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

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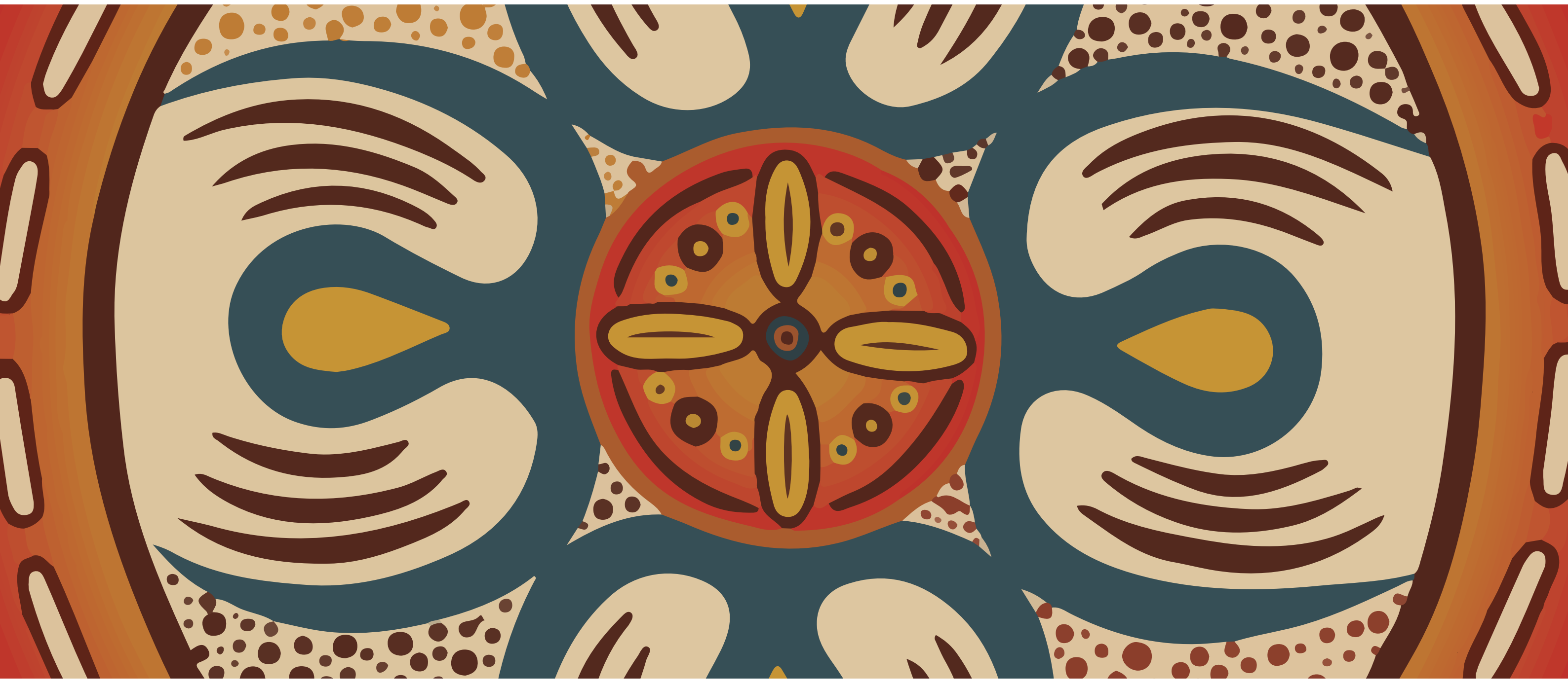

Accepted clinical resource RACGP

Dementia Training Australia

NACCHO
National Aboriginal Community Controlled Health Organisation

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Authors

Dr Mary Belfrage Research Consultant and Clinical Advisor, The University of Melbourne and Royal Australian College of General Practitioners.
Dr Jo-anne Hughson Research Fellow, The University of Melbourne.
Harold Douglas Research Officer, The University of Melbourne
Associate Professor Dina LoGiudice Geriatrician, Royal Melbourne Hospital, The University of Melbourne and National Ageing Research Institute.

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Contact

Associate Professor Dina LoGiudice
Building 21, Royal Park Campus, Royal Melbourne Hospital
Email: dina.logiudice@mh.org.au

General statement

This guide was developed as part of the Let's CHAT (Community Health Approaches To) Dementia Research Project. The Let's CHAT Dementia Research Project is working with twelve Aboriginal Community Controlled Health Services nationally to support increased detection of cognitive impairment and better dementia care in Aboriginal and Torres Strait Islander populations. The guide aims to include cultural principles in the translation of clinical evidence into recommendations on health promotion and prevention, detection and management of cognitive impairment and dementia, including recommendations about care at the end of life, and carer health and wellbeing. **The guide has been endorsed by the National Community Controlled Health Organisation (NACCHO), and approved by the Royal Australian College of General Practitioners (RACGP) as an *Accepted clinical resource.***

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Box 1: Stakeholders involved with the guide's development and review

Let's CHAT Dementia Indigenous Reference group (IRG), Project Management Group (PMG) and Translation working group (TWG) members	Prof David Atkinson (PMG) Prof Dawn Bessarab (IRG and PMG) Kate Bradley (TWG) Venessa Curnow (IRG, PMG & TWG) Gail Daylight (IRG) Terrence Donovan (IRG) Prof Briony Dow (PMG & TWG) Prof Leon Flicker (PMG) Kristine Garrett (TWG) Kirsty Hampton (TWG) Diane Jones (TWG) Roslyn Malay (IRG & TWG) Dallas McKeown (IRG) Prof Dimity Pond (PMG & TWG)

	Dr Kylie Radford (PMG) Dr Sarah Russell (PMG) Dr Kate Smith (PMG & TWG) Robyn Smith (TWG) Andrew Stafford (PMG & TWG) Adj. Prof Edward Strivens (PMG) Noeleen Tunny (PMG) Margaret Winbolt (TWG)
Delphi process participants	Thirty-nine clinicians, researchers and other health practitioners - Aboriginal, Torees Strait Islander and non-Indigenous - with clinical and cultural expertise in all or some of the following domains: • culturally appropriate Aboriginal & Torres Strait Islander health care • primary health care • specialist dementia care • dementia research
Aboriginal Health Organisation representatives	NACCHO policy officers, VAHS clinicians (Aboriginal, Torres Strait Islander and non-Indigenous)

Finally, we would like to thank the staff, patients and communities of the health services who partnered in this project for their generosity of interest and commitment to improving cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people.

