
Timely Diagnosis of Dementia: Can we do better?

A report for Alzheimer's Australia
Paper 24

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Timely Diagnosis of Dementia: Can we do better?
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FOREWORD

As Federal President of the Australian Medical Association, it gives me great pleasure to provide a foreword to this important publication.

I am a family doctor in a busy practice. I understand only too well the difficult judgements and emotions that are involved in making a diagnosis of dementia.

This publication emphasises the difficulty of diagnosis given the insidious nature of the disease and the mixed emotions and denial that families and the individual may experience, and notes the professional practice of GPs to be very sure of the clinical symptoms before communicating that there may be an issue of dementia.

There is a strong case for ensuring timely diagnosis so that the individual and their families can plan their finances and make arrangements for powers of attorney as well as indicating their wishes in respect of their care.

Although the journey with dementia will be difficult, those who have a timely diagnosis that is well communicated will be better positioned to deal with what will inevitably be a traumatic time in their lives. The prolonged uncertainty that can surround the diagnosis of dementia creates a lot of uncertainty for the individual and, however traumatic a diagnosis can be, it can also be a relief because the individuals and the family know that something is wrong.

It is an important part of a GP's work to be familiar with the clinical symptoms of dementia and listen to the family carers who are likely to be the best positioned in providing information about the cognitive capacity of the individual.

We must look carefully at the barriers to timely diagnosis that are identified in this paper and assess strategies that have been described for addressing those barriers. It is crucial that any future primary care reforms have a greater focus on improving the care that patients get at the service level.

I congratulate the authors on putting together this valuable publication and hope it generates discussion of an important issue.



Dr Steve Hambleton
President
Australian Medical Association

EXECUTIVE SUMMARY

Timely diagnosis of dementia: Can we do better?

This publication was commissioned from the University of Newcastle by Alzheimer's Australia because of longstanding concerns of both people with dementia and their carers about the delays in the diagnosis of dementia and the subsequent management of the condition in primary care.

This publication shows that these concerns are supported by evidence based research. In Australia, symptoms of dementia were noticed by families an average of 1.9 years prior to the first health professional consultation and there was an average of 3.1 years before a firm diagnosis was made – a finding consistent with overseas studies. People from non-English speaking backgrounds were diagnosed later after the onset of dementia compared with the rest of the population. Delays in diagnosis result in lost opportunities for earlier medical and social interventions for those with dementia and their families.

In part, this situation can be accounted for by the complexity of the diagnosis of dementia. The differential diagnosis of dementia includes depression and anxiety, thyroid disease and many other medical conditions. There is also the problem of differentiating dementia from normal ageing. Dementia itself is insidious and likely to require specialist intervention and consultation with third parties, particularly family carers. Even after a diagnosis of dementia has been made, further differentiation is required as to the specific type of dementia that a patient may have.

With our growing and ageing population, dementia will become increasingly more common in primary care. However, at present dementia remains a condition that many GPs are not familiar or comfortable with.

Timely diagnosis has benefits. It can allow the person with dementia to make choices about their future while they are still able; to plan finances, powers of attorney and care in advance; to access medications that may relieve symptoms; and to receive support from community services which can enable them to continue living in their community for as long as they can.

However, it is not only the absence of a simple test and the complexity of dementia that creates delays in diagnosis. Other barriers to earlier diagnosis are clearly evidenced in the literature and these include the following:

- **Patients and carer factors** include lack of awareness that there are memory problems (this is particularly a problem for patients living alone with no carer), and difficulty distinguishing between normal age-related memory changes and dementia. There may be reluctance to seek help, fear of loss of independence or concerns about how dementia is perceived.
- **GP barriers** include lack of skills to recognise the possible presence of dementia in a patient. Dementia is a diagnosis that requires assessment over several consultations over several months. GPs may have difficulty differentiating normal ageing from dementia and may not be aware of the benefits of early diagnosis. There may be an attitude that since there is no therapy there is no point in making a diagnosis.

Many doctors may also fear damaging the doctor–patient relationship; many lack skills of how to communicate the diagnosis; others have a desire to protect the patient from the diagnosis. Some GPs may be reluctant to diagnose if they think there are no services or specialists in their area that can assist the individual. Time-limited consultations are also a factor. Many GPs do not feel equipped to discuss legal issues that arise with a diagnosis of dementia.

- **Systemic factors** can prevent effective management of dementia with multidisciplinary approaches and carer input. GPs may perceive lack of support and communication from specialists, service providers (e.g. Aged Care Assessment Team, community nurses) – often functioning independently. There may be difficulty gaining accurate reports from carers. Medicare does not fund separate consultations with carers. Although there are some screening tests available, they are not diagnostic of dementia and a case-finding approach is used for detection of dementia. There has been no health promotion activity in primary care to reduce the risk of dementia.

