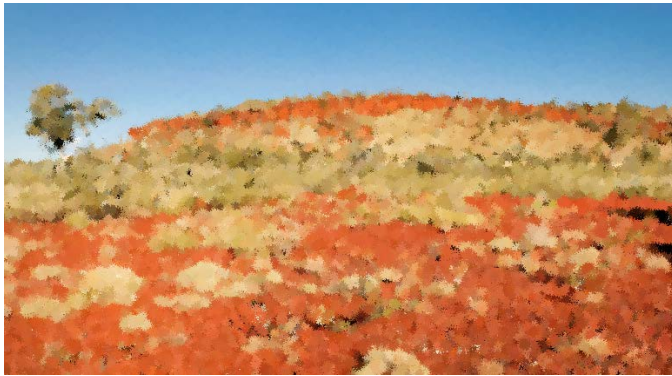




**An Australian Government Initiative**

# **Dementia Service Coordination in Aboriginal Communities in Central Australia**



**Dementia Collaborative Research Centre**

**Assessment and Better Care**

**September 2012**

WESTERN AUSTRALIAN CENTRE FOR  
**HEALTH X AGEING**

 **DCRC**  
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## ACKNOWLEDGEMENTS

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## CONTENTS

Executive Summary .....	1
Recommendations to support the implementation of guidelines .....	3
Background .....	5
Literature Review .....	7
Methodology .....	12
Results .....	13
Education programs and resources on dementia .....	19
Outcomes and Recommendations.....	22
References .....	32
Appendices .....	35

1. Poster : Pathways to diagnosis for people with Dementia living in Aboriginal communities
2. Poster Care planning for People with Dementia living Aboriginal Communities
3. Care plan
4. List of abbreviations
5. Newsletter to stakeholders and community
6. Proformas for collecting data from service providers and educators

# DEMENTIA SERVICE COORDINATION IN ABORIGINAL COMMUNITIES IN CENTRAL AUSTRALIA

## EXECUTIVE SUMMARY

The Indigenous Dementia Services Study completed in 2010 by the Western Australian Centre for Health and Ageing, University of Western Australia, determined that the key issues for people with dementia and their families living in Central Australia were poor service coordination and insufficient local education (Jensen et al 2010). Caregivers and other local service providers are often unaware of the range of services available and how to access them. Service providers do not always coordinate their visits to clients with other services, or Aboriginal communities. A number of culturally appropriate educational resources have been developed, however there is generally a lack of awareness of what is available, how to access and use them and who can provide training. Dementia guidelines on assessment, diagnosis, management, educational resources and referrals to local support and education services need to be reviewed, updated and effectively disseminated to improve the quality and coordination of dementia care in remote communities.

This project has developed culturally safe and sustainable dementia guidelines to ensure that pathways meet the needs of Aboriginal people living in remote communities. These guidelines complement the Northern Territory Framework for Action on Dementia 2010-2015 and use the following stages identified in the *Dementia services pathways – an essential guide to effective service planning* document produced by KPMG and funded by the Department of Health and Ageing:

- Awareness, recognition and referral
- Initial assessment and diagnosis and post diagnosis support
- Management, care, support and review
- End of life

These guidelines were developed through:

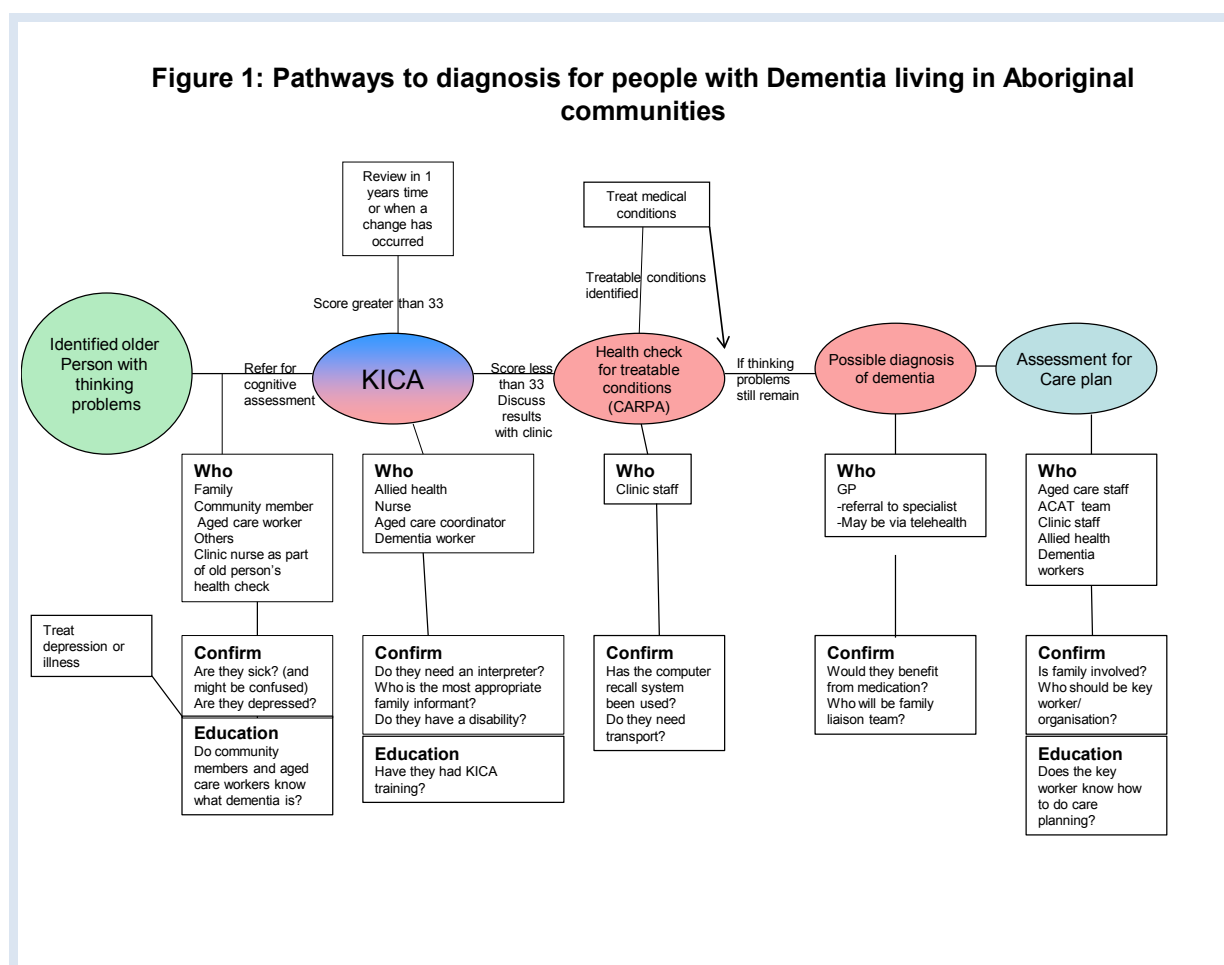
1. Collating currently available Aboriginal dementia education resources and courses ensuring that they cover the needs of the target groups: health professionals, aged care team leaders and workers, people with dementia, caregivers and community members
2. Determining the services available for people with dementia in the region
3. Developing pathways for Aboriginal dementia care that incorporate the services and education available in the region, including assessment, diagnosis, management, education and referrals to services

These guidelines will require review within five years from the date of publication.

The study was initially conducted within an Aboriginal community in Central Australia using an action research methodology. Interviews were conducted with service providers in the community as well as with visiting service providers to the community, and those providing education to community and workers. The pathway to diagnosis and care of some older people identified as having ‘thinking problems’ were followed. A visual representation of this pathway was developed which provided a framework for further discussion (Figure 1).

Meetings were held with relevant organisations to discuss the implications of the research and ways in which diagnosis and care could be improved in the future. This resulted in some changes in practice as the project was being conducted, such as increased use of interpreters.

The resulting pathway diagram was presented to service providers and families in two other communities and was adjusted to accommodate for differences between these communities. Further feedback was provided by a steering committee that represented relevant service providers and families. The visual representation of the pathways for diagnosis is pictured below, followed by recommendations developed to improve the care of people with dementia living in remote communities as a result of this project.



## RECOMMENDATIONS TO SUPPORT THE IMPLEMENTATION OF GUIDELINES

### AWARENESS, RECOGNITION AND REFERRAL

1. As part of the NT Dementia Framework (key priority area 3), a comprehensive plan is developed to improve the awareness and knowledge of dementia in remote communities. This should include education for health professionals, aged care workers and community members, including shire workers, and store managers. The plan would be reviewed annually by the Northern Territory Dementia Framework Reference Group (NTDFRG).

### INITIAL ASSESSMENT AND DIAGNOSIS AND POST-DIAGNOSIS SUPPORT

2. Education is widely provided to health professionals, including those in hospitals about the use of the KICA. The use of interpreters should be emphasised. This could be coordinated by Alzheimer's Australia.
3. Changes are recommended to the CARPA protocol on adult health checks that include a cognitive assessment every second year for those over 55 years of age and recommends that the appropriate tool for use with people in remote communities is the Kimberley Indigenous Cognitive Assessment (KICA).
4. The review of the KICA in the light of findings from the project, and that a more in-depth learning package be made available on line
5. Patient information record systems are rationalised so that information about people living in remote communities is easily available for all health and aged care providers with the consent of the person or their family.
  - a. For NTDoH harmonisation of the three current electronic patient information systems (hospital, community and remote)
  - b. Communication between ACCHO patient information systems and those of the NTDoH also be improved
  - c. Recall systems on patient information records system be utilised to ensure that health checks are completed by clinic staff as soon as possible after a KICA (which indicates some cognitive decline) has been completed.
  - d. Further adaptation of patient records may need to be considered with the introduction of the Personally Controlled Electronic Health Records for all Australians
6. A case manager or key worker is appointed for each person living with dementia to advocate and ensure that *the assessment process continues at a reasonable pace*. This would be overseen by ACAT teams.

