



The University of Melbourne

# Best-practice guide to cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people attending primary care

**Key messages: context, clinical recommendations, cultural elements.**

Version 1.2.4 16 May 2022



This resource:

- was developed from key evidence and guidelines for clinical aspects of health care provision combined with key cultural and other elements that support effective healthcare for Aboriginal and Torres Strait Islander peoples<sup>1</sup>
- provides context, clinical recommendations and pertinent cultural elements within each of the major areas of primary care for cognitive impairment and dementia; that is, health promotion and prevention, detection and diagnosis, and living with cognitive impairment and dementia, including carer health and wellbeing.
- is for general practitioners and other clinicians and staff working within Aboriginal and Torres Strait Islander Community-Controlled Health Organisations, and for those in the mainstream primary health system. It has been developed to assist health care staff better understand Aboriginal and Torres Strait Islander cultural considerations, health care needs and preferences.
- is a clinical summary version of the full guide which is available at: <https://www.racgp.org.au/clinical-resources/clinical-guidelines/guidelines-by-topic>
- has been endorsed by the National Aboriginal Community Controlled Health Organisation (NACCHO) and approved by the Royal Australian College of General Practitioners as an *Accepted clinical resource*.

Specific guidance on how to implement some of the recommendations is outside the scope of this guide. Practitioners may need to consult other resources for further details. Wherever possible, it is preferable to use locally developed resources, and to access local cultural knowledge for example through Aboriginal and Torres Strait Islander organisations, Elders and communities.

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<sup>1</sup> This guide was developed by clinicians and non-clinicians with extensive experience in primary health care for Aboriginal and Torres Strait Islander peoples and with strong engagement from Aboriginal and Torres Strait Islander stakeholders. A modified Delphi Process methodology was used to reach consensus on specific cultural and clinical content. The guide draws on the current accepted international and national guidelines relating to dementia and cognitive impairment (1–7) and aligns with the principles outlined in the NHMRC “Engaging Aboriginal and Torres Strait Islander people in guideline development” (8). The following groups collaborated on the creation of this resource: the Let’s CHAT Dementia Translation Working Group, particularly in the scoping phase; 39 clinical and cultural experts in dementia and Aboriginal health care participated in the two-phase modified Delphi process; representatives from the National Aboriginal Community-Controlled Health Organisation and the Victorian Aboriginal Health Service, and the Let’s CHAT Dementia Project Management Group and Indigenous Reference Group reviewed and provided detailed feedback and recommendations on draft versions of the guide.

## Overview

- Aboriginal and Torres Strait Islander older people and Elders are deeply respected and hold very important roles in families, Communities and on Country.
- The population of older Aboriginal and Torres Strait Islander people is increasing, and the rate of dementia is 3-5 times higher than in the non-Indigenous Australian population. These two factors contribute to a rapidly growing number of Aboriginal and Torres Strait Islander people with dementia.
- There are a range of activities throughout the life course to promote brain health and to prevent dementia.
- Although age is the strongest risk factor for cognitive impairment and dementia, most people do not develop dementia as they get older.
- More Aboriginal and Torres Strait Islander people experience younger age of onset than non-Indigenous Australians.
- The recommendations in this document need to be considered keeping in mind:
  - cultural and generational understandings of dementia, identity and family
  - the diverse range of cultural, community and healthcare settings in which people live and access health services.
- Many Aboriginal and Torres Strait Islander people of middle and older age have been directly impacted by historical forced removal from family, Country and culture, and this has implications for their care in relation to dementia and cognitive impairment.
- Availability, appropriateness of, and access to services is variable across urban, rural and remote settings.
- Aboriginal and Torres Strait Islander people are more likely to access healthcare and other services that are culturally safe and trauma-informed and that are provided by people who are respectful and trusted. Involving Aboriginal and Torres Strait Islander staff in a person's care is a key element in providing culturally safe care. Building rapport and ensuring continuity of care is another element of culturally safe care.
- Strong cultural practice and identity, including connection to people and kinship ties, connection to place and Country, and cultural activities and ways of being, support overall health and wellbeing.

