



Dementia
Training
Australia

Cultural Assessment for Aboriginal and Torres Strait Islander People with Dementia

Guide for Health Professionals



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Lex Collard, Aboriginal Health Liaison Officer

**Humanities/Centre for Aboriginal Studies Flexible Learning Engagement Team,
Curtin University:**

Michelle Robert-Libia, Naomi Prisgrove

Artist:

Ron Gidgup

Message from Aboriginal and Torres Strait Islander Advisory Group (ATSIAG):

The ATSIAG offers you the use of these products in the service of Elders throughout the country. We accept that what we have advised in the production of these resources is open to scrutiny from those who have an interest in their use: communities, agencies, age care providers, individuals and families. We welcome your feedback. And we trust that you will find the resources beneficial to your thinking, your practices of care, and your lives.

This document was prepared by:

Staff members of the Western Australian Dementia Training Study Centre (WA DTSC):
Stuart Crowe (Project Officer WA DTSC), Terrie Simpson (Project Officer WA DTSC),
Andrew Stafford (Director WA DTSC), Katrina Fyfe (Centre Coordinator WA DTSC)

**Cultural Assessment for Aboriginal and Torres Strait Islander People with Dementia
- Guide for health professionals**

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Purpose of this user guide

This guide should be used in conjunction with the Dementia Training Australia (DTA) *Cultural Assessment Record for Aboriginal and Torres Strait Islander People* (hereafter referred to as *the record*). It is a supplement to the Cultural Assessment training workshop. Within this booklet the word “Aboriginal” is used to refer to all Aboriginal and Torres Strait Islander people. Wherever possible reference to specific communities or groups is made.

Who should read this guide?

This user guide is essential reading for anybody wishing to use the record who has not recently attended a training workshop for it. It is also a useful “refresher” for those who only have occasional interactions with Aboriginal people with dementia. In addition, this guide includes further information regarding the historical, political and social events which may have impacted the lives of Aboriginal people.

Attending an Aboriginal cultural awareness or cultural competence course prior to using the record or attending the associated workshop is highly recommended.

The DTA Cultural Assessment Record

The record has been designed to assist healthcare providers to provide culturally safe care for Aboriginal people. The assessment commences a process that ensures that an Aboriginal person retains connections to family, community and culture for as long as possible. These factors are integral to an Aboriginal person’s ongoing sense of identity and well-being. By supporting these connections, the outcomes of the assessment may positively influence the social, emotional, physical and psychological wellbeing of an Aboriginal person living with dementia.



Section I: Culture

“Culture” is not only a reflection of the person’s cultural background, but also their individual lived experiences, both past and current. Culture influences a person’s illness experience, and is particularly important when understanding the symptoms of a person with dementia¹.

Cultural competence:

“... a set of skills, attitudes and practices that enable the healthcare professionals to deliver high-quality interventions to patients from diverse cultural backgrounds. Improving on the cultural competence skills of the workforce has been promoted as a way of reducing ethnic and racial inequalities in service outcomes¹.”

Owiti et al. (2014)

Cultural Safety

The concept of cultural safety was originally developed in New Zealand with the intention of improving health in the Maori people. The term “safety” was deliberately used to incorporate the positive connotations of protection from danger, risk and hazards to health. It includes consideration of physical, mental, social, spiritual and cultural components of wellbeing².

Cultural safety

“Cultural safety goes well beyond cultural awareness and cultural sensitivity. It gives people the power to comment on care leading to reinforcement of positive experiences. It also enables them to be involved in changes to health services and programs. Cultural safety explicitly acknowledges the experience of the recipient of care. Its focus is on the level of clinical care interaction, focusing on the individual patient (based on feelings of being safe in health care interactions) and the practitioner’s personal attitude”³

Nguyen (2008)

The overarching aim of cultural safety is to provide “care in a manner that is **respectful of a person’s culture and beliefs**, and that is **free from discrimination**”². It requires positive actions by the individual health care workers and their organisations.

Cultural safety can be viewed as the final step on a pathway that begins with cultural awareness (Figure 1).