7. Telehealth with geriatricians or other appropriate medical specialists be developed and implemented to provide a service to people in remote communities as well as education to service providers.

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## MANAGEMENT, CARE, SUPPORT AND REVIEW

8. A key agency is identified to take the main responsibility for each person with dementia to coordinate their care planning and ensure that quality care is delivered. This would be in consultation with the ACAT team, and could be a different agency for each person, depending on their individual needs. Contingencies need to be in place for continuity of care if that agency or worker leaves the community. This could be monitored by the ACAT team member who visits that particular community. More ACAT staff are required if they are to take more than a monitoring role.
9. A care plan is developed between families and providers with the key worker/agency taking responsibility for this. Input should be sought from all providers, including clinic staff, and made available to each. The format should be appropriate for the region, using pictures to illustrate the domains for those workers with limited literacy skills. A review of the plan should occur at least annually. A summary of medical care for co-morbidities should be included.
10. Education is provided for aged care coordinators and workers in care planning.
11. Regular team meetings (can be via telephone) and supported by all appropriate agencies working within each community to ensure coordination of services and to ensure that action identified in the care plan is completed by team members by the expected date.

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## END OF LIFE

12. Education around particular legislation on end of life decision making should be available to all families and care providers. The Northern Territory is in the process of developing legislation to enable binding end of life decision making for all and the education program associated with the implementation of this legislation should include Indigenous people living in remote communities.
13. The NT Framework on Dementia Reference Group developed a plan to ensure that Residential Care Facilities have a large percentage of Aboriginal clients provide a 'culturally safe' environment.



## BACKGROUND

### DEMENTIA SERVICES IN REMOTE COMMUNITIES

#### CENTRAL AUSTRALIAN INDIGENOUS DEMENTIA SERVICES STUDY

In 2010 the Indigenous Dementia Services Study which was funded by the NHMRC, was conducted by the Western Australian Centre for Health and Ageing (WACHA) into the unmet needs of Aboriginal people with dementia and their caregivers. The two sites for the research were in the Kimberly Region of Western Australia and Central Australia. The results of the study in the Kimberley have been reported elsewhere (Smith et al 2011).

The Central Australian study consisted of in-depth interviews and a mapping study of current services in the region. The project was guided by a steering committee of local service providers and assisted in providing access to people to be interviewed in the communities. Twelve carers of people with dementia and four aged care workers and twenty two service providers were interviewed.

Thematic analysis of all the transcribed interviews was used to develop a list of unmet needs.

- Caring for old people
- Perspectives on dementia
- Culturally centred care
- Indigenous workforce
- Training and education
- Community issues
- Service provision issues

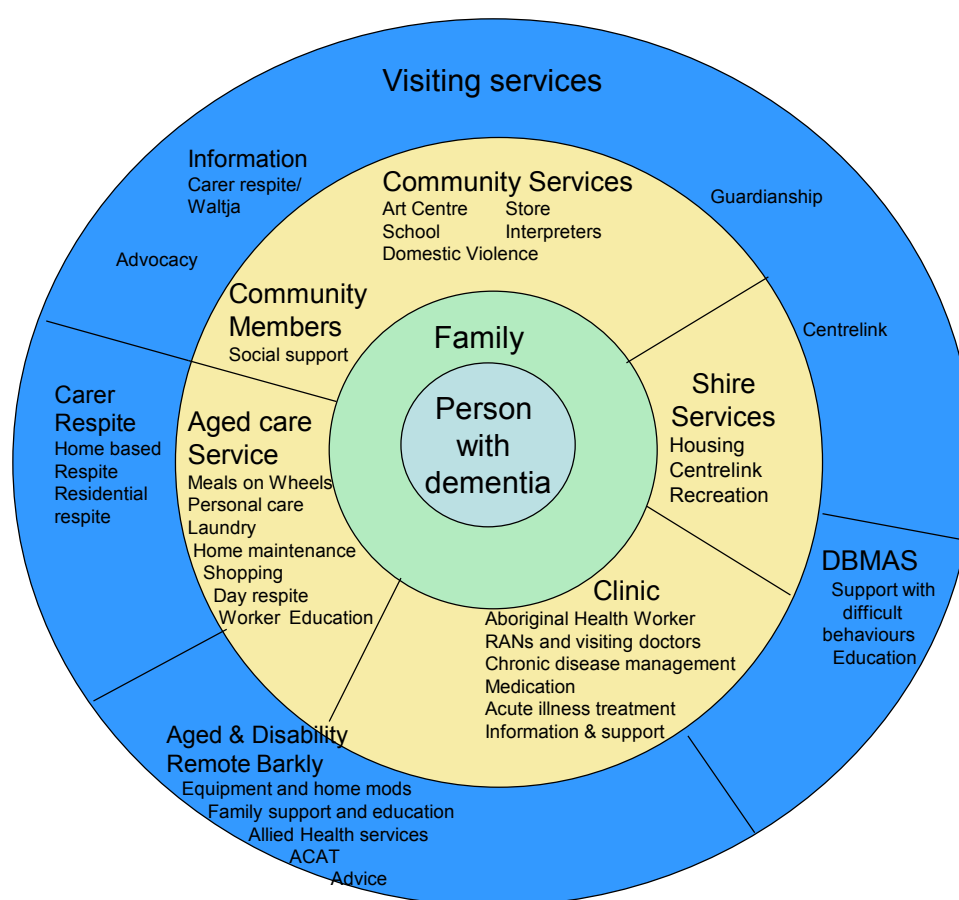
These needs were similar to those found in the Kimberley study but the service delivery context differs. Central Australia has a large number of small communities which are separated by large distances. As part of the study, information for mapping the current aged care service delivery in the region was completed using the aged care information data base provided by Carelink as well as information gained from in-depth interviews with service providers. Aged care services, which deliver programs in remote communities such as Home and Community Care (HACC) and Community Aged Care Packages (CACPs), are provided by a variety of organisations including local government shires, Aboriginal community controlled organisations and a number of other non-government organisations (NGOs). Other visiting services are provided from regional centres including the Aged Care Assessment Team (ACAT), allied health professionals, specialist dementia services such as Dementia Behaviour Management Assistance Service (DBMAS) and innovative programs such as the 'troopy program' which provide carer respite.

While there were many unmet needs identified, the complex service delivery context has meant that service coordination and communication issues that were identified were of particular significance.

Caregivers and other local service providers were often unaware of the range of services available and how to access them. Visiting services may not coordinate their visits to clients with other services or with the shire or Aboriginal community. At times many services visit each community individually when they could be better coordinated.

Figure 2 illustrates the complexity of aged care services which are potentially available in one community.

**Figure 2: Aged Care Services Potentially Available to Remote Communities**



The findings from the Indigenous Dementia Services Study formed the basis for this current project in establishing pathways for care and education for people with dementia living in Aboriginal communities.

## LITERATURE REVIEW

A significantly ageing population has highlighted the need to focus on sustainable aged care services and support systems in Australia. It is estimated that by the year 2050, people over sixty-five years will represent twenty three percent of the total Australian population, and, with a proportionally lower work participation rate will be heavily dependent on government services (Commonwealth of Australia 2010). At the same time, prevalence rates of dementia which occur more commonly in this age group will increase, as will the need for specialised and suitably tailored care regimes (Brodaty and Cumming 2010). Typified by cognitive decline associated with a range of disease processes (Imperio and Pusey-Reid 2006), dementia is expected to be present in 1.13 million Australians by mid-century and predicted to be the most costly health condition in the country into the 2060s (Access Economics 2009).

Dementia collectively refers to a series of diseases which are characterized by multiple cognitive impairments (Imperio and Pusey-Reid 2006). Normal functions of daily living are impacted on by progressive changes in domains such as memory, mood, behaviour and language (Willis 1999; Australian Institute of Health and Welfare 2006; Abbey, Palk et al. 2008). Alzheimer's disease is the most commonly occurring form of dementia, presenting in up to 50-60% of dementias (Draper 2004). Diagnosis is based on a series of clinical symptoms which may be behavioural, psychological or the result of brain imaging investigations (Black, Logiudice et al. 2001).

Vascular dementia is the next most common form, occurring in up to 20% of cases, and can occur in combination with the Alzheimer's type (Kitwood 1997; Draper 2004). It may be caused by stroke, cardiovascular or cerebrovascular disease or hemorrhage, and may develop incrementally after cerebral injury (Black, Logiudice et al. 2001). Other dementia types include Dementia with Lewy Bodies, Frontotemporal dementia or those associated with rare causes such as brain tumor (Black, Logiudice et al. 2001; Draper 2004).

Physical assessments and blood examinations may be useful in diagnosing a particular dementia type or to exclude other similarly manifesting conditions such as Parkinson's Disease, Vitamin B12 deficiency, infection, HIV, syphilis or thyroid dysfunction (Draper 2004). Pathologically, a reduced size of the medial temporal lobes unseen in the normally ageing brain is apparent in even the mildest cases of Alzheimer's disease associated cognitive decline (McGrath, Holewa et al. 2007) and while Computed Tomography (CT) and Magnetic Resonance Imaging (MRI) may be useful, post-mortem examination provides the only definitive diagnosis (Black et al. 2001). Depression and delirium are two closely resembling (or possibly co-occurring) conditions which may be treated with accurate diagnosis.

The greatest risk factor for dementia is age, while other factors such as genetics, viruses, trauma, obesity and some disease states including diabetes, stroke, hypertension and depression have been identified (Imperio and Pusey-Reid 2006; Bartlett, Gray et al. 2007). Treatment may include medication, memory or behavioural therapy and appropriate interventions such as physical activity

can shape the course of the disease, despite its progressive and irreversible elements (Draper 2004). An awareness and understanding of physical dementia co morbidities such as falls, sleep disorders, oral disease and malnutrition (Kurrle 2011) contribute to management.

