THANK YOU

Thank you to all the people who told us about their experiences looking after older people with dementia / memory problems across the Kimberley
The Indigenous Dementia Services Study (IDSS)
The IDSS study follows on from two earlier studies; the development of the Kimberley Indigenous Cognitive Assessment (KICA) tool in 2003-2004; and the prevalence study in 2005-2006. With the knowledge that memory problems / dementia are common, the current study aims to develop new approaches to caring for people with dementia in remote communities in the Kimberley.

Steering Committee (SC)
The SC guides and advises the study and includes past and present carers for persons with dementia and representatives from services. The SC met twice in Broome (August 2007, March 2008) and recently in Mowanjum (August, 2008).

Scoping Study
42 staff from a range of government and non-government services were interviewed (in confidence) over the phone. The questions were developed by the team and steering committee. Information from the interviews was written up and later analysed for common themes, interesting or stand out points.

In Depth Interviews
26 interviews have been tape recorded and typed. This has included 15 past and present carers and 14 workers in health or aged care in Derby, Mowanjum, Dampier Peninsula, Looma, Warmun and Balgo.

Focus Groups and Community Meetings
The team is now holding focus groups with carers and workers in the communities involved, and discussing all of the information and ideas people have suggested at meetings with community councils and service providers.

What Happens Next?
By the end of the year all of the information will have been collected and new ideas for caring for people with memory problems discussed with communities where these new approaches are to be tried out and evaluated in 2009. These ideas will be shared with communities across the Kimberley and Australia.
In September 2008 we are going to start the dementia project in Central Australia.

We will have a new project officer who will be based out of the Centre for Remote Health office in Alice Springs.

This project officer will be talking to a steering committee, Aboriginal carers and aged care workers and other professionals in the region. They will ask questions about what Aboriginal people with dementia need help with and who should deliver this help. We also would like to know how to attract more workers into aged care. The project officer and other staff will discuss this information with interested community members and councils.

This will enable ideas to be exchanged between the two regions (the Kimberley and Central Australia) about what is working and what the unmet needs are in different regions with quite different aged care services and supports. This information will then be more applicable to other rural and remote regions.

Different models of practice will then be trialled for 6 months and evaluated in up to 3 communities around the region.

A report on the Kimberley and Central Australian studies will then be written and recommendations for future sustainable models for Indigenous aged care made to government. This will enable Aboriginal people and people who work in the regions to inform Indigenous aged care policy and practice.

This project will be completed in early 2010.
Relationships

People spoke about how they came to be minding the person with dementia. Often this reflected cultural responsibilities; the part the person with dementia has played in their life, for example passing on cultural knowledge or helping to raise children; and at other times, the impact of illness, accidents and premature deaths.

‘Well, we see it as our responsibility to look after in the way, in the, um, in this situation she is. Being old.’

‘I was married to... her son... and she was looking after me ... when I had my first child, she was always caring for me... that’s why I am looking after her.’

‘Well we came together from the bush when I was a little girl about 11 years old ...I came to [Catholic] Mission ... I took him once to hospital with me... I stay with him right through till he get better ... we bin in [Community] for long ... and I went to school in [Community] I was in the dormitory ...by nuns or whatever they call them...I went to high school in [Town] for 2 years... long time since I lose my husband here.’

‘But with the old ones, oh like mum says to me... she is not supposed to be talking to my husband, she is not allowed to have nothing to do with him, she is not allowed even to look at him. The only time it changes is when he started giving her ice cream [laugh]. She said ‘my Countryman, my ancestors won’t mind this ice cream it’s too good’ [laugh]. But do you know what I mean. So she’s started teaching me, when I didn’t know. So that’s and a lot of things like that.’

Family Based Care

People spoke about the importance of keeping the person with dementia with family for as long as possible.

‘Keep them home with their own mob families you know... Close where they can remember things every time we repeat things to them you know ... They start remembering things then ... Properly you know but when they go with gardias [non-Indigenous people] they just ... Forget.’

‘It’s a big job... it is yeah trying to work and juggle family at the same time. Three of them at school, one’s at home and looking after her is like four kids in one because she’s like a big kid herself (laughs) yeah it’s hard but it’s good company having her around even for the little kids they learn a lot off her as well. Yeah its good for her sometimes she teaches in languages, words right and wrong how to respect others. She does a lot of things.’
People felt strongly that projects with people with dementia and the families that mind them must be self determined and community driven to be successful, as well as community based so people can stay on country.

'[name] spoke about the need to have a really strong council and community, and how this was why the pensioner units had worked.'

'older people want to stay in land and on country… we have to visit more often and encourage clinics to make more home visits, community and councils to take problems more seriously.'

'any project / initiative needs to be community driven / input from the community. Must be culturally informed, as only way that project will work. Must involve family (of those with dementia) and the community and the council in the project…other projects that have been developed with good intentions by white people that just haven't worked because of one little thing.'