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Cover artwork

Artwork by Maar Nation-Gundijmara artist, Sherry Johnstone. Sherry designed the work to represent the aims of the Let's CHAT Dementia 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."*

Conflict of interest

No individuals or agencies involved in the development of this guide have financial or other conflicts of interest.

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

Introduction

This is a guide to support best practice in primary health care settings for Aboriginal and Torres Strait Islander people in relation to cognitive impairment and dementia. *Primary health care settings* include Aboriginal Community Controlled Health Services (ACCHS) as well as non-ACCHS general practices and community health services. The guide focuses on clinical aspects of health care provision and aims to combine evidence-based clinical knowledge with key cultural and other elements that support effective health care for Aboriginal and Torres Strait Islander people. Wherever possible the evidence from these different knowledge systems is aligned to strengthen recommendations. The guide has sections on health promotion and prevention, detection and management of cognitive impairment and dementia, including recommendations about care at the end of life, and carer health and wellbeing. These recommendations span the life course, recognise the cultural diversity of Aboriginal and Torres Strait Islander peoples and are for the whole primary care team including Aboriginal and Torres Strait Islander health workers and practitioners, doctors, nurses, allied health workers, mental health workers, and health promotion and public health practitioners. The recommendations in this guide were agreed on through extensive consultation with clinical *and* cultural experts, including a modified Delphi process, in order to reach consensus.(9) When relevant, the guide should be used in conjunction with other evidence-based clinical guidelines.

Why do we need a guide for Aboriginal and Torres Strait Islander people?

Key messages:

- **Acknowledgement of the cultural context of health and healthcare for Aboriginal and Torres Strait Islander peoples**
- **Importance of responsive culturally safe trauma-informed health care**
- **Awareness of myths about dementia in Aboriginal and Torres Strait Islander populations**

Cultural Principles

A Guide specifically for Aboriginal and Torres Strait Islander people is needed in order to ***include cultural principles in the translation of clinical evidence into health care that are effective in improving health outcomes***.(8) Key cultural principles common to the broad cultural and linguistic diversity of Aboriginal and Torres Strait Islander peoples include:

- The importance of:
    - family and relationships and what that means for care of people, cultural and family responsibilities, decision-making, etc
    - connection to place/Country/home
    - respect for Elders and their role in the Community
- A holistic way of being: a whole-person, whole-of-life understanding of social, emotional, spiritual and physical health and wellbeing (consensus endorsement from modified Delphi process).

In dementia-related health care these principles align with clinical evidence about the developmental origins of health and disease, individual and social determinants including psychosocial stressors as risk factors for dementia, and how important social connection is in protecting from dementia.(1,2,10,11)

Providing responsive culturally safe trauma-informed health care for Aboriginal and Torres Strait Islander peoples

Given the greater prevalence of cognitive impairment and dementia and wide-ranging disparities generally in health and other social outcomes between Aboriginal and Torres Strait Islanders and non-Indigenous Australians (12), improving health outcomes requires a targeted response that takes into account:

- the impact of colonisation over generations, including the grief and trauma for children and their families and communities caused by the policies of forced removal of children from families, the *Stolen Generations*
- the impact of social determinants on health and wellbeing including on risk and prevalence of cognitive impairment and dementia
- the availability of services across urban, rural, and remote settings including services that are culturally acceptable to people
- other issues around accessing health care including engagement and trust.

The key elements of services that support culturally safe care:

- have strong input from Aboriginal and Torres Strait Islander people into design and delivery of services including locally informed responses based on Community preferences and cultural practices
- are family-centred, strengths-based, flexible service models that include availability of outreach and home visiting
- have culturally informed environmental elements (architecture, spatial and visual cues, soundscape, smell, etc).(13,14)

Aboriginal and Torres Strait Islander people have experienced historical, intergenerational, collective and often individual trauma. Trauma can be defined as "an event, series of events, or set of circumstances that is experienced by an individual [or community] as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's [or community's] functioning and mental, physical, social, emotional, or spiritual well-being."(15) There is growing recognition of the impact of trauma on life-long health and wellbeing (16,17), including the risk of developing dementia (10,18), and the value of *trauma-informed* service models to better engage and provide effective health care to people who have experienced significant trauma. The principles underpinning trauma-informed services are:

- acknowledgment of trauma and its effects
- giving attention to ensuring safety and building trust
- adopting collaborative approaches between providers and clients/patients
- making integrated and linked health and social support services available.(13,15,19–21)

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, establishing good rapport, and ensuring continuity of care are also important elements of culturally safe care. (13)

Myths about dementia

The Guide also aims to challenge myths or assumptions surrounding dementia in Aboriginal and Torres Strait Islander populations that are **not supported by evidence**, specifically: that people do not live long enough to get dementia; that Aboriginal and Torres Strait Islander people experience high rates of alcohol-related dementia; and that Aboriginal and Torres Strait Islander people are intrinsically susceptible to earlier ageing and dementia.

Ageing, cognitive impairment & dementia

Cognitive impairment is not a manifestation of ordinary healthy ageing. Cognitive impairment may be due to reversible causes or may indicate early dementia. Cognitive impairment requires careful clinical assessment. Mild cognitive impairment (MCI), also called *cognitive impairment not dementia* (CIND) and classed within the International Classification of Diseases (ICI-11) as Mild Neurocognitive Disorder (22), describes objectively assessed cognitive impairment that may fluctuate but does not significantly impact on a person's capacity to function in daily life. MCI describes a spectrum of impairment, has multiple causes some of which are preventable, and has a varied natural history. It may revert to normal cognition *or* not progress significantly over time *or* progress to dementia. (1) MCI is more common than dementia with up to 19% of people 65 and over in the general population being identified with MCI depending on diagnostic criteria. Of those, 39% diagnosed in specialist settings and 22% in the general population develop dementia within 3-10 years. (1)

Dementia, also referred to as Major Neurocognitive Disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (23) is a collective term for a group of neurodegenerative conditions that affect global brain functioning including memory, thinking, behaviours, physical functions, and the ability to perform everyday tasks (see Box 2 for different types of dementia).