Dementia as it occurs in Indigenous Australians has received relatively poor attention. The average shorter lifespan of Aboriginal people has led to some common misconceptions about the prevalence of dementia in this population. Recent studies in the Kimberley region of Western Australia have revealed dementia rates to be 12.4% of people over 45 years, 27% of people over 65 yrs, five times those found in the mainstream population, particularly high in the 45 to 59 year age bracket where co morbidity risk factors may have impact (Smith, Flicker et al. 2008). These rates concur with the only other prevalence study on older Indigenous people, where dementia rates were found to be 20% of people over 65 yrs in remote areas of North Queensland (Willis 1999). Not unlike the general population, the diagnosed dementias were primarily of the Alzheimer's type, with vascular dementia being second most common. The dementia risk factors for Aboriginal people living in the Kimberley are older age, male gender, no formal education, being a smoker, or having had a previous stroke or head injury (Smith et al 2010, Smith et al 2010).

It is conjectured that the general health and frequency of co morbidities in Indigenous Australians predisposes them to the dementias, particularly in relation to risk factors such as cardiovascular disease, diabetes, previous stroke, head trauma and current smoking or chewing of tobacco (Willis 1999; Alzheimer's Australia NT, University of Western Australia et al. 2006; Smith, Flicker et al. 2008). Furthermore, conditions of socio-economic disadvantage, lack of formal education and inequitable access to health care and support services weigh on incidence rates (Broe 2008).

Providing appropriate care alongside appropriately timed access to community-based services is crucial in effective management for people with dementia and their caregivers, while delaying or avoiding entry into permanent residential care (Australian Institute of Health and Welfare 2011). In Aboriginal communities, service provision must ensure cultural safety, whereby the individuality of each service user is acknowledged and power differentials between provider and recipient observed (Taylor and Guerin 2010).

A culturally centred approach to aged care service provision was evident with the development of the Yuendumu Old People's Programme in the Warlpiri community, north west of Alice Springs (Smith, Grundy et al. 2010). The service developed over several years by incorporating community direction, collaboration and decision-making to allow for local ownership and cultural sustainability. It involves a family model of care with services delivered by local people in accordance with the Warlpiri kinship system, and incorporates a purposefully designed aged care facility which structurally accommodates gender and avoidance relationships. Furthermore, the service recognizes the quality standards and medical knowledge outlined in mainstream guidelines as mutually applicable within their community controlled framework (Smith, Grundy et al. 2010).

Community consultation was also a key element in the Lungarra Ngoora Community Care trial project which occurred in the Looma community of Western Australia's Kimberley region (Western Australian Centre for Health and Ageing 2010). Based on extensive qualitative enquiry into the unmet need of the frail aged and people with a disability, the project showed the benefits of increased access to culturally relevant activities, health assistance, meals and transport, while increasing the number of local Aboriginal staff and educational opportunities. Project outcomes were positive, with growth in the number of service users and strong community support for the model to continue.

The Looma project also addressed a need for improved service coordination, which, in remote Aboriginal communities is made difficult by a lack of resources and complicated or duplicated information systems for consumers. Geographical isolation and the existence of dispersed, smaller populations adds further obstacles (Lindeman 2011). Specifically, dementia management guidelines and clinical pathways have been identified as an area of concern for clinicians, service providers, community members and caregivers in the Kimberley region (Western Australian Centre for Health and Ageing 2010; Smith, Flicker et al. 2011).

A lack of integration or awareness of support services could lead to less optimal outcomes such as premature entry into residential care (Australian Institute of Health and Welfare 2011; Low, Yap et al. 2011). This is further complicated in rural settings by independently structured organisations working to service scattered populations (Innes, Cox et al. 2006; Smith 2010). It is surmised that in order to reduce service fragmentation, an ideal model of care should involve case management within an integrated system which is directed by consumer choice (Low, Yap et al. 2011).

Clinical guidelines and care pathways for community-dwelling people with dementia were developed by Queensland University of Technology in 2008 for policy makers and health providers to assist in the planning and delivery of dementia care (Abbey, Palk et al. 2008). A further dementia service planning resource has been produced by KPMG for the Department of Health and Ageing (KPMG 2011) which is framed by four service delivery aspects: Awareness, recognition and referral; Initial assessment and diagnosis and post diagnosis support; Management, Care, Support and Review and End of life.

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## AWARENESS, RECOGNITION AND REFERRAL

Different perspectives of dementia exist among Indigenous people. An understanding of abnormal behaviour is often relative to the community and cultural context bearing its own beliefs, practices and standards (Pollitt 1997; Arkles, Jackson Pulver et al. 2010). An Aboriginal consideration of dementia may centre on being of 'sick spirit' (Arabena 2007), or associate the disease with non-Indigenous origins (NPY Women's Council 1995). Recent enquiry into dementia awareness amongst Indigenous people revealed generally poor knowledge using a modified Alzheimer's Disease Knowledge Test for Indigenous Australians (Garvey, Simmonds et al. 2011). This was especially evident amongst younger people.

A lack of vocabulary in Indigenous languages to distinguish dementia from other brain disorders is evident (Lindeman 2010). Importance must therefore be placed on a whole-of-community approach to dementia education to enhance awareness and facilitate early intervention measures.

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## INITIAL ASSESSMENT AND DIAGNOSIS AND POST DIAGNOSIS SUPPORT

A recommended pathway for initial diagnosis and assessment of dementia in lower density populations and remote areas focuses on a general practice or practice-nurse led investigation which initiates diagnostic testing and specialist referrals with the possibility of using telemedicine and online resources (Access Economics 2009). The elimination of possible health conditions which may present similarly such as delirium or vitamin B<sub>12</sub> deficiency is essential at this stage.

It is well established that the timely assessment and diagnosis of dementia is critical in the establishment of intervention measures, care regimes, and furthering the ability of caregivers to sustain care at home of a person with dementia and gain access to appropriate respite (Brodaty and Cumming 2010; Cotter, Condon et al. 2011; KPMG 2011). Home and Community Care services (HACC) are most often the first point of contact with the service system for all levels of care. The role of HACC services in assessing cognitive impairment is variable and is usually limited to screening tests (when the individual assessor recognises this need and has the skills to conduct screening tests), with referral to more specialist services for comprehensive assessment and diagnosis. Aged Care Assessment Team (ACAT) assessments are required to access Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) or the dementia specific EACH-D using a multi-disciplinary, comprehensive and holistic needs diagnosis (DoHA 2006).

Assessment practices in Central Australian remote communities have been found to be inconsistent between service providers, resulting in variable service outcomes (Lindeman and Pedler 2008). Although training has been implemented to address these issues (Lindeman 2006), challenges remain. A local policy decision to channel all assessments for community care through the local ACAT to date has not been evaluated.

Development and validation of the culturally sensitive Kimberley Indigenous Cognitive Assessment (KICA) has enabled an appropriate and reliable dementia screening tool for Aboriginal people living in remote communities (Alzheimer's Australia NT, University of Western Australia et al. 2006). This has been validated for use in the Kimberley, the NT and North Queensland. Unlike many assessment tools, it is available at no cost, and able to be downloaded. Two primary aspects of the KICA involve the cognitive screen (KICA-Cog) where a score at or below 33/39 indicates the need for a doctor's referral for further investigations or a dementia diagnosis, and the informant based KICA -Carer, where 3/16 or above suggests further examination (Western Australian Centre for Health and Ageing).

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## MANAGEMENT, CARE, SUPPORT AND REVIEW

Receiving care at home or 'ageing-in-place' is a priority for many people with dementia and their caregivers, and is reflected in national aged care policies (Brodaty and Cumming 2010; Smith, Grundy et al. 2010; Low, Yap et al. 2011). Indigenous people have identified the importance of remaining on their communities and the associated benefits in terms of health and well-being (NPY Women's Council 1995; Harrison 1997; Smith, Flicker et al. 2011). For the majority of older Aboriginal people, separation from their country is far more detrimental than the endurance of physical hardships.

A review of aged care pathways following ACAT assessments found people who were recommended for residential care, who did not receive community based or respite care after their recommendation, were more likely to end up in this setting (Australian Institute of Health and Welfare 2011). Older people who had only received community-based care after assessments were least likely to enter residential care. Sufficient and effective community support services are most often necessary to meet the care needs at home.

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## END OF LIFE

Palliative care and End of Life concerns are crucial to dementia service provision and must be approached in a culturally sensitive manner. Funding community-based palliative services should provide the most culturally appropriate means of end-of-life care, while establishing community links and enabling service coordination (McGrath, Holewa et al. 2007).

Willis (1999, p.48) identifies key aspects of dying which relate to Pitjantjatjara people of central Australia's Western Desert area. Included is the importance of dying in home country, the importance of providing palliative care services through matrilineal kin structures and the provision of complex supportive medical treatments including advanced pain management. The culture of dying must be integral to palliative services (Willis 1999) and reflect the values of each group. For example, Informed Consent which is guided by principles of autonomy and self-determination may apply differently amongst Aboriginal people, where decision-making is family based, and medical intervention concepts are difficult to interpret and access (McGrath and Phillips 2008).

Enquiry into Indigenous palliative care in the Northern Territory has revealed a significant lack of services (McGrath, Holewa et al. 2007) including home-based resources, after-hours medical care and pharmacy. Rather, aspects of palliative care must be sourced from available acute care services. An increase in the number of Aboriginal health workers to provide palliative support as well as the provision of palliative care education for health professionals and community members is imperative (McGrath, Holewa et al. 2007; McGrath, Patton et al. 2007).