## Definitions

- *Cognitive impairment* means changes in memory or thinking.
- *Mild cognitive impairment* is a diagnosed condition and describes a category of cognitive impairment that does not impact on a person's capacity to function in daily life.
- *A diagnosis of dementia* requires:
  - evidence of cognitive impairment *and*
  - functional decline that is a change from the previous level of function *and*
  - these changes having been noticed by others *and*
  - the exclusion of other causes of cognitive impairment such as depression, medications, delirium and other causes.

## Health promotion and prevention

### Context

- Living well supports ageing well and brain health. Living well includes:
  - having meaningful social and cultural connection
  - following health promotion recommendations about healthy eating, physical activity and healthy weight
  - being involved in life-long learning and activities, including employment, that stimulate the brain
  - not smoking and following recommendations of safe alcohol consumption
- Risk factors for cognitive impairment and dementia include:
  - increased age
  - cardiovascular and related risk factors including high blood pressure, stroke, high cholesterol, atrial fibrillation, smoking, diabetes, obesity, renal disease and low physical activity
  - psychosocial stressors including trauma, social and cultural isolation, racism and depression
  - hearing impairment
  - excessive alcohol use
  - traumatic brain injury
  - epilepsy
  - air pollution
  - delirium
  - low level education
  - anticholinergic medications
- Psychological trauma has a significant impact on brain health throughout the life course. This includes the trauma of early life adversity, the specific impact of the policies of forced removal of children from family, Country and culture (the Stolen Generations) and intergenerational impact.
- Alcohol-related dementia is not a common type of dementia in Aboriginal and Torres Strait Islander populations.
- Strengthening protective factors and effectively identifying and managing modifiable risk factors can have a major impact on preventing or delaying onset and progression of dementia.
- High quality primary health care across the life course can support brain health and contribute to reducing cognitive impairment and dementia.

## Clinical recommendations

- Aim for best-practice clinical targets in chronic disease management, especially conditions that directly impact brain health such as cardiovascular disease (including hypertension, hypercholesterolaemia and atrial fibrillation), diabetes and renal disease.
- Assess hearing and remediate hearing impairment.
- Encourage annual health checks (MBS 715 and equivalent items) to ensure regular identification of health risk factors and to support primary and secondary disease prevention.
- Strongly invest in health promotion and non-communicable (chronic) disease prevention programmes that support:
  - social and cultural connection
  - avoiding uptake of and supporting cessation of smoking
  - healthy eating
  - physical activity
  - healthy weight
  - life-long learning
  - safe alcohol consumption
- Optimise other key primary care programs, including:
  - antenatal care
  - parenting and family support
  - early childhood developmental tracking and support
  - supporting school attendance and engagement in learning
  - ear and hearing health including health promotion and prevention of middle ear disease
  - effective social and emotional wellbeing, mental health and alcohol and other drug services
  - specific focus on the health care needs of older people
  - disability care and services.

## Cultural focus

- Health promotion information and programs should be culturally appropriate and tailored to individual, family and Community understandings of health and wellbeing.
- Many Aboriginal and Torres Strait Islander people will have several risk factors for dementia across the life cycle. Messages about risk and prevention need to be communicated sensitively.

## Detection & diagnosis of cognitive impairment and dementia

### Context

- Mild cognitive impairment and dementia are underdiagnosed in primary care settings.
- The commonest causes of dementia are Alzheimer's disease, vascular dementia or a mixture of these.
- Timely recognition and management of mild cognitive impairment and dementia have the potential to delay progress of disease.
- Identification and assessment of risk factors and asking questions about memory and thinking can help detect cognitive impairment. The consensus, based on clinical and cultural consultation, is to start this at 50 years in Aboriginal and Torres Strait Islander populations.
- Any concern or indication of cognitive impairment requires timely clinical assessment.
- Diagnosis of dementia may occur over time and several consultations.
- There is wide variation amongst Aboriginal and Torres Strait Islander peoples in knowledge, understanding and explanations for the impact of ageing and for dementia. This may reflect different culturally informed understandings and/or health literacy.
- Navigating the dementia journey is complex and it is important that people have access to accurate, timely information and advocacy.

