



An Australian Government Initiative

# Guidelines for Diagnosis and Care of Aboriginal People with Dementia in Remote Communities



**Dementia Collaborative Research Centre  
Assessment and Better Care  
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WESTERN AUSTRALIAN CENTRE FOR  
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# Guidelines for Diagnosis and Care of People with Dementia in Remote Communities

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These guidelines have been developed as part of a project *Addressing dementia service coordination in Australian Aboriginal communities* conducted by the Western Australia Centre for Health and Ageing and was funded by the Dementia Collaboration Research Centres. These guidelines have been developed in Central Australia and while every effort was made to provide general information for Indigenous people in all remote communities, there may be some issues related to legislation or services organisation that will need to be adapted for other regions. These guidelines will need to be reviewed within five years from the date of publication.

## 1 Purpose of Guidelines

These guidelines have been provided to ensure that people with dementia who live in remote communities are correctly diagnosed and receive the services that they, and their families, require. They are directed at health professionals and aged care coordinators.

These guidelines should be used in conjunction with the 2008 *Clinical Practice Guidelines and Care Pathways for People with Dementia Living in the Community* developed by Queensland University of Technology (QUT). QUT specifically identified a gap in the evidence when implementing their guidelines with Aboriginal and Torres Strait Islander people. This document provides additional information based on this action research project that will guide people who are supporting those with dementia and their families in remote Indigenous communities. Factors which will influence adaptations to the more general guidelines from QUT include cultural factors (importance of kinship networks, attitudes and the understanding of

dementia), poor literacy levels including many people having English as a second (third or fourth) language, availability of services in remote areas and different models of service delivery.

The guidelines presented here are organised according to 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

## **1.1 Development of the Guidelines**

These guidelines have been developed under the guidance of a steering committee of stakeholders in dementia care in Central Australia, including government, shire, Aboriginal community controlled organisations and non-government organisations (NGOs) providing services to people with dementia and interpreter services. One Aboriginal community was purposively sampled and following consultation, baseline information was obtained about how older people with cognitive decline were identified and diagnosed and cared for in the community.

A pathway of diagnosis was then agreed upon with those in the community and visiting service providers. This was then implemented by following this pathway for three clients who had been identified as possibly having dementia. Draft guidelines were then presented to service providers in another two communities with different service provision and the guidelines were amended in response to their feedback. Further refinement was provided by the steering committee to produce these final guidelines. Additional community information was collected and can be found in the accompanying report of the project.

## **2 Awareness, Recognition and Referral**

### **2.1 Community Awareness**

There is a high degree of tolerance for individuality in many communities and a history of a lack of government support for carers, consequently people in Indigenous communities may not recognise that an old person with memory problems may have dementia or that there is support available. Education about dementia needs to occur at the community level, and for the family and paid carers. There are educational resources specifically developed for Indigenous communities including the DVD and flip chart 'Looking out for Dementia' (2009), which has been developed by Alzheimer's Australia (AA) NT and is available in three Indigenous languages, and English.

### **2.2 Health Professional and Aged Care Worker Education**

Aged care workers should receive formal education through the Vocational and Education Sector (VET) on Aged Care and there are dementia modules which are part of the Certificate III and IV in Aged Care. Education providers need skills in working in the cross cultural and remote context. Informal education can be provided by dementia specific services such as Dementia Behaviour Management Assistance Service (DBMAS) or health professionals.

Health professionals may need certified education in the particular needs of people with dementia and their families which can be provided through short courses including a short course in *Responding to dementia in Indigenous communities* which is available through the Centre for Remote Health.



Non-Indigenous health professionals, both those based in the community and visitors should receive cross cultural training to ensure that they practice in a culturally safe manner with both Aboriginal workers and families. They would benefit from a cultural mentor, such as an Aboriginal Health worker for ongoing support in this area.

## 2.3 Definition of Dementia

**Dementia** — progressive disturbance of thinking and behaviour, overall loss of function, often includes loss of ability to learn or remember. Usually **slow onset**. Problems with memory, orientation, language, personality, ability to carry out everyday activities, maintain relationships. Can also be hallucinations, delusions, anxiety, depression, other symptoms, e.g. wandering, agitation, and increased confusion at the end of the day (sundowning). Common causes include Alzheimer's disease, vascular cognitive impairment (CARPA Standard Treatment Manual 2009 p 176-178.)

