

THE FUTURE OF ALZHEIMER'S DISEASE IN AUSTRALIA



Preparing our healthcare system to deliver optimal care for Australians impacted by Alzheimer's disease.

WHITE PAPER

FOREWORD

As clinicians, researchers, and care providers, we stand at the precipice of an exciting journey to optimise care for all Australians affected by Alzheimer’s disease.

The potential advent of disease-modifying therapies represents a critical moment in time for us to come together and effect meaningful and beneficial change for the future of care in this country.

We know our current system is not perfect. Though we are all committed to providing the best care to our patients and their families, resources, time and process limitations can impact our capabilities.

From complicated clinical pathways and non-standardised diagnostic mechanisms to inadequate resourcing and underutilised educational opportunities, significant work is needed to prepare our system for an increasingly complex patient load.

These challenges are not insurmountable. Working together in a growing collaborative gives us hope that we can meet them.

This White Paper – informed by the outcomes of an expert Think Tank and an extensive consultation process – is a testament to this commitment.

The recommendations proposed within are beacons of opportunity – the beginnings of numerous activities that we must bring together to pave the path ahead.

As we begin to travel down this path, we acknowledge work is already underway to lay the foundations for improvements across the system, led by some of the most dedicated and skilled individuals and organisations in the country.

Now, together, we will build on this work and drive these initiatives forward. By combining our experience, knowledge, and resources, we have the chance to ensure our system is thoughtfully designed and well prepared for the positive changes to come.

Listed in alphabetical order:

- **Ms Janice Besch**, Chief Executive Officer, Australian and New Zealand Society of Palliative Medicine; Future of Alzheimer’s Disease Think Tank MC
- **Professor Henry Brodaty**, Scientia Professor, Centre for Healthy Brain Ageing (CHeBA); Future of Alzheimer’s Disease Think Tank Chair
- **Professor Amy Brodtmann**, Co-head of the Dementia Theme, the Florey Institute of Neuroscience and Mental Health, and Royal Melbourne Hospital, and Austin Health; Future of Alzheimer’s Disease Think Tank Chair
- **Dr Stephanie Daly**, General Practitioner with dementia speciality, Dementia Training Australia; and Future of Alzheimer’s Disease Think Tank Chair
- **Ms Maree McCabe**, Chief Executive Officer, Dementia Australia; and Future of Alzheimer’s Disease Think Tank Chair
- **Ms Margie Melano**, Health Systems Consultant; and Future of Alzheimer’s Disease Think Tank Chair
- **Professor Dimity Pond**, General Practitioner with dementia speciality; and Future of Alzheimer’s Disease Think Tank Chair

CONTENTS

Snapshot	2
Introduction	6
1. Case finding and early investigation	9
2. Diagnosis and diagnostic mechanisms	12
3. Treatment access and delivery	16
4. Education and raising awareness	18
5. The role of primary care	21
6. System integration and whole of care	24
Summary of recommendations	28
Conclusion	30
References	31

Alzheimer's disease (AD) is the most common form of dementia and a major contributor to the burden of disease in Australia.^{1,2,3} In many people, the first indicator of AD is mild cognitive impairment (MCI).¹ MCI is defined as significant memory loss without the loss of other cognitive function.⁴ Research suggests that people with MCI are three-to-five times more likely to develop dementia, especially AD.⁴

In alignment with the priorities set out in the National Preventive Health Strategy, there is a need to enhance the focus on prevention of disease as a means of improving the health of all Australians.⁵ For AD, this means better information, earlier identification and intervention, targeting risk factors and addressing the broader causes of the condition.

There are over 328,000 Australians who may be affected by MCI and mild dementia with suspected AD.^{7*} Disease-modifying therapies (DMTs) are one strategy which has the potential to delay progression of AD, however, also pose significant challenges to an already overburdened healthcare sector.^{6,7}

* Includes total potential population with MCI or mild dementia suspected due to AD, before any assumptions relating to cognitive screening, referral to specialist, referral for diagnostic testing (as reported in the RAND 2019 report) are applied.

Current processes for the diagnosis and management of MCI and dementia due to AD are inadequate to deal with the anticipated increase in patient demand.⁶ But there is a window of opportunity to prepare the sector and ensure models of care, infrastructure and the workforce can meet the needs of this increasing patient population.

Without adequate preparation – across the length of the clinical pathway and within primary, secondary and community/residential aged care settings – it will not be possible to provide timely access to DMTs and optimal ongoing care to those diagnosed with MCI and dementia due to AD.

This White Paper details the challenges currently facing the sector and provides recommendations for rising to the challenges and optimising the future management of AD in Australia.

SNAPSHOT CHALLENGES & RECOMMENDATIONS

1. CASE FINDING AND EARLY INVESTIGATION

Early identification and intervention for MCI can greatly improve patient outcomes, but there are challenges and barriers to ensure those with MCI are identified and adequately assessed.

RECOMMENDATIONS

- 1.1 Normalise the concept of 'brain health checks' and discussing cognitive health in the primary care setting
- 1.2 Undertake a research project to determine the clinical picture of MCI in the primary care setting
- 1.3 Support the role of practice nurses in the discussion and assessment of MCI
- 1.4 Investigate the potential of online cognitive assessment tools.

Refer to Section 2 for recommendations regarding diagnostics.

Refer to Section 4 for recommendations regarding health professional education.

2. DIAGNOSIS AND DIAGNOSTIC MECHANISMS

A lack of standardised diagnostic mechanism clinical pathways pose a challenge to referrals and diagnosis, limiting the ability of primary care professionals to play a central role.

RECOMMENDATIONS

- 2.1 Establish standardised referral, diagnostic and support pathways
- 2.2 Develop guidelines for the conduct and analysis of different diagnostic assessments, including appropriate assessments for primary care and when to refer to specialist care
- 2.3 Establish a process for initial diagnostic assessments in primary care
- 2.4 Map existing infrastructure, support and training services to identify gaps
- 2.5 Support multicultural health professionals to champion discussions of MCI and AD in their communities
- 2.6 Establish/improve mechanisms for the collection of disease-specific data
- 2.7 Support the development of dementia-friendly communities
- 2.8 Conduct a research project on the impact of an MCI/AD diagnosis.

3. TREATMENT ACCESS AND DELIVERY

While the Australian healthcare system has the infrastructure and skill to deliver an infusion DMT, challenges remain around ensuring equitable access to treatment.

RECOMMENDATIONS

- 3.1 Explore the potential for case managers or care coordinators to support the recently diagnosed to access treatment and support services
- 3.2 Upskill practice nurses and pathology centres to administer DMTs
- 3.3 Develop information resources for primary care providers to support them if and when DMTs become available in Australia.

4. EDUCATION AND AWARENESS RAISING

Stigma and misconceptions associated with MCI/AD can result in a reluctance to present for cognitive review, impacting the ability of primary care professionals and specialists to offer optimal care.^{22, 24}

RECOMMENDATIONS

- 4.1 Develop an education and awareness raising campaign for the general public on MCI, AD and the importance of early identification, to reduce stigma and facilitate early presentation for cognitive review
- 4.2 Develop culturally appropriate education and awareness raising resources to address stigma among Indigenous Australians
- 4.3 Develop culturally appropriate education and awareness raising resources to address stigma among culturally and linguistically diverse populations
- 4.4 Conduct an audit of existing medical education programs on cognition to identify availability and gaps
- 4.5 Develop medical education for primary care professionals on MCI, AD, and the importance of early identification, to reduce stigma and facilitate early presentation for cognitive review
- 4.6 Explore opportunities for peer-to-peer education spanning primary and secondary healthcare settings
- 4.7 Incentivise primary care professionals who undertake further cognition education
- 4.8 Promote the importance of including cognitive education in medical school and specialist training programs.

5. THE ROLE OF PRIMARY CARE

Primary care is well-positioned to play an important role in the case finding of MCI/AD. However, challenges around access, reimbursement and training need to be addressed to allow primary care to play a central role.