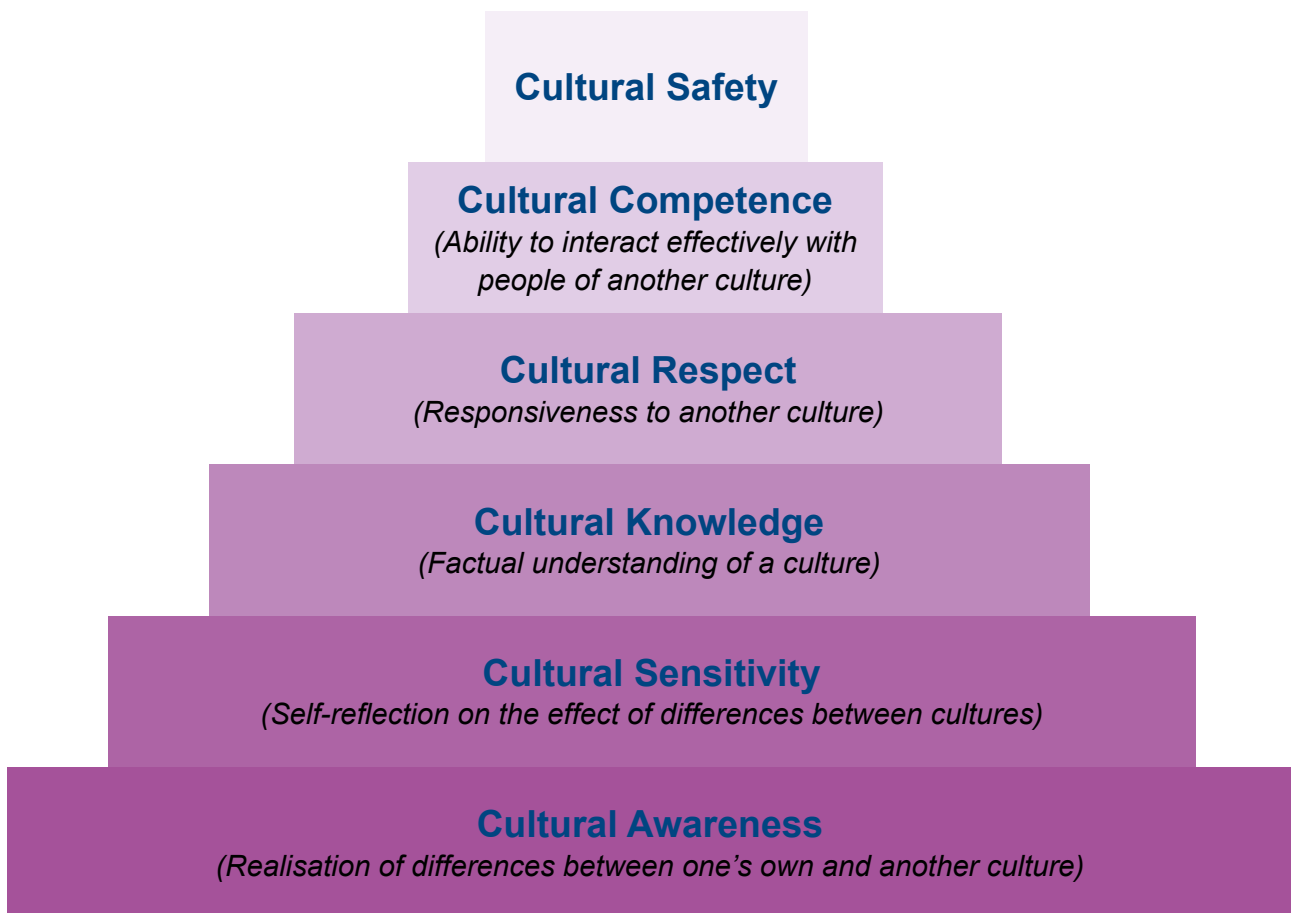


Figure 1 Pathway to cultural safety*

Cultural safety cannot be achieved unless health care providers, both the people and the organisation, are culturally competent.

Culturally competent assessment of Aboriginal people

Culturally competent assessment provides a foundation by which an Aboriginal person's social and cultural components of living are identified, so that these vital connections may

be retained to maintain his or her sense of identity and well-being. The information gained by undertaking an assessment that is focussed on an individual's needs and circumstances may be used to achieve a range of positive health benefits for them, their family carers and other family members. Importantly, within the context of providing care for Aboriginal people, culturally competent assessment is only the commencement of a process by which the person can retain their social and cultural connections for as long as possible.

*The 'Pathway to cultural safety' has been developed by T Simpson and incorporates concepts from Owiti JA et al (2014), Eckermann, A-K, Dowd, T. & Jeffs, L. (2009). Culture and nursing practice. In J.Crisp & C. Taylor, (Eds.), Potter and Perry's Fundamentals of Nursing, 3rd Ed., (pp. 118-124). Mosby: Sydney., and NACCHO (2011)

Section II: Dementia in the Australian Aboriginal context

Overview

Dementia is the ninth National Health Priority of the Australian Federal Government⁴

Presently there are an estimated 400,833 Australians living with dementia⁵

The prevalence of dementia in Aboriginal Australians is between 3 and 5 times higher than that in the general Australian population⁶

Aboriginal people tend to have a younger onset of dementia than the general Australian population- between 45 and 64 years of age, compared with 65 to 84 years⁷

An appreciation of the factors influencing chronic disease in Aboriginal people is essential for understanding the social context of the person with dementia.

There are many factors thought to contribute to the high incidence of dementia in Aboriginal people. These include higher prevalence of risk factors for the development of dementia than in the general Australian population, such as:

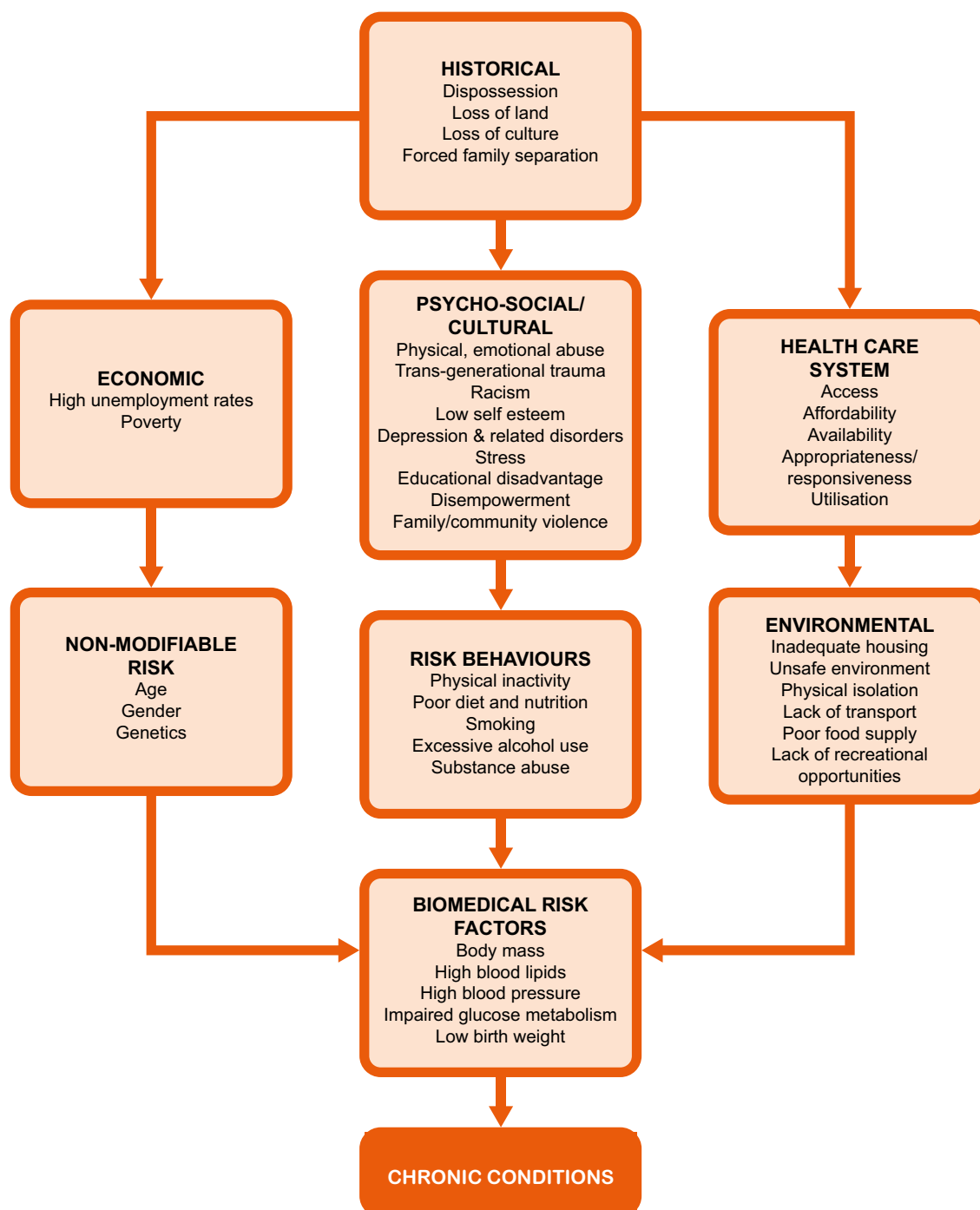
- Cardiovascular disease
- Diabetes
- Early life stress
- Head injury
- Smoking
- Stroke
- Epilepsy
- No formal schooling⁸

Of particular note is the effect of chronic diseases as many are more prevalent in Aboriginal people, and occur at a younger age than in the general Australian population⁹. The interrelationships between these factors and chronic diseases are shown in Figure 2.



Section II: Dementia in the Australian Aboriginal context

Figure 2 Factors contributing to chronic health conditions in Aboriginal communities¹⁰.



Section II: Dementia in the Australian Aboriginal context

The Aboriginal experience of dementia

Peoples' experiences of ill-health are greatly influenced by their history and culture. Socio-economic determinants, historical experiences and world-view all influence the health profile of any person, and his or her historical, social, cultural and gendered narrative is integral to understanding their experience of dementia.

Many Aboriginal people have experienced racism and discrimination as a result of laws and practices that were commonplace in the twentieth century. The memory of these experiences may continue to affect Aboriginal people with dementia.

Aboriginal societies generally place a very high priority on the needs and care of the aged members of their family, kinship groups and communities¹². Ideally, the needs of an Aboriginal person with dementia would be met within a community setting. However, this is not always possible.

“Older people are looked up to and have an essential role in kinship, community, and in transmitting cultural knowledge. Dementia impacts on this role and has consequences for the person, the family and community....the person with dementia is part of the community and is supported by family, networks and services. Relationships between the person with dementia, their family and community holds special significance. All are interdependent”¹²

Aboriginal people may view dementia in a very different way to the Western medical model. Dementia is viewed differently in Aboriginal culture and there is no Aboriginal word for it. It therefore often goes unrecognised as a medical condition¹³.

“The causes of Aboriginal dementia...is part of a natural process. The body, mind and spirit naturally get older including the brain... It may not need to get fixed as long as the individual is safe and the family and the community is safe there may not be any need to do anything at all”¹⁴.

Eric Deeral

When an elderly Aboriginal person moves into a residential aged care facility (RACF), the experience can become one of re-institutionalisation at a time of greatest vulnerability for themselves and their family. Taking a cultural safety and cultural competence approach optimises the quality of care and improves the impacts of placement on the person with dementia, their family carer and their family.

Section III: Aboriginal history, politics and social impactors

A knowledge of the historical events, politics and social issues that may have affected the lives of Aboriginal people with dementia can be very helpful in ensuring that their care is provided sensitively and the likelihood of them experiencing distress is minimised.

Autobiographical or personal memories guide behaviour and shape self-concepts¹⁵. In dementia, autobiographical memories are lost, with the most recent memories usually being lost first¹⁶. As an individual's personal memory recedes, their sense of reality is related to the most recent time period they are able to recall. This may be a time many years in the past. Therefore, in order to understand a person's feelings, reactions and behaviours it is necessary to have an understanding of the time periods which are shaping the person's current sense of reality, and those that may affect them in the future.