There is some evidence that strategies adopted overseas and in respect of other chronic diseases in Australia hold the promise of achieving timely diagnosis and better management of dementia. Possible strategies canvassed in this publication are as follows:

- **Patient/carer strategies include**
 - public awareness campaigns to increase awareness of dementia, including checklists for those concerned about their memory, and what the ‘normal’ ageing process is
 - initiatives to assist people in coming to terms with whether they may have dementia
 - initiatives to increase recognition of and the level of support for carers
 - increase public awareness of resources available through Alzheimer's Australia and other websites and printed materials
 - funding of home visits by nurses to assess the home situation.
- **Strategies to better support GPs at the service level include**
 - training and education through workshops including changing negative views of dementia, the benefits of early diagnosis of dementia, how to communicate the diagnosis to patients, and what lifestyle factors can help reduce the risk of and the progress of dementia
 - incentives to spend more time in the assessment process
 - incentives to spend time with carers to better understand the issues in relation to their patient.
- **System change** could be achieved through
 - making more effective use of practice nurses to assist with the screening process for those who have concerns about their memory through the use of Medicare incentives

- a greater emphasis on a team approach perhaps through the new Medicare Locals bringing better linkages between medical, nursing and social services
- including dementia in national health promotion activities and making the link between physical and brain health, particularly with respect to low blood pressure, lower cholesterol, no smoking, and good management of diabetes.

- **Reducing stigma surrounding dementia.** All the above actions in themselves may help contribute to a more positive approach in primary care to the diagnosis and management of dementia. However, it is likely to need, in addition, a well-directed public awareness campaign that assists in reducing the stigma of the disease and in particular the fatalism that attaches to the condition in terms of it being an inevitable part of old age.

BACKGROUND

The term dementia describes a collection of symptoms caused by disorders affecting the brain. The most common cause of dementia is Alzheimer's disease; however, there are a large number of other causes of dementia – some are reversible, but the majority are not. It is an insidious, complex and variable condition that affects thinking and cognition, behaviour, and the ability to perform everyday tasks. In early stages of dementia, these changes may not be obvious as the symptoms tend to develop slowly and may be wrongly attributed to 'normal' aging. However, as the disease progresses, the symptoms become more obvious as the decline in cognition and functional ability begins to interfere with the person's normal social or working life. Most forms of dementia are terminal, and there are, as yet, no treatments or interventions that can effectively prevent, or cure the disease.

Differentiating normal changes in memory and thinking associated with ageing and the pathological symptoms of early dementia is one of the major challenges faced by general practitioners (GPs). Together with the progressive nature of dementia, these factors make it extremely difficult to determine the date of onset of dementia, and to estimate incidence rates for the condition.^{1,2} That is, estimating incident cases of dementia is difficult because not all cases are visible as people with dementia because the onset usually occurs with mild symptoms¹ and attributing the changes to an illness process may not be recognised by the person with dementia or their general practitioner (GP). Thus, whilst it has been reported there are 1500 new cases of dementia diagnosed each week in Australia, a figure which is expected to grow to 7,400 by 2050³, there are estimates that about 50% of mild dementia cases in the community remain undiagnosed⁴.

Currently in Australia, over 268,000 people live with dementia and this figure is projected to rise to almost one million in 2050⁵ in accord with our growing and ageing population. The associated health and residential aged care expenditure for those affected with dementia is projected to increase 364% to \$17.8 billion by 2033⁶.

Although the risk of dementia increases with age, dementia is not a natural part of ageing. Younger onset dementia affects approximately 16,000 Australians and describes those diagnosed with dementia in their 30, 40 and 50's⁷. Dementia is not widely recognised as a chronic condition that can affect those other than older adults, or a condition for which evidence suggests addressing modifiable risk factors (e.g. keeping physically and mentally active; healthy diet, no smoking, alcohol in moderation; protecting your head from injury; participating in social activities; and managing blood pressure, cholesterol, blood sugar and weight) can also reduce the risk or delay the onset or progression of dementia⁸. Also, dementia can cause a lack of insight such that the person with dementia may not be aware they have a problem^{9,10}. Hence, people need to be familiar with this condition and factors that may influence it so they have the opportunity to optimise their health and minimise risk or delay progression of decline whilst they are able.

Some of the signs and symptoms that emerge with disease progression are:

- memory loss (e.g. forgetting names of objects, orientation to time and place – short-term memory is generally affected before long-term memory)
- communication difficulties (e.g. word finding)

- reasoning difficulties (e.g. thinking and planning)
- decreased emotional control
- changes in social behaviour
- problems with spatial awareness
- inability to perform activities of daily living independently.