RECOMMENDATIONS

- 5.1 Explore the potential for specific aged-care primary care practices
- 5.2 Determine the financial supports required to better support primary care practitioners to play a role in cognitive assessments and dementia care
- 5.3 Establish standardised referral, diagnostic and support pathways.

Refer to Section 2 for recommendations regarding diagnostics.

Refer to Section 4 for recommendations regarding health professional education.

6. SYSTEM INTEGRATION AND WHOLE OF CARE

The current model of care for people with MCI/AD is sub-optimal with people facing challenges relating to access and receiving care, as well as issues of capacity and best practice for those working within the system.

RECOMMENDATIONS

- 6.1 Support the development of a national framework for the management of MCI/AD in Australia
- 6.2 Develop mechanisms that link primary and secondary care settings for diagnosis and ongoing management
- 6.3 Establish multidisciplinary teams (MDTs) to help coordinate and optimise care
- 6.4 Undertake a review of Medicare rebates for cognitive assessment
- 6.5 Support efforts to address workforce capability issues, such as upskilling workers and expanding the capacity of services.

INTRODUCTION

As the most common form of dementia in Australia, AD is a major contributor to death and disability, with widespread impacts on individuals, their families and the broader community.^{1,2,3} In many people, the first indicator of AD is MCI.¹ MCI is defined as significant memory loss without the loss of other cognitive function.⁴ Research suggests that people with MCI are three-to-five times more likely to develop dementia, especially AD.⁴

AD IN AUSTRALIA: THE STATISTICS



Currently, there are no preventative or curative treatment options for Australians diagnosed with AD.⁶ Models of care focus on residential aged care or in-home services. If a potential treatment was made available, it could be part of the solution to the long-term funding issues raised in the Royal Commission into Aged Care Quality and Safety.⁹

The National Preventive Health Strategy emphasises the need to enhance the focus on prevention of disease, through better information, earlier identification and intervention, targeting risk factors and addressing the broader causes of the condition.⁵

There are over 328,000 Australians who may be affected by MCI and mild dementia with suspected AD.^{7*} Disease-modifying therapies (DMTs) are one strategy which has the potential to delay progression of AD,⁶ however, also pose significant challenges to an already overburdened healthcare sector.^{6,7}

It is anticipated the introduction of DMTs will generate significant interest among the public, leading to an increase in people seeking assessment, diagnosis and treatment for MCI. However, current processes for the diagnosis and management of MCI and AD are inadequate to deal with an increase in patient demand.⁶

There is a window of opportunity to prepare the sector for the potential introduction of DMTs, to ensure models of care, infrastructure and the workforce can meet the needs of an increasing patient population.

A recent assessment of the Australian healthcare system conducted by the RAND Corporation identified broad systemic challenges that need to be addressed in preparation for a potential DMT,⁶ including:

- Addressing **workforce capacity** and training gaps
- Clarifying the **treatment access** and delivery pathway
- Defining the appropriate and most efficient **diagnostic pathways**
- Challenging the **discrimination** facing those with early-stage AD, including MCI
- Determining the **role of primary care** and the support and education needed
- Establishing **system-wide integration** and collaboration to ensure an individual's experience within the Australian health system is efficient, supportive, and consistent.

RISING TO MEET THE CHALLENGE

On 26 February 2021, stakeholders from various health service and government settings across Australia came together virtually for the **Future of Alzheimer's Disease Think Tank**.

Through a series of breakout sessions, participants discussed the challenges associated with the potential introduction of DMTs in Australia, the opportunities to address these challenges and the actions required to start preparing the sector for this anticipated change in the disease management landscape.

A list of Think Tank participants is provided in Box 1.

Box 1. The Future of Alzheimer's Disease Think Tank Participants

The development of this White Paper has been made possible by the meaningful input and contributions of Think Tank participants (listed in alphabetical order):

- | | |
|---|---|
| <p>Ms Julie Anderson Aged and Community Services Australia</p> <p>Professor Kaarin Anstey Dementia Centre for Research Collaboration</p> <p>Ms Janice Besch (MC) Australian and New Zealand Society of Palliative Medicine</p> <p>Professor Henry Brodaty (Chair) Centre for Healthy Brain Ageing (CHeBA)</p> <p>Professor Amy Brodtmann (Chair) Royal Melbourne Hospital, Austin Health, and the Florey Institute of Neuroscience and Mental Health</p> <p>Associate Professor Roger Clarnette University of Western Australia</p> <p>Professor Steve Collins National Dementia Diagnostics Laboratory, The Florey Institute of Neuroscience and Mental Health</p> <p>Associate Professor David Darby Royal Melbourne Hospital</p> <p>Dr Stephanie Daly (Chair) Dementia Training Australia</p> <p>Professor Leon Flicker University of Western Australia</p> <p>Associate Professor Roslyn Francis Australasian Radiopharmaceutical Trials Network</p> <p>Dr Dan Grant MTP Connect</p> <p>Dr Debra Graves Royal College of Pathologists of Australasia</p> <p>Professor Susan Kurrle Faculty of Medicine and Health, University of Sydney</p> <p>Professor Jodi Liu RAND Corporation</p> <p>Dr Kevin London Australia and New Zealand Society of Nuclear Medicine</p> <p>Dr Marita Long Dementia Training Australia</p> <p>Professor Lee-Fay Low Faculty of Medicine and Health, University of Sydney</p> | <p>Professor Colin Masters The Florey Institute of Neuroscience and Mental Health</p> <p>Ms Karen McBeath Central Coast Local Health District</p> <p>Ms Maree McCabe (Chair) Dementia Australia</p> <p>Ms Margie Melano (Chair) Health Systems Consultant</p> <p>Professor Philip Morris Royal Australian and New Zealand College of Psychiatrists</p> <p>Dr Tom Morris HammondCare</p> <p>Vasikaran Naganathan Australian and New Zealand Society for Geriatric Medicine</p> <p>Ms Grace Ongley The Psychogeriatric Nurses Association Australia</p> <p>Ms Marissa Otuszewski Federal Department of Health</p> <p>Associate Professor Giancarlo Pascali Radio-pharmacy Sciences Special Interest Group at Australian and New Zealand Society of Nuclear Medicine</p> <p>Professor Dimity Pond (Chair) General Practitioner with dementia speciality</p> <p>Ms Lesley Pugh Australian Primary Health Care Nurses Association</p> <p>Dr Chrys Pulle Dementia Trials Australia</p> <p>Mr Carl Rhodes RAND Corporation</p> <p>Professor Chris Rowe Australian Dementia Network</p> <p>Dr Geoffrey Schembri Australasian Association of Nuclear Medicine Specialists</p> <p>Dr Cathy Short Queen Elizabeth Hospital</p> <p>Professor James Vickers Wicking Institute</p> <p>Ms Justine Watkins Agency for Clinical Innovation</p> <p>Associate Professor Michael Woodward Austin Health Memory Clinic</p> |
|---|---|

6 * Includes total potential population with MCI or mild dementia suspected due to AD, before any assumptions relating to cognitive screening, referral to specialist, referral for diagnostic testing (as reported in the RAND 2019 report) are applied.

Following the Think Tank, a consultation Green Paper outlining the outcomes of these discussions was disseminated among professional, clinical, advocacy and policy experts.

Over a six-month period, stakeholders were invited to submit their feedback to further define the challenges faced by the sector and determine the path ahead.

This resulting White Paper summarises the outcomes from the Think Tank and this consultation period. It outlines the key challenges and proposes recommendations to meet them, to optimise the future management of AD in Australia.

1 CASE FINDING AND EARLY INVESTIGATION

Early identification of MCI and early intervention can greatly improve the long-term outcomes of a patient with AD. However, there are challenges and barriers to identifying people with suspected MCI and ensuring they are adequately assessed.