Many older Aboriginal people experienced enormous hardship as a result of political policies and social attitudes throughout the last century¹⁷. A number of historians consider there to be four eras of Aboriginal history since the arrival of Europeans, as based on government policies of the time. These are:

- Segregation/ "Protection": Prior to approximately 1936
- Assimilation: 1937 - 1972
- Self-Determination and Self-Management: 1972 - 2004
- Interventionist: 2004 onwards

It is likely that most Aboriginal people living with dementia currently residing within RACFs will have experienced the devastating effects of the *Segregation* and *Assimilation* policies in particular.

The legacy of forcible removal remains in the lives of Aboriginal individuals and communities to this day¹⁸

The Australian Human Rights Commission

Further reading

These websites may be useful for additional information about recent Aboriginal history:

Australian Museum Indigenous Australia Timelines

<http://australianmuseum.net.au/indigenous-australia-timeline-1500-to-1900>

<http://australianmuseum.net.au/indigenous-australia-timeline-1901-to-1969>

<http://australianmuseum.net.au/indigenous-australia-timeline-1970-to-present>

This site provides a succinct description of a number of key events in Aboriginal history, and related government policy, since the arrival of Europeans.

Bringing them home: The 'Stolen Children' report

<https://www.humanrights.gov.au/publications/bringing-them-home-report-1997>

This report details in depth the experiences of many Aboriginal people affected by forcible removal.

Section IV: Assessment of Aboriginal people with dementia

Assessing the historical, social, cultural and gendered factors is central to the process of culturally competent, person centred, psychosocial assessment for an Aboriginal person with dementia, their family carers and other family members.

Cultural consultation

Cultural consultation is a model originally developed to promote the cultural competence of clinicians with the intention of creating a culturally safe environment for clients in mental health settings¹⁹. It aims to directly improve patient experiences and outcomes from care for diverse client populations. The process of cultural consultation provides clinicians with a better understanding of the social context of illness experience and the impact of factors such as identity, psychosocial environment, migration and government policies.

Cultural consultation considers a wide range of issues to provide the social, cultural, and political context of the person's experience and behaviour in order to guide care planning and service delivery.

Throughout the process, it is critical that health professionals avoid sweeping generalisations or cultural stereotypes. It is important to focus on the individual person's experiences and narrative, to identify specific cultural issues that may impact on their experience of dementia currently or in the future.

It is also important to consider the culture of the service being provided during the consultation. Values, models, assumptions, institutional practices and legislation may create misunderstandings, interactional problems or conflicts that are sometimes mistakenly attributed to a person's cultural or personal background¹⁹.

During cultural consultation, issues that may be considered are shown in Table 1.

Table 1 Issues to consider during cultural consultation. Adapted from Kirmayer L J et al. (2003)

Family systems	Structure, roles, and value systems
Identity issues	Age and gender roles and lifecycle transitions (for example, the significance for identity and social status of being an Elder)
Violence	Exposure to organised violence in a historical context
Intergenerational impacts	Fracturing of extended families due to forced or voluntary separations, loss of communal supports, creation of tensions between generations
Racism	The effects of subtle or covert racism or other biases on the provision of services
Prior experiences of health systems	Previous experiences with health care and healing practices and traditional systems of medicine
Religious and spiritual practices	The importance of religious practices for coping and social support, particularly in the psychological containment of grief and anxiety
Misdiagnosis	The prevalence of dissociative and somatoform symptoms leading to misdiagnosis. (e.g. Post traumatic stress disorder being misidentified as a psychotic disorder)

Section IV: Assessment of Aboriginal people with dementia

Aboriginal Elders

“...keepers of various knowledge within Aboriginal communities. Elders bridge the past and the present and provide guidance for the future. They teach important traditions and pass on their skills, knowledge and personal experiences.”

<http://australianmuseum.net.au/indigenous-australia-family#sthash.wUI2vQkh.dpuf>

Yarning (Using a narrative approach to assessment)

Interviewing or “assessing” a person can take many forms. This includes:

- Hostile interview, which is a form of dialogical combat
- Limited survey interview, which relies on closed questions and the interviewer acts automatically recording responses without interacting socially
- Rapport interview, where the interviewer is a human being acting in a particular role
- Yarning

Yarning is an informal conversation that is culturally friendly and recognised by Aboriginal people as meaning to talk about something, someone or provide and receive information²⁰. This narrative approach to assessment is a way of learning about the Aboriginal person with dementia through story-telling. Yarning is conducive to an Aboriginal way of doing things; its strength is in the cultural security that it creates for Aboriginal people.

To have a yarn is not a one-way process, rather a reciprocal and mutual dialogue whereby a person and/or their family tells their story in a supportive environment. For yarning to work well, a supportive, open and non-judgmental approach is used. The person and/or their family must feel comfortable and be able to talk openly when telling their story.

Yarning requires connecting as individuals and building relationships rather than simply establishing rapport²¹.

Social yarning is the first stage of the process and is about establishing a connection by sharing information about each other. For Aboriginal people this will typically include identifying their country and family connections. In stating who you are, where you are from and why you are wanting to yarn, the relationship shifts from “professional-to-client” to “person-to-person”, enabling a more real and honest engagement.

Yarning can be “messy” and “time consuming”. It does not follow a set agenda and the conversation can meander²¹. Keeping the person on track is sometimes difficult. When interviewing an Elder or Aboriginal leader it is disrespectful to interrupt if you think they are straying from the topic. There is also the danger that in cutting the person off and trying to bring them back on track you will lose some valuable information.