The diagnosis of dementia requires evidence of cognitive impairment, functional decline, corroboration by informants, a change from previous level of cognitive functioning and exclusion of reversible causes. Dementia is progressive and eventually terminal. It is well documented that the number of people with dementia world-wide is rapidly rising, especially in low- and middle-income countries and populations. (24) There is also evidence that prevalence has decreased in some higher-income populations.(1) In Australia around 9% of people over 65 years are estimated to have dementia (25) and in the absence of new treatments absolute numbers of people affected are predicted to double by 2050. (26) The prevalence of dementia is 3-5 times higher in Aboriginal and Torres Strait Islander populations. (10,27) As with the general population, age is the greatest risk factor but many Aboriginal and Torres Strait Islander people experience younger age of onset. The prevalence is similar in remote, rural and urban settings. (27,28) The population of older Aboriginal and Torres Strait Islander people is also rising rapidly leading to a growing number of Aboriginal and Torres Strait Islander people with dementia. (29)

Box 2: Description of the most common types of Dementia (1,29)

Alzheimer's disease: Most common, estimated 50%-75% of dementia worldwide, characterised by short-term memory loss, apathy and depression in the early stages. Onset is gradual and decline is progressive. With refinement in diagnosis, this group is increasingly recognised as having mixed disease.

Vascular dementia: Estimated 20%-30% of dementia, caused by cerebro-vascular conditions eg multi-infarction or stroke. Often associated with hypertension, atrial fibrillation and other risk factors for cardio- and cerebro-vascular disease. Symptoms in the early stages like Alzheimer's disease, with less memory loss and more prominent mood fluctuations. Onset can be sudden. Physical frailty is also a feature. The course of the disease is less predictable than Alzheimer's disease, with decline more often stepwise than gradual as vascular events progressively occur.

Mixed dementia: Common and probably much more common than previously identified, has features of different types of dementia.

Dementia with Lewy bodies: Second most common neuro-degenerative dementia, associated with development of abnormal cells (Lewy bodies) in the brain. Characterised by marked fluctuations in cognitive functioning, confusion, visual hallucinations and difficulty judging distance which increases the risk of falls. Can have symptoms similar to Parkinson's disease (for example, tremor and rigidity). Progression tends to be more rapid than Alzheimer's disease.

Frontotemporal dementia: thought to account for <5% of dementia, relatively more common in males, younger onset. Early symptoms include personality and mood changes, disinhibition and language difficulties.

Identification and management of risk factors can prevent or delay onset of dementia in many cases. (1,2) Dementia and MCI are widely under-recognised in health care settings despite the importance of timely diagnosis for responsive and effective care.(1) A commissioned systematic review of dementia prevention, intervention and care published in The Lancet in 2017 recommended appropriate aims of key interventions as "maximising cognition, decreasing distressing associated symptoms, reducing crises, and improving quality of life" of people with dementia. (1) Australian NHMRC-endorsed clinical practice guidelines and the European Association of Palliative Care suggest that appropriate goals throughout dementia care should be to ***optimise quality of life***, ***maintain function*** and ***maximise comfort***. (6,7) In addition, health care and support services for families and carers are a key part of dementia care. (1,6)

Health promotion & prevention

Key messages and recommendations

- **Living well supports ageing well. *Living well* includes meaningful social and cultural connection, eating well, physical activity, healthy weight, engagement in learning and employment, not smoking, and consuming alcohol in safe amounts**
- **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**

The most effective strategies to reduce the risk of dementia are those that support good health; the principle that ***ageing well*** is best supported by ***living well***. This life-course approach is strongly culturally resonant and well supported by clinical evidence; growing a strong brain and then looking after it, strengthening protective factors throughout life, and minimising harm and risk factors. (1,6,30) Neurodevelopment in pregnancy, in the early years of life and throughout childhood builds brain capacity and cognitive reserve. Good physical and mental health, as well as how the brain is used through middle and later life helps to maintain cognitive function and protect against cognitive decline.

An estimated 40% of dementia in the general population is preventable (2), and progression of disease can be delayed, through management of ***modifiable risk and protective factors*** (see Box 3). The main risk factors for dementia, in addition to age, are vascular conditions (hypertension, stroke, atrial fibrillation, smoking), metabolic and other non-communicable chronic disease (diabetes, renal disease, obesity, hyperlipidaemia), developmental and psychosocial factors (childhood trauma and early life adversity, low education, depression, social isolation), hearing impairment in midlife, history of traumatic brain injury, exposure to air pollution and epilepsy. (1)

Box 3: Modifiable protective and risk factors for dementia (1,4,5,10,27,32)

Protective factors for dementia – strengthening, building cognitive reserve

Early life:

- **healthy pregnancy**
- **secure home environment**
- **good diet**
- **good hearing & language acquisition**
- **strong development & engagement in education and learning**

Middle & later life:

- social & cultural connection
- healthy lifestyle
- good diet & healthy weight
- smoking cessation
- regular physical activity
- safe alcohol consumption
- education & employment
- cognitive stimulation

Risk factors for dementia – damaging, reducing or limiting cognitive reserve

Childhood and adolescence:

- **childhood trauma & early life adversity**
- **middle ear disease & hearing impairment**
- **low level education**
- **smoking**

Middle life:

- hearing impairment
- hypertension
- other cardiovascular risk factors including atrial fibrillation, dyslipidaemia
- smoking
- diabetes
- obesity
- psychosocial stressors
- excessive alcohol intake
- traumatic brain injury
- air pollution

Later life:

- stroke
- history of head trauma
- epilepsy
- delirium
- history of depression/chronic grief
- social isolation/loneliness
- physical inactivity
- anticholinergic medications (33)

It is likely that a higher proportion of dementia is preventable in Aboriginal and Torres Strait Islander populations given higher rates of these modifiable risk factors. For example, high rates of preventable middle ear disease in early life are associated with long term hearing loss in Aboriginal and Torres Strait Islander populations. (31)