CHALLENGE: ESTABLISHING AN APPROPRIATE APPROACH TO CASE FINDING

Population-based screening is not considered to be suitable or realistic for the identification of MCI in the broader community.¹⁰ Questions regarding the appropriate age for such screening, and the capacity for General Practitioners (GPs) to take on the additional responsibility for routine cognitive screening, limit the practical implementation of this approach.

Diagnostic case finding – commencing from the age of 65 or 70 years and when MCI is suspected – may be a more appropriate and practical solution. However, more work is required to confirm how this process can occur effectively, including determining who is responsible for case finding and establishing reimbursement mechanisms, pathways, and access to a suite of materials/tools to support this work.

In addition, it is important to understand not everyone with MCI progresses to dementia, and not all cases of MCI are caused by AD. There is a need to gain a clearer insight into what factors or characteristics increase the risk of progression from symptoms of MCI to dementia. Having these data from a real-world population would help the system determine how to best prioritise referrals for diagnostic assessments.

RECOMMENDATIONS:

1.1 Normalise the concept of ‘brain health checks’ and discussing cognitive health in the primary care setting.

Establishing a baseline of cognitive health for patients in their 50s can help to lay a foundation for cognitive assessments in the future. It also provides an opportunity to address modifiable lifestyle risk factors.

Assessments such as the Montreal Cognitive Assessment (MoCA) and Alzheimer’s Disease Assessment Scale–Cognitive Subscale (ADAS-Cog) could be used.

1.2 Undertake a research project to determine the clinical picture of MCI in the Australian primary care setting.

Research could be undertaken in primary care to determine the ‘real-world’ risk factors and true rates of progression from MCI to dementia due to AD. Input could be sought from public health epidemiologists to support this.

Associate Professor
Kathryn Goozee
Director and CEO, KaRa
Institute of Neurological
Diseases

“Prevention and early diagnosis of AD are inextricably linked. People over 50 with a family history of dementia are often acutely aware of the risk. Establishing a baseline assessment with a MoCA and ADAS-Cog is a means to assess cognitive health in the future. It is also an opportunity to address modifiable lifestyle risk factors that may be amenable to change.”

“I have offered this type of service and there are many who have welcomed this approach. It also helps to reduce the stigma as you are approaching the issue proactively.”

CHALLENGE:
ENCOURAGING EARLY PRESENTATION FOR COGNITIVE REVIEW

For a diagnostic case finding approach to be successful, people need to be willing to present to primary care for cognitive review. However, the significant stigma associated with MCI and AD can make people unwilling to acknowledge the early signs of cognitive decline.¹¹

A United Kingdom survey completed by 500 adults showed people 50 years and older have a greater fear of being diagnosed with dementia than cancer.¹² In addition, there is broad public perception that all memory loss is a normal part of ageing.^{13,14}

Cultural attitudes towards cognitive decline can make certain populations, including Indigenous Australians and people from culturally and linguistically diverse backgrounds, reluctant to discuss these issues with their General Practitioner (GP).⁸

In addition, a lack of understanding of the consequences of cognitive decline and a lack of access to appropriate healthcare services in which to undergo cognitive assessment, can impact the early identification of MCI.

RECOMMENDATION:

There is an opportunity to develop education to raise awareness about memory loss, risk factors for MCI/AD and the importance of early identification and intervention to slow disease progression.

See Section 4 for more detailed recommendations on education and awareness raising initiatives.

CHALLENGE:
ENSURING SUSPECTED CASES OF MCI ARE INVESTIGATED APPROPRIATELY

When a person presents with suspected cognitive decline, primary care professionals need to be equipped with the right skills and tools to investigate appropriately.

There is a need to upskill primary care professionals to improve their understanding of MCI and the important role they play in identifying and referring patients with symptoms of MCI for specialist assessment and diagnosis.

Case finding is further complicated by the lack of preferred cognitive screening assessments available in the primary care setting. Current assessments available in primary care are not accurate enough to determine if someone has MCI or is simply anxious/worried well. For example, on the Mini-Mental State Exam (MMSE), a person with MCI or mild AD can still score 30/30 and therefore not be appropriately identified. This assessment may also result in ‘false-positives’ for people with limited education, developmental delays or limited comprehension of English.

Other assessments are available, including the Addenbrookes Cognitive Examination (ACE) and Montreal Cognitive Assessment (MoCA). However, guidance on how and when to use these is currently limited.

RECOMMENDATIONS:

1.3 Support the role of practice nurses in the discussion and assessment of MCI.

Practice nurses are available and willing to meet the need for cognitive assessments in the primary care setting.

1.4 Investigate the potential of online cognitive assessment tools.

An evaluation is currently underway to assess the capacity and accuracy of online cognitive testing.

A research study to investigate the applicability of these tools in the Australian context would be beneficial.

There is a need to develop guidelines to support cognitive assessment in primary care.

See Section 2 for more detailed recommendations on establishing diagnostic mechanisms for primary care.

There is an opportunity to develop education for primary care providers about MCI, AD and the importance of early identification.

See Section 4 for more detailed recommendations on education and awareness raising initiatives.

Lesley Pugh
 Nurse Practitioner,
 Australian Primary Health
 Care Nurses Association

“We need to include practice nurses in training and upskilling with GPs so that a whole of practice approach could be applied to case finding.”

WHAT RESOURCES ALREADY EXIST TO SUPPORT CASE FINDING AND EARLY INVESTIGATIONS?



Dementia Training Australia (DTA) Cognition Workshops

Online resources and face-to-face workshops are available through DTA to boost the confidence of primary care professionals in the diagnosis and management of dementia including Alzheimer’s disease.



Online cognitive assessment tools:

Cogstate is a neuroscience technology company working to develop simplified measurements of cognition. It has established partnerships with the pharmaceutical industry and validated some online tests. The company’s learning tests can detect learning deficits in cognitively unimpaired, amyloid positive participants.

C A S E S T U D Y

PRACTICE NURSES, LIKE CATHY, STAND READY TO SUPPORT COGNITIVE HEALTH IN PRIMARY CARE



Practice nurse Cathy is an active and much-loved member of her practice in a regional Victorian town.

She supports the work of the practice’s GPs by managing patient vaccinations, routine health screens and chronic disease management activities – such as blood glucose monitoring.

Cathy has strong rapport with the practice’s regular patients. Her schedule allows her time to talk with her patients, hear their concerns and answer their questions, free of the time pressures so often associated with GP appointments.

Cathy participates in regular educational activities as part of her CPD requirements and is keen to upskill in areas that would be relevant to her local community.

She is well-positioned to upskill in cognitive health assessment and take on a central role promoting cognitive health within her local community.

2 DIAGNOSIS AND DIAGNOSTIC MECHANISMS

There is no recommended process for diagnosing MCI due to AD in clinical practice. The lack of standardised testing and clear clinical pathways poses a challenge to referrals and diagnosis and limits the ability of primary care professionals to play a central role.

CHALLENGE: NO STANDARD DIAGNOSTIC PATHWAY

There is no single recommended method for diagnosing MCI due to AD. Current diagnostic mechanisms include positron emission tomography (PET) to identify the presence of amyloid or tau proteins and lumbar puncture to assess cerebrospinal fluid (CSF) biomarkers.^{6,15,16,17}

PET imaging is not readily available at many sites across the country.⁶ Recent MBS funding has been provided for screening PET to be available.¹⁸ Specific amyloid tracer remains unfunded and is difficult to arrange, costly to access and is currently predominantly restricted to use in research. Standardised and robust CSF kits are available, however there is a misconception that a lumbar puncture is a high-risk procedure with anecdotal feedback provided during *The Future of Alzheimer's Disease Think Tank* suggesting that Australians would prefer to avoid a lumbar puncture procedure due to its invasive and potentially painful nature.