### Clinical recommendations

- Use a case finding approach: identify and assess risk factors *and* ask questions about memory and thinking for all patients 50 and older, for example in the annual health check. Appropriate questions are:
  - Do you have any concerns about your memory or thinking?
  - Does anyone in your family have any concerns about your memory or thinking?
- Any concern or indication of cognitive impairment, which may be raised by the patient, a clinician or a family or community member, should prompt full clinical assessment, comprising:
  - history from patient and family/carer (when appropriate): onset and progress of symptoms, medications, other illnesses, behavioural & psychological symptoms
  - general examination including cardiovascular and gait assessment
  - cognitive assessment using a tool such as MMSE, KICA-Cog, etc.
  - differentiation from delirium, depression and medication effects, especially anticholinergic effect
  - standard pathology testing: FBE, biochemistry (renal function and electrolytes, liver function, Ca, glucose),

	<ul style="list-style-type: none"> <li>thyroid function, B12 &amp; folate and urinary microscopy &amp; culture. Consider syphilis serology. <ul style="list-style-type: none"> <li>imaging: CT brain</li> </ul> </li> <li>When cognitive impairment is identified, referral to specialist services (geriatrician, psycho-geriatrician, memory clinic or general physician) should be considered for comprehensive assessment and advice, refinement of diagnosis and/or initiation of dementia medication, as per NHMRC guidelines. (6)</li> </ul>
<b>Cultural focus</b>	<ul style="list-style-type: none"> <li>The wording and way of asking questions will vary depending on the cultural context and relationship between clinicians and patients.</li> <li>People may have cultural beliefs about changes in thinking or memory and/or changes in behaviour or personality. They may attribute these changes to the normal effects of ageing or another influence rather than something that may be addressed by healthcare and services.</li> </ul>

## Living with cognitive impairment and dementia

### Prognosis, planning & decision making

<b>Context</b>	<ul style="list-style-type: none"> <li>People have a right to know and understand their diagnosis and prognosis.</li> <li>Personal preferences should be respected at all stages of cognitive capacity and dementia including through supported, collective and proxy (e.g. next-of-kin, power of attorney) decision-making.</li> <li>Goals of care should be to support quality of life, maintain function and maximise comfort.</li> <li>Future planning should be timely and part of regular care of someone with mild cognitive impairment or dementia from early in diagnosis.</li> </ul>
<b>Clinical recommendations</b>	<ul style="list-style-type: none"> <li>Introduce conversations about personal preferences and planning early in the course of dementia, and revisit regularly with the patient and family members as the person with dementia's situation changes.</li> <li>Consider and offer assistance with: <ul style="list-style-type: none"> <li>identifying shared decision makers</li> <li>appointment of powers of attorney (medical and financial)</li> <li>development of formal advance care plans and funeral plans</li> </ul> </li> <li>Identify who is involved in shared and collective decision-making and/or care to support clear communication and</li> </ul>