Overall there is stronger evidence for risk factors than protective factors however some evidence of protection exists for:

- **Mediterranean diet:** A diet characterised by high intake of vegetables, grains, legumes, olive oil as the main source of fat, only moderate consumption of fish, poultry and dairy, low-moderate intake of wine and a small amount of red meat. (34) This diet is high in fibre, low in saturated fats, moderate in protein and rich in macro- and micro-nutrients. There is evidence of positive benefit regarding cardiovascular prevention. (1)
- **Cognitive stimulation:** Although the evidence of benefit is not strong (1) and mainly affects the targeted skills undergoing training.
- **Physical activity:** Especially for mild cognitive impairment. The indirect benefits of exercise include reduction in other risk factors such as lipid profile, obesity, hypertension and diabetes. (1)
- **Social engagement:** In longitudinal studies this appears to be protective. This finding has not been substantiated in intervention studies although it is observed that people who are socially isolated have a higher risk of dementia. (1)

Traditional Aboriginal and Torres Strait Islander diets are low in fat despite a high content of animal-based foods (wild animals are lean) and high in a wide variety of plant-based foods including roots, starchy tubers, seeds, fruits and nuts. These diets have not been studied with respect to prevention of dementia but available data suggests that people who lived on these diets were lean, physically fit, healthy and had low prevalence of chronic diseases such as diabetes, cardiovascular disease and obesity, all of which are significant risk factors for dementia. (35,36) In addition, traditional diets are likely to be associated with higher levels of physical activity, of social and cultural connection, and of cultural knowledge and skills (education) all of which are protective and/or reduce risk of dementia.

Dementia risk factor management includes reducing both the incidence (primary prevention) and impact (secondary prevention) of cardiovascular disease, renal disease, diabetes, obesity and hearing impairment, and supporting resilience and social and emotional wellbeing. (4) There is strong evidence of the impact of early life adversity on lifelong health and wellbeing and a range of other social indicators such as engagement in education and employment (37–39), and this has been specifically linked to increased risk of dementia. (30) Specifically in relation to cognitive impairment risk reduction, there is strong evidence that treating hypertension reduces dementia incidence (all types) and possibly mild cognitive impairment also, and emerging evidence also suggests a protective effect against cognitive decline with hearing aid use for people with hearing impairment. (2)
The health promotion and disease prevention messages are similar for these chronic conditions: eating well, the harms of smoking, the importance of physical activity, maintaining healthy weight, ensuring safe/non-harmful alcohol consumption, and having meaningful social and cultural connection. In addition, effective secondary prevention requires optimal diabetic control and management of lipids and blood pressure as per standard clinical guidelines. (13,40–43)

Primary care has a key role in proactively managing modifiable dementia risk factors in its provision of health care and support services throughout the life course. (5) Encouraging annual health checks (MBS 715) to ensure regular identification of health risk factors is one way to support primary and secondary disease prevention. As well as ***targeted chronic disease prevention and management***, other key primary health programs that impact on brain health and dementia risk include:

- antenatal care: optimising *in utero* neurodevelopment
- early childhood services including developmental tracking and early intervention, assessing readiness for school and supporting engagement in education and learning
- preventing and treating middle ear disease and effectively managing hearing impairment and language acquisition
- parenting and family support services including recognition of intergenerational psychological trauma
- alcohol and other drug services

- a broad range of mental health and social and emotional wellbeing services
- specific focus on health care needs for older people
- disability care and services

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

Detection and diagnosis of cognitive impairment and dementia

Key messages

- **Mild cognitive impairment and dementia are underdiagnosed in primary care settings**
- **Timely recognition and management of mild cognitive impairment and dementia has 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 recommendation is that this starts at 50 in Aboriginal and Torres Strait Islander populations.**
- **Any concern or indication of cognitive impairment requires timely clinical assessment**
- **When cognitive impairment is identified, referral to specialist cognition services *may* be considered for comprehensive assessment and advice, refinement of diagnosis and/or initiation of dementia medication**
- **A diagnosis of dementia requires evidence of cognitive impairment and functional decline that is a change from previous level of function and has been noticed by others, and the exclusion of other causes**
- **Navigating the dementia journey is complex and it is important that people have access to accurate, timely information and advocacy.**

Dementia and cognitive impairment are widely under-recognised in health care settings (1,44) and there is ongoing debate about how to optimise detection. Despite the lack of effective treatments for dementia syndromes, there are potential benefits to ensuring a timely (early) recognition of cognitive impairment by:

- identifying and treating reversible causes of cognitive impairment including depression, delirium, medication effects – especially medication with anticholinergic activity (see Box 4), thyroid disease, calcium or B12 deficiency, tumour, etc
- implementing secondary prevention which may slow the progression of disease by strengthening protective factors and managing modifiable risk factors and comorbidities
- prompting engagement of appropriate clinical and social services, which can assist in improving the quality of life of the person with dementia and their carers and families, including:
  - regular review by the primary care team
  - considering comprehensive geriatric assessment to refine diagnosis, initiate specific treatments for dementia, assess commonly associated conditions, advise the primary care team and contribute to the care plan
  - provision of appropriate support services
- enabling expression of preferences, planning and decision making while the person has cognitive capacity
- identifying carer role, consideration of carer needs and provision of appropriate carer support services

Unlike population health programs such as cervical cancer screening, evidence of benefit has not been established for population screening for dementia (1,2,6) and possibility of harm has been cautioned. Possible harms include: generating anxiety, unnecessary investigations and costs in the context of false positive screening results; identification of conditions for which there is no effective treatment; and potential for discrimination or financial loss. (1,6,44)

Strongest current consensus supports ***detection of cognitive impairment by clinical assessment*** in response to ***(i) symptoms or concerns that have been raised*** and ***(ii) identifying those at high risk and/or asking questions about memory and thinking and/or use of a cognitive screening tool***. (1,4,6,44,45) Concerns about cognition may be raised by patients themselves, family members, clinicians and/or others. These concerns may be general in nature or more specific such as forgetfulness about appointments, not managing medications or chronic conditions as well as previously, an episode of delirium or confusion, or other changes in behaviour.