Care pathways must reflect the priorities and perspectives of the person with dementia and their families (Harrison 1997). This can be best achieved by improvements to the systems of service

communication and coordination. For Aboriginal people in remote central Australia, a culturally safe and community led approach is vital.

## METHODOLOGY

### ETHICS APPROVAL

Ethics approval was gained from the Central Australian Human Ethics Committee. A further research proposal was submitted to and approved by NTDoH Remote Health.

### STEERING COMMITTEE

A steering committee was established at the beginning of the project and terms of reference were developed. Members were recruited by the project officer on the basis of their involvement in the previous research project and their involvement with dementia and aged care in Indigenous communities. They included service providers from Alice Springs who provided visiting specialist services to remote communities, the Aboriginal Interpreter Service and Central Australian shire aged care coordinators. The steering committee provided overall guidance to the project, including the selection of the community where the project was initially conducted.

### COLLECTION OF INFORMATION

The study was initially conducted within the small Indigenous community of Ti Tree in Central Australia using an action research methodology. The community has a population of about 350 people including a number of outstations. It was selected on the advice of the steering committee based on criteria developed by the project officer. These criteria included the number of old people in the community (approximated by the number of clients of the Remote/Barkly Aged and Disability Team), the services currently in the community (clinic, aged care service, and visiting services), the availability of local workers/interpreters, the governance of the aged care service and clinic and demonstrated interest by the community and shire.

Four visits were conducted to the community, two of which occurred with the NTDoH Aged and Disability Remote/Barkly Allied Health key worker whose responsibilities included ACAT assessment and support. Her presence provided both an introduction to clients and staff, as well as effective follow up of any issues around care or support for any older people which were raised. Interviews were conducted with service providers in the community and some informal education sessions on dementia were provided. The pathway to diagnosis and care of some older individuals who were identified as having 'thinking problems' were followed. A visual representation of this pathway was developed which provided a framework for further discussion which is included below.



During this period, visiting service providers to the community, and those providing education to community and workers in Alice Springs were interviewed. Meetings were also held with relevant organisations to discuss the implications of the research and ways in which diagnosis and care could be improved. This resulted in some changes in practice, such as increased use of interpreters, as the project progressed.

The resulting pathway diagram was presented to service providers and families in two other communities, Ntaria and Titjikala and was adjusted to accommodate for differences identified in these communities. Further feedback was provided by the steering committee.

A written record of all meetings was kept by the research officer for use in the research and any later evaluation.

Extensive guidelines were developed as a result of the information gained from this project and with feedback from the steering committee. A poster about diagnosis and care planning, suitable for display in clinics and Aged Care centres was also developed along with a suggested care plan form.

## RESULTS

### TI TREE

During the first visit, both the aged care coordinator, and the clinic manager identified old people in the community who seemed to have cognitive deficits, but there had been no official diagnosis of dementia of any old people. Both parties indicated that the other would have taken responsibility for this. Clinic staff reported that they were often overstretched with other health matters, and knew that the Aged Care service would bring any important health issues to their attention. Clinic staff indicated that they would be unable to take responsibility for cognitive assessments of clients who were suspected of having dementia, although on the second visit one Remote Area Nurse (RAN) indicated an interest in doing these assessments. Both the Aged Care Service and the clinic reported that they would also seek assistance and advice from the Allied Health Professional from the Aged and Disability Remote/Barkly Team (NTDoH) who visited the community every 6 – 12 weeks.

Three of Aged and Disability's older clients had been identified as having cognitive decline which may be due to dementia and assessments using the KICA tool were completed with them on this visit. An interpreter from the Aboriginal Interpreter Service travelled from Alice Springs to Ti Tree since there were no trained interpreters available in Ti Tree. The interpreter was provided with some education about dementia including the NT AA 'Looking out for dementia' DVD and flip chart. Difficulties in interpreting for one client indicated that further education of health professionals was required to work effectively with interpreters.

All three old people scored below 33 /39 on the KICA, indicating cognitive deficits were present. Results were presented verbally to both the clinic and the aged care service. On return to Alice Springs the completed KICA was placed on the Patient Information Record System used by the clinic, and a hard copy was given to the Aged Care service.

A follow up visit occurred four weeks later to conduct KICA training with clinic staff. None of the health checks listed in the CARPA Standard Treatment Manual for clients who had been assessed on the previous visit had been completed by the clinic to ascertain whether there were health reasons for their cognitive decline. One of the clients had been acutely sick and sent to hospital in Alice Springs. Clinic staff indicated that transport to get to the clinic had been the issue for the other two older people. They suggested that the Aged Care service should take responsibility for transporting their clients to the clinic for these health checks.

Meetings were held with the local manager of shire services, Centrelink staff, the safe house, clinic staff and the store manager. An informal education session was provided at the Aged Care Service and the safe house worker attended along with the aged care staff. They were shown the 'Looking out for Dementia' DVD and there was a discussion about dementia. It was apparent from these meetings that community and service providers in the community had limited knowledge about dementia and could benefit from further education. The school was approached to provide some general education but the principal felt that this did not fit into the current curriculum.

After the first visit to Ti Tree, discussions were held with visiting service providers from Alice Springs. Since the Aged and Disability Remote/Barkly team were responsible for the assessment and care of old people and people with disabilities, they agreed that they would be the most appropriate health professionals to take responsibility for screening for dementia.

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## CURRENT SERVICES IN TI TREE

A proforma was developed (Appendix 7) to collect information from relevant service providers for the area. A list of service providers had been completed as part of earlier research by WA Centre for Health and Ageing in Central Australia. The proforma was initially sent by email accompanied by an information sheet about the project. This was followed up by telephone or personal contact if required.

The following table outlines local and visiting services provided for older people in Ti Tree at the time of the project (Table 1).

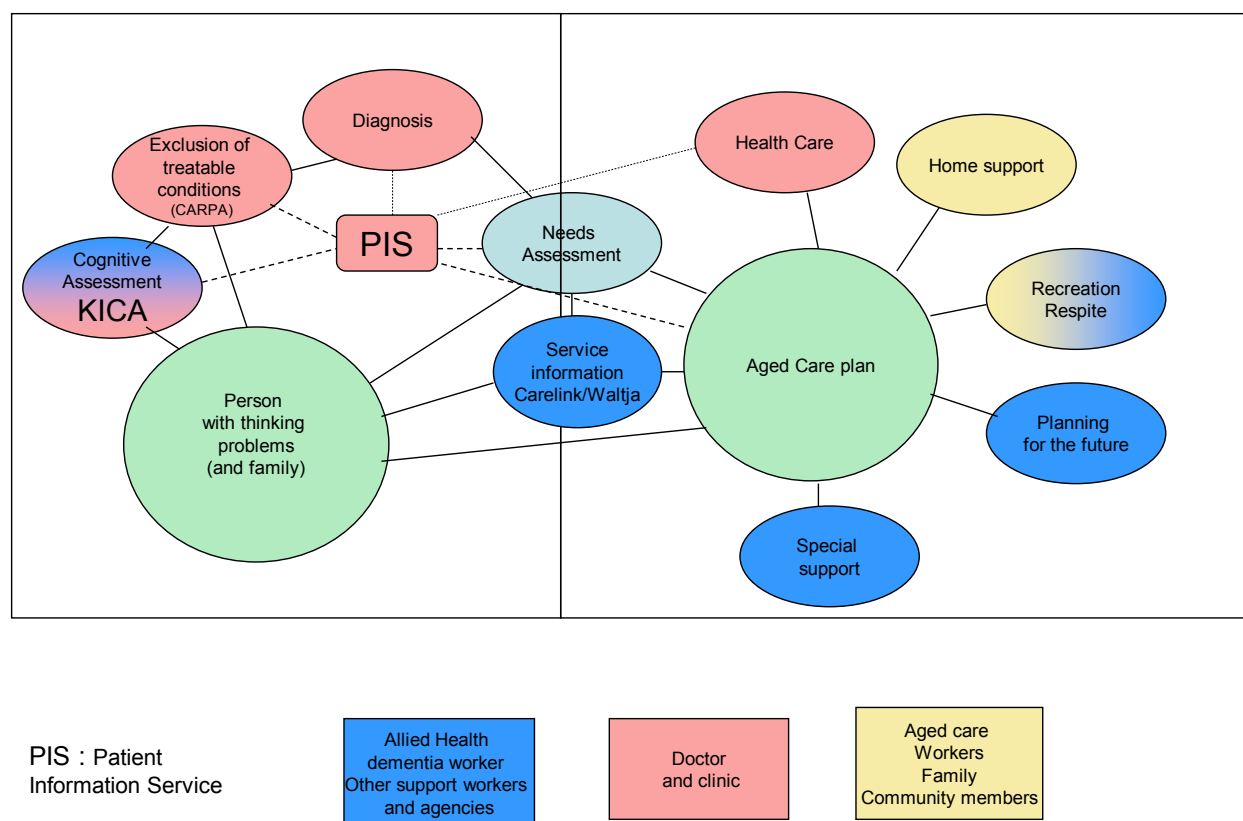
**Table 1: Ti Tree Services available for older community members**

