



**Alzheimer's
Australia**
Living with dementia

Dementia: A Major Health Problem for Indigenous People

**Briefing prepared for
Parliamentary Friends
of Dementia**

PAPER NO 12 • AUGUST 2007



Executive Summary

In making dementia a National Health Priority, the Australian Government has recognised dementia as one of the biggest health problems facing Australia now and into the future. It has not been widely understood that dementia is also a major health problem for Indigenous people. Recent research in the Kimberley region suggests that the prevalence rates of dementia among remote and rural Indigenous people could be 4-5 times higher than those in the Australian community more generally. Research is needed in respect of those Indigenous people living in urban areas.

A National Indigenous Dementia Strategy has been developed to provide a framework for the action needed to address the issue of dementia among Indigenous people. Progress has been made but resources are urgently needed within Alzheimer's Australia and Indigenous organisations to implement the strategy.

A single point of national coordination within government would assist greatly in the implementation of the National Indigenous Dementia Strategy and in specific projects that have cross-portfolio implications, such as the work of the WA researchers and any future research into dementia in urban Indigenous communities.

The Evidence

The evidence for the high prevalence rate of dementia among rural and remote Indigenous people is provided by the pioneering work of researchers engaged on the Dementia and Cognitive Impairment in Kimberley Indigenous Australian's project.¹ Over a number of years this important research has focussed on:

1

The development of an assessment tool (the Kimberley Indigenous Cognitive Assessment tool) in order to identify those Indigenous people who may have dementia.

2

Using this assessment tool and validating the outcomes of that assessment by specialist assessment.

3

Identifying the gaps in the provision of services for people with dementia and their families in the Kimberley region.

This is the first research to be done on the number of Indigenous people with dementia in Australia based on a validated assessment instrument. The KICA, like the Mini Mental State Examination comprises a number of simple tests designed to assess cognitive capacity. The KICA includes questions and recognition of objects that are culturally appropriate to people in the Kimberley region of Western Australia. The Department of Health and Ageing provided funding for the tool to be validated in the Northern Territory. It can be varied to be culturally appropriate for other communities as necessary.

¹ This work has been funded by NHMRC grants and has involved Kate Smith, Professor Leon Flicker, A Dwyer, Professor O. Almeida, Professor N. Lautenschlager from the WA Centre for Health and Ageing at the University of Western Australia; Dr. Dina LoGiudice (National Ageing Research Institute) and Dr. D. Atkinson (Kimberley Aboriginal Medical Service).

² The KICA is available on www.healthykimberley.com.au together with a training kit for its use.

The Prevalence of Dementia

There are approximately 2100 Indigenous people aged over 45 years in the Kimberley region. A target sample was selected of 400.

To make the research possible, community approval was obtained, there was careful selection and training of Indigenous workers and interpreters and the patient lists of community clinics were used to identify community members 45 years or older. In the six remote Indigenous communities that took part, all community members over the age of 45 years were approached. One town was also included, of which one third of eligible residents were randomly sampled.

The method of research was first to assess individuals using the KICA assessment tool. Subsequently, within three months, the same individuals were assessed by two independent experts blinded to the KICA results. The consensus diagnosis was agreed by two independent experts using information from the clinical assessments.

Most of those Indigenous people approached agreed to participate in research – there was a low refusal rate, below 10 percent. 55 percent of the participants were female, the mean age was 60 years and 40 percent of participants had no formal education.

AGE (YRS)	DEMENTIA NUMBERS		DEMENTIA PREVALENCE RATES		DEMENTIA PREVALENCE RATIO
	sample	Australia	sample	Australia	
45-59	5	3539	0.026	0.001	26.00
60-69	12	12322	0.169	0.0085	19.88
70-79	11	49804	0.164	0.04	4.10
80+	17	108713	0.567	0.19	2.98
Total	45	174377	0.124	0.026	4.8

The prevalence of dementia (45+ years) was 12.4 percent, compared to a rate of 2.6 percent in the Australian population. In other words the prevalence of dementia among this group of Indigenous people in the Kimberley was nearly five times higher than in the general Australian population. The research indicated that prevalence was higher among males – in the general community, the rate is generally higher among females. Dementia of the Alzheimer's type was most common, followed by Vascular dementia.