In addition to PET and CSF, blood biomarker tests are emerging and may be able to act as a preliminary tool to identify patients suitable for further investigations in the future.¹⁶

Other imaging technologies, such as computed tomography (CT) and magnetic resonance imaging (MRI) are also crucial diagnostic imaging services that can help to rule out other causes of a patient's clinical presentation.¹⁹ However, there are several scans undertaken that are ineligible for Medicare Benefits Schedule (MBS) rebates.¹⁸ As new therapies become available, and the interest in case investigation increases, there will be an increased demand for these imaging services.

Regardless of the diagnostic assessment performed, the diagnosis of MCI due to AD requires consideration of the patient's history and other cognitive assessments, with guidance provided by a multidisciplinary team and specialists using their clinical judgement to observe a pattern of decline.⁶

Margie Melano
Think Tank Chair,
System Integration

“The issue we face is there is limited understanding of diagnostic pathways and limited understanding of and lack of access to fit-for-purpose tools. Using the wrong tool means even when people present with concerns, they can be inaccurately assessed as completely fine.”

RECOMMENDATIONS:

2.1 Establish standardised referral, diagnostic and support pathways.

There is a need for clearer referral, diagnostic and support pathways.

These pathways should highlight the role primary care can play to undertake cognitive testing and support diagnoses, including actively supporting people through the diagnostic journey.

Seek input from people living with AD/dementia, their carers and families on their experience with diagnosis to identify opportunities for improvement.

2.2 Develop guidelines for the conduct and analysis of different diagnostic assessments, including appropriate assessments for primary care and when to refer to specialist care

There is a need for standardised guidelines to guide referral and conduct of different diagnostic assessments, including the analysis of biomarkers via PET scans and CSF analysis and the use of MRI and CT scans for differential diagnosis. These guidelines may support a change in MBS rebates available for referral to such imaging.

There is also a need for guidance on suitable diagnostic testing for different patient populations, including Indigenous Australians and other people from culturally and linguistically diverse backgrounds.

CHALLENGE: LIMITED SPECIALIST AVAILABILITY

Memory clinics and geriatric clinics currently serve as the primary channel for the diagnosis of AD. However, waitlists can be more than six months.⁶ In addition, geriatric clinics will only manage patients over the age of 65 years.^{6,20}

Accessing assessment and care via the private sector can be cost-prohibitive, especially among a cohort of patients who may have had to reduce or leave employment due to their symptoms.

While specialists' capacity to manage AD is currently not considered an issue based on current incidence rates, if case finding were to increase with the introduction of DMTs, there would be a significant strain on capacity and resources, further increasing delays in access to specialist care.

Relying solely on specialist services, such as Geriatricians and Neurologists, for an AD diagnosis is not sustainable. However, despite some specialists indicating that primary practice is the preferred setting for cognitive review and initial diagnostic testing, GPs are currently unable to refer for biomarker testing or additional neurological investigations.

Professor Amy Brodtmann
Neurologist, and Think Tank Chair,
Diagnosis, and diagnostic mechanisms

“The more healthcare professionals who can conduct cognitive screens, and then escalate any impairments to appropriate channels, the better.”

RECOMMENDATION:

2.3 Establish a process for initial diagnostic assessments in primary care.

Primary care professionals are well-positioned to play a strong role in starting conversations around MCI and AD.

Ideally, primary care professionals should be able to case identify, conduct a thorough medical history, conduct appropriate cognitive screening assessments and order non-specialist screening tests, such as blood biomarker tests (once available).

Diagnostic pathways/frameworks would clarify how symptomatic patients could be more thoroughly assessed before being referred to specialists for more advanced imaging tests.

This could also enhance access to diagnostic pathways in regional and rural areas.

To support this, there will be a need to make case finding and diagnostic assessments available and reimbursable via primary care.

See Section 5 for more detailed recommendations on the role of primary care.

CHALLENGE: THE IMPACT OF A DIAGNOSIS

Receiving a diagnosis can have a major impact on an individual's mental health, and that of their family, often causing them to withdraw from care.^{27,28}

They feel a sense of grief and hopelessness at a perceived lack of restorative options including the availability of any treatment to delay the onset of disease. There can also be a sense of shame and social isolation associated with a diagnosis.²⁸

There is a need to understand more about the acceptance and processing of a diagnosis to provide support and services to people affected.²⁵

RECOMMENDATIONS:

2.7 Support the development of dementia-friendly communities.

Support the current drive towards the creation of dementia-friendly communities in which people and organisations, such as banks, retail and government services, are trained how to communicate with people with a cognitive impairment.

Please note, this is a current focus area for *Dementia Australia*, as outlined in *A Roadmap for Quality Dementia Care*, published in early 2021.²⁹

2.8 Conduct a research project on the impact of an MCI/AD diagnosis.

Undertake a research project to better understand the impact of receiving a diagnosis of MCI due to AD and clarify the most effective support services required during this time.

CHALLENGE: INEQUITY OF ACCESS TO DIAGNOSTICS

Access to specialist services and diagnostic mechanisms can be impacted by a variety of geographic, cultural and socioeconomic factors.

Regional and rural access – people in regional and rural areas have limited access to services and specialists.²¹ While telehealth has been an effective tool to help deliver care in regional and rural areas, it is not considered an efficient replacement of in-person assessment during the diagnostic phase of care.

Cultural stigmas – a hesitancy to acknowledge or address issues of cognitive decline, and misconceptions about mental health issues in general among family members, can prevent individuals from seeking assessment and diagnosis.^{8,22}

Low health literacy – people with low levels of health literacy may not know where to start to seek help for issues of cognitive decline.²³ This can be particularly pertinent for people from Aboriginal and Torres Strait Islander communities, or people from culturally and linguistically diverse backgrounds.⁸

Poor understanding of cognitive issues – a misconception that cognitive decline is simply a normal part of ageing can mean people delay seeking assessment and diagnosis.^{13,14,24}

Costs to access services – costs to access diagnosis in the private setting can be prohibitive.²¹ Alternatively, while diagnosis and care in the public setting are covered by Medicare, the costs to travel to these services (particularly from regional and remote areas) may prevent people from seeking assessment and diagnosis.²¹

Autonomy/individual capacity – while the individual's capacity/executive functioning may be diminished or diminishing, there is a sustained effort required from the individual's family/carer to support the process towards a diagnosis.²⁵ Families are often blocked from contributing to the discussion. Additionally, an individual may undergo a Mini Mental State Exam (MMSE) with their doctor and be assured that everything is ok, when it is evident to the family that things are not ok.²⁶

RECOMMENDATIONS:

2.4 Map existing infrastructure, support and training services to identify gaps.

Compile a central list of existing infrastructure, support and training services. List to include the support they provide at each point in the patient journey, where they can be extended, what gaps remain and what resources/timeframes are required to address these gaps (e.g., DA, ADNET, DTA, CDAMS, Wicking Dementia, all Colleges and current CDPC guidelines).

2.5 Support multicultural health professionals who can champion discussions of MCI and AD in their communities.

There is a need to explore ways to reduce cultural stigmas associated with MCI and AD.

Care coordinators, culturally appropriate support services and resources may help people navigate the diagnostic journey.

2.6 Establish/improve mechanisms for the collection of disease-specific data.

The anticipated increase in patients accessing treatment may represent an opportunity to build on the available mechanisms for the collection of disease-specific data, including:

- Continuing the work of the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) to build a national picture of the current diagnoses of MCI/early-stage AD
- Growing a Clinical Quality Register (such as the existing ADNeT) that provides an account of MCI/early-stage AD at a more granular level to provide data on the benefits of early intervention.

This may involve the scaling up of current efforts to build a Dementia Clinical Quality Register such that it can provide a detailed and harmonised source for the national dementia data effort.

WHAT RESOURCES ALREADY EXIST TO SUPPORT THESE DIAGNOSIS AND DIAGNOSTIC MECHANISM RECOMMENDATIONS?