It can be difficult to know when to bring things to a close. Do not be afraid to set a time limit for the conversation.

Section IV: Assessment of Aboriginal people with dementia

The strengths of yarning include:

- It facilitates obtaining a lot of detail
- Aboriginal people are able to talk freely about their experiences
- It enables deeper information to emerge that would have not have been discovered in more formal processes
- It is conducive to the Aboriginal way of doing things; its strength is in the created cultural security.
- It cuts across the formality of identities and demands human to human interaction²¹

Further reading

Further information about yarning.

<https://vimeo.com/204126926>

Tips on yarning

- Acknowledge to the Aboriginal person with dementia and their family/carer that that there may be a lot that you don't know about their culture. Ask them to tell you if you say anything that they find culturally offensive, as this will help you to improve your communication practice and style.
- Involve family carers and other key family members as partners in developing the narrative.

- Be patient. You will not usually have a complete picture at the end of one (or even a number) of discussions. The absence of information is acceptable while allowing time to develop trust getting to know the individual and their family.
- Direct forms of questioning are not always the best approach for obtaining information on sensitive issues. As a guide, be mindful of your approach when discussing issues such as:
 - People who have died, especially those who have died recently.
 - Gender and sexual health, or “men’s and women’s business”.
 - Sexual abuse; sexual preference.
 - Ceremonial or religious practices.
 - Elder abuse: financial or other forms.

When an Aboriginal person dies you cannot use their name for a period of time. This is an area where you need to be very cautious and respectful.

You may always ask, “Is this something you prefer not to speak about?”. You might consider getting input from Aboriginal people who can provide the appropriate cultural expertise for specialist consultation on sensitive issues.

Section V: Undertaking the assessment

The DTA *Cultural Assessment for Aboriginal and Torres Strait Islander People* (the record) has been designed to facilitate yarning and culturally safe discussion, enable documentation of the information gathered and generate constructive, person-centred care strategies and interventions.

The record is designed to facilitate the free-flowing documentation of an individual's personal circumstances without the limitations of text boxes or tick lists. The record can be annotated with arrows, highlights, underlines, et cetera, in order to communicate the essential elements of the information gathered during discussions with the person with dementia and/or their family/carers.

The record provides a framework for undertaking culturally safe assessment and generating the cultural and social care considerations which can be integrated with other components of care planning. It attempts to strengthen cultural competence in assessment to inform health professionals of practises to improve service delivery to the Aboriginal person with dementia, their family carer or other family members.

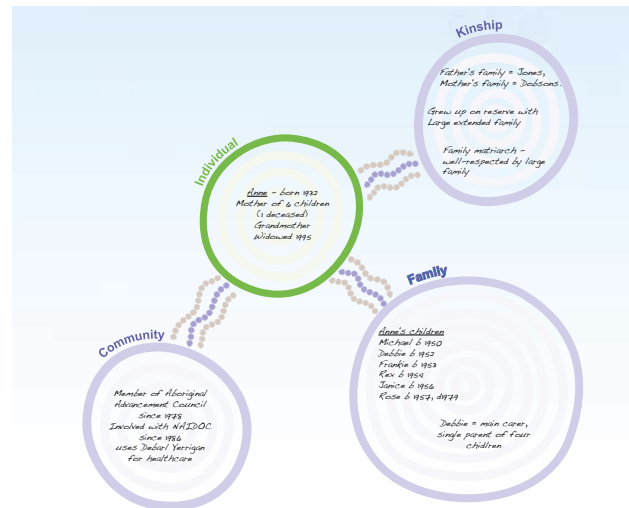
The factual information on the record should be completed in the presence of the Aboriginal person with dementia and/or their family/carers. However, the “implications” and “reflections” sections may be completed separately when there has been time to consider all the information gathered.

The record has a number of sections:

Family and relationships

In the “individual” circle, put the most relevant information about the person with dementia i.e. their name, how they should be addressed, when they were born etc.

Use the “family”, “kinship” and “community” circles to record details of the significant people and organisations in the individual's life.



Connection to country

Mark on the map the significant cultural regions and places for the individual i.e. their “country” and other places they may have lived, or where other significant people in their lives are from. Note the names of the language group and/or kinship group they identify with and the languages or dialects that they speak, and document this in the “Cultural, Language and Spiritual Considerations” section.



Further information

Consult the language map www.aiatsis.gov.au/explore/articles/aboriginal-australia-map

Section V: Undertaking the assessment

The timeline

In the green “Personal History” section, record information of the individual’s life and significant events against the historical timeline and policy eras. This might include when they were born, if and when they went to school, married, jobs, birth of children, relocations, death of loved ones and so on. Use notes and symbols, boxes, bubbles, arrows or other notation devices that best represent the information.

Refer to the events and eras in the “Aboriginal History” column to gain an understanding of the factors that may have impacted on the person’s life. The timeline may be used to further guide conversation with the person and/or their family/carers.