Active case finding could include:

- **Assessing risk factors** especially individual behaviours/lifestyle factors (smoking, alcohol use, obesity, lack of physical activity), non-communicable diseases (diabetes, hypertension, other heart disease, renal disease), stroke, epilepsy, head injury, hearing impairment, and psycho-social factors especially loneliness, depression, social isolation, chronic grief and trauma
- **Asking questions about memory, thinking and confusion** eg "Do you have any concerns about your memory or thinking?" "Is anyone in your family worried about your memory or thinking?"
- **Using cognitive screening tools** eg Clock Drawing Test, Kimberley Indigenous Cognitive Assessment (KICA), Standardised Mini Mental State Examination (SMMSE)

Cognitive screening tools are indicative but not diagnostic of cognitive impairment and results need to be interpreted in the context of the person's life experience (eg cultural factors, language, education level) and other clinical findings.

Given the prevalence of cognitive impairment and dementia and of risk factors in Aboriginal and Torres Strait Islander populations, case finding should be considered from the age of 50. (27,28) 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 health care and services. The wording and way of asking questions will vary depending on the cultural context and relationship between clinicians or healthcare workers, and patients.

Box 4: Commonly used classes of drugs with anticholinergic effect (46)

Antihistamines

Gastrointestinal antispasmodics

Antivertigo/antiemetics

Antidepressants

Bladder antimuscarinics

Skeletal muscle relaxants

Antipsychotics

Antiarrhythmics

Antiparkinson agents

Any indication or concern about the possibility of cognitive impairment requires full clinical assessment. (2,6) Full clinical assessment should include thorough history taking and physical examination, further cognitive assessment, consideration of reversible causes of cognitive impairment including medications, depression and delirium, and standard pathology testing (see Box 5). **When cognitive impairment persists not due to reversible causes, a brain CT should be arranged. Referral to a geriatrician or specialist cognition service *may be considered*** for comprehensive assessment and advice regarding ongoing management, to refine diagnosis and/or to initiate dementia medication. (1,3,6) GPs and the primary care team are best placed to provide coordinated continuity of care in a local and trusted setting. Specialist cognition services should primarily be used to support GPs and the primary care team to provide direct care and support to the patient and family. Availability of telephone advice for GPs (secondary consultations) and consultations via telehealth may limit the need for travel and still provide access to specialist services when they are needed.

A diagnosis of dementia is usually conducted over several consultations and requires:

- evidence of cognitive impairment
- evidence of functional decline
- cognitive impairment and/or functional decline noticed by others (family and other community members, clinicians)
- a change from previous level of cognitive functioning
- exclusion of other/reversible causes.

Box 5: Initial assessment when cognitive impairment is identified or suspected (1,6)

1. Take collaborative history from patient and family/carer including onset and progression of symptoms, medications, other illnesses, associated behavioural and psychological symptoms.
2. Assess cognition using appropriate cognitive screening tool eg KICA-Cog/MMSE/MOCA.
3. Conduct general physical examination including cardiovascular and gait assessment.
4. Differentiate from delirium, depression and medication effects especially medications with anticholinergic action.
5. Conduct standard pathology testing; FBE, biochemistry (renal function and electrolytes, liver function, Ca, glucose), thyroid function, B12 & folate and urinary microscopy & culture. Consider syphilis serology.
6. Conduct imaging; CT brain.
7. When cognitive impairment is confirmed or highly suspected consider referral to a geriatrician or specialist cognition service.

Living with cognitive impairment and dementia

Key messages

- **People have a right to know and understand their diagnosis**
- **Autonomy and personal preferences should be respected at all stages of dementia including through supported and proxy decision-making**
- **Goals of care should aim to optimise quality of life, maintain function and maximise comfort**
- **Holistic care includes medical, social, psychological, physical, environmental, cultural and spiritual domains**
- **High quality primary health care as well as dementia-specific care is needed**
- **Key elements of effective models of care include regular review supported by an integrated multidisciplinary case management approach**
- **Family support and looking after the health and wellbeing of carers can improve the quality of life for carers and for people living with dementia**

Principles of care

Holistic, family-centred care that respects the dignity and preferences of people strongly reflects Aboriginal and Torres Strait Islander cultural principles. These principles also have broad clinical consensus in recommendations for care of people living with dementia. (3,5–7) Health care should be provided within services that are culturally safe, appropriate and increase engagement and access. Traditional healers may be an important part of the care team in some settings and for some people.

Dementia is a chronic, progressive condition for which there is no cure and which is eventually terminal. These features support an overall approach that should aim to **optimise quality of life**, **maintain function** and **maximise comfort** throughout the disease trajectory (1,6) with frequent review and assessment that makes sure current health needs are recognised and specific goals of care adjusted over time. High quality primary health care as well as dementia-specific care is needed including elements of holistic care, which includes medical, social, psychological, physical, environmental, cultural and spiritual domains. The needs of people with dementia and their families and carers are complex, and effective health care and social support requires a culturally informed multidisciplinary approach that is well coordinated. (3,6) Different people and cultural groups will evaluate their quality of life differently. It may be useful to assess quality of life through use of a culturally tailored and validated tool. (47)

Diagnosis, prognosis and decision making

People need to have clear and accurate information about their diagnosis and prognosis, about what health care and support services are recommended and available, and about who will be involved in their care. (6) Information and discussions about the diagnosis, prognosis and planning should be provided with relevant language and cultural translation. Timeliness of information depends on individual circumstances and should be gradual and relevant to the stage of the disease. (3,44)

It is important to encourage a person living with dementia and their family to consider possible future preferences and wishes, to think about who should be involved in conversations and decision-making about care, and to provide opportunities to talk about this from early in the progress of dementia. For many Aboriginal and Torres Strait Islander families and communities responsibility for decisions about individuals is deeply shared. (48) It is important to make sure the right people are present in discussions about prognosis, care and decision-making processes. Many people have things they want to do when faced with the knowledge of a life-limiting condition. For many Aboriginal and Torres Strait Islander people it is most important to stay on country or to return to country. There may also be practical issues about personal affairs that need to be arranged. It is highly recommended that people living with dementia make formal arrangements such as appointing an appropriate trusted person(s) with medical and financial powers of attorney, attend to financial and other affairs, document care preferences and consider formalising relevant care instructions in Advance Care Directives. (3,6) These are complex conversations and need to be revisited over time as circumstances and understandings change. Primary care staff can provide clinical advice about prognosis and other issues underpinned by cultural knowledge and understanding. Staff may need training and support so these conversations can be had with confidence and skill and with respect, openness and sensitivity to the grief and uncertainty that people experience as dementia progresses. (7,49) These are conversations that are deeply personal *and* cultural. They are about values and spirituality as well as practical matters.