Local-level diagnostic pathways

Some Primary Health Networks (PHNs) have already devised diagnostics pathways. There may be an opportunity to work with PHNs to up-scale these pathways.



Integrated services

The Cognitive, Dementia and Memory Service (CDAMS) is in place in Victoria.

CASE STUDY

NEUROLOGISTS LIKE MATTHEW, SUPPORT A POTENTIAL ROLE FOR PRIMARY CARE PRACTITIONERS IN THE DIAGNOSIS OF MCI



Matthew sees his patients with suspected MCI due to AD at regular Memory Clinics. He has a five-month waitlist for new patients, which he anticipates will extend with the potential introduction of DMTs in Australia.

When a patient is first referred for assessment from primary care, Matthew needs to order a series of assessments to build a clinical picture and confirm the indicators of MCI. In an ideal world, a patient would present to Matthew's memory clinic already having undergone some of these assessments – saving time and resources and allowing Matthew to gain a more in-depth insight into the patient's condition at an earlier timepoint.

If primary care professionals were supported through training, access and reimbursement to initiate these initial diagnostic tests, only patients with positive indicators for MCI would be referred to the memory clinic. This would result in Matthew being able to make a more timely diagnosis and determine the best course of action for his patient.

Dr Geoff Schembri
President, Australasian
Association of Nuclear
Medicine Specialists

“Resourcing remains a key component to the streamlining of diagnostic pathways. Specialty units are effective but are often overwhelmed. Effective screening before patients attend these speciality units should be explored and GPs would play a key role here.”

3 TREATMENT ACCESS AND DELIVERY

The infrastructure and skill required to deliver an infusion DMT exists within the Australian healthcare system. However, challenges remain around ensuring access to infusion services and capacity to deliver infusions to a broader patient population.

CHALLENGE: NAVIGATING TREATMENT AND THERAPY OPTIONS FOLLOWING A DIAGNOSIS

Families of those diagnosed with MCI or dementia due to AD experience significant confusion with navigating treatment and therapy options following a diagnosis.

Currently, there is no mechanism in place for case management or care coordination. Case managers, care coordinators or navigators can play a vital role in linking primary and secondary care settings, as well as ensuring patients' access to allied health and psychosocial supportive mechanisms in addition to pharmacotherapy.

RECOMMENDATION:

3.1 Explore the potential for case managers or care coordinators to support the recently diagnosed to access treatment and support services.

Dedicated care coordinators could provide family members and those recently diagnosed with accurate and reliable on-hand support to navigate the system during key milestones of living with AD including diagnosis, treatment and palliative care.

Please note, this is something that many groups have advocated for, including Centre for Healthy Brain Ageing (CHeBA) and Dementia Australia. A trial of care navigators was also conducted in the Hunter region of NSW.

Maree McCabe
CEO, Dementia Australia,
and Think Tank Chair,
Discrimination of
early-stage AD

“Exploring the establishment of dedicated “linking” professionals would provide family members and those recently diagnosed with accurate and reliable on-hand support to navigate the system during key milestones of living with Alzheimer’s disease and other forms of dementia, including diagnosis, treatment and end of life care.”

CHALLENGE: MANAGING INTEREST IN A NEW TREATMENT OPTION

The potential launch of a new treatment option for MCI/AD will generate significant attention from the public. This will drive patients (predominately ineligible) to their primary care providers who will need to be supported with reliable information, to ensure the expectations of their patients are effectively managed.

RECOMMENDATION:

3.3 Develop information resources for primary care providers about DMTs.

If a DMT becomes available in Australia, there will be a need to prepare primary care professionals with information and education about the treatment including how to talk with their patients about this new option.

CHALLENGE: RESTRICTED ACCESS TO TREATMENT IN REGIONAL AND RURAL AREAS

Ensuring access to infusion therapy will be important for the success of any future DMTs. People living in regional and remote areas may face barriers to access treatment if infusions need to be administered in the specialist setting.²¹

The level of monitoring and assessment that will be required for patients receiving a DMT via infusion requires clarification. Depending on the level of monitoring required, it may be possible to administer the infusions in the primary care setting under the supervision of a GP or practice nurse.

RECOMMENDATION:

3.2 Explore potential to upskill practice nurses and pathology centres to administer DMTs.

Depending on the level of monitoring and assessment required for the administration of DMTs, there is potential to upskill practice nurses in primary care and pathology centres to administer treatment. This will help to improve access in regional and rural areas.

Professor Henry Brodaty
Clinician, Researcher and
Policy Advisor, Centre for
Healthy Brain Ageing (CHeBA)

“People with dementia, their carers and family should be empowered to be involved in the design and delivery of post-diagnostic care.”

CASE STUDY

PATIENTS LIKE EDDIE, WANT TO BE ABLE TO ACCESS TREATMENT WITHIN THEIR LOCAL COMMUNITIES

Eddie is a national park ranger and proud Yawuru man from Broome in WA. He was recently diagnosed with MCI and is interested in the potential benefit that DMTs will have for his future health outcomes.

Eddie plays an important leadership role in his local community and is reluctant to travel to receive medical care.

It is his hope that if a DMT were to become available to him, that he would be able to receive it in the comfort of his local community, within a culturally sensitive healthcare setting.



4 EDUCATION AND RAISING AWARENESS

Stigma and misconceptions associated with MCI/AD can cause reluctance to present for cognitive review.^{22,24} Additionally, many people, including health professionals, perceive memory loss as a normal part of ageing.²⁴

There is a need to raise awareness among the general public about the signs and symptoms of MCI to help facilitate early intervention. There is also a need to educate and support primary care professionals and specialists to ensure patients are receiving optimal care when needed.

CHALLENGE: A LACK OF AWARENESS OR UNDERSTANDING ABOUT MCI AMONG THE GENERAL PUBLIC

The lack of awareness and understanding about MCI/AD can hinder early identification and intervention.²⁴ Many people, including some health professionals, may perceive memory loss as a normal part of ageing. As such, people may not present for, or be offered, assessment and diagnosis until their condition has deteriorated further.

RECOMMENDATIONS:

4.1 Develop an education and awareness raising campaign for the general public on MCI, AD and the importance of early identification, to reduce stigma and facilitate early presentation for cognitive review.

There is an opportunity to develop an education and awareness raising campaign for the public that encompasses:

- awareness that memory loss is not a normal part of ageing
- risk factors for MCI/AD and how to modify risk
- availability of potential interventions to slow disease progression
- spectrum of neuropathology associated with dementia including AD and the importance of early intervention to slow disease progression.

Work with those with lived experience, including individuals with dementia, carers and families to provide insights to develop and drive this activity.

4.2 Develop culturally appropriate education and awareness raising resources to address stigma among Indigenous Australians.

Engage with dedicated Aboriginal and Torres Strait Islander organisations and communities to determine their communication and education needs.

4.3 Develop culturally appropriate education and awareness raising resources to address stigma among culturally and linguistically diverse populations.

Work with local cultural organisations and communities to determine their communication and education needs.

Provide information and resources in a variety of languages and formats to enable easier access to information.

CHALLENGE: A LACK OF ACCESS TO, AND UPTAKE OF, MEDICAL EDUCATION IN COGNITIVE HEALTH

Currently, there is minimal specialised training on cognition in undergraduate medical curricula in medical schools and in post-graduate medical education. This has resulted in healthcare professionals relying on in-practice training and “on the job” experience to build their skills in cognition.

There is no ‘dementia healthcare speciality’, however opportunities may exist for the development of dementia specialist training (e.g., one example is The University of Tasmania’s Understanding Dementia Massive Open Online Course (MOOC) Training).

“We need to ask primary care what support and education they need.”

Professor Colin Masters
Neuropathologist and Dementia Researcher, The Florey Institute of Neuroscience and Mental Health

RECOMMENDATIONS:

4.4 Conduct an audit of existing medical education programs on cognition to identify availability and gaps.

An audit of existing cognitive medical education programs that are available online could maximise the use of existing resources, including Dementia Training Australia’s validated workshops and those embedded in gerontology specialty advanced training programs.