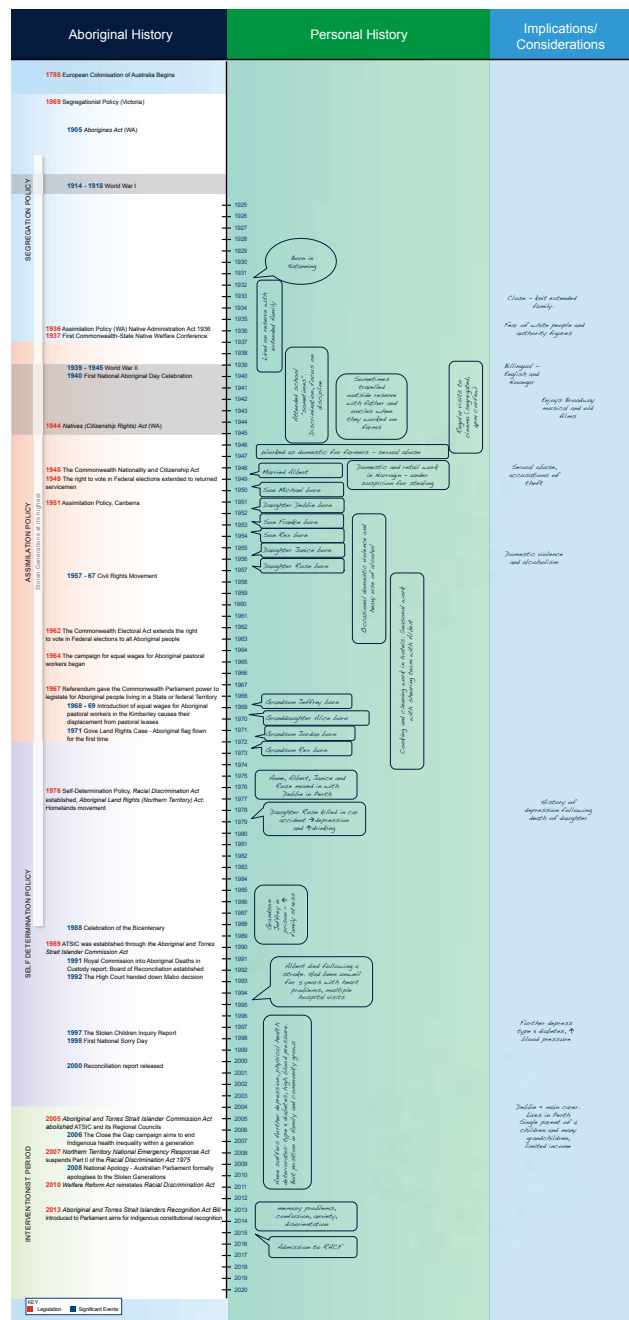
In the blue “Implications/Considerations” section document the consequences of significant events in the person’s history and how this may impact on their behaviour or reactions to particular situations.

Additional notes, reflections or summaries

In the “Family, Homelife and Relationships” section, document information about the most significant people, key events and family dynamics.

Under “Cultural, Language and Spiritual Considerations” include the person’s language group, mob or other language groups with which they are associated, the languages they speak and any requirements they have to practice ceremonial or spiritual customs.

Use the “Environmental Considerations” section to document any specific requirements relating to the environment. This might include the places, either indoors or outdoors, that the person likes to spend time, the types of landscapes they prefer, the music they might like to listen to and so on.



Section V: Undertaking the assessment

A living document

The record is designed to be a “living document”; one that continues to evolve and grow over time as relationships and interactions with family and the person with dementia progress. At a minimum, the following should be considered when undertaking any assessment.

The family

- Who is included within their family group?
- Mother’s side? / Father’s side?
- Who are the key people to be contacted for different scenarios?
- Establish the importance of extended family or kinship group and any other significant or meaningful relationships.
- Connect with members of the Aboriginal community who may be able to add information to the person’s story.
- Be guided by family.
- Are there any negative interfamily / community relationships, or feuding, that needs to be known about?
- What have been the person’s issues at home, good and bad relationships that may be continuing to affect them: familial, financial, social, alcohol and drug issues?
- What are their important connections to community?

Connection to country

- Where is their cultural region and language group?
- Do they have ongoing connection to country through travel, cultural obligations or regular contact with family or friends?
- Is their first or preferred language an Aboriginal language, or English? Is an interpreter required? Does their spoken language require clarification for “sense” and “meaning”? Do they rely on gestures or sign language to communicate?
- What communication styles will suit the person?

Education

- Level of Western education / attainment and employment experience?
- Any ceremonial education that might shape cultural or gender norms, roles or practices that might influence behaviour?

Historical experiences

- What significant factors have shaped their experience: have there been episodes during the person’s life of institutionalisation, such as in missions, children’s homes, reserves, prisons or the armed forces?
- Has the person been affected by policies that restricted their freedom e.g. forcible removal from family, curfews, segregation, locked gates, denial of freedom of association or movement, separation from family members?

Section V: Undertaking the assessment

Environmental needs

- What types of environments are familiar and comforting?
- What types of environments have a negative impact?

Activities

- What activities and sensory stimulation will suit their cultural background and personal preferences, e.g. music, art etc.
- What about cultural foods?



Section VI: Example case study – “Anne”

This case study is of a fictitious person.

Read through this case study and see how the information gathered has been documented.

Anne is a Noongar woman, a mother and grandmother born in 1932 in Katanning. Her father’s extended family are the Jones’ and her mother’s extended family are Dobson’s. In her early years Anne remembers living on the reserve with her brothers, sisters, cousins and friends and her large extended family. She felt much loved, nurtured and encouraged by her kinship group of aunts, uncles, cousins and grandparents from both her mother’s and father’s side. However she also recalls being fearful of the reserve staff.

From about the age of eight years Anne remembers travelling with her family beyond the reserve when her father and uncles were allowed to work on the farms of the surrounding districts. Anne remembers at these times meeting a whole lot more of her relatives and also that, away from the reserve, her family members talked a lot more Noongar language. This didn’t seem to happen much at the reserve or in town.

