself and I do everything for him, this is my role as stated in our vows. Through sickness and in health until death do us part.

When you come into contact with a person with Alzheimer's please take the time to understand them; do not ignore them, don't take their dignity away from them. Give them the respect they deserve for they do have feelings and they do hurt, for they cannot defend themselves. Do not pass judgement for they try very hard to please those who take care of them.

Peter is a loving and gentle man in every way. Our journey with this disease has been long, at times interesting and a continuing learning process.

Do not pity us 'The Carers'; just be there for us and understand how we attempt to cope, for you cannot walk in my shoes, but you can walk in my footprints.

Please learn and understand from us the carers, for one day this could be you, the one with Alzheimer's or the one caring for your loved one; for this disease knows no age, no race and no status. Then you may ask who cares for the Carer?

I wish to thank all the organisations who are helping Peter and I. Thankyou very much for your time.

Written By: Faye Kingston

October 2006-11-14

Contact Phone: 0403 794 196