Name of Service	Staff	Services provided
<b>Local Services</b>		
Ti Tree Aged Care Service (Central Desert Shire)	Coordinator, Assistant Coordinator, Aged Care Workers (4)	Meals on wheels, laundry assistance, personal care, case management
Ti Tree Clinic (NTDoH)	Remote Area Nurses and Aboriginal Health Workers, one based at 6 mile outstation.  Irregular visiting doctor about once a month.	Health and medical care including filling of dossette boxes.
Centrelink	Centrelink officer based in shire office	Manage Centrelink payments for client
Central Desert Shire services	Manager, and others including housing officer, environmental health officer	Provision of housing and house maintenance  Other shire services
Safe house	Coordinator	Support for victims of family violence
School (NT Education)		Primary & secondary school programs
<b>Regular Visiting Services</b>		
Aged and Disability Remote Barkly Team (NTDoH)	Allied Health Professional (currently an occupational therapist) who acts as key worker for that community visiting every 6-12 weeks. Often visits with Aboriginal Liaison Officer. Other Allied Health professionals visits as needed	ACAT assessments. Other functional assessment, case management, provision of assistive equipment, organisation of home modifications as needed, home programs, informal education to Aged care workers
Carer Respite – Troopy Program (Frontier Services)	Coordinator from Alice Springs	Provision of vehicle to Aged Care service for them to take clients (and their families) away from the community for respite
Central Desert Shire	Aged Care Manager	Oversight of aged care services including recruitment, mentoring and support for staff, infrastructure and training
STEPS	Visiting vocational trainer contracted by the Central Desert Shire	Provides training for aged care workers in Cert III and IV of aged care

Name of Service	Staff	Services provided
<b>Visiting Services (Irregular or on request)</b>		
Dementia Behaviour Management Support Program (Frontier services)	Officer who visits from Alice Springs as requested	Support for family for people with dementia with challenging behaviours. Education for aged care staff and other community members
Centrelink Social Work		Regular visits to provide extra support to clients identified by Shire Centrelink officer
ACAT dementia (NTDoH)	Nurse	Limited visit to communities
Aged care Advocate (Centrecare)	Advocate	Limited visiting to communities
<b>Alice Springs Services</b>		
Carelink information (Frontier Services with input from Waltja)	1800 number providing information on services	
Psychogeriatric Service (NTDoH)	Clinical nurse consultant Memory and Diagnostic clinic	
Carer respite (Frontier Services)	1800 number providing coordination of residential respite	
Old timers Residential Care (Frontier Services)		Residential respite
Hetti Perkins Residential Care (Frontier Services)		Residential respite
Alice Springs Hospital	Occupational therapists, speech pathologists	KICA Assessments
Guardianship		Assessment and management as required

As a result of initial visits Ti Tree the following visual representation of the services and pathways was developed to promote discussion with agencies (Figure 3).

**Figure 3: Pathways to care for Aboriginal People living with Dementia in Ti Tree**



## CONSULTATIONS WITH VISITING STAFF

Meetings were held with visiting service providers during this time. A meeting was held with the NTDoH Aged and Disability Remote/Barkly Team, the psycho geriatric service and the Aboriginal Interpreter service regarding the KICA assessment as there appeared to be inconsistencies in the way this was conducted by staff. Some staff had received training in administration through the Centre for Remote Health short course in *Recognising and Responding to Dementia in Aboriginal Communities* but newer staff members had not received this training.

Information about the project was presented at the Alice Springs Aged Care Network, at a training session for the team leaders of the McDonnell Shire Aged Care forum and to the NTDoH Central Australian Remote Management group. Meetings were also conducted with Palliative Care Services and the physiotherapist from Hetti Perkins residential care facility in Alice Springs. These forums provided an opportunity to gain further feedback about the proposed pathways from a variety of stakeholders in dementia care in Central Australia.

During the course of the project, the project officer had a number of discussions with members of the Northern Territory Dementia Framework Reference Group (NTDFRG) about issues related to assessment for dementia. This group, which consists of employees of the NT Department of Health and relevant Non-Government Agencies, are charged with implementing the NT Dementia Framework for Action Plan. As a result, the Centre for Remote Health was asked to provide a representative on the reference group.

A newsletter (appendix 6) was produced part way through the project to inform community members and stakeholders of the project progress and to encourage further feedback.

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## PRESENTATION OF PATHWAYS TO ADDITIONAL COMMUNITIES

Once a structure and visual presentation of pathways had been developed these were presented to another community for feedback and adjustment to ensure generalisability of the process. The steering committee, including shire aged care coordinators, provided suggestions on appropriate communities, and Ntaria (Hermannsburg) was selected, as having a number of older residents who showed signs of cognitive decline and a team leader who had been working at the aged care service for some time. Additional issues were the existence of a different community controlled health service. A visit was conducted with the key worker from the Aged and Disability Remote Barkly Team. This visit included a KICA assessment of one client with the assistance of an interpreter from the Aboriginal Interpreter service from Alice Springs. Meetings were held with clinic and the aged care staff. A funeral at the time meant that other agencies were not available.

A further visit was made to Titjikala with the NTDoH Aged and Disability Remote/Barkly key worker. Meetings were held with both clinic staff and aged care staff and the pathway was discussed. An informal education session using the *Looking out for Dementia* DVD was conducted with aged care staff. As there were no older people in the community who appeared to have dementia, the workers had difficulty applying the information to their community.

General issues were raised by those consulted in these communities about the difficulties associated with caring for older people these included

- Transport within communities between clinic and aged care is difficult, as the clinic may not have the facilities to transport people to appointments
- Transport to Alice Springs or other regional centres for medical appointments is also a challenge. The bush bus does not provide a frequent service to most communities and so people require accommodation in town while they wait for the return trip. If the community is less than 200km from Alice Springs, then people are not eligible for the Patient Assisted Travel Scheme (PATs)
- There should be greater coordination between community agencies about planned respite to ensure family needs are met. There should also be consultation with agencies in Alice Springs to enable health checks, and services such as rehabilitation to be provided.

## EDUCATION PROGRAMS AND RESOURCES ON DEMENTIA

A proforma, similar to that for service providers, was developed (appendix) to collect information about education programs and resources on dementia. The proforma was initially sent by email accompanied by an information sheet about the project. This was followed up by telephone or personal contact if required. A list of resources about dementia and education providers is presented below in Table 2.

**Table 2: Educational Resources on Dementia**

	DESCRIPTION	AVAILABILITY
<b>Community Members</b>		
<i>Looking out for Dementia</i>	<i>DVD/flipchart</i> <ul style="list-style-type: none"> <li>Available in 3 NT Aboriginal languages and English</li> <li>Evaluation available online</li> </ul>	Alzheimer's Australia NT
<i>Strengthening Dementia Care in Indigenous communities</i>	<i>Poster, DVD, Comic book, facilitators handbook</i> <ul style="list-style-type: none"> <li>describing the impact of alcohol on dementia</li> </ul>	Alzheimer's Australia SA and Aboriginal and Alcohol Council of SA
<i>Australian Indigenous Mental Health Information</i>	<i>Poster</i> <ul style="list-style-type: none"> <li>Describing characteristics of delirium, dementia, and depression</li> </ul>	Menzies School of Health Research
	<i>Poster</i> <ul style="list-style-type: none"> <li>Describing different aspects of dementia</li> </ul>	Western Australian Centre for Health & Ageing
<b>Vocational Education and Training</b>		
<i>Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities(2<sup>nd</sup> Ed)</i>	<ul style="list-style-type: none"> <li>Includes facilitators notes, student handbook, Assessment sheets, Flip chart, brochures, jigsaw puzzle, DVD <i>The bad hawk that steals</i></li> <li>Cultural content may not be appropriate for some communities</li> <li>- CHCAC319A provide support to those affected by dementia;</li> <li>- CHCAC416A facilitate support responsive to the specific nature of dementia;</li> </ul>	Alzheimer's Australia

	<ul style="list-style-type: none"> <li>- HLTIR404B work effectively with Aboriginal and Torres Strait Islander people.</li> </ul>	
<i>The Dementia Story</i>	<i>DVD for Aboriginal aged care workers (Cert III in aged care)</i>	Kimberley Aged and Community Services
<b>Health Professionals</b>		
CARPA Standard Treatment Manual	Protocol on dementia, including <ul style="list-style-type: none"> <li>• Differential diagnosis with delirium and depression</li> <li>• Appropriate assessment</li> <li>• Health checks required</li> <li>• Diagnosis</li> <li>• Some care planning guidelines</li> </ul>	CARPA c/- Centre for Remote Health
Dementia Guidelines	Brief guidelines for screening, appropriate assessment tools, diagnosis and management	Kimberley Aboriginal Medical Service
Kimberley Indigenous Cognitive Assessment	<ul style="list-style-type: none"> <li>• Full assessment tool available on line</li> <li>• Downloadable DVD demonstrating KICA-Cog using an interpreter</li> </ul>	Western Australia Centre for Health & Ageing

**Table 3: Dementia Education Programs**

DESCRIPTION		AVAILABILITY
<b>Community Members</b>		
	<ul style="list-style-type: none"> <li>• No formal education programs available</li> <li>• Ad hoc education may occur when needed, usually around the needs of a particular old person</li> </ul>	



DESCRIPTION		AVAILABILITY
<b><i>Vocational Education and Training</i></b>		
<i>Certificate IV in Aged Care</i>  <i>Certificate III in Aged Care</i>	<ul style="list-style-type: none"> <li>- CHCAC319A provide support to those affected by dementia;</li> <li>- CHCAC416A facilitate support responsive to the specific nature of dementia;</li> </ul> <p>HLTIR404B work effectively with Aboriginal And Torres Strait Islander people.</p> <ul style="list-style-type: none"> <li>- Assessment of client need in remote area HACC services - collaborative care planning. Is one module</li> </ul>	<p>Training available through</p> <ul style="list-style-type: none"> <li>• RTOs contracted by NT shires</li> <li>• Alzheimer's Australia</li> <li>• Formal training is available from Batchelor Institute or less formal courses can be conducted by the Centre For Remote Health</li> </ul>
<b><i>Health Professionals</i></b>		
<i>Recognising and Responding to Dementia in Indigenous Communities</i>	<ul style="list-style-type: none"> <li>• 2 day short course, or a topic in Remote Health Practice Graduate Program</li> </ul>	Centre for Remote Health

RANs with NTDoH are the largest group providing services in remote communities. Education days are held twice a year for one day. These sessions include requirements such as immunisation and use of the electronic health record, and the education coordinator indicated that there would not be sufficient time to include further education on dementia. The short course '*Recognising and Responding to dementia in Indigenous communities*' has been poorly attended by RANS with the majority of participants being Allied Health Professionals and aged care coordinators or aged care workers.