4.5 Develop medical education for primary care professionals on MCI, AD and the importance of early identification, to reduce stigma and facilitate early presentation for cognitive review.

There is an opportunity to develop education for primary care professionals that encompasses:

- awareness that memory loss is not a normal part of ageing
- the importance of early diagnosis
- training to identify and assess patients with potential MCI/AD who may benefit from specialist care
- talking about cognition with their patients and their families/carers
- delivering the news of a dementia diagnosis to patients and their families/carers.

Any educational activities should target both GPs and practice nurses to encourage a whole-of-practice approach to MCI and AD diagnosis and care.

PHNs represent a potential avenue for the delivery of education and care coordination to primary care and for expanding cognitive support in lower socioeconomic populations.

4.6 Explore opportunities for peer-to-peer education spanning primary and secondary healthcare settings.

Health services could provide the opportunity for primary care professionals to undertake specialised training to become recognised as a specialist provider of cognitive care services. These primary care practices could then be linked with specialist practices or memory clinics for mentorship and guidance.

Please note, the Australian Dementia Network (ADNet) has a focus on education and training for health professionals across Australia as part of its Memory Clinic Initiative.

Expand access for GPs to Community of Practice run by Dementia Australia, which currently engages those working in residential and community aged care who have a desire to transform dementia care and improve practice.

Please note, the program is currently being evaluated by Swinburne University to determine if the model can lead to better practice in dementia care.

4.7 Incentivise primary care professionals who undertake further cognition education.

Explore opportunities for tailored reimbursement for primary care practitioners with speciality interest training in cognition. For example, remuneration based on level of advanced training or speciality achieved.

Use CPD accredited activities as an incentive for completing cognition education.

4.8 Promote the importance of including cognitive education in medical school and specialist training programs.

There is an opportunity to promote the inclusion of additional specialised cognitive education in medical school and specialist training programs, especially for specialists who will work in areas of known risk factors for dementia such as cardiology, obesity and diabetes.

CASE STUDY

MEMBERS OF THE PUBLIC LIKE ABDUL, NEED TO BE EMPOWERED WITH INFORMATION

Abdul is a plumber from metropolitan Sydney. He is very close with his father and has recently noticed some changes in his father's cognition. Abdul is unsure if these changes are a normal part of ageing or if this is something he should be worried about.

He does not know where to turn to for reliable information and does not know how to raise the topic of conversation with his father or other family members.

Abdul's situation would be helped by a public health campaign raising awareness about cognition. Abdul's father, who speaks and reads most confidently in Arabic, would benefit from translated information and support resources.



5 THE ROLE OF PRIMARY CARE

Primary care is well-positioned to play an important role in the case finding of MCI/AD. Primary care professionals can monitor patients over time, allowing them to identify a pattern of cognitive decline.

Primary care services are also typically easier to access than speciality care. Once challenges, including access, Medicare reimbursement and training, are addressed, primary care can play a more integral role in case finding, diagnosis and ongoing care of people with MCI/AD.

CHALLENGE: ACCESSING APPROPRIATE PRIMARY CARE SERVICES OVER THE LONG-TERM

In some regions, people do not have ready access to primary care services and/or do not have the longer-term relationship with a GP clinic that is required to determine MCI over time. This includes not only regional and rural areas, but also socioeconomically disadvantaged communities in metropolitan areas.²¹

The Aged Care Royal Commission has recommended setting up specific GP practices that will manage aged care. This may help to ensure patients at risk of MCI and dementia can build a longer-term relationship with a specialised clinic. The establishment of new clinics may also help improve access to primary care services in general.

RECOMMENDATION:

5.1 Explore the potential for specific aged-care primary practices.

Conduct a needs analysis to identify the gaps in primary care services and the potential value of specific aged-care primary practices.

CHALLENGE: LACK OF STRUCTURED REIMBURSEMENT FOR COGNITIVE ASSESSMENT IN PRIMARY CARE

In addition to geographic barriers to care, time, resources and reimbursement limitations may make GPs reluctant to take on the additional responsibilities of cognitive assessment.

Currently, there is no structured reimbursement via Medicare for patients aged between 50 and 75 years, which means primary care professionals may be reluctant to provide cognitive review and assessment. In addition, Medicare rebates for the involvement of practice nurses are insufficient.

RECOMMENDATION:

5.2 Determine the financial support required to better support primary care professionals to play a role in cognitive assessments and dementia care.

Consider updates to Medicare rebates for cognitive assessments and dementia, based on the approach to chronic disease management plans.

Explore practice incentive payments (e.g., targets for the percentage of patients over 65 years of age who have completed a health brain plan or a cognitive assessment).

Explore other innovative payment mechanisms to support primary care involvement in the diagnosis of MCI/AD:

- This may include looking at other national or international models of funding, such as the 'enrolment for care' model employed by the Coordinated Veterans' Care (CVC) program.

CHALLENGE:
LACK OF SPECIALISED COGNITIVE ASSESSMENT SKILLS IN PRIMARY CARE

A lack of specialised cognition training may mean primary care professionals do not have the skill or the confidence to discuss concerns about cognition with their patients.

Cognitive assessments are difficult to initiate, especially when a patient believes they are not cognitively impaired or insist the initial symptoms are a result of other areas of stress in their life.

It is critical for primary care practitioners to work alongside the family and other allied health and social care services to identify if and when a cognitive assessment should be conducted.

Further, clarity on which assessments to use and when, depending on the severity of impairment and the areas of the brain that are affected, is essential. Once a cognitive assessment is conducted, a diagnostic pathway/referral framework will help support GPs with the best next steps for their patients.

RECOMMENDATION:

5.3 Establish standardised referral, diagnostic and support pathways.

Refine referral, diagnostic and support pathways, specific to patient location, and ensure this information is made easily available to primary care professionals via a national resource or repository of information.

See Section 2 for a more detailed overview of diagnostic process recommendations.

There is a need to develop guidelines to support cognitive assessment in primary care.

See Section 2 for more detailed recommendations on establishing diagnostic mechanisms for primary care.

There is an opportunity to develop education for primary care providers about MCI, AD and the importance of early identification.

See Section 4 for more detailed recommendations on education and awareness raising initiatives.

Dr Marita Long
General Practitioner,
with dementia speciality

“Primary care must be central to the process of diagnosis of Alzheimer’s disease. This includes looking at younger Australians, for example in their late 40’s, and raising the concept of brain health and exploring assessment of cognition at that point.”

CHALLENGE:
MANAGING COMPLEX CARE NEEDS IN PRIMARY CARE

Patients with MCI or early-stage AD have complex and extensive care needs. Patients, especially those with comorbidities such as diabetes, cardiovascular disease or depression, can require more than just care from a GP. There is a need to form holistic support networks with allied health and social care services to ensure patients receive optimal care once they are diagnosed.

RECOMMENDATION:

There is an opportunity to establish multidisciplinary teams (MDTs) to help coordinate and optimise care.

See Section 6 for more detailed recommendations about MDTs and integrated care.

WHAT RESOURCES ALREADY EXIST TO SUPPORT THE ROLE OF PRIMARY CARE RECOMMENDATIONS?



A GP Specialist interest group with RACGP is also being established.

GP’s can register with Australian New Zealand Society for Geriatric Medicine (ANZSGM).

C A S E S T U D Y

GENERAL PRACTITIONER NERIDA, NEEDS SUPPORT TO PLAY A CENTRAL ROLE IN THE ASSESSMENT OF MCI

Nerida is a busy GP in a metropolitan practice in Brisbane. In any one day she will manage a wide range of health complaints, from childhood illnesses to chronic disease management and women’s health screenings.

While Nerida acknowledges that primary care professionals have an important role to play in the assessment of their patients’ cognitive health, she is concerned about her lack of education and training in the area.