Dementia is difficult to diagnose and significant delays from symptom-onset to diagnosis of dementia have been reported both here and overseas. In Europe, the average time to diagnosis after the caregiver first noticed symptoms was 20 months; caregivers waited, on average, 47 weeks before bringing the affected person to the attention of a physician.¹¹ Also, delays of up to 4 years from the recording of cognitive symptoms in primary care notes to the diagnosis of dementia being made have been reported¹².

In Australia, symptoms of dementia were noticed by families an average of 1.9 years prior to the first health professional consultation and there was an average of 3.1 years before a firm diagnosis was made; this is consistent with other overseas studies.¹³ Additionally, evidence suggests that people of non-English speaking backgrounds (NESB) are diagnosed later after the onset of dementia compared with the rest of the population.¹⁴ LoGuidice and colleagues (2001) suggested that this may be due to a lack of recognition of the early symptoms of dementia (i.e. attributing memory loss to old age) or due to many older adults of NESB living with and supported by family, rather than living alone and, thus, being less likely to present in early stages of decline. However, the commonality of perceptions demonstrates the need for information and support to all people, regardless of cultural or linguistic backgrounds when dealing with dementia.¹⁵ Delays in diagnosis result in lost opportunities for earlier medical and social interventions for those suffering dementia and their families¹³ and suggests room for improvement in dementia care.

Clinical assessment is particularly difficult for mild cases of dementia and family input may be integral to early detection of symptoms. Often caregivers or family members, or the person with dementia, alert the GP to the patient's symptoms (e.g. memory decline, changes in mood and activity) that could suggest the possibility of dementia. Since current policy does not support routine dementia screening, early diagnosis of dementia based on caregiver concerns and patient symptoms is critical for the early identification of reversible aetiologies, to delay progression of dementia, and potentially reduce the patient and caregiver burden¹⁶. The following discussion draws upon the available evidence to elaborate current practice in the diagnosis and management of dementia in primary care, outlines the major barriers to achieving optimal care, and suggests possible strategies to address these.

METHOD

A structured search method was used to locate the relevant body of publications. The literature search was conducted during March and April 2011, was limited to English language articles and to the years from 2008 to present. An extensive database of literature, which was updated in 2009 and encompassed the current topic from previous years since 1995, existed and was also utilised. Details of the search strategy can be found in Appendix 1. This discussion is based on this literature review and explores current practice and the barriers to timely diagnosis and effective management of dementia in the primary care setting.

CURRENT PRACTICE IN THE DIAGNOSIS AND MANAGEMENT OF DEMENTIA

There is no simple test to diagnose dementia.¹⁷ Instead, diagnosis requires the GP's clinical judgment, and information from the patient and their families, along with the use of screening tests (see below) and referral to geriatricians or other specialists if required. The GP's clinical judgment may be based on his or her personal observation, patient history or upon a history from the caregiver/informant of a decline in the patient's memory and other aspects of cognition, along with impaired functioning in everyday life.¹⁸

Differential diagnosis

One of the challenges of diagnosing dementia is that other illnesses or medical problems have symptoms similar to those of dementia – such as memory change or changes in personality. Some of the other causes that give rise to similar symptoms are depression, anxiety, thyroid disease, vitamin deficiency and adverse effects of medications.

For example, a family member may report that a usually talkative and outgoing individual has suddenly become apathetic and withdrawn. Such changes in personality may be indicative of early signs of dementia, though such symptoms could also be due to depression or physical illness. Whilst people with dementia have high rates of depression, people with depression often report disturbances in their cognition and memory.¹⁸ Approximately 50% of older adults who develop dementia have minor depressive disorder or depressive symptoms that interfere with functioning; 15% to 20% have major depressive disorder¹⁹.

GPs also need to identify and treat any other reversible causes of cognitive impairment such as infections, subdural haematoma, intracerebral lesions, neoplasms, metabolic disturbances, fluid and electrolyte disturbances, hypoxia and malnutrition. Conditions that may aggravate dementia also need to be considered in the diagnostic process (e.g. cardiac or renal failure, nutritional deficiencies, hearing or visual impairments).

Even after a diagnosis of dementia has been made, further differentiation is required as to the specific type of dementia that a patient may have. The main types of dementia include Alzheimer's disease, vascular dementia, mixed Alzheimer's/vascular dementia, and Lewy body dementia. Other subtypes are frontotemporal, focal and subcortical dementias.¹⁸

The ambiguity of early signs and symptoms of dementia allow for a wide range of diagnostic possibilities and require a well-structured approach for appropriate differential diagnoses.²⁰ If an individual presents with symptoms of dementia, a GP will usually conduct an interview, and may also use a screening test to see if there are signs suggesting cognitive impairment.