It is an important principle that people *at all levels of cognitive capacity* have a right to express preferences and to be involved in decisions about themselves (50) and it is imperative that those with diminished capacity are protected from harm and have advocacy *for their wishes* when they are not able to advocate for themselves. This can be optimised by discussion and planning ***early in the course of dementia***, and by respectful, supported and proxy decision making as capacity lessens. (2,50)

Complexity of medical management & other health care

When mild cognitive impairment (MCI) is diagnosed the most important principles of management are to address modifiable risk factors and protective factors as previously discussed, to manage comorbidities and to provide regular review to track progress and accurately identify changes in cognition and functioning.
When dementia is diagnosed these same principles apply. Rigorous management of risk factors and comorbidities supports general health and wellbeing and can significantly slow progress of the disease at all stages of dementia. There is a wide range of associated symptoms that may develop especially as dementia progresses. Regular review built on trust is key to effective care. (6)

Clinical aspects of dementia care should include ***high quality primary health care*** as well as ***dementia-specific care***.
High quality primary health care includes:

- monitoring general health and wellbeing including social and emotional wellbeing and mental health
- timely access to acute care and chronic disease management

- regular review of therapeutic targets, balancing benefits and potential harms of all medications. Maintain medications that are of current benefit without significant risk and cease or reduce medications that are no longer useful or are causing adverse effects
- immunisation as per standard guidelines
- healthy lifestyle advice
- oral health and dental care
- hearing and vision checks
- allied health including targeted care for specific conditions eg diabetes (diabetes nurse educator, podiatrist, dietician, optometrist) and/or to optimise function and general conditioning (eg physiotherapist, occupational therapist, others)
- other services such as transport, advocacy and social support.

Box 6: Clinical elements of dementia care in primary health setting

General medical care

- Standard primary care including acute care, immunisation, etc
- Social & emotional wellbeing
- Social and cultural connections
- Risk factors & comorbidities
- Oral and dental care
- Medication review
- Encouraging physical activity, social connection and cognitive activity

Allied health & nursing

- Aboriginal health worker/practitioner
- Case management
- Diabetes & other chronic disease management
- Pharmacist: medication monitoring & review
- Physio: falls, mobility, exercise
- OT: functional independence
- Audiology, optometry
- Podiatry, dietician, other
- Psychology, social work, counselling
- Traditional healer

Tracking function

Cognition (decision-making, finances, safety)

ADLs (self-care, driving)

Risk assessments

Nutrition & hydration

Pain

Falls

Continence

Elder abuse

Monitoring responsive behaviours or BPSD*

Depression
Agitation
Anxiety
Sleep disturbance
Aggression
Wandering

*Behavioural & psychological symptoms of dementia

Referral

1. Geriatrician/memory service/psychogeriatrician/other specialist
   - Comprehensive assessment/review
   - Advice re general & BPSD management
   - Dementia medication
2. Allied health & nursing
3. Palliative care services
4. My Aged Care enrolment and assessment for access to funded services including Commonwealth Home Support Program (CHSP) and Aged Care Assessment Team (ACAT)

The major recommendations for primary care regarding dementia-specific care are (see Box 6):

- Monitoring therapeutic response to dementia medications to optimise cognition, adjusting dosage and deprescribing as indicated. (See Box 7 for common medications and PBS prescribing conditions) (52)
- Regular assessment and management of **common dementia-related risks:**
  - ***Depression*** is very commonly associated with cognitive impairment and with dementia and widely under-recognised. For Aboriginal and Torres Strait Islander people depression may be in the context of having had children taken or having been taken from family (the Stolen Generations) and other complex grief and trauma. Monitoring changes in quality of life, social and cultural connection are also important to support social and emotional wellbeing.
  - ***Other* BPSD** (behavioural and psychological symptoms of dementia, also known as neuropsychiatric symptoms) (53) such as anxiety and agitation. Onset or escalation of these symptoms, including

    depression, may be triggered by underlying issues of unmet need, frustration, pain, difficulty in communication, effects from medications, acute illness such as infection, delirium or decrease in executive functioning as disease progresses. Effective responses to BPSDs must be specific to the individual and their symptoms or signs. This requires careful observation and assessment which may be supported by standard tools to assess and monitor pain, discomfort and behaviours.(6) Specific causes should be treated whenever possible. Non-pharmacological measures, including providing company, soothing environments, activities and distraction should be utilised, and are the recommended first-line treatment options.(54) Person-centred psychosocial interventions have been shown to decrease neuropsychiatric symptoms of dementia, at least in the short term. (2) Current evidence indicates that antidepressant treatment for people with dementia is not effective. (2) There is minimal evidence of benefit and substantial evidence of harm for use of antipsychotics. These are rarely indicated and, if used, should be monitored closely to ensure benefit to the patient and to identify adverse effects. (1,3,55) Sleep disturbance is common. There is evidence of benefit from maintaining diurnal rhythm and standard sleep hygiene. (1)
  - ***Nutrition and hydration*** should be assessed regularly as people with dementia are at high risk of malnutrition and poor hydration. These need regular assessment.
  - ***Chronic pain*** is common in older people with dementia and is frequently under-recognised, underestimated and undertreated. (53,55) *Pain should always be considered* and can be assessed by specific questioning and by behavioural-observational assessment tools.
  - ***Falls*** Assess any falls in past 12 months - frequency, context and characteristics. If a person reports recent falls or is considered to be at risk undertake formal multifactorial risk assessment. (56)
  - ***Continence*** Incontinence may be primarily due to dementia as disease progresses or may be due to other causes such as urinary tract infection or constipation. (57)
  - ***Elder abuse*** Abuse may be physical, psychological, sexual, financial or from neglect. (58) Risk factors for Elder abuse in the general population include: dementia, social isolation, reduced autonomy, controlling behaviours in carers, difficulties remembering and/or communicating experiences, aggressive behaviours. (1,58)
- ***Tracking cognitive and functional capacity*** including using standard tools
- ***Assessment of fitness to drive and management of finances***
- ***Care coordination and case management***
- ***Referral to relevant services***
  - consider specialist services (e.g. geriatrician, memory clinic, psychogeriatrician) to refine diagnosis, for assessment and advice about complex behaviours and/or comorbidities and for possible dementia medication
  - full range of allied health and nursing services (see Box 6)
  - funded clinical and social services accessed through My Aged Care for Aboriginal and Torres Strait Islander people aged 50 and older, and through the National Disability Insurance Scheme (NDIS) for those under the age of 50, should be considered early in care.
  - palliative care services