Skill levels in many communities are such that VET training for Aged Care workers is focused on topics such as hygiene and Occupational Health and Safety. Dementia topics are therefore only be taught to highly skilled worker.

## OUTCOMES AND RECOMMENDATIONS

The following recommendations for change have been developed as a result of the project.

### AWARENESS, RECOGNITION AND REFERRAL

Consultations and visits to the remote communities during the project, and visiting staff demonstrated limited knowledge about dementia in remote communities. This is confirmed by findings from the evaluation of the *Looking out for Dementia* DVD and flip chart (Lindeman and Taylor 2010).

#### Recommendation 1

As part of the NT Dementia Framework (key priority area 3), a comprehensive plan is developed to improve the awareness and knowledge of dementia in remote communities. This should include education for health professionals, aged care workers and community members, including shire workers, and store managers. This would be reviewed annually by the Northern Territory Dementia Framework Reference Group (NTDFRG).

### INITIAL ASSESSMENT AND DIAGNOSIS AND POST-DIAGNOSIS SUPPORT THE USE OF THE KICA

The project unearthed some inconsistencies with the administration of the KICA. The KICA was found to be administered by the following health workers.

**Table 4: KICA Administrators**

WHERE	WHO
Acute setting	Doctors Occupational Therapists Speech Pathologists Psychogeriatric service/ACAT
Community setting (Alice Springs)	ACAT staff - Psychogeriatric Service - Allied Health Professionals DBMAS

WHERE	WHO
Residential Care	RNs
Remote Communities	ACAT staff <ul style="list-style-type: none"> <li>- AHPs</li> </ul> Clinic staff <ul style="list-style-type: none"> <li>- RANS</li> <li>- AHWs</li> </ul> Aged care team leaders

Discussions with Allied Health Professionals (AHP) in Alice Springs Hospital indicated that there was often difficulty in finding appropriate carers who could complete the KICA carer. They also indicated that at times medical staff requested a KICA assessment for an old person who the AHPs considered were experiencing delirium.

On these occasions they would report this to the doctor, and not complete the assessment, but they indicated that medical staff would sometimes then administer the assessment themselves.

In the remote setting, the main workers who completed assessments using the KICA were the NTDoH Aged and Disability Remote/Barkly Team of allied health professionals. The main difficulties identified were not using interpreters, having family members present during assessment and not completing the full KICA. Finding appropriate family members to complete the KICA carer was identified as an issue.

Alzheimer's Australia had distributed a KICA kit to all of the remote clinics in the NT in 2011. The kit included a copy of the KICA document, a comb, pannikin and an action plan. There was no education or follow up with clinic staff. Staff at clinics visited as part of the project and NTDoH Aged and Disability Remote/Barkly staff did not know of the kit or where to find it in the clinic.

## Recommendation 2

Education is required for health professionals, including those in hospitals about the use of the KICA. The use of interpreters should be emphasized. This could be coordinated by Alzheimer's Australia.

As part of the project, a number of people consulted referred to the protocol for dementia, delirium and depression the Central Australian Remote Practitioners Association (CARPA) Standard Treatment Manual as well as the protocol on older person's health checks. The steering committee considered that it was appropriate that a cognitive assessment should be included in the older people's health checks.

### Recommendation 3

Changes are recommended to the CARPA protocol on older person's adult health checks that include a cognitive assessment every second year for those over 55 years of age and recommends that the appropriate tool for use with people in remote communities is the Kimberley Indigenous Cognitive Assessment (KICA)

## RECOMMENDED CHANGES TO THE KICA AND GUIDELINES

As a result of discussion with AHPs administering the KICA to Indigenous people from remote communities of Central Australia it was felt that some changes to the questions and guidelines would be helpful and are recommended.

**Table 5: KICA recommendations for change**

Item	Change recommended	Reason
Education	<ul style="list-style-type: none"> <li>That clinicians do not administer the KICA without adequate education</li> <li>Development of on-line training package</li> </ul>	Too many inconsistencies with delivery reduces reliability
Clearer guidelines on	<ul style="list-style-type: none"> <li>When KICA should be conducted</li> <li>Times required between assessments</li> <li>Dementia/delirium issues</li> <li>Need to check vision/hearing, and how to</li> <li>The physical environment including presence of family</li> <li>A suggested introduction</li> <li>Links to communication website regarding how to question effectively</li> <li>Interpretation of the score, as being only part of the assessment</li> </ul>	<ul style="list-style-type: none"> <li>Currently unclear in CARPA STM and not consistent with guidelines sent out with KICA kits</li> </ul>

	<ul style="list-style-type: none"> <li>• The use for Cognitive Assessment not capacity</li> <li>• What should happen to KICA score and report</li> </ul>	
<i>Use of interpreter</i>	<ul style="list-style-type: none"> <li>• A trained interpreter is strongly recommended</li> <li>• In absence of interpreter an AHW/ aged care worker could be utilised</li> <li>• An untrained family member is not suitable</li> <li>• Both interpreter (or other worker) will need training in what KICA is</li> </ul>	Interpreters are difficult to find in remote communities and are not being used

<i>KICA Screen</i>	Clear guidelines developed	Statement unclear
<i>KICA cog</i>		
<i>Orientation</i>	<ul style="list-style-type: none"> <li>• Alternative question</li> <li>• Perhaps change to weather, or alternative question</li> </ul>	<ul style="list-style-type: none"> <li>• Pensions are no longer paid on a particular week</li> <li>• People didn't always seem clear of season</li> </ul>
<i>Verbal fluency</i>	Should include collection of bush tucker	Insufficient animals in Central Australia
<i>Visual Naming</i>	<ul style="list-style-type: none"> <li>• Change crocodile to dog (or accept big Perrente as answer)</li> <li>• Alter campfire picture (or also accept handbag)</li> </ul>	<ul style="list-style-type: none"> <li>• No crocodiles in Central Australia</li> <li>• Not well recognised</li> </ul>
<i>KICA Carer</i>	<ul style="list-style-type: none"> <li>• Essential part of assessment, but can be difficult to find appropriate person especially in acute setting. Needs to be noted and recognised that validity of score will be affected</li> </ul>	
<i>Checklist</i>	<ul style="list-style-type: none"> <li>• Emphasise score is only part of assessment, but observations form important part of decision making process</li> </ul>	

The above list of issues related to the KICA was distributed to NTDFRG for discussion at a meeting in July 2011. There was general agreement that these issues were valid Territory wide with the group already having taken some steps towards addressing them, particularly around increasing the use of interpreters. The NTDFRG recommended that these issues should be taken back to developers of the KICA for discussion and action.

#### **Recommendation 4**

The KICA requires review by the KICA development team and adjustment in the light of findings from the project, and that a more in-depth learning package, be made available on line.

### **COMMUNICATION AND RECORD KEEPING FOR DIAGNOSIS**

The complex service delivery context outlined above also means complex communication of patient information. NT DoH have three computerised systems which may contain information about an older person:

- Hospital,
- Community (CICIS) which includes Aged and Disability Allied Health staff
- Remote clinics (PICIS)

Aboriginal Community Controlled Health Services (ACCHOs) use a different patient information system (Communicare). There is an NT wide Patient Information System, which all health service users can choose to be part of which allows communication between NT DoHA and the Aboriginal community controlled sector. This is not well utilised by those in communities whose health service is provided by NTDoH.

A major issue identified was the delay between the KICA being completed by AHPs and the health checks being completed by the clinic. The chronic disease patient recall system could be utilised effectively to ensure that these delays were reduced, this did not occur. Clinic staff interviewed indicated that they thought the AHPs should instigate the recall system for those clients who score poorly on the KICA. The AHPs indicated that this is not their role as they have access to the PICIS for data input, but do not have authority to utilise the patient recall system. The project officer submitted a request to the DoH Remote Health PCIS Clinical Reference Group to for clarification but the committee did not make a decision, leaving it for the two parties to resolve, since neither was able to instigate a recall on PICIS. This issue was not resolved at the completion of the project.

### **Recommendation 5**

Patient information record systems are rationalised so that information about people living in remote communities is easily available for all health and aged care providers with the consent of the person or their family.

- For NTDoH harmonisation of the three current electronic patient information systems (hospital, community and remote)
- Communication between ACCHO patient information systems and those of the NTDoH be improved
- Recall systems on patient information records system be utilised to ensure that health checks are completed by clinic staff as soon as possible after a KICA (which indicates cognitive decline) has been completed.
- Further adaptation of patient records may need to be considered with the introduction of the Personally Controlled Electronic Health Records for all Australians

### **Recommendation 6**

A case manager or key worker be appointed for each person living with dementia to advocate and ensure that the assessment process continues at a reasonable pace. This should be overseen by ACAT teams.

The ACAT coordinator reported that diagnosis of dementia was usually made by the visiting General Practitioner. There were no clients living in remote communities who had received a diagnosis of dementia from a specialist. She reported that this was because of the limited availability of geriatricians in Central Australia and that older people did not see the value of travelling to town for a diagnosis.

### **Recommendation 7**

Telehealth with geriatricians or other appropriate medical specialists be developed and implemented to provide a service to people in remote communities together with education to service providers.

### CARE PLANNING

Care planning issues raised were of a generic nature for all older people, not just those with dementia. There is currently limited, coordinated care planning in remote communities. Service providers involved with the care of an older people in a community will each have a plan for their service delivery for that person. Consequently, the clinic, the allied health service, the aged care service, providers of other community based care including respite services will each have individual service delivery plan. Communication strategies between agencies within the community as well as visiting services, is therefore of great importance.