'If carers could have more of an input into what they see as important, what should be done…what happens. Gave eg of working in government departments and seeing that services are delivered from a non-Indigenous approach and that this is not always appropriate or works. That Indigenous people need to be able to say what they want, too many are accepting of what is said.'

Everyone agreed that it was very important to have more Indigenous people working in Aged Care. For many, this was seen as the best way to ensure that the needs of the person with dementia were met. People felt aged care workers needed to be better paid, and their roles in the community more valued. Some of the barriers Indigenous people face to working in remote communities and towns was also acknowledged.

'well they should get more like more Aboriginal workers for them … You know… Like where they are now they should have more Aboriginal workers and people they know you know... Countryman that they can talk about things families and everything… That kind you know'

'yeah they need some aboriginal people working in HACC to show them where the places are to take out for activities'

'better paid workers = higher valued staff' 'more staff = empowerment'

'supervision is important, and knowing what motivates people to come to work. Having good supervisors that will know why someone will or won't come to work.'

'noted that staff retention is the main problem for remote HACC, as there is not enough pay. Also noted that jealousy is a very real problem and prevents a lot of people from becoming workers…other issues for staff included needing a break, sorry business, pension week, having to do paperwork.'
People spoke a lot about training. The importance of cultural awareness and cultural safety training for non-Indigenous staff. Greater access to KICA training for clinicians. Generally, more training on dementia for health and aged care workers and families that are caring for the person with dementia.

‘Cultural awareness. That’s the biggest thing they need to understand what, how that person lived. How they, you know, respond to families and things like that. And don’t just come in and you know, assume that they are doing the best for them when they don’t understand… That’s the biggest thing that cultural awareness… make them understand how we live, how we approach things for our old people, you know, how we do it for them… Well, what we trying to do with in our organisation now is start up a cultural awareness um thing, well that we um presented it to like on the mines … or new people that just come into town and didn’t know and show them our culture and make them understand where we are you know and where we come from… and what we trying to do, you know … And, we slowly, we putting it together, that cultural awareness thing. But um, just the now to be aware that how people lived. Cause nobody, no-one, no-one lived the same.’

‘So there’s little things now that are getting really bad I’m finding I don’t know. What do they do with people with dementia? Just let em go or? What happens?’

‘People have trouble understanding that madness that comes with dementia and the permanence, this has an impact on peoples tolerance ie … when is it going to stop?’

People spoke about the issues affecting remote communities, the distance to main services, competing priorities of need where everything is needed (eg child health, environmental health, housing are all important and may compete for council, community and service provider attention). Also the need to give family carers more practical support was raised, as was the issue of elder abuse. Some people thought that Aboriginal people were more accepting of the changes that come with dementia, and may see these as a normal part of aging and not seek help. Others acknowledged the strength that comes with art, living on country, cultural knowledge, spirituality, family and kinship roles.

‘one of the strengths of Aboriginal families / communities is in looking out for each other, and not being so put off by the changed behaviour.’

‘The other thing that we also see is elder abuse… in the community. So just making people more aware that that does go on and that does happen and how we can you know recognise it because a lot of people don’t talk about it… And it happens in Aboriginal families and non-Aboriginal families… And that may simply be neglect, not changing their nappy, not making sure they are showered, not giving them a good feed. So they’re all forms of elder abuse and it can be emotions as well so it… and demanding money, taking the nanna key card. I mean that’s all forms of elder abuse. So, I think more community awareness about how can we look after our grannies better, and how can we prevent them from been abused.’
People spoke about the importance of good relationships and communication between service providers and with families. The use of interpreters was considered essential. Being able to be flexible in the way services were delivered was a strength. There was a need for more clarity with assessment, referral, clinical pathways, protocols and guidelines. Gaps in services (e.g., specialists, respite, HACC) were also noted.

‘people visiting the community and not informing the clinic – if we can’t work with each other than how are we going to work with the community.’

‘they should be working in closer like err well it should be a two way thing community and the service provider and the carer and the person that’s being cared for and the whole family in general that sort of thing gotta be sit down and worked out together.’

‘it is necessary as an OT to find out more that just the surface issues, that is the deeper functional issues that the person may not tell you straight out… it can be difficult to elicit this information when visiting, gave eg of people nodding their heads. This is why the OT tries to work in with the clinics, and all of the partnerships and networks.’

‘need to use interpreters more as sure that patients just say yes a lot of the time and won’t understand.’

There is some good news...

There is some good news to report. Dina LoGiudice, one of the founding members of the project team recently got married - finally.

She and her Irish bachelor Michael Ryan tied the knot in a small church ceremony in wintry Melbourne on the 14th June. The ceremony was attended by close family and friends including two members of the project team Leon and Kate.

The next day the happy couple flew to Ireland to celebrate with the Ryan family, of which there are many, and another church celebration was held.

There was more eating and drinking, this time of beer, bacon and potatoes. Dina and Mike are now back home, trying to lose a few kilos and adjust to married life. Both report enjoying their new life together, but Dina is realising that old domestic bachelor habits are hard to break, but she is patiently waiting..
Indigenous Dementia Services Study Team

Who’s working on this project?