It was on these trips that Anne became aware that often she and the other kids would have to hide away in the bush from the white people. She was eventually told by her parents that this was to protect them from being taken away from their family by the native welfare or police protectors. At these times she really experienced the fear and distress that this caused her and her family.

Sometimes Anne would be made to attend the local school by the superintendent at the reserve. At other times she would be sent home and felt it was just for being black. The older white kids were always calling the Noongar kids offensive names and fighting. Her parents were sometimes very strict on her and her siblings about whether they were behaving themselves at school. At other times she recalls her parents arguing with the teachers and principal about the discrimination towards the Noongar kids.

At 15 Anne was told by the reserve superintendent that she would be going to work for a local farmer as a domestic. This employment was an unhappy experience for her, as she was away from her family and because she experienced a lot of sexual harassment from her employer. She refused to work for him when it became abuse. Her next years were spent continuing to work as a domestic and doing some limited retail work in Narrogin. In her job Anne felt she was always under suspicion by the shopkeeper for stealing. Being in town meant that Anne and her cousins and friends could go to the cinema, which was segregated, where they would watch the war newsreels, movies and Broadway musicals which they all loved. They only attended the weekend matinees as the 6pm curfew restricted the movement of Aboriginal people within the town.

Section VI: Example case study – “Anne”

Anne married Albert at 17 and they had six children: Michael in 1950, Debbie 1952, Frankie 1953, Rex 1954, Janice 1956 and Rose in 1957. None of her children were born in hospital as Aboriginal women could only receive medical help at childbirth on the hospital veranda. This was a period when there was limited work available and social conditions were harsh. Anne and her husband drank alcohol regularly to excess and at times she experienced domestic violence. Anne spent most of her middle years doing casual cooking and cleaning work in local hotels and for a shearing team when Albert could get seasonal work.

In 1975 Anne, Albert and her two youngest children Janice and Rose, who were still at high school, moved to Perth to live with her oldest daughter Debbie in state housing. Albert's employment in Perth was irregular. Debbie was a single mother with four children: Jeffery born in 1969, Alice 1970, Jordan 1972 and Rex Jnr born in 1973. Debbie relied upon both her small income from casual work as a relief receptionist and some child welfare payments.

On moving to Perth Anne was able to reconnect with many of her relatives who she had not seen for a long time. Through them she became actively involved in arts, sports and community politics. In 1978 she became a member of the Aboriginal Advancement Council which was a strong supporter of the move to establish community controlled health, education and legal services at the time.

In 1979 Anne and Albert suffered the loss of their youngest daughter in a car accident. This initiated a period of depression for Anne, and her and Albert's drinking increased. In 1985 their oldest grandson began a five year prison sentence and they worried that he would not be able to straighten himself out when he finished his sentence.

In 1986 Anne joined the National Aboriginal and Islander Day Observance Committee (NAIDOC) and has been involved in the annual program of events until the last few years when she began to 'slow down'. She still enjoys attending “Noongaroke”, a community version of karaoke used as a community fundraiser for funerals and other community campaigns.

Over the next five years Albert suffered a lot of angina and heart related stress, and had a number of emergency visits to hospital. Albert died in 1995 following a stroke. Anne subsequently developed depression, type II diabetes and high blood pressure. For her health care she uses Derbarl Yerrigan Health Service to access GP and allied health services. She has a strong relationship with the doctors and staff and it allows her to stay in touch with the community and to access a lot of community information through the Noongar grapevine.

Section VI: Example case study – “Anne”

Over the last three years, Anne has gradually become more forgetful, and now often becomes confused and anxious when she has trouble recognising her children and grandchildren. Anne loses her patience more often with the grandkids whereas before she was always warm and loving. She forgets to take her medication and sometimes neighbours have brought her back home because she has forgotten where she lives. Debbie is finding it more difficult to care for her mum and is worried that she will wander off during the night and something bad will happen to her.

Most family members of Anne’s children and grandchildren have looked to Anne for leadership and guidance when key decisions in their own families have to be made. Anne has always provided care, advice and support to her children and grandchildren about coping with the challenges from society, of what it means to be Noongar. As her memory loss becomes more pronounced they are concerned about what is happening to the person they know and love as the matriarch of their family.

Recently Anne has begun to use a lot more Noongar words and phrases than before and is remembering things from when she was a girl on the reserve, and is at times weepy and resentful about some of the treatment her family experienced by white authorities . However Debbie has noticed that when she plays CDs of old Broadway and wartime hits Anne’s attitude usually improves quickly for a while, but drops off again soon after.

Debbie feels she cannot continue to care for Anne, and as there are no other family members who are in a position to provide for her she has decided to place her in residential care. She fears the impending loss of her mother from the family home and the reduced income from the aged pension and the carer’s allowance. Debbie’s siblings and cousins are not coping well with Anne’s dementia or with Debbie’s needs, leading to a decision of Anne going into care. Debbie says there are very different levels of understanding within the immediate and extended family of her mother’s condition and of the level of her care needs. Debbie resents the blame that she is feeling from other influential members of the family due to their shared anxiety that Anne will not fit in well at the facility, and that the care workers won’t be able to care for her appropriately.

Section VII: Case study 2: Greg's story

Use this additional fictitious case study to practice using the record and to document the information.