She is also keen to hear more about the reimbursement mechanisms that will support her to take on these additional responsibilities.



6 SYSTEM INTEGRATION AND WHOLE OF CARE

The current model of care for people with AD is sub-optimal. There are several challenges to people accessing and receiving care, as well as issues of capacity and best practice for those working within the system.

CHALLENGE: THE LACK OF A NATIONAL CARE FRAMEWORK OR GUIDELINES

There is no current national care framework or guidelines for the management of MCI/AD. This means that pathways for case finding, diagnosis and treatment are inconsistent and confusing, and there is no standardisation of assessment or diagnostic mechanisms. *Note: A framework is currently in development via Centre of Health Brain and Ageing (CHeBA).*

The roll out of any new treatment options will require a coordinated, national approach. All levels of government need to act together to ensure there is a national strategy and framework to manage MCI and dementia due to AD. This includes coordination between primary care and secondary/hospital settings.

RECOMMENDATION:

6.1 Support the development of a national framework for the management of MCI/AD in Australia.

Support the work that is already underway to develop and adopt a National Service Framework/Guidelines to set a standard of care that all professionals need to attain in the management of patients with MCI/AD.

CHALLENGE: RESTRICTIONS ON MEDICARE REIMBURSEMENT

If primary care professionals are to play a greater role in cognitive assessments and referral for diagnostic testing, there is a need to explore changes to the current models of reimbursement.

There is also a need to address current challenges in the funding of testing and diagnosis – both at the specialist level and regarding referral to imaging services, such as MRI and CT, that are used to rule out the presence of other conditions that could account for a patient's clinical presentation e.g., vascular dementia.

RECOMMENDATION:

6.4 Undertake a review of Medicare rebates for cognitive assessment.

Updates to Medicare rebates will be required to support primary care to play a central role in cognitive assessments and dementia care.

Updates to Medicare rebates may also be required for referrals to MRI and CT scans to rule out other causes of a patient's clinical presentation prior to further investigations.

See Section 5 for more detailed recommendations regarding financial supports in primary care.

CHALLENGE: THE LACK OF MECHANISMS FOR COORDINATED OR INTEGRATED CARE

People diagnosed with MCI or dementia due to AD have complex care needs. Currently, there is a disconnect between primary and secondary care settings, meaning these complex care needs may be sub-optimally addressed.

A holistic model of care that addresses the physical, psychological and social needs of a person, involving allied health and social supportive services needs to be more widely adopted in the management of MCI/AD. Mechanisms including multidisciplinary teams, case managers or care coordinators have the potential to support a more integrated model of care.

Case managers or care coordinators could play a vital role in linking primary and secondary care, as well as ensuring patients' access to allied health and psychosocial supportive mechanisms.

RECOMMENDATIONS:

6.2 Develop mechanisms that link primary and secondary care settings for diagnosis and ongoing management.

Investigate and optimise the linkages between primary and secondary care settings to enable GPs and practice nurses to interact and learn from specialists.

Consideration may be given to the concept of a 'hub-and-spoke' model of care, where GPs who have undertaken specialised training can establish primary care memory clinics with oversight from local secondary care.

- The 'hub-and-spoke' model may also work in supporting rural primary care to assess and diagnose MCI. Rural practices can be linked with metro practices or specialist centres.

Integrated care services with a single access point for patients may help to ensure people of any age experiencing symptoms of dementia or living with dementia (and their carers, and families) have timely access to diagnosis and a direct, clear pathway to early and ongoing support services.

Please note, this is a current focus area for Dementia Australia, as outlined in A Roadmap for Quality Dementia Care, published in early 2021.²⁹

6.3 Establish MDTs to help coordinate and optimise care.

There is opportunity to use multidisciplinary models of care to establish treatment teams to provide coordinated care to patients with MCI/AD and complex care needs.

Primary care-based MDTs comprising GPs and allied health/social care professionals can provide coordinated care to patients diagnosed with MCI/AD and address their complex care needs including ensuring specialist involvement and patient follow up.

Professor Dimity Pond
General Practitioner with dementia speciality

"Our current model may need to be tweaked because of a shortage of GPs during and post the COVID-19 pandemic. This could include the GP and other professionals in an MDT type setting, meeting together via Zoom or telehealth."

CHALLENGE: BUILDING WORKFORCE CAPABILITIES

There is a need to address deficits in workforce capabilities in the short-term and to implement initiatives to support the sustainable transformation of dementia care in the longer term.

RECOMMENDATIONS:

6.5 Support efforts to address workforce capability issues, such as upskilling workers and expanding the capacity of services.

Upskill healthcare professionals at the frontline of care to identify the initial signs and symptoms of dementia, including GPs, practice nurses, pharmacists, and allied health professionals.

Expand the capacity of imaging services to support diagnostics.

Expand the specialist workforce and incentivise junior medical trainees to pursue a career in geriatrics or neurology.

Explore the key personnel needed to address the specific needs of the community, including Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse populations.

Upskill aged care workers and adequately resource facilities providing dementia care, to reduce the use of antipsychotics and incorporate non-pharmacological approaches to care.

Attract new trainees to memory clinics which would include additional government funding/support.

Please note, this is a current focus area for Dementia Australia, as outlined in A Roadmap for Quality Dementia Care, published in early 2021.²⁹

C A S E S T U D Y

FAMILIES AND CARERS LIKE THE WALSH FAMILY, NEED THE CONFIDENCE OF A HOLISTIC MODEL OF CARE FOR THEIR LOVED ONE

Tina Walsh's mother, Betty, has been diagnosed with AD and is currently residing in an aged care facility after her daily care needs became too great for the Walsh Family to manage at home.

Betty and her family benefit greatly from the supportive care provided by social workers and occupational therapists, enabling Betty to maintain a level of independence within the care facility.

Betty's family need the confidence of knowing that her psychological and social wellbeing will be considered equally as important as her physical health and any treatment that she receives.



SUMMARY

OF RECOMMENDATIONS

FOCUS AREA	RECOMMENDATIONS
1. Case finding and early investigations	<ul style="list-style-type: none"> 1.1 Normalise the concept of 'brain health checks' and discussing cognitive health in the primary care setting. 1.2 Undertake a research project to determine the clinical picture of MCI in the primary care setting. 1.3 Support the role of practice nurses in the discussion and assessment of MCI. 1.4 Investigate the potential of online cognitive assessment tools.
2. Diagnosis and diagnostic mechanisms	<ul style="list-style-type: none"> 2.1 Establish standardised referral, diagnostic and support pathways. 2.2 Develop guidelines for the conduct and analysis of different diagnostic assessments, including appropriate assessments for primary care and when to refer to specialist care. 2.3 Establish a process for initial diagnostic assessments in primary care. 2.4 Map existing infrastructure, support and training services to identify gaps. 2.5 Support multicultural health professionals to champion discussions of MCI and AD in their communities. 2.6 Establish/improve mechanisms for the collection of disease-specific data. 2.7 Support the development of dementia-friendly communities. 2.8 Conduct a research project on the impact of an MCI/AD diagnosis.
3. Treatment access and delivery	<ul style="list-style-type: none"> 3.1 Explore the potential for case managers or care coordinators to support the recently diagnosed to access treatment and support services. 3.2 Upskill practice nurses and pathology centres to administer DMTs. 3.3 Develop information resources for primary care providers to support them if and when DMTs become available in Australia.
4. Education and awareness raising	<ul style="list-style-type: none"> 4.1 Develop an education and awareness raising campaign for the general public on MCI, AD and the importance of early identification, to reduce stigma and facilitate early presentation for cognitive review. 4.2 Develop culturally appropriate education and awareness raising resources to address stigma among Indigenous Australians. 4.3 Develop culturally appropriate education and awareness raising resources to address stigma among culturally and linguistically diverse populations.