Currently communication between agencies is variable and often dependent on the interests of particular workers. An important factor is the longevity of staff both within a community, or regular visiting workers. In Ti Tree both the Aged Care Coordinator and the clinic manager had been resident in the community for a number of years, which meant that while there was no formal communication between them, ad hoc communication was fairly effective. In Ntaria, clinic staff met monthly with Aged Care staff to discuss their mutual clients, and one of the clinic staff spends one afternoon a week visiting 'vulnerable' clients in the community. In Titjikala, communication was limited between agencies. NT DoH AHPs visit communities infrequently (aiming for every six weeks, if possible) and rely on good communication with both Aged Care Service and clinic staff to provide them with information about clients. These AHPs provide the ACAT services within each community and so should be providing a coordination role. The level of communication they have with each agency is variable and dependent on; the limited time in a community, the time between visits and the number of communities they are responsible for. Their visits may occur when other key staff members are out of the community or absent during a period of staff turnover.

#### **Recommendation 8**

A key agency should be identified to take the main responsibility for each person with dementia to coordinate their care planning and ensure that quality care is delivered. This would be in consultation with the ACAT team, and could be a different agency for each person and dependent on an individual's needs.

Contingencies need to be in place for continuity of care if that agency or worker leaves the community. This should be monitored by the ACAT team member who visits that particular community. More ACAT staff are required if they are to take more than a monitoring role.



Care plans were present on files at the aged care services visited but the quality depended on the experience of the aged care coordinator. These plans clearly outlined the services that the aged care service provided, but did not necessarily address other issues of concern for the old person or their family. Shires had developed care plans but these may not be utilised in every community.

#### **Recommendation 9**

A care plan be developed between families and providers with the key worker/agency taking responsibility for this. Input should be sought from all providers, including clinic staff, and made available to each.

The format should be appropriate for the region, using pictures to illustrate the domains for those workers with limited literacy skills. A review of the plan should occur annually, at the very least. A summary of medical care for co-morbidities should be included.

#### **Recommendation 10**

Education to be provided for aged care coordinators and workers in care planning.

#### **Recommendation 11**

Regular team meetings implemented (could be via telephone), supported by all appropriate agencies working within each community, to ensure coordination of services and that action identified in the care plan is completed by team members by the expected date.

### **END OF LIFE**

In the past any old people who had high care needs were transferred to residential care facilities in Alice Springs. With the establishment of more community based support services including HACC, Community Aged Care Packages and Aboriginal and Torres Strait Island Flexible Aged Care people with higher support needs can be supported in the community. Old people usually wish to die in their own community, rather than away from their country. This requires a high degree of commitment to care from family members, some families are unable to provide, despite support from aged care

services. There is limited support and advice from palliative care services from NTDoH who can provide advice to those carers in community, although they have little ability to provide direct services.

For those old people who are in residential care facilities in Alice Springs, there may be the ability for 'reverse respite' where old people are able to return to their country for short periods of time.

There appears to be little knowledge about legislation around end of life decision making or any evidence this was occurring. There can be cultural difficulties in discussing this sensitive area which have been outlined by McGrath and Phillips (2008).

#### **Recommendation 12**

Education around legislation on end of life decision making should be provided to all families and care providers. The Northern Territory is in the process of developing legislation to enable binding end of life decision making for all and the education program associated with the implementation of this legislation should include Indigenous people living in remote communities.

The project did not visit residential care facilities in Alice Springs although it did consult with the physiotherapist working at one facility. She confirmed previous research by WACHA (Smith et al 2011) which indicated that these facilities may not provide an environment that meets the cultural needs of old people from remote communities.

Staff members need to be trained to work with people with dementia but other considerations include:

- The employment of Aboriginal staff, who can speak the language of the residents
- Provision of activities that are appropriate for Aboriginal residents such as making damper
- An appropriate outside environment including access to safe seating by a fire
- Appropriate furniture including beds that can be lowered to the ground
- Space for extended family to visit

#### **Recommendation 13**

The NT Framework on Dementia develop a plan to ensure that Residential Care Facilities who have a large percentage of Aboriginal clients provide a 'culturally safe' environment.

## DEVELOPMENT OF APPROPRIATE DOCUMENTS FOR DISSEMINATION

A lengthy set of guidelines were developed as a result of information gained from this research project and feedback from the steering committee. Two A5 posters, suitable for display in a clinic or aged care service were developed, one outlining diagnosis pathways and the other care planning. The guidelines are organised using the stages identified in the *Dementia services pathways – an essential guide to effective service planning* document produced by KPMG for the Commonwealth Department of Health and Ageing:

- Awareness, recognition and referral
- Initial assessment and diagnosis and post diagnosis support
- Management, care, support and review
- End of life

A care plan proforma, which could be utilized by all agencies involved with a particular old person, was developed to complement the care planning poster. These two documents are based on the International Classification of Functioning, Disability and Health framework (2001) which provides a common language about disability for all levels of care. The guidelines, posters and care plan are attached as appendices of this report.

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## CONCLUSION

Current Gaps in Service include limited education of Remote Area Nurses on dementia, and limited availability of specialist medical services to confirm a diagnosis of dementia.

The prevalence of dementia in remote Indigenous communities including those of Central Australia is required for effective service planning. While the prevalence study in the Kimberley indicated 5.2 times the prevalence in non-Indigenous communities' local issues, such as the difference in cigarette smoking, may influence the level in other communities.

Future directions, as a result of this project, include an evaluation of the pathways developed, evaluation of current care planning activities with a view to increasing their effectiveness and increased education of community members, aged care workers, and health professionals

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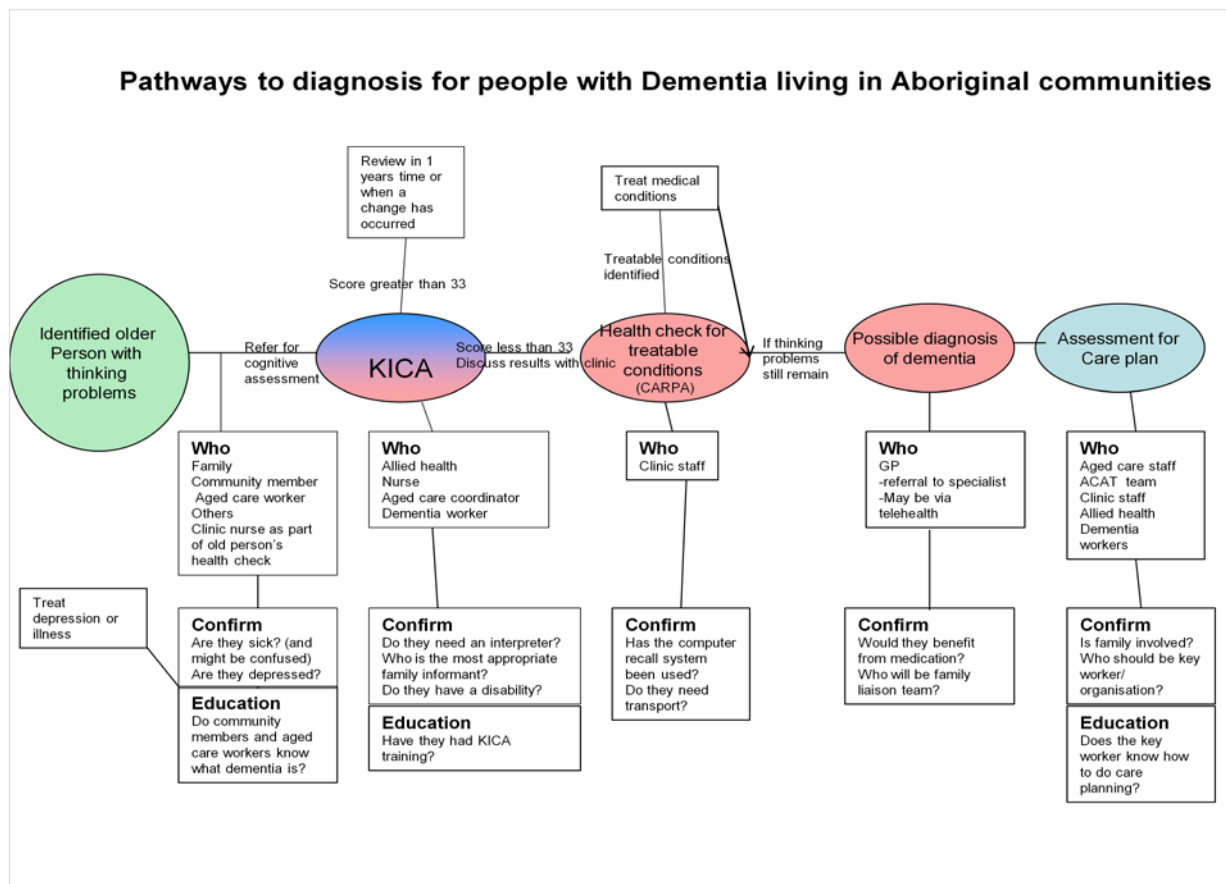
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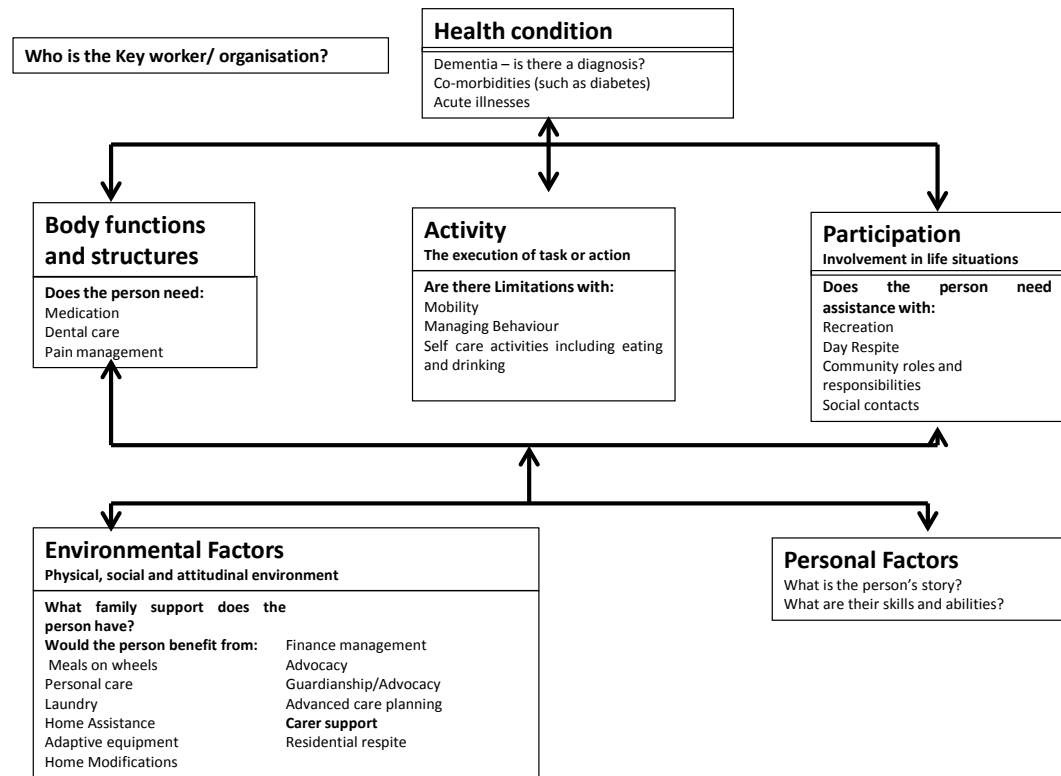
## APPENDICES