Among the important risk factors were age, male gender, previous stroke, head injury, smoking and low education.

The research is regarded as robust, but there were some limitations. Access to health care is more restricted for this population and it is possible that risk factors may have been under reported in medical records and by participants and carers. Nor is it possible to undertake brain imaging as part of the study. It is also possible that the younger age group may have been under represented due to the higher

mobility of that group and the higher number of refusals to participate from the younger age group.

Research is needed into the prevalence of dementia among urban Indigenous Australians. However, it would be a reasonable hypothesis to assume that the rate of dementia for urban Indigenous people will also be significantly higher than among the general population. It should also be remembered that two thirds of Indigenous people live in non-urban environments.



A National Indigenous Dementia Strategy³

Over 30 Indigenous people from across Australia took part in a two day National Indigenous Dementia Forum in October 2006. The Forum was organised by Alzheimer's Australia and funded by the Australian Government through the National Dementia Support Program. The Forum participants agreed that a national program of action was needed to address dementia as an integral part of a national approach to successful ageing for Indigenous Australians.

³ The National Strategy is contained in **Beginning the Conversation**, which reports comprehensively on the National Indigenous Dementia Forum.

The participants nominated six key action areas to be included in a National Indigenous Dementia strategy:

- 1 Community Awareness and Prevention.** Alzheimer's Australia to develop and deliver community awareness raising and prevention programs targeting Aboriginal and Torres Strait Islander people.
- 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.
- 3 Research.** Aboriginal and Torres Strait Islander people to implement a research agenda in partnership with existing organisations to determine the prevalence of dementia in communities; identify potential risk factors; address the unmet needs of people with dementia and their families and carers; and improve dementia services for Aboriginal and Torres Strait Islander people.
- 4 Diagnosis, referral and treatment.** Provide flexibility in responses to the needs of Indigenous people, their families and the services involved in the diagnosis, referral and treatment of people with dementia.
- 5 Workforce issues.** Ensure funding is allocated to developing a sustainable 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 the community.
- 6 Partnerships and collaborations.** Alzheimer's Australia and the National Indigenous Dementia Advisory Group oversee the development of strategic operational and training partnerships with appropriate organisations.



Progress

An important start has been made in identifying the extent of the prevalence of dementia among Indigenous people.

Through funding by the Australian Government under the NDSP, Alzheimer's Australia has recruited a National Indigenous Liaison Officer (venessa.curnow@alzheimers.org.au) and Alzheimer's Australia South Australia now has an Indigenous Officer.

Of critical importance is increasing the awareness and understanding of dementia among Indigenous people. The Australian Government has funded, through Alzheimer's Australia, the development of a Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities. Plans are in hand to ensure a wide distribution of this product by the Department of Health and Ageing.

The aims of the Resource are multipurpose:

- Awareness raising in Aboriginal and Torres Strait Islander communities.
- Empowering Aboriginal and Torres Strait Islander people to access available services and supports.
- Supporting the training of Aboriginal and Torres Strait Islander health professionals and others working in Aboriginal and Torres Strait Islander communities.
- Enabling workers and communities to develop strategies to reduce the impact of dementia.

The University of Western Australia have secured a further grant from National Health and Medical Research Council to assess and analyse service gaps for people with dementia in the Kimberleys. This important work will provide much needed information on what dementia specific and other services are needed for Indigenous people in rural and remote areas.



**Alzheimer's
Australia**
Living with dementia

National
Dementia
Helpline
1800 100 500



The National Dementia Helpline
is an Australian Government Initiative