Case finding versus screening in the identification of dementia

Given the difficulty in identifying individuals who have dementia, and the reported underdiagnosis of the disease, one option that has been raised is population-level dementia screening of all individuals over a certain age. This might be done in the primary care setting, for example, if dementia screening was included in all health assessments of people aged 75 or older (i.e., the 75 Plus Health Assessments), and at subsequent annual check-ups. However, dementia guidelines do not advocate this approach. Also, as screening tools^a are not sufficiently sensitive or specific enough to establish a diagnosis of dementia, this would result in many false positives, causing distress to those identified and potential high costs to the health system as these people are referred for further assessment.²¹⁻²⁴ Instead, a case-finding approach to the detection of dementia is recommended. Case-finding means that the patient presents with, or the caregiver reports of, symptoms suggestive of dementia and the GP acts upon this to establish the diagnosis of dementia.

Screening tools

Tests of cognitive functioning are very important in the diagnostic process and screening tools can be used in the primary care context both to give an indication of the extent of cognitive problems and to track the level of cognitive performance over time. These initial dementia screening tools are brief and simple, such as requesting recall of the date, copying a diagram, learning a short list of words, or naming common objects. They are not diagnostic of dementia but can provide an indication of a problem with cognitive functioning.¹⁸ A person may perform well on a screening tool despite the presence of cognitive problems, especially if the same screening tool is used at regular intervals. A person's performance could also be affected by stress, fatigue or anxiety rather than cognitive decline. As such, screening tools and more comprehensive assessment tools need to be interpreted with consideration to the person's presentation and behaviour in the assessment context. Appendix 2 contains brief descriptions of common screening tools.

Screening tools can provide GPs with evidence that there may be some cognitive impairment but should not be relied upon to diagnose dementia. If screening results suggest cognitive impairment, more comprehensive neuropsychological assessments should be undertaken in a specialist setting. These more comprehensive assessments (e.g. the Cambridge Cognitive Examination – CAMCOG) explore different areas of cognitive function such as memory, language, reasoning, calculation and ability to concentrate.²⁵ They are able to distinguish between different patterns of decline and are, therefore, important to help identify the type of dementia affecting the person²⁶.

^a A screening tool in this instance refers to an instrument used to assess for cognitive impairment and detection of dementia.

Guidelines for dementia diagnosis and management

A number of international guidelines have been established for the diagnosis and management of dementia in primary care. These include the New Zealand Guidelines (evidence-based guidelines, which were originally released in 1997, and were published online in 2003²⁷), Canadian consensus guidelines (originally developed in 1989 and revised in 1998 and 2006²⁸), guidelines originally published in Scotland in 1998 and revised in 2006 to incorporate advice on new treatments such as cholinesterase inhibitors and use of other drugs,²⁹ and several guidelines from the United States including the US Preventive Services Task Force (USPSTF).

Australian Guidelines for GP management of dementia have also been published: *The Royal Australian College of General Practice (RACGP) Guidelines*.^b These are consensus guidelines and do not differ in their core recommendations from other international guidelines. The RACGP guidelines encourage case finding but not screening, early intervention, ongoing management of dementia symptoms, and partnership with carers and other service providers.²²

The RACGP guidelines suggest that when dementia is suspected – whether as a result of a screening test or of family or patient concerns – the GP obtain a full clinical history, interview the patient and family together and separately, and ascertain the patient's ability to undertake daily activities (e.g. bathing, dressing, managing finances). The Instrumental Activities of Daily Living (IADL) scale to assess functioning is recommended by the RACGP Guidelines, as is a home visit by the GP and/or members of their team to allow the quality and safety of the home environment to be ascertained. Other issues for the GP to consider include safety associated with driving, medication compliance, legal capacity and legal matters (e.g. advance care directives, enduring guardianship and enduring power of attorney).³⁰

The RACGP guidelines recommend a complete and thorough physical examination, directed towards known and possible co-morbidity as well as addressing possible reversible causes of memory loss.³¹

The recommendations reinforce that detection and diagnosis of early dementia is a lengthy, challenging process that usually involves third parties both in the diagnostic process (e.g. carer, specialist) and management of the syndrome (e.g. carer, government-funded support workers – HACC).

^b *Care of patients with dementia in general practice guidelines* can be accessed at: <http://www.racgp.org.au/Content/NavigationMenu/ClinicalResources/RACGPGuidelines/CareofPatientswithDementia/20060413dementiaguidelines.pdf>.