## 2.4 Different Types of Dementia

There has been little study of the prevalence of different types of dementia in Indigenous communities. Smith et al (2008) found the prevalence of dementia and cognitive impairment in older Indigenous Australians in the Kimberley was 5.2 times higher than in the non-Indigenous population, with the main difference occurring in the 45-69 year age group. Investigations such as brain imaging were not accessible, with CT scanning only becoming available in the Kimberley region after the completion of the study, limiting the ability to determine dementia types; however indications are that the prevalence of different types was not dissimilar to the non-Indigenous population.



## **2.5 Detection**

Concerns about the cognitive decline of an older person may be expressed informally through family members, aged care workers, or community members.

More formal sources of detection may occur through referral to the health clinic or Aged Care Assessment Team (ACAT). It is recommended that Aboriginal and Torres Strait Islander people are recommended to have an Adult Health Check every two years which is funded by Medicare. This check focuses on general health, the risk of chronic disease and lifestyle issues. For those over 55 years, Older Person's Health Check is recommended which, in addition, includes factors such as risk of osteoporosis and hearing.

Current guidelines in the CARPA Standard Treatment Manual recommend follow up around memory and dementia only if they are frail and if carers express concern. This is inadequate as cognitive decline is frequently not recognised until later in the process. The project recommends that the Older Person's Health Check include a cognitive assessment such as the Kimberley Indigenous Cognitive Assessment (KICA) and this recommendation has been submitted to the CARPA Standard Treatment Manual editors.

## **3 Initial Assessment, Diagnosis and Post diagnosis support**

The KICA is the recommended cognitive screening tool for Indigenous people who are over 45 years and live in remote communities. This was developed in the Kimberley region of Western Australia and has been validated for use in the Northern Territory with the KICA screen also validated in northern Queensland.

Carers, both family and paid carers are an invaluable source of information about cognitive decline, particularly memory loss, in a person. If this is reported to a health professional, they should exclude any source of delirium, and then consider administering the KICA, including the KICA carer.

### 3.1 Cognitive Assessment

The KICA is freely available on-line through the Western Australian Centre for Health and Ageing website ([www.wacha.org.au](http://www.wacha.org.au)). It consists of:

- Patient assessment (social history, medical history, smoking and alcohol history, KICA-Cog, KICA-depression)
- Family report (medical report, smoking and alcohol history, KICA-Carer, KICA-Behaviour and KICA-ADL)
- Instruction booklet
- Report and checklist
- An instructional DVD demonstrating the KICA- Cog using an interpreter

Like other cognitive assessments, the KICA- Cog includes items that examine attention and concentration, orientation, short and long term memory, praxis, and language and executive function. These items are less language based than on most other cognitive assessments but it is important to use interpreters if English is not the person's first language. Best practice is the use of trained interpreters through the Aboriginal Interpreter Service. Interpreters require some education about dementia to be most effective. The *KICA* DVD available is a useful tool for this, as well as the DVD produced by NT AA *Looking out for Dementia*.

As indicated in the instruction booklet, some tasks may need to be adapted, or excluded for people with disabilities, particularly those with a visual impairment. A score of less than or equal to 33/39 on the KICA Cog indicates possible dementia and the need for medical screening to eliminate causes other than dementia.

Given that the KICA is only a screening test, observations recorded on the KICA results and checklists are important in providing additional information which should be taken into account when interpreting the results. For example the assessor may have some doubts about whether the person has heard all the questions accurately, or their concentration may have waned over the assessment. Results of individual tasks in the KICA-Cog may also give an indication of the type and severity of the dementia.

The KICA is intended to be administered by non-specialist staff, and it is recommended that staff become familiar with its use. Training where available is, recommended.

The following table outlines specific guidelines for the use of the KICA.