### APPENDIX 1: POSTER: PATHWAYS TO DIAGNOSIS AND CARE FOR PEOPLE WITH DEMENTIA LIVING IN ABORIGINAL COMMUNITIES



ACAT	Carelink 1800 052 222	DBMAS	Guardianship	Carer Respite	Aged Care Advocacy	Remote Barkley Aged Care & disability	Alzheimer's Association
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## APPENDIX 2: CARE PLAN FOR OLDER PEOPLE LIVING ABORIGINAL COMMUNITIES





## APPENDIX 3: COMBINED SERVICES CARE PLAN

Date ..... Review Date .....

Name .....

Age/ DOB .....

Address .....

Key Organisation/ Worker .....

What other people/Organisations are involved? .....

### Health Conditions

.....  
.....  
.....  
.....  
.....  
.....

### Body Structures and Functions

What parts of the body are affected?

.....  
.....  
.....  
.....  
.....

Do they need medication? .....

Do they complain of pain? Where? .....

### Activity

Do they have problems with:

- Mobility .....
- Behaving in strange ways .....
- Looking after themselves .....
- Eating/ drinking .....
- Showering .....
- Going to the toilet .....
- Getting Dressed .....

## Participation

Do they need assistance with:

- Recreation or things to do during the day.....
  - Hunting/ bush tucker .....
  - Painting .....
  - Church .....
  - Attending sporting events .....
  - Other activities .....
- Community responsibilities .....
- Cultural activities (eg sorry, business) .....
- Child care .....
- Participation in community meetings .....
- Other activities .....
- Meeting with friends .....

## Personal Factors

What is their story?

.....

.....

.....

.....

.....

.....

.....

What are their skills and abilities?

.....

.....

.....

## Environmental Factors -Physical, social and attitudinal environment

What family and other support do they have? .....

.....

.....

.....

.....

.....

Do they need support with:

- Meals on wheels .....
- Personal care .....
- Laundry .....
- Home Assistance .....
- Adaptive equipment .....
- Home Modifications .....
- Managing their money .....
- Making decisions .....
- Guardianship/Advocacy .....
- Residential respite .....

Does the carer or family need more support?

.....

.....

.....

.....

.....

.....

Do family and carers need education about ageing issues including dementia? .....

Would they benefit from thinking about what they want in the future? (Advanced care planning)

.....

.....

.....

.....

.....

**Action Plan**      Review Date .....

Who will be the key worker? .....

Who	Action	Date Due	Date completed

This care plan has been developed for use by all of the services involved with a particular older person, including aged care services, clinic staff, ACAT staff, carer respite and other services as required.

This will provide a consistent approach, ensure accountability for the most effective and responsive service.

## APPENDIX 4: LIST OF ABBREVIATIONS

<b>ACAT</b>	Aged Care Assessment Team
<b>ACCHO</b>	Aboriginal Community Controlled Health Organisation
<b>AHPs</b>	Allied Health Professionals
<b>CARPA</b>	Central Australian Rural Practitioners Association ( who produce a Standard Treatment Manual for use in remote communities)
<b>CCIS</b>	Community Care Information System (NT DoH)
<b>DBMAS</b>	Dementia Behaviour Management Assistance Service
<b>CACP</b>	Community Aged Care Package
<b>DoHA</b>	Australian Department of Health and Ageing
<b>EACH</b>	Extended Aged Care at Home
<b>KICA</b>	Kimberley Indigenous Cognitive Assessment
<b>NTDoH</b>	Northern Territory Department of Health (the department changed its name during the project from Northern Territory Department of Health and Families)
<b>NTDFRG</b>	Northern Territory Dementia Framework Reference Group
<b>PATS</b>	Patient assisted travel service
<b>PCIS</b>	Primary Health Care Information System (NT DoH)
<b>RAN</b>	Remote Area Nurse
<b>VET</b>	Vocational Education and Training
<b>WACHA</b>	Western Australian Centre for Health and Ageing



An Australian Government Initiative



# DEVELOPMENT OF PATHWAYS TO CARE AND EDUCATION FOR ABORIGINAL PEOPLE LIVING WITH DEMENTIA IN CENTRAL AUSTRALIA

## PROJECT UPDATE MAY 2011

This project started in August last year and aims to develop culturally safe and sustainable pathways to provide the care and support that people with dementia and their carers need in remote communities.

### Steering committee

A steering committee of local service providers and other stakeholders has now met five times to support the research and has provided information, advice and networking. After much discussion Ti Tree was selected as the community to trial the project in because it has a large number of old people, an effective aged care service which works well with their clinic, and expressed an interest in providing better services to old people with dementia.

### Visiting Ti Tree

The research officer, Heather Jensen, has visited Ti Tree four times and met with the aged care and clinic staff. She has also talked to Centrelink staff, people at the store and other interested people in the community. One visit was with Annemarie Drummond, the OT from the Barkly Remote Aged and Disability team who is responsible for allied health services in Ti Tree. They conducted KICA assessments with a number of clients who were referred by the Aged Care Service. They worked with the Aboriginal Interpreter Service from Alice Springs. They also conducted an education session

with the aged care staff and staff from the safe house and showed the Alzheimer's Association DVD 'Looking out for Dementia' and the KICA DVD. On another visit Heather did some training with clinic staff about how to use the KICA.



### Assessment and Diagnosis

Since that visit Heather has been following the progress of those clients who were assessed to make sure that the process of assessment and diagnosis works.

She has found some problems with people being diagnosed with dementia. This is partly due to some inconsistencies in the way that the KICA is administered, particularly making sure that interpreters are used when they are needed. A meeting was held with the Remote Barkly Aged and Disability and ACAT staff to develop a consistent approach what should happen with the information and what follow up is needed.

Once someone has been shown to have limitations in their cognitive ability the clinic should do blood and other tests as per the CARPA<sup>1</sup> manual to ensure that there are no medical problems that need to be treated. Sometimes this may need follow up because the clinic gets busy with other tasks. After these tests have been done the person needs to be diagnosed by a doctor, preferably a specialist such as a geriatrician. This is one of the more difficult processes because of their lack of availability in Central Australia.



## Care Planning

Local services such as meals on wheels and laundry services are provided by the local aged care service and they are often the ones who will first notice changes in an old person's thinking. This works well in a community such as Ti Tree which has an effective aged care service, but this is not the case in all communities. Referral to other agencies such as DBMAS<sup>2</sup> is dependent on the knowledge of the aged care coordinator and there is need for more education and policy development around care planning. Most people will be also seen by Aged and Disability Allied Health Professionals who could be more involved with care planning.

Heather has also been talking to the services in Alice Springs who work with people with dementia to find out their role in supporting people in remote communities and how they accept referrals.

## Education

Heather has been gathering information about education that is available because it is important that all people involved in supporting people with dementia have a good understanding about the disease. This includes families and other community members, aged care workers, clinic and allied health workers.

## Guidelines

Heather is developing draft guidelines which will outline the steps to be taken to ensure that people get the services they need. She is getting feedback from people at Ti Tree and other service providers, and will participate in a workshop about dementia assessments in Darwin.

## Next Steps

Heather will continue to seek feedback about the guidelines and will visit another community to see if they need to be adapted to work there. This community is still to be decided. She is also developing other recommendations about how services could work better together, and the education needs for all those involved. Once these are more finalised she will visit services and government agencies to let them know these results and advocate for the changes recommended.

- 1 *Central Australian Rural Practitioners Association Standard Treatment Manual*
- 2 *Dementia Behaviour Management Advisory Service*

EDUCATIONAL PROGRAMS

Organisation					
Contact Name					
Name of course or resource	Description of course/resource	Target Group	When does it happen	Accredited course	



## Development of pathways to care and education for Aboriginal people living with dementia in Central Australia

Name of service	
Contact person	
Eligibility criteria	
Referral source	
Referral form	
Assessment process for service	
Service provided	
Discharge process	