BARRIERS TO TIMELY DIAGNOSIS AND EFFECTIVE MANAGEMENT OF DEMENTIA

Appraisal of the barriers to diagnosis and management of dementia have identified patient/carer, GP, and systemic factors^{10, 16} that interact to inhibit optimal detection and management of dementia. Importantly, these barriers operate within a socio-cultural context in which dementia is not well recognised, accepted and understood. Consequently, general ideas about 'dementia' may be subject to distortion by the non-medical meaning of the word demented (e.g. wild, crazy, uncontrolled) – features which may fuel fear and avoidance of the topic. Such conceptualisations are far removed from the decline in memory and planning ability associated with the medical meaning of early dementia. However, as long as misconceptions embedded with stigma prevail, fear and avoidance are likely to act as major barriers that impede detection, diagnosis and management of this chronic condition.

Within the context of pervasive societal stigma and low public awareness of dementia, barriers to better diagnosis and management of the condition can be conceptualised within a systems framework, whereby consumers interact with GPs and specialists who work, in turn, within the constraints of Australia's primary health care system. Barriers that inhibit appropriate and timely diagnosis can operate alone or in combination at any level of this system, from behaviours and attitudes of consumers' right through to Federal government policy and regulations. The following sections address specific barriers at each level in turn.

Patient/carer factors

Ideas about dementia and ageing

Individuals with dementia and their families may have difficulty distinguishing the early signs of dementia (e.g. memory loss, emotion changes, functional disability) from their perception of 'normal' ageing.^{10, 32} Also, the early symptoms of dementia may be discounted relative to other concerns – the patient being hesitant to bother the GP with less urgent matters,³³ patient stoicism and a belief that healthcare needs rationing,³⁴ and a lack of knowledge on the part of the patient or their family.¹⁰ Family members may unwittingly, gradually take over social roles from the patient and thereby protect the patient by compensating in daily life and delay conscious recognition of decline by offsetting impairments.^{35, 36} Therefore, patients/carers may not recognise early symptoms as a health issue and/or may choose not to report them to a GP. Furthermore, the derogatory connotations associated with dementia may also actively discourage people from considering dementia as a possible explanation for their symptoms.

Suspicion of dementia may delay people in consulting their GPs with concerns about dementia symptoms which, in turn, delays GPs' confirmation and disclosure of a dementia diagnosis to patients and their caregivers.³⁷⁻³⁹ Dementia is a distressing diagnosis and a number of difficulties may arise even after a GP makes the initial diagnosis. These include:

- patients or their families denying the diagnosis and wanting their family member (or themselves) 'fixed'⁴⁰

- resistance to diagnostic confirmation^{41, 42}
- the family not wishing the diagnosis communicated to the person with dementia.^{43, 44}

Fear and social stigma may also lead to withdrawal and social isolation and, since dementia is often a taboo subject, those with the disease feel they have little recourse and may develop a fatalistic reaction to the diagnosis, feeling that nothing can be done.⁴⁵

Lack of insight into declining abilities

Lack of insight into declining abilities can become a problem for the person with dementia – that is, they may not be aware of their problems.^{9, 10} Alternately, they may be aware of their deficits though fear of loss of independence may lead to avoidance of professional assistance. For example, the person with dementia may be concerned that if they tell their doctor about thinking/memory issues they may lose their driving licence. A need for independence and mobility could cloud their judgment of their capabilities, hinder their disclosure of declining abilities to their GP, and impede detection of their symptoms.

The person with dementia who lives alone

This lack of insight can make early diagnosis particularly difficult should the person with dementia live alone.^{10, 46} The ability of the person with dementia may be impaired to the extent that they are unable to provide an accurate history, or to independently attend a medical appointment.⁴⁷⁻⁵¹ Furthermore, not having family input can hinder the use of some screening instruments, such as functional assessments that depend on caregiver observation and report.⁵² Therefore, not having a carer can complicate detection, assessment and care of the person with dementia. Evidence suggests that people with dementia living alone are less likely to receive an accurate and timely diagnosis of dementia from their GP.⁵³

GP factors

Time-limited consultation context

The GP consultation is a setting where brief provider–patient interactions usually encompass multiple symptoms and health conditions; a setting where early symptoms of dementia – such as memory impairment – may not be readily apparent unless they are directly raised or assessed.¹⁶ Thus, the insidious and inconsistent nature of early stage dementia poses particular challenges for diagnosis in primary care.

The RACGP guidelines recommend that assessment and management of dementia encompass several consultations over weeks or months, and long-term planning is arranged with the patient and their family. Diagnosing early dementia is a lengthy process that has ongoing, long-term implications for patient care.