ITEM	GUIDELINE
<b>When to be used</b>	<ul style="list-style-type: none"> <li>• When a family member or other carer expresses concern about cognitive decline</li> <li>• As part of Older Person's Health Check (as per CARPA standard treatment manual)</li> <li>• After checks have been done for possibility of delirium and/ or depression</li> <li>• No more than every 3 months</li> </ul>
<b>Who should do KICA</b>	<ul style="list-style-type: none"> <li>• <b>Acute Setting</b> – doctors, occupational therapists, speech pathologists, ACAT/psychogeriatric service</li> <li>• <b>Urban Community</b> – ACAT staff, Allied Health Professionals (AHPs), DBMAS</li> <li>• <b>Residential Care</b> Registered Nurses, AHPs</li> <li>• <b>Remote Communities</b> ACAT staff, AHPs, RANs, AHWs, Aged care team leaders</li> </ul>
<b>Use of interpreters</b>	<ul style="list-style-type: none"> <li>• For all clients who do not have English as a first language</li> <li>• Best practice is use of trained interpreters from Aboriginal Interpreter Service</li> <li>• Alternative may be Aboriginal Health Worker or Aged Care worker</li> <li>• Family member is unsuitable</li> <li>• Interpreter will need education about dementia – e.g. KICA DVD</li> </ul>
<b>Physical Environment</b>	<ul style="list-style-type: none"> <li>• Somewhere that client feels comfortable</li> <li>• Distraction free</li> <li>• Preferably no family members</li> </ul>
<b>Physical Disability</b>	<ul style="list-style-type: none"> <li>• KICA Cog can be altered for people with a disability</li> <li>• Should be wearing hearing aids, and glasses if they have them</li> <li>• For those with visual impairment objects can be given to them for recognition and naming</li> <li>• Enlarged pictures can be used for visual naming and recall, but if not able to see them, these questions can be eliminated and the score adjusted accordingly</li> </ul>

ITEM	GUIDELINE
<b>KICA carer</b>	<ul style="list-style-type: none"> <li>• This is as important as the KICA- Cog and must be completed</li> <li>• If a family member is not available, aged care workers can be used or someone who knows the person well</li> </ul>
<b>KICA-Cog</b>	<ul style="list-style-type: none"> <li>• Adaptations can be made for regional differences <ul style="list-style-type: none"> <li>○ inclusion of collection of bush tucker in places where there are not many animals to hunt</li> <li>○ use of alternative pictures if not easily recognised</li> </ul> </li> </ul>
<b>Checklist</b>	<ul style="list-style-type: none"> <li>• Important to complete all sections</li> <li>• Score is only part of assessment</li> <li>• Observations form important part of decision making process</li> </ul>

### 3.1.1 Record keeping and Communication

Many health professionals including allied health professionals, and doctors are visitors to communities and sharing appropriate information is essential to ensure a diagnosis can be made in a timely manner. All remote clinics have an electronic patient information record system and the KICA record and checklist should be made available to clinic staff through this system. If the KICA is completed in the hospital system, then results should also be made available on the electronic record so that the information becomes available for remote clinic staff.

The clinic recall system should be utilised to ensure that medical checks are conducted and there is follow up from the doctor.

Transport to the clinic may need to be organised and should be coordinated between the clinic and the aged care service to ensure that the required medical checks are completed. Use of the chronic disease recall system on the computerised patient information system will ensure that these checks occur.

## **3.2 Diagnosis**

### **3.2.1 Exclusion of delirium and depression**

The main indicator that confusion or cognitive deficits are caused by delirium is that there is a rapid onset of symptoms, particularly confusion, which may be accompanied by fluctuations in levels of consciousness and inattention. Causes of delirium may be an infection such as a urinary tract infection or pneumonia, side effects of medication, intoxication from substance misuse or withdrawal, severe constipation, low blood glucose, a head injury or hypoxia. These need to be excluded before a cognitive assessment for dementia is administered. The Confusion Assessment Method (CAM) which is freely available on line is a useful tool for assessment of delirium. Care particularly needs to be taken in the hospital setting as delirium may still be present and confusion may be exacerbated by the unfamiliar environment.

Depression may occur with dementia, or may appear like dementia. People with depression may present with a sense of hopelessness, loss or guilt and a lack of interest or pleasure in things they may usually enjoy. It may be accompanied by changes in appetite and weight, sleep disturbances and trouble sleeping. When people with depression are assessed using the KICA-Cog they may tend to answer many questions with 'I don't know' rather than incorrect answers. The KICA-depression or Geriatric depression scale can be used to assess further.

### **3.2.2 Exclusion of other conditions**

Cognitive decline may be caused by a number of other conditions, many of which are reversible. These include; some medications, hypothyroidism, lack of Vitamin B12, poorly functioning liver or kidneys, alcohol induced, or acquired brain injury or brain tumours. Dementia can also be associated with other diseases, including Parkinson's disease, HIV, syphilis, Jacob Creutzfeld disease

The following table (adapted from Draper 2004) lists diagnostic tests which should be conducted to exclude other causes of cognitive decline.