A case management approach is consistently recommended to support people living with dementia and their families through the complexity of health and social service systems. This ensures coordination of care and clarity about a point of contact for carers. (1,3)

Box 7: Medications used to improve cognition in dementia (1,3)

Class of drug	Names of drugs	Dementia type	Initial prescription AUTHORITY	Ongoing prescription AUTHORITY Streamlined
Cholinesterase inhibitors -increases neurotransmitter acetylcholine	Donepezil Galantamine Rivastigmine	Alzheimer's disease Dementia with Lewy Bodies	1. Specialist Physician or GP/NP* in consultation with Specialist Physician 2. MMSE/SMMSE >10 or <10 if meets education/language criteria 3. Sole PBS-subsidised therapy for dementia	1. GP/NP* or Specialist Physician 2. Demonstrate meaningful response, one or more: • increased quality of life • improved cognition • improved behaviour 3. Sole PBS-subsidised therapy for dementia
NMDA (N-methyl-D-aspartate) receptor antagonist - blocks glutamate to decrease calcium entry into brain cells	Memantine	Alzheimer's disease Dementia with Lewy Bodies	1. Specialist Physician or GP/NP* in consultation with Specialist Physician 2. MMSE/SMMSE 10-14 3. Sole PBS-subsidised therapy for dementia	

*nurse practitioner

COVID-19

The COVID-19 pandemic has important implications for dementia care. Access to health care and supports for people with dementia and their carers and families may be disrupted during outbreaks or due to public health directives in place to prevent spread of the virus.

In addition, a significant correlation has been found between dementia and COVID-19 cases and deaths in a global study. (59) UK statistics derived from death certificates indicate that dementia is currently the most common underlying condition of people dying from COVID-19.(2) In 2020, rates of COVID-19 infection in Aboriginal and Torres Strait Islander communities have been low and there have been no deaths (60), reflecting an effective First Nations-led public health response. (61) Other First Nations communities around the world, for example in Brazil (62), are recording higher rates of infection and mortality than in the general population. The ongoing success of minimising the impact of this pandemic on Aboriginal and Torres Strait Islander communities will be reliant on continued prioritisation at all levels of planning and response. (61)

Carer health and wellbeing

Carers are central to provision of health and personal care for a person living with dementia. Carers of people living at home are usually family members. In Aboriginal and Torres Strait Islander communities, carer responsibilities may be shared by many people. (63) The demands of caring for a person living with dementia are high and carers commonly experience chronic grief as the condition progresses and the needs of the person living with dementia increase. (7) Carers often experience poorer health outcomes with significant impact on physical health, mental health especially depression and anxiety, and overall quality of life. Absenteeism from work occurs due to requirements to be available to provide care, including attending appointments, and due to carer ill-health. A key element of dementia care is care of carers. (1,3,6,7)

Education about the behaviours and symptoms of a person living with dementia can increase understanding, provide strategies and skills to better manage aspects of care, 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. (1,64)

Spouses of people living with dementia are at increased risk of dementia themselves. (1) Carers of Aboriginal and Torres Strait Islander people living with dementia are often family and Aboriginal and Torres Strait Islander community members. Therefore, in addition to the carer risk, they potentially have other risk factors for dementia; that is, they are part of the target population of *this* Guide with regards to health promotion, prevention and detection of cognitive impairment. Carers need general primary health care, age-appropriate screening for dementia risk factors and case finding for cognitive impairment, and assessment of quality of life, as well as recognition of their carer-related needs.

End-of-life care

It is characteristically difficult to predict the course of dementia, which varies from one person to another and with different dementia syndromes, but eventually dementia is a life-limiting condition. It is also important to consider the end-of-life needs of the many people living with dementia whose cause of death may be from other conditions. (1)

The end of life is supported by careful conversation, early preparation and planning to make sure the values and wishes of the person living with dementia are respected. (7) Death may be a taboo subject of conversation in some communities or for some individuals. (48) Connection to country is profoundly important for many Aboriginal and Torres Strait Islander people and may be a key part of planning and care. The availability of responsive, timely care to manage symptoms, optimise comfort and provide psychosocial and spiritual support is also key. (7,65) Common symptoms at the end of life, such as pain, swallowing difficulties, pressure sores and agitation, are often under-detected and undertreated. (1) Referral to specialist palliative care services may be considered, when available, to provide 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. Mourning practices and protocols, for example how people are spoken of after their death, vary amongst Aboriginal and Torres Strait Islander communities. Local cultural protocols in relation to end of life and bereavement should be identified and respected. The place of death and burial needs to be carefully considered.

Finally, a respectful and practical role for the clinic team is to 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.

Conclusion

By creating a better understanding of the cultural context and lived experience of Aboriginal and Torres Strait Islander people and based on clinical evidence, this guide aims to improve the general health and wellbeing of Aboriginal and Torres Strait Islander people, to address the much greater burden of cognitive impairment and dementia compared to the non-Indigenous Australian population, to encourage action to strengthen protective factors and address the much higher rates of risk factors many of which are modifiable, to improve detection of cognitive impairment, and to improve the care of Aboriginal and Torres Strait Islander people and their families who experience dementia.