At present, only the Mini Mental State Exam (MMSE) can be used by GPs for determining whether someone may be eligible for subsidised prescriptions of medications for treating Alzheimer's disease. It has been reported that the MMSE can take up to 20 minutes to complete,¹⁸ but even if it takes only 5 to 10 minutes to complete, this tests practicality in the time-limited primary care context where consultations are conducted in 10 to 15 minute blocks. Nonetheless, should the person's score on the MMSE suggest they are eligible for subsidised medication, the GP has to refer them to a specialist as GPs cannot prescribe the initial medication for treating Alzheimer's disease.

Difficulty diagnosing early stage dementia

Diagnostic uncertainties and a lack of education about dementia contribute to GPs' difficulty diagnosing dementia (see 14 for a review). GPs can have difficulty differentiating normal ageing from early dementia^{47, 48, 54} and also recognising and responding to the symptoms of dementia.^{48, 55} They may lack confidence, doubt their diagnostic expertise^{10, 47, 54, 56-59} and perceive the diagnosis of dementia as a specialist domain.⁶⁰

GPs are also concerned with the risk of misdiagnosis⁶¹ and conveying the diagnosis with aptitude and empathy. Many GPs are not familiar with the existing guidelines with respect to dementia, and are generally unaware of the potential benefits to consumers of early diagnosis of dementia.⁶² GPs' recognition of dementia appears associated with dementia severity – being better in moderate and severe cases – and better at ruling out than at identifying dementia.⁵³

Negative view of dementia

Like the patient-related factors, GP barriers include attitudinal components as well as pragmatic concerns. Attitudinal barriers include:

- a belief that as there are no effective therapies there is no point making the diagnosis^{38, 43, 47-49, 60, 63-66}
- dementia not being viewed as important^{48, 55}
- a perception that there is no real need to determine a specific diagnosis^{47, 48}
- assessment considered a low priority compared with physical care⁴⁸
- the goal of care being quality of life rather than a cure.⁵¹

Access to specialists

General medical education in Australia does not equip GPs with the full-range of clinical and psychosocial skills for dementia diagnosis and disclosure. As such, it is recommended that GPs refer patients suspected of dementia to specialists in this area (e.g. geriatrician, psychogeriatrician, neurologist) to confirm the diagnosis and convey the diagnosis to the person with dementia and their carer, if they have one. Specialist referral is also necessary for the person with dementia to have access to publicly subsidised medications that can help to slow the progress of cognitive decline. However, access to psychogeriatricians and geriatricians is limited, especially in rural areas.^{39, 67}

Diagnosing dementia may have negative consequences

The GPs' notions of how patients may respond to a diagnosis of dementia can inhibit diagnostic disclosure. Factors include:

- fear of damaging the doctor–patient relationship^{60, 66}
- perceiving the patient as too fragile for a diagnosis of dementia
- a desire to protect the patient⁶⁸
- considering the patient as unable to comprehend/cope with the diagnosis^{50, 54, 59, 60, 66, 69-72}
- fear of the patient possibly becoming dependent, ashamed, and seeing themselves as crazy.⁶⁶

GPs' awareness of the negative lay perceptions and connotations associated with the word dementia, or perceived as being demented, may underlie these factors.⁷³

Communicating the diagnosis of dementia is challenging

Dementia seems an emotive issue for GPs, as reflected in their perceptions of their patients' reactions to the diagnosis as well as their own. That is, GPs report a deep sense of grief and loss;⁵¹ disbelief, denial, apprehension and fear;⁷⁴ and that the diagnosis will open a Pandora's box⁷⁵. Consequently, even if a diagnosis has been reached, communication of this appears particularly difficult.

GPs report that communicating the diagnosis is one of the most difficult aspects of diagnosing dementia;^{37, 38, 56, 76-78} particularly when communicating the diagnosis to patients themselves, rather than communicating this to the caregivers of the person with dementia.^{50, 79} Communicating the diagnosis is often accompanied by the ethical dilemmas associated with the locus of control (e.g. in medical decision making) shifting to someone other than the person with dementia.⁵¹

Even when specialist services are available, there can be issues with communication of dementia diagnoses to patients. For example, recent qualitative research findings⁸⁰ indicate that even specialist referral may not necessarily result in a definitive diagnosis.

Responsibility for auxiliary issues

Most GPs do not feel equipped to discuss legal issues⁸¹ though the guidelines suggest they do so, along with other issues that may not be a part of medical training (e.g. a patient's driving capability). The RAGGP guidelines note that it is important for the GP to determine the person with dementia's capacity to make decisions, their fitness to drive, and also the eligibility of the person with dementia and carer (if applicable) for financial and other resources (e.g. pensions and sickness benefits). The guidelines also recommend that GPs raise legal and business 'forward planning' issues soon after diagnosis whilst the person with dementia still has the capacity to express their wishes, and to assist the family to investigate respite care and institutional options. Should GPs' lack confidence to address auxiliary issues, or lack information and access to relevant support services, these can be significant barriers to dementia care.