<b>Routine Investigation</b>	<b>Reason for Investigation</b>
Full blood count	To exclude anaemia and infections (e.g. UTI)
Urea, creatinine and Electrolytes	To exclude kidney and metabolic disorders
Calcium	To exclude high calcium e.g. due to tumours
Liver function tests	To exclude liver failure or tumours
Serum Vit B12 and red blood cell folate	To exclude deficiency states and pernicious anaemia
Erythrocyte sedimentation rate (ESR)	Often abnormal in inflammatory conditions such as vasculitis and infections
Thyroid function tests	To exclude overactive and underactive thyroid
Brain CT scan (where available)	To exclude strokes, tumours, subdural haematomas and hydrocephalus and to determine whether atrophy is present
Chest Radiograph	To exclude tumours and infections
Neuropsychological examination	To distinguish mild cognitive impairment from early dementia and to assist in diagnosing the type of dementia
ECG	To exclude cardiac causes of vascular dementia
Fasting blood sugar level	To exclude diabetes mellitus
Syphilis serology	To exclude syphilis
EEG	To exclude epilepsy and encephalopathy

Routine Investigation	Reason for Investigation
HIV screen	To exclude AIDS related dementia
Genetic screening	To exclude Huntington's disease, familial forms of dementia and frontotemporal dementia
Review of Medication	To ensure that medication is not contributing to confusion

(Adapted from Draper, 2004)

### 3.2.3 Types of dementia

A diagnosis of general dementia can be made by a general practitioner. Different types of dementia are generally diagnosed by a medical specialist such as a geriatrician, neurologist, psychiatrist or general physician. Currently there are few specialists visiting remote Indigenous communities and people may find it difficult to visit a regional centre for diagnosis. There is strong evidence that telehealth can provide accurate diagnosis if someone based in the community collects the required information (cognitive assessment results, medical results, family reports etc) before the consultation.

It has been argued that diagnosis of the type of dementia is of little relevance to Indigenous people given the high level of co morbidities they experience. However, a diagnosis means that potential treatments, such as the use of cholinesterase inhibitor medication in the case of Alzheimer's disease, or anticoagulation therapy in the case of vascular dementia can be prescribed. Diagnosis of the type of dementia also provides a clearer prognosis for the person their carers and the health professionals involved which will improve care planning.



### **3.3 Informing the person and their family about diagnosis**

The diagnosing doctor should inform the person and their family. This could be completed via video conference. The identification of which family members attend should be decided with the assistance of an Aboriginal person who knows the family. An interpreter may be required. The aged care coordinator or a health professional who knows the older person and their family well (e.g. Remote Area Nurse) and lives in the community should be present, so that they can follow up on questions and provide the necessary support after the consultation.

## **4 Management, Support, Care and Review**

Most remote communities have local Aged Care Services which provide support services which include meals on wheels, laundry services and personal care through HACC and other Australian Government funding. Services are administered through a variety of governance structures including local government, non-government organisations (NGOs) such as Frontier Services, or as local Aboriginal Aged Care services.

### **4.1 Assessment**

HACC assessments, which indicate the level of need for HACC services, may be completed by aged care team leaders in remote communities. Other aged care services require an assessment by a member of the Aged Care Assessment Team (ACAT), who are usually based in a regional centre and visit remote communities. These services include residential respite, Community Aged Care Packages, and other funding packages which provide support for people with higher care needs while still living in their community. New Australian Government Aged Care Reform may mean there are some changes in assessment and reporting requirements.

Other, assessments around specific issues may be completed by clinic staff, visiting health professionals such as AHPs and dementia support services.

## 4.2 Care Planning and coordination

There is currently limited coordinated care planning in remote communities. Service providers involved with the care of an older person in a community will each have a plan for their service delivery for that person. This may mean that the clinic, the Allied Health service, the Aged Care Service, providers of other community based care including respite services will each have a service delivery plan. Communication strategies between agencies within the community as well as visiting services, is therefore essential. It is recommended that one agency take a lead role in coordinating services for each older person with one worker designated to become the 'key worker' for a particular client. The responsibilities of the 'key worker' would be to ensure that a comprehensive care plan is completed which includes all the required services and that the care plan is implemented and reviewed. This should be monitored by the ACAT team.