FOCUS AREA	RECOMMENDATIONS
4. Education and awareness raising (con't)	<ul style="list-style-type: none"> 4.4 Conduct an audit of existing medical education programs on cognition to identify availability and gaps. 4.5 Develop medical education for primary care professionals on MCI, AD and the importance of early identification, to reduce stigma and facilitate early presentation for cognitive review. 4.6 Explore opportunities for peer-to-peer education spanning primary and secondary healthcare settings. 4.7 Incentivise primary care professionals who undertake further cognition education. 4.8 Promote the importance of including cognitive education in medical school and specialist training programs.
5. The role of primary care	<ul style="list-style-type: none"> 5.1 Explore the potential for specific aged-care primary care practices. 5.2 Determine the financial supports required to better support primary care practitioners to play a role in cognitive assessments and dementia care. 5.3 Establish standardised referral, diagnostic and support pathways.
6. System integration and whole of care	<ul style="list-style-type: none"> 6.1 Support the development of a national framework for the management of MCI/AD in Australia. 6.2 Develop mechanisms that link primary and secondary care settings for diagnosis and ongoing management. 6.3 Establish multidisciplinary teams (MDTs) to help coordinate and optimise care. 6.4 Undertake a review of Medicare rebates for cognitive assessment. 6.5 Support efforts to address workforce capability issues, such as upskilling workers and expanding the capacity of services.

CONCLUSION

The potential introduction of DMTs in the management of MCI/AD poses a significant challenge to primary care professionals, specialists and the health system.

However, the recommendations of this White Paper provide potential ways forward that need to be fully considered if these challenges are to be addressed across the whole of the clinical pathway.

This comprehensive record of challenges and opportunities, informed by experts in the field, represents the first step towards improving the quality and coordination of patient care for all Australians and their families facing a diagnosis of AD.

REFERENCES

1. Dementia Australia (2020) Alzheimer's disease. Available at <https://www.dementia.org.au/about-dementia/types-of-dementia/alzheimers-disease>. Accessed November 2021.
2. Australian Bureau of Statistics (2021). Causes of Death, Australia, 2020. Available at <https://www.abs.gov.au/statistics/health/causes-death/causes-death-australia/latest-release>. Accessed November 2021.
3. World Health Organization (WHO) (2021). Dementia. <https://www.who.int/news-room/fact-sheets/detail/dementia>. Accessed November 2021.
4. Dementia Australia. Mild Cognitive Impairment. Available at: <https://www.dementia.org.au/about-dementia-and-memory-loss/about-dementia/memory-loss/mild-cognitive-impairment>. Accessed November 2021.
5. Department of Health (2021). Draft National Preventive Health Strategy 2021–2030. Available at: https://consultations.health.gov.au/national-preventive-health-taskforce/draft-national-preventive-health-strategy/supporting_documents/Draft%20NPHS%20March%202021.pdf. Accessed November 2021.
6. Baxi SM et al. (2019). Assessing the Preparedness of the Australian Health Care System Infrastructure for an Alzheimer's Disease-Modifying Therapy. RAND Australia. Available at: https://www.rand.org/pubs/research_reports/RR2891.html. Accessed November 2021.
7. Biogen data on file.
8. Australian Institute of Health and Welfare 2021. Dementia in Australia 2021: Summary report. Cat. no. DEM 3. Canberra: AIHW. Available at: <https://www.aihw.gov.au/getmedia/13eeb292-dc65-445c-9ba0-874ef2f54996/aihw-dem-3.pdf.aspx> Accessed November 2021.
9. Royal Commission into Aged Care Quality and Safety (2021). Final Report: Care, Dignity and Respect. Available at: https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf. Accessed November 2021.
10. Mate KE et al (2017). An evaluation of the additional benefit of population screening for dementia beyond a passive case-finding approach. *Int J Geriatr Psychiatry* 32(3):316–23.
11. Phillipson L et al (2012). Exploring dementia and stigma beliefs: A pilot study of Australian adults aged 40 to 65 years. *Alzheimer's Australia*. Available at: https://www.dementia.org.au/sites/default/files/Stigma_Report.pdf. Accessed November 2021.
12. Evans H. Dementia 'more feared than cancer' by older patients. Article in: *Nursing Times*. Published 4 August 2014. Available at: <https://www.nursingtimes.net/roles/older-people-nurses-roles/dementia-more-feared-than-cancer-by-older-patients-04-08-2014/>. Accessed November 2021.
13. Dementia Australia. Memory loss. Available at: <https://www.dementia.org.au/about-dementia/memory-loss> Accessed November 2021.
14. Dementia Australia. Memory changes. Available at: <https://www.dementia.org.au/about-dementia/memory-loss/memory-changes> Accessed November 2021.
15. Anoop A et al (2010). CSF Biomarkers in Alzheimer's Disease Diagnosis. 2010; 2010:606802.
16. Lee JC et al (2019). Diagnosis of Alzheimer's disease utilizing amyloid and tau as fluid biomarkers. *Exp Mol Med*. 51(5):1-10. doi: 10.1038/s12276-019-0250-2.
17. Mehta L and Thomas S. (2012). The role of PET in dementia diagnosis and treatment. Available at: <https://appliedradiology.com/articles/the-role-of-pet-in-dementia-diagnosis-and-treatment>. Accessed November 2021.
18. Australian Government Department of Health. MBS Online. Available at: <http://www.mbsonline.gov.au> Accessed November 2021.
19. Johnson KA et al (2012). Brain Imaging in Alzheimer Disease. *Cold Spring Harb Perspect Med* 2(4): a006213.
20. Health Direct. What does a geriatrician do? Available at: <https://www.healthdirect.gov.au/what-does-a-geriatrician-do>. Accessed November 2021.
21. Dementia Australia (2020). Health and hospital services for people living with dementia in rural, regional and remote NSW – a submission to the Upper House Inquiry into health outcome and access to health and hospital services in rural, regional and remote New South Wales. December 2020. Available at: <https://www.parliament.nsw.gov.au/lcdocs/submissions/69856/0279%20Dementia%20Australia.pdf> Accessed November 2021.
22. Dementia UK. After a diagnosis of dementia, understanding and challenging stigma and discrimination. Available at: <https://www.dementiauk.org/wp-content/uploads/2020/08/Understanding-and-challenging-stigma-and-discrimination-1.pdf> Accessed November 2021.
23. Oliveira D et al (2019). Is poor health literacy a risk factor for dementia in older adults. *Systemic literature review of prospective cohort studies*. *Maturitas*; 124:8–14.
24. Bradford A et al (2009). Missed and Delayed Diagnosis of Dementia in Primary Care: Prevalence and Contributing Factors. *Alzheimer Dis Assoc Disord*. 23(4):306–14.
25. Khanassov V et al (2021). Needs of patients with dementia and their caregivers in primary care: lessons learned from the Alzheimer plan of Quebec. *BMC Fam Pract* 22:186. DOI:10.4061/2010/606802
26. Lacy M et al (2015). Standardized Mini-Mental State Examination Score and Verbal Memory Performance at a Memory Centre: Implications for Cognitive Screening. *Am J Alzheimers Dis Other Demen*. 2015; 30(2):145-52.
27. Alzheimer's Society. The psychological and emotional impact of dementia. Available at: <https://www.alzheimers.org.uk/get-support/help-dementia-care/understanding-supporting-person-dementia-psychological-emotional-impact>. Accessed November 2021.
28. Dementia UK. After a diagnosis of dementia Emotional impact of the diagnosis. Available at: <https://www.dementiauk.org/wp-content/uploads/2020/08/emotional-impact-of-the-diagnosis.pdf> Accessed November 2021.
29. Dementia Australia. A roadmap for quality dementia care – Parliamentary Friends of Dementia paper. Available at: <https://www.dementia.org.au/sites/default/files/2021-03/PFOD-Roadmap-paper-noPrev-March-2021.pdf> Accessed November 2021.