Systemic factors

Lack of streamlined communication to detect dementia

Effective management of dementia involves a multidisciplinary approach with carer input, if possible. However, communication issues permeate the patient/carer, GP and dementia management context with inherent barriers to optimal management emerging at the various levels in the process of dementia care. For instance, at the GP level, GPs may perceive a lack of support from, and communication with, specialists.¹⁰ At the GP–patient/carer interface, health professionals may consider a comprehensive, longitudinal approach essential for diagnostic accuracy with dementia. However, by the time carers raise concerns with the GP, the person with dementia and their family may have been living with the symptoms of dementia for some time and they may be seeking an immediate answer.⁷²

Another consideration is the difficulty of gaining access to carer input and accurate reports from carers.⁵² Specifically, although the importance of carer input for the diagnosis and management of dementia is well recognised, many doctors may not have enough time or resources to adequately consult with carers. One factor contributing to this issue is that Medicare does not fund separate consultations with carers, although carers may be included in certain Enhanced Primary Care items (e.g. case conferences).

Detection of dementia

Although the guidelines recommend case finding rather than screening for dementia,²⁴ it has been argued that case finding may limit detection of dementia^{22, 82, 83} as patients may not report symptoms that could cue the GP to explore the possibility of dementia. However, even after a positive result on a screening tool, some patients who perceive themselves as having no cognitive symptoms may refuse further assessment.⁸⁴ Additionally, it is possible that GPs may not follow-up on screening results – the GP consultation occurs in a time-limited context and urgent or physical complaints may be prioritised. Also, GPs are aware that screening instruments are not diagnostic and that a poor result may be due to influences other than dementia (e.g. limited education, depression, anxiety, fatigue).

Lack of streamlined communication makes management of dementia care difficult

Whilst it is acknowledged that dementia care requires a team effort,^{72, 85} the experiences of multidisciplinary working, particularly in mental health can be challenging.⁸⁶ For instance, Robinson and colleagues (2009)⁸⁵ note that despite GPs being identified as a key group to promote the coordination of services, the small business culture and medical professional orientation of the GP practice context does not equate well with building collaborative agendas with community-based providers.

Professional boundaries and medical dominance can limit communications in the health care context.⁸⁷ Along with limited interdisciplinary communication,^{72, 88} service providers (e.g. ACAT, community nurses, GPs, home carers) often function independently, albeit in awareness of each other's work.⁷² Although service providers desire transfer of information between services and coordinated service provision, a lack of information transfer between providers and between clients, families and other providers, results in poor service coordination.⁸⁵

Dementia is not widely conceptualised as a chronic condition

Despite the evidence, dementia is not well recognised as a chronic health condition where the risk may be reduced, or the progression delayed, by lifestyle changes. Also, screening and diagnosis of dementia may not be seen as a priority. Issues such as lack of staff time (e.g. consultation time, arranging referrals, follow-up, recalls and reminders), competing work demands, limited availability of referral services, poor feedback from agencies, and issues of financial remuneration can act as barriers to the uptake of health promotion, prevention and early intervention activities.⁸⁹ For dementia, these barriers may combine with a lack of awareness about the benefits of diagnosis, risk reduction and appropriate management of the disease.

Summary

Collectively, barriers at the levels of consumers, GPs and specialists, and the broader primary care system work to hinder detection, diagnosis, disclosure and management of dementia. Consequently, it is not surprising that both national and international research suggests that efficient dementia diagnosis and syndrome management is impeded by a number of factors in primary care.^{10, 16, 39, 90, 91} Dementia is a stigmatised condition and strategies are needed to familiarise and raise awareness of this condition both at the lay and health professional levels, to enhance detection and management of this chronic condition. The following section offers suggestions and strategies that may help to address these concerns.

SUGGESTIONS/RECOMMENDATIONS

Public awareness campaigns

Raise awareness and destigmatise dementia

The detection of dementia where the person with dementia still has the capacity to make life decisions and contribute to their care planning process is the goal of high-quality health care.¹⁶ Stigma and lack of awareness contribute to the delay in diagnosis that is often experienced. This barrier could be addressed by a national public awareness campaign through Alzheimer's Australia to help people recognise the symptoms of dementia. This would build on the checklists^c and other resources already available for those concerned about their memory. However, it also needs to be widely acknowledged that persons with dementia may lack insight into their condition and of the important role carers or family members can play. For those who live alone, greater public awareness may increase people's willingness to seek help at early stages,⁸⁶ or at least encourage them to raise the issue with their GP. The public awareness campaign would aim to:

- make an unfamiliar condition familiar
- raise awareness to enable better detection and management of the condition
- reduce the negative ideas associated with dementia
- raise awareness that dementia is a chronic condition to be lived with as optimally as possible
- raise awareness of healthy lifestyle changes that may reduce the risk of developing dementia
- raise awareness that, whilst genetic predisposition may play a role, it is a condition that could happen to anyone
- encourage those concerned about their memory to contact Alzheimer's Australia or other agencies.