Aged Care Services are required as part of their funding agreement to develop a care plan of the services they provide in response to their assessment. If an older person receives a Commonwealth funded care package such as CACP or EACH there is a legislative requirement that the organisation that holds the funds (the Aged Care Service) provide case management. For other older people there should be flexibility in who should be their 'key worker', as it will depend on the needs of that older person, who provides the most support to that person, and who has a strong relationship with them and their family. This will often be the aged care team leader in a community but will depend on the services offered in that particular community.

Strategies must be built in to ensure continuity when there are staff changes. Almost all older people will have had an ACAT assessment and consequent plan which needs to be reviewed at least annually. Therefore the ACAT team should take responsibility to ensure there is continuity of care by monitoring the implementation and review of the care plan developed by the key worker. If the 'key worker' leaves the community, the ACAT team should ensure, in consultation with others, that someone else is selected to take on this role. Case conferences to develop a care plan may be appropriate in some instances, but care must be taken that the old

person and their family feel comfortable to express their concerns and issues. A family meeting with the 'key worker' may be more appropriate. Skill levels of Aged Care Team leaders vary considerably and they may need support to develop a comprehensive care plan. This support needs to be provided by their employer or other health professionals in the field. Care plan proformas should be developed and made available within each Aged Care Service. These should include pictorial symbols to accommodate staff who may have limited literacy levels.

A comprehensive care plan would address the following issues:

<b>Issue</b>	<b>Community care</b>	<b>Visiting Services and Assessments as required</b>
Food	Meals on wheels Sufficient drinking water	Dietician if required Speech pathologist swallowing assessment if required
Personal Hygiene	Personal care Laundry	Occupational Therapy (OT) Assessment & equipment Continence advice and equipment
Mobility	Transport around the community	Physiotherapy Assessment and equipment Driving assessment if required Transport into regional centre as required
Day activity	Centre based day respite Recreation Home based respite	Advice regarding activities from AHPs or DBMAS
Behavioural and Psychological issues	Assess for depression	Support from DBMAS if required
Carer Support	Information & support from Aged Care Service & clinic to build resilience Day/home based respite Carer pension as required	Residential respite Centrelink
Accommodation	Appropriate Housing	OT Assessment and home modifications as required Advocacy if required
Finances	Centrelink Advocacy if abuse suspected	Guardianship if required Advocacy if abuse suspected

Issue	Community care	Visiting Services and Assessments as required
Health	Medication for dementia if appropriate Treatment of co morbidities by clinic	Dental care Medication review if required from pharmacist

Access to information about all services that are available to support an older person in a particular local area is provided by Commonwealth Carelink Centres through an on-line and telephone information service. They can be contacted on 1800 052 222.

### 4.3 Communication and reporting

Effective communication between organisations both within a community and those that visit is essential for the provision of services to older people. This is particularly important if there is a high turnover of staff in either of the services. Regular meetings between Aged Care workers and clinic staff are one effective strategy. The appointment of a key agency/ key worker will facilitate coordination.

### 4.4 Co-morbidities and other health issues

Many old people living in Indigenous communities will have a number of chronic diseases which will co-exist with dementia. These conditions, which may include diabetes, cardiovascular disease and possibly renal disease, will require consistent monitoring and treatment by health clinic staff. Clinic staff need to be skilled in communicating with people with dementia and their families, and be able to effectively take blood and urine samples from the older person. Aboriginal Health Workers and Aged Care workers will be helpful in obtaining consent for these procedures.

As the cognitive ability of the person declines with the progression of the disease, the person and their family will need to discuss, with a doctor or geriatrician, the value of medical interventions (eg dialysis), that may prolong life even when their quality of life has declined.

Some older people in the community may be taking a variety of medications and regular review by medical staff should be undertaken to ensure that these are not contributing to confusion. A Home Medicines Review by a pharmacist could be of benefit for those who are taking a large number of medications. Some people with dementia will require assistance in taking medication needed to maintain their health. Guidelines from NT DHF (2008) indicate that any medication that, in other circumstances, an individual would administer to themselves or to their family members can be administered by staff with the consent of the old person or their family.

As the old person's ability to communicate deteriorates, it may be difficult to ascertain if they are experiencing pain. The Abbey Pain Scale (freely available online) is used to assess pain levels for people with dementia and may be effective, but further evidence is needed to assess its effectiveness for Aboriginal people. Evidence suggests that the administration of regular paracetamol can decrease anxiety and improve engagement with others. Other health issues including infections such as urinary tract infections or pneumonia need to be attended to. Oral care needs attention and if a dentist is required they will need skills in working with people with dementia.