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Further resources

Resources designed for use with Aboriginal and Torres Strait Islander peoples

Kimberley Indigenous Cognitive Assessment (KICA) Resources (including KICA-Cog and KICA-Dep) Available at: https://www.aboriginalageingwellresearch.com/

Caring for Spirit – Aboriginal and Torres Strait Islander Online Dementia Education (Aboriginal Health and Ageing Team, Neuroscience Research Australia) Available at: https://caringforspirit.neura.edu.au/

Resources for Aboriginal and Torres Strait Islander Communities (Dementia Australia) Available at: https://www.dementia.org.au/resources/for-aboriginal-and-torres-strait-islander-communities

Good Spirit Good Life Quality of Life Tool and Resources (Aboriginal Ageing Well Research, University of Western Australia) Available at: 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. Available at: https://headspace.org.au/assets/Uploads/Resource-library/Health-professionals/Clinical-Toolkit/PHQ9.pdf

Dementia resources

People with dementia: A care guide for general practice (Cognitive Decline Partnership Centre) Available at: 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 (Cognitive Decline Partnership Centre) Available at: https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/

Prevention

National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people: evidence base. National Aboriginal Community Controlled Health Organisation and Royal Australian College of General Practitioners. 3rd Edition. East Melbourne; 2018. Available at: https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/Resources/Evidence-base-to-a-preventive-health-assessment-3rd-edition.pdf

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Trauma-informed care

Practice Guidelines for Clinical Treatment of Complex Trauma. Kezelman C.A. & Stavropoulos P.A. (2019). (Blue Knot Foundation) Available at: https://www.blueknot.org.au/Resources/Publications/Practice-Guidelines/Practice-Guidelines-2019

Healing Foundation Fact Sheets: Working with Stolen Generations. (The Healing Foundation) Available at: https://healingfoundation.org.au/working-stolen-generations/

BPSD resources

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

Palliative Care resources

Dying to Talk: Aboriginal and Torres Strait Islander Discussion Starter. (Palliative Care Australia) Available at: https://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/

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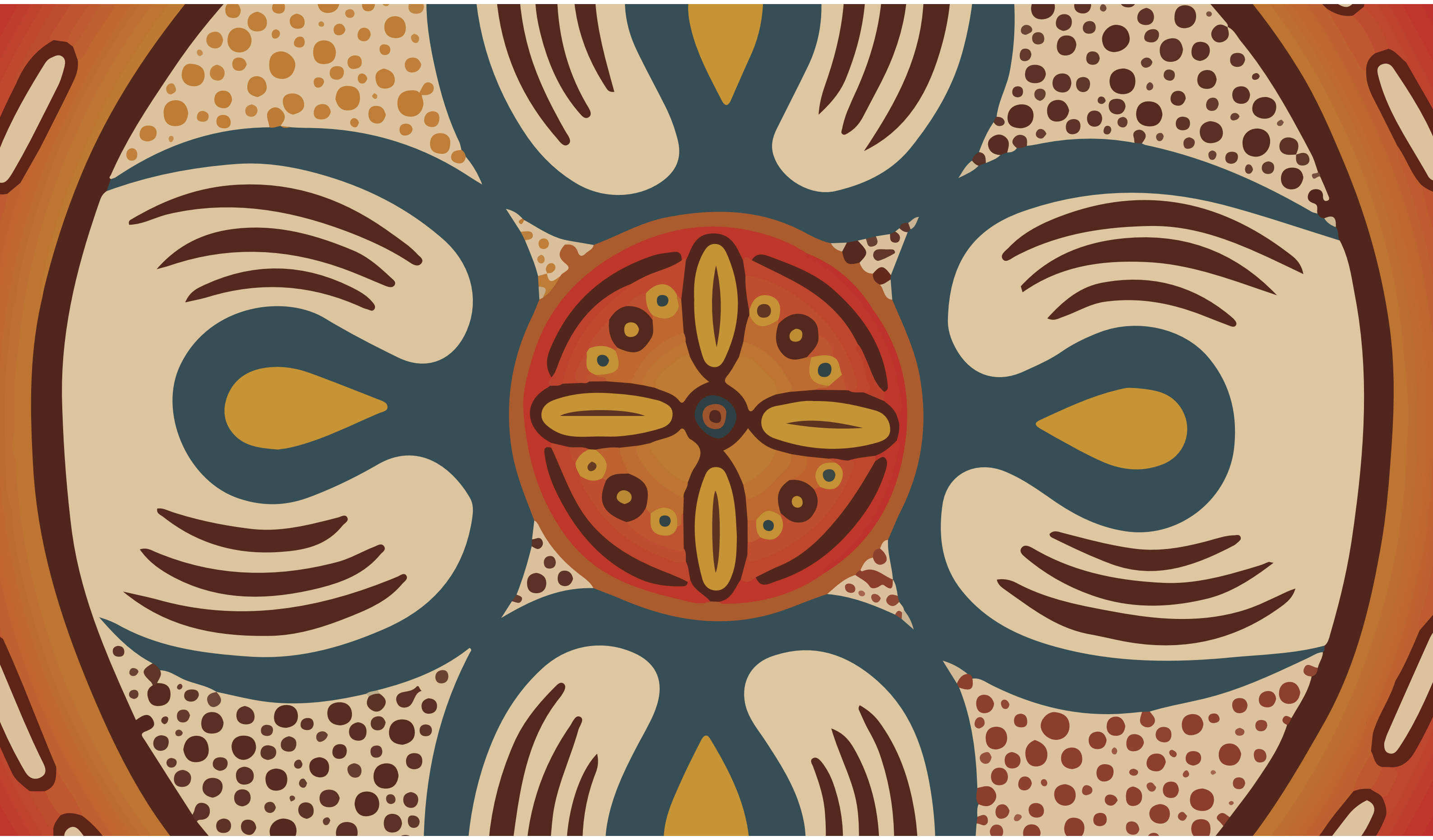
Contact information

Associate Professor Dina LoGiudice
Building 21, Royal Park Campus, Royal
Melbourne Hospital
Email: dina.logiudice@mh.org.au



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