	protect privacy.
<b>Cultural elements</b>	<ul style="list-style-type: none"> <li>• Information and discussions about diagnosis, prognosis and planning should be provided with relevant language and cultural translation.</li> <li>• Responsibility for decisions about individuals may be deeply and collectively shared with others.</li> <li>• Quality of life is evaluated differently by different people and different cultural groups. It may be useful to assess quality of life through use of a culturally tailored and validated tool, such as the Good Spirit, Good Life tool (see Key Resources).</li> </ul>
<b>Medical management &amp; other health care</b>	
<b>Context</b>	<ul style="list-style-type: none"> <li>• Goals of care should be to support quality of life, maintain function and maximise comfort.</li> <li>• Holistic care includes medical, social, psychological, physical, environmental, cultural and spiritual domains.</li> <li>• High quality primary health care as well as dementia-specific care is needed.</li> <li>• Health and social needs change as cognitive impairment and dementia progress.</li> <li>• Key elements of effective models of care include regular review supported by continuity of care and an integrated multidisciplinary case management approach.</li> </ul>
<b>Clinical recommendations</b>	<ul style="list-style-type: none"> <li>• Regular review and care planning of the following points to identify changes in needs as condition progresses: <ul style="list-style-type: none"> <li>○ Social and emotional wellbeing including quality of life, social and cultural connection, anxiety, depression and other behavioural and psychological symptoms of depression (BPSD)</li> <li>○ Risk assessments: falls, incontinence, pain, nutrition, Elder abuse</li> <li>○ Track cognition and function: capacity to make decisions, activities of daily living (ADLs) including self-care, driving, management of finances</li> <li>○ Medication review</li> <li>○ Healthy lifestyle advice: physical activity, healthy diet, healthy weight, smoking cessation, safe alcohol</li> <li>○ Immunisation</li> <li>○ Dental and oral care</li> <li>○ Vision</li> <li>○ Hearing</li> <li>○ Planning and decision-making</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Carer health and well being</li> <li>○ General health care review</li> <li>○ Other support services</li> <li>● Referral to and connection with aged care services and community support and services through My Aged Care (for people aged 50 and over), or through the National Disability Insurance Scheme (NDIS) (if &lt;50) should be considered early in care.</li> <li>● Family and carers need to have a clear point of contact (eg. key contact or case manager) to help navigate and coordinate the complex health care and service system.</li> </ul>
<b>Cultural focus</b>	<ul style="list-style-type: none"> <li>● Appropriate health care is holistic and family-centred.</li> <li>● Health care and other services should be based on principles that are culturally safe and appropriate, and that increase engagement and access.</li> <li>● Care may require a trauma-informed approach.</li> <li>● Traditional healers may be an important part of the care team for some people.</li> </ul>
<b>Carer health &amp; wellbeing</b>	
<b>Context</b>	<ul style="list-style-type: none"> <li>● Family support and looking after the health and wellbeing of carers is an important part of dementia care and can improve the quality of life for carers and for people living with cognitive impairment and dementia.</li> <li>● Carers often experience poorer health outcomes with significant impact on physical health, mental health and wellbeing, and overall quality of life.</li> <li>● Education about the behaviours and symptoms of a person living with cognitive impairment and dementia can increase understanding, provide strategies and skills for carers to know how to respond effectively to care needs, and decrease distress and negative impact of care on carer wellbeing. Education is most effective when it is part of comprehensive and ongoing carer support.</li> </ul>
<b>Clinical recommendations</b>	<ul style="list-style-type: none"> <li>● Regularly assess carer health and wellbeing. Consider using tools such as the KICA-Dep and the aPHQ-9 (see Key Resources below).</li> <li>● Many carers of Aboriginal and Torres Strait Islander people living with cognitive impairment and dementia are Aboriginal and/or Torres Strait Islander themselves and need general primary health care, age-appropriate screening for dementia risk factors and case finding for cognitive impairment, as well as recognition of their carer-related needs.</li> </ul>

<b>Cultural focus</b>	<ul style="list-style-type: none"> <li>• Carers of Aboriginal and Torres Strait Islander people with dementia may be: <ul style="list-style-type: none"> <li>◦ older and have complex health needs themselves and/or responsibilities for caring for grandchildren and others in the community</li> <li>◦ younger and may have young families themselves and/or complex health and social issues</li> </ul> </li> <li>• Carers and family members may have cultural and spiritual beliefs about changes in thinking or memory and/or changes in behaviour or personality. They may attribute these changes to normal effects of ageing rather than something that may be addressed by health care and services and this may have implications for the care of the person with cognitive impairment or dementia.</li> <li>• Carer responsibilities may be shared by many people.</li> </ul>
<b>End-of-life care</b>	
<b>Context</b>	<ul style="list-style-type: none"> <li>• The end of life is best supported by early preparation and planning to make sure the values and wishes of the person living with dementia are respected.</li> <li>• Talking about cognitive impairment, dementia and death requires skill and sensitivity.</li> </ul>
<b>Clinical recommendations</b>	<ul style="list-style-type: none"> <li>• Be familiar with local cultural protocols and practices in relation to end-of-life and bereavement.</li> <li>• Ensure the availability of responsive, timely care to manage symptoms, optimise comfort and provide psychosocial and spiritual support.</li> <li>• Consider referral (when available) to specialist palliative care services for direct patient care and/or support to the primary clinical team, including by telehealth, with advice around end-of-life planning, symptom management, psychosocial supportive care and grief counselling.</li> <li>• Visit family soon after a death to check on immediate needs of family and carers and, whenever relevant, to clear away medications and other healthcare-related equipment from the home environment.</li> </ul>
<b>Cultural elements</b>	<ul style="list-style-type: none"> <li>• Connection to Country is profoundly important for many Aboriginal and Torres Strait Islander people and may be a key part of end-of-life planning and care.</li> <li>• Discussion about death must always be addressed carefully; it may be a taboo subject in some Communities or for some individuals.</li> <li>• The place of passing and burial needs to be carefully considered.</li> <li>• Mourning practices and cultural protocols, for example how people are spoken of after their passing, vary amongst Aboriginal and Torres Strait Islander communities.</li> </ul>