## **4.5 Carer Support**

While general awareness of dementia in the community is helpful, carers need 'just in time' education to build resilience. This can be provided by clinic or Aged Care staff, or visitors such as allied health professionals, or specialist dementia services. This education could be tailored to an individual, or if there are other people with dementia in the community could be offered to a group if appropriate. This education could include:

- More information about the condition and likely course of the disease
- Strategies for dealing with behavioural and psychological symptoms of dementia including any sexual issues
- Communication strategies
- Practical information for caring including information about food/ eating, and strategies to reduce anxiety
- Activities that the person can engage in
- Ways to modify the environment to improve mobility and other living skills
- Strategies to manage continence issues
- Stress reduction strategies for the carer

## **4.6 Community Issues**

Older people in communities may hold positions of responsibility for a number of decisions and community members may find it difficult to challenge senior people's decisions if they start to develop dementia. These community members may seek advice from health professionals or other workers. This is an area that needs to be treated with considerable sensitivity with the ultimate responsibility lying with the community.

Old people may be vulnerable to neglect and abuse. Aged Care or clinic staff may need to advocate on their behalf. Possible solutions to financial abuse may be addressed by negotiation with the store and other community agencies or in the final instance through guardianship.

## **4.7 Legal Issues and Advanced care planning**

Each jurisdiction has particular legislation regarding advanced care planning and guardianship and information about these can be found on the appropriate government website. The Northern Territory does not have advanced care planning legislation at the time of writing these guidelines.

Advanced Care Directives require consultation with appropriate family and community members. An Aboriginal worker will be best placed to know who should be involved, who will have responsibility for decision making and who is able to communicate with others. Families will need considerable time to consider the best outcomes around the complex decision making process.

## **5 End of life**

As the symptoms of dementia progress it becomes more difficult to manage the person at home, due to difficulties in feeding, continence, pain management and the risk of pressure areas if they have reduced mobility. It is possible but requires strong commitment from family members, a well-resourced aged care service and willingness from clinic staff. Some support may be available from regional palliative care services.

### **5.1 Admission to residential care**

The implications of permanent admission to residential care are great given that most high support facilities are based in regional centres and Aboriginal people have a strong desire to die on their country. There may, however not be sufficient care available in a remote community to support the person at home.

Residential care facilities that provide care for Aboriginal people from remote communities need to develop strategies to provide a culturally safe environment for



the old person and for their family to visit. Staff 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

Where resources are available, reverse respite should be made available where the person with dementia is able to return to their country for a short period, which may coincide with cultural business.

## **5.2 Medical Care**

As indicated in the previous section, medical decisions to prolong life will need considerable discussion with relevant family members as the condition progresses. Advanced medical care directives will need to be reaffirmed by family.

These discussions must be conducted with great sensitivity due to cultural considerations around death and also so that there is no blame attributed to a family member for shortening the life of the old person. Palliative care services are well placed to provide assistance and advice with these discussions.

## **5.3 Grief and Loss**

Both the carer and the person with dementia experience loss over an extended period as death approaches. Health professionals involved will need to maintain an awareness of this and family may benefit from support to deal with this grief. If this grief extends over a long period, then bereavement services may be useful.

When an Aboriginal person dies, there are a number of important cultural processes which need to be conducted. Negotiations should have already occurred to ensure

that the appropriate person has been identified who will contact other family and community members.

### Reference

Central Australian Rural Practitioners Association (CARPA) (2009). CARPA Standard Treatment Manual 5<sup>th</sup> Edition. Alice Springs 17/05/12