Greg is a Martu man, a father and grandfather born in the Western Desert in approximately 1957. Greg is among the last generation of children of any known family group to have lived a traditional desert life without prior contact with either Europeans or other Martu living in surrounding settlements. Greg and the family group, consisting of twenty women and children (no adult men), were removed by authorities from their subsistence lifestyle because of the Woomera missile tests. The Percival lakes area occupied by the family group was used as a dump area for the Blue Streak missile tests. Greg and his family had avoided the patrol that had been looking for them for a period of months.

The experience of being located by the patrol, was traumatic for Greg and his family. This was the first time they had encountered white men and their technology: vehicles, aeroplanes and rocket debris. Although Greg could not comprehend what was happening he sensed the stress and anxiety of his family. For the first time Greg heard the English language, ate Western food and was made to put on clothes. During the few nights between being located and moved into Jigalong, the family were tied by the ankles to stop them from escaping.

Life at Jigalong was very structured compared to the one Greg knew and this was very stressful for him and his family. There were many new experiences associated with the settlement such as the food, going to school and the system of authority. The missionaries and government workers at Jigalong were very paternalistic and Greg struggled to make sense of the traumatic experiences such as authorities removing children from their families and community.

However he also met many relatives who had been in Jigalong for some time and he learned to speak several language dialects, effectively expanding his communication with a larger group of Martu relatives and others from around the Pilbara region. Greg's family group were initially very dependent on other Martu who had been living at the settlement for a longer period and who had knowledge of the white man's ways. He remembers good times as well as tensions between his own family group and people from other language groups and all the other difficulties associated with living at Jigalong.

Greg's schooling was infrequent and basic and what he was taught was completely foreign to him. He struggled to find explanations for what the teachers were trying to teach about the white man's numbers and letters. Because of this Greg's literacy and numeracy skills are very poor and this has impacted on him throughout his life when he had to deal with white man's business.

Section VII: Case study 2: Greg's story

After about three years of enduring the many tensions associated with living at Jigalong, Greg's family moved away to the bush where they felt life was safer. The family travelled back to their own country, visiting important cultural places. Greg and the other children learned a lot of stories, steadily acquiring knowledge in preparation for becoming adults with the attendant obligations and responsibilities. Greg's cultural education continued throughout his teenage years leading up to the ceremony when he and the other boys of his age became men. This clearly shaped the rest of Greg's life when he inherited the rights and responsibilities of a Traditional Owner for his father's country. However, he avoids speaking about it except to the few of his own people who have a right to know.

After this important occasion Greg was free to make certain adult decisions. From the age of 16 he was drawn to explore life on the surrounding stations where he learned to ride and muster. On one pastoral lease near Nullagine he met Alice whose family had been working there for a couple of generations. Alice had grown up doing domestic work. She had cared for the children of the station manager, was a good cook and an able station hand at mustering time. At around 18 years of age, Greg and Alice became a couple and they soon had two kids, Cliff and Val, born in 1978 and 1980.

Greg stayed on the station for a few more years but was getting homesick for his family and country and he thought about moving his family back to Jigalong. At this time a lot of Martu people were settling in the area and building communities with schools. Alice wasn't keen on leaving the station life which she loved and believed was right for the kids. A teacher and governess had just been employed for the station kids which allowed her to give Cliff and Val access to an education without leaving the station. Greg decided his future was not going to be tied to pastoral lease and he and Alice went their separate ways, although they have always kept in touch.

Through word of mouth Greg heard some Martu men could get jobs with mining companies and he was one of the first of the Jigalong mob to get a labouring job with BHP. Greg moved to Newman as his employment was located nearby. However, the job only lasted about a year and when it fell through he became dependent on social security, grog, town food, and moving around to wherever he could get a bed. A great many of Greg's middle years were spent underemployed, without his own accommodation, with a poor diet, high alcohol use and stress, a situation which he is still in at this point.

Despite this, Greg remained very involved in cultural business, spending a lot of time travelling back to Jigalong and throughout the Pilbara region for meetings with other Traditional Owners and Elders. At community meetings he is known to have strong views about the land use agreement that was negotiated between local organisations and mining interests. Due to his shared responsibilities with other Traditional Owners for passing on stories and dances, he

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has spent a lot of time involved in local community politics related to land management and heritage protection issues. He is frequently asked to assist younger men on cultural matters related to the local ranger program and is a key person for teaching cultural matters to younger generations. For some years he has been a guest speaker at the local schools where he talks to students about learning the Martu way.

Greg has always been in contact with his children. Alice lives with Val and her three grandchildren in Nullagine. Cliff works for the Land Association in Port Hedland and is married with four children. Greg is now 57 and chronically ill with diabetes, has chronic leg ulcers and is confined to a wheelchair. He has a small one bedroom unit but struggles to look after himself. Greg's high healthcare needs mean that he has frequent stays in Newman hospital. The hospital regime reminds him of the ways of the missionaries and government officials from his early days at Jigalong.

Cliff and Val can't usually visit Greg at the same time, but when they do visit they make sure to speak to the Aboriginal Hospital Liaison Officer (AHLO) to discuss his situation. At the latest visit from Cliff the AHLO informed him that Greg is displaying signs of depression and the onset of dementia. The hospital staff recommended that Greg needs more long term care and arranged for an ACAT assessment.

Cliff would have liked to take Greg home but he and his family are on a three year waiting list for state housing accommodation in Port Hedland, and would not be able to take him until then. There is a small four bed community aged care facility in Jigalong but this is not acceptable for Greg or Cliff, as Greg's brother passed away there 15 years ago. Although it was a significant event in his life, Greg won't speak about it when asked and has made it clear that doesn't want to live there. Greg is therefore being admitted to a RACF which is far away from his country.



Section VIII: References

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