## **Resources**

- Good Spirit Good Life Quality of Life Tool: available from <https://www.aboriginalageingwellresearch.com/>
- Healing Foundation Fact Sheets: Working with Stolen Generations: <https://healingfoundation.org.au/working-stolen-generations/>
- KICA Resources (including KICA-Cog and KICA-Dep): <https://www.aboriginalageingwellresearch.com/>
- The Adapted Patient Health Quality Questionnaire (aPHQ-9) – a nine-item culturally adapted and validated screening tool for depression in Aboriginal and Torres Strait Islander Australians: <https://headspace.org.au/assets/Uploads/Resource-library/Health-professionals/Clinical-Toolkit/PHQ9.pdf>
- Behaviour management: A guide to good practice. Managing behavioural and psychological symptoms of dementia: <https://dementia.com.au/resources/library/understanding-and-responding-to-behaviour-resources/behaviour-management-a-guide-to-good-practice.html>
- Dying to Talk: Aboriginal and Torres Strait Islander Discussion Starter. <https://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/>

## **Key references**

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dementia: A Delphistudy and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014 Mar 1;28(3):197–209.

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### **Other resources**

People with dementia: A care guide for general practice – developed by the Cognitive Decline Partnership Centre

<https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/>

Clinical practice guidelines and principles of care for people with dementia and Consumer companion guide – developed by the Cognitive Decline Partnership Centre <https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/>

### **Prevention**

National Aboriginal Community Controlled Health Organisation and Royal Australian College of General Practitioners. National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people: evidence base. 3rd Edition. East Melbourne; 2018.

The Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice. [Internet]. 9th edition. East Melbourne: RACGP; 2016. Available from: <https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/guidelines-for-preventive-activities-in-general-pr/preventive-activities-in-older-age/dementia>

### **Trauma-informed care**

Kezelman C.A. & Stavropoulos P.A. (2019) *Practice Guidelines for Clinical Treatment of Complex Trauma*. Blue Knot Foundation.

<https://www.blueknot.org.au/Resources/Publications/Practice-Guidelines/Practice-Guidelines-2019>

### **BPSD**

Dementia Collaborative Research Centre. Behaviour management: A guide to good practice. Managing behavioural and psychological symptoms of dementia. Sydney; 2012. <https://dementia.com.au/resources/library/understanding-and-responding-to-behaviour-resources/behaviour-management-a-guide-to-good-practice.html>

*Last search date: May 2022*

This resource was developed with funding from a National Health and Medical Research Council Boosting Dementia Grant and was produced in collaboration with Dementia Training Australia. Dementia Training Australia is supported by funding from the Australian Government under the Dementia and Aged Care Services Fund.

The authors have no conflicts of interest to declare.

#### Suggested citation

Belfrage M, Hughson J, Douglas H, LoGiudice D and the Let's CHAT (Community Health Approaches To) Dementia team (2022). Best practice guide to cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people attending primary care. Key messages: context, clinical recommendations, cultural elements.

#### For more information:

Bradley K, Smith R, Hughson JA, Atkinson D, Bessarab D, Flicker L, Radford K, Smith K, Strivens E, Thompson S, Blackberry I. Let's CHAT (community health approaches to) dementia in Aboriginal and Torres Strait Islander communities: protocol for a stepped wedge cluster randomised controlled trial. BMC Health Services Research. 2020 Dec;20(1):1-3.

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*Sherry designed the logo to represent the Let's CHAT study, as follows: "The design has 12 smaller circles in the bigger circle in the middle to represent the 12 ACCHSs working together. The four message sticks in the middle circle also are to pass on the information and awareness. The four people around the middle circle are listening to the CHAT. The dots in between the people represent the different tribes/ nations, etc. The stitch-like lines between the writing in the circle represent the different journeys people with dementia and cognitive impairment are on, trying to manage their condition."*

*Let's CHAT Dementia artwork by Maar  
Nation-Gundijmara artist,  
Sherry Johnstone.*



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