Management, care, support and review	
Assessment	<ul style="list-style-type: none"> <li>• Care Assessment completed by aged care or ACAT workers</li> </ul>
Care Planning and key worker	<ul style="list-style-type: none"> <li>• Need care plan proforma which may utilise pictures if literacy an issue</li> <li>• Use carelink telephone service for info re services 1800 052222</li> <li>• Completed with family and maybe other agencies but care taken to not overwhelm person and family</li> <li>• Use interpreter if required</li> <li>• Should include all services required not just those provided by service by key agency</li> <li>• Need key worker from most relevant agency to ensure that plan is implemented and reviewed and continuity of care if staff leave</li> <li>• Plan needs to be monitored by ACAT staff due to high staff turnover</li> <li>• Aged care staff may need education in care planning</li> <li>• Regular meetings can improve communication</li> </ul>
Co-morbidities and other health issues	<ul style="list-style-type: none"> <li>• Health staff needs skills in communicating with someone with dementia in a culturally safe manner</li> <li>• Gain consent for procedures – ask Aboriginal worker for advice</li> <li>• Give time to discuss medical interventions such as dialysis</li> <li>• Keep watch for health issues such as UTI</li> <li>• Consider home medicines review as medications may cause confusion</li> <li>• Check that someone is ensuring they take medication</li> <li>• Check oral health and pain levels</li> </ul>
Carer Support	<ul style="list-style-type: none"> <li>• ‘Just in time’ education for carers</li> <li>• Other education to build carer resilience</li> <li>• Ensure carer’s financial needs met by Centrelink</li> </ul>
Community issues	<ul style="list-style-type: none"> <li>• Advise may be required by community re the older person’s ability to complete community responsibilities</li> </ul>
Legal issues	<ul style="list-style-type: none"> <li>• Check for abuse and neglect</li> <li>• Community may instigate measures (with store) to manage money</li> <li>• May require guardianship</li> <li>• Consider advanced care planning – Aboriginal worker can ensure all relevant people are involved.</li> </ul>

End of Life	
Admission to residential care	<ul style="list-style-type: none"> <li>• Last resort as old people want to pass away on country</li> <li>• Residential care facility needs to be culturally safe</li> <li>• Consider reverse respite if possible</li> </ul>
Medical issues	<ul style="list-style-type: none"> <li>• Ensure no one can be seen to have blame about death</li> </ul>
Grief and Loss	<ul style="list-style-type: none"> <li>• Ensure negotiations are completed with appropriate people for end of life arrangements</li> </ul>

Guidelines for use of KICA	
<b>When to be used</b>	<ul style="list-style-type: none"> <li>•When a family member or other carer expresses concern about cognitive decline</li> <li>•As part of older person's health check (as per CARPA standard treatment manual)</li> <li>•After checks have been done for possibility of delirium (and depression)</li> <li>•No more than every 3 months</li> </ul>
<b>Who should do KICA</b>	<ul style="list-style-type: none"> <li>•<b>Acute Setting</b> – doctors, occupational therapists, speech pathologists, ACAT/psychogeriatric service</li> <li>•<b>Urban Community</b> – ACAT staff, Allied Health Professionals (AHPs), DBMAS</li> <li>•<b>Residential Care</b> Registered Nurses, AHPs</li> <li>•<b>Remote Communities</b> ACAT staff, AHPs, RANs, AHWs, Aged care team leaders</li> </ul>
<b>Use of interpreters</b>	<ul style="list-style-type: none"> <li>•For all clients who do not have English as a first language</li> <li>•Best practice is use of trained interpreters from Aboriginal Interpreter Service</li> <li>•Alternative may be Aboriginal Health Worker or Aged Care worker</li> <li>•Family member is unsuitable</li> <li>•Interpreter will need education about dementia – e.g. KICA DVD</li> </ul>
<b>Physical Environment</b>	<ul style="list-style-type: none"> <li>•Somewhere that client feels comfortable</li> <li>•Distraction free</li> <li>•Preferably no family members</li> </ul>
<b>Physical Disability</b>	<ul style="list-style-type: none"> <li>•KICA Cog can be altered for people with a disability</li> <li>•Should be wearing hearing aids, and glasses if they have them</li> <li>•For those with visual impairment objects can be given to them for recognition and naming</li> <li>•Enlarged pictures can be used for visual naming and recall, but if not able to see them, these questions can be eliminated and the score adjusted accordingly</li> </ul>
<b>KICA carer</b>	<ul style="list-style-type: none"> <li>•This is as important as the KICA- Cog and must be completed</li> <li>•If a family member is not available, aged care workers can be used or someone who knows the person well</li> </ul>
<b>KICA-Cog</b>	<ul style="list-style-type: none"> <li>•Adaptations can be made for regional differences <ul style="list-style-type: none"> <li>•inclusion of collection of bush tucker in places where there are not many animals to hunt</li> </ul> </li> <li>•use of alternative pictures if not easily recognized</li> </ul>
<b>Checklist</b>	<ul style="list-style-type: none"> <li>•Important to complete all sections</li> <li>•Score is only part of assessment</li> <li>•Observations form important part of decision making process</li> </ul>



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