The public awareness campaign needs to target the general public (i.e. not only older adults) to address some of the barriers posed by patient/carer factors such as: lack of recognition of the signs and symptoms as being a medical condition rather than changes due to age, and acknowledgment that the nature of the condition may cause lack of insight into symptoms and changes. Lack of insight into change in capabilities has implications for living safely with dementia, such as a review of driving ability. This could be incorporated into promoting dementia as a chronic condition to be lived with as optimally as possible, as noted above.

The carer role needs recognition and endorsement

The benefit of the GP incorporating the carer, when there is one, as having a major role in care of the person with dementia has to be acknowledged. The carer needs to be included in the assessment process when possible and the Commonwealth Carelink

^c See www.alzheimers.org.au/common.files/NAT/20100903-AANO-worreid-about-your-memory-checklist.pdf

and Alzheimer's Australia phone numbers given to the carer. At present, GPs are not remunerated through the Medicare Benefits System for consultations with carers. Carers need to be able to discuss their caring responsibilities with a GP or other primary health care professional for information or advice (e.g. access to services and support groups such as Alzheimer's Australia). Current Medicare and Enhanced Primary Care (EPC) items need to be reviewed and extended to include carers. Currently, such discussions are done 'on the run' as part of another consultation (either with the carer about another matter, or with the person with dementia).⁹²

The distress and burden of caring for a person with dementia is well recognised and it has been suggested that all carers should be screened for depression⁹² and assisted to access support services as necessary. It can be beneficial for the person with dementia and their carer have the same GP, which enables monitoring of both the person with dementia and their carer, though this may not always be practical. Furthermore, discussing the care of a person with dementia in their absence raises questions of ethical medical practice. Therefore, open discussion between the medical profession, carers, the general community and other stakeholders regarding issues such as patient confidentiality when cognitive decline is present needs to be encouraged.⁹²

Increasing expectations of community service

Information about the community services available and how to access them needs to be offered as soon as possible after diagnosis. An expectation of appropriate referral to support services needs to be established. This support needs to focus on what persons with dementia can do and encompass a recognition and acceptance that life goes on after diagnosis. Carers need to be made aware of the availability of services, as many do not utilise services because they are not aware of them.⁹³ Doctors need to be aware of these support services so that they can provide referral for patients.

Support for carers

Carers have a major role in the early detection of dementia as well as the ongoing care of the person with dementia. The strain upon them in these roles needs to be acknowledged, and the availability of support services and how to access them promoted. Information, counselling and education can empower carers, giving them more confidence to manage their caring role and, thereby, improving the quality of life for both them and the persons with dementia they care for.⁹⁴ Assessment processes (e.g. through ACATs and HACC services and/or a dementia diagnosis) should instigate access to information, counselling, carer education and ongoing support.⁹⁴ Improving public promotion of such services, destigmatising dementia and encouraging referrals from health professionals could enable better service use.⁹³

GP factors

Improving detection of dementia involves education and initiative – an attitude change

Factors curbing detection of dementia by GPs include attitudinal components as well as pragmatic concerns such as the complexity of the diagnosis and time-limited consultations. The barrier of time constraints could be addressed by establishing a longer consultation time for complex presentations, such as dementia, with appropriate reimbursement commensurate with assessment processes. However, that dementia is a presenting condition requiring further assessment needs to be recognised within the consultation context. This could be done by having specific Medicare items, such as for diagnosing dementia and for conducting an assessment.

As the foregoing discussion revealed, detection of early dementia is particularly difficult. Recently, a four stage process to try to capture the often diverse clinical presentation has been proposed³⁵ This process identifies

1. a trigger phase (not testing, but suspecting the possibility that dementia may be emerging);
2. a disease-orientated diagnosis (a formal diagnosis of dementia results from a step-by-step and iterative assembly of evidence);
3. assessing care needs (careful and repeated assessment of the patient's care needs is necessary to guide those involved helping the patient over a period of many years); and
4. the inclusion of carers in the diagnostic approach (i.e., also assessing the carer's needs). Monitoring the changes and adapting care accordingly is also required³⁵.

Addressing these issues would be challenging in a brief consultation context. Therefore, for management of suspected dementia, delineating a structured assessment approach which acknowledges the need for longer consultations within the RACGP guidelines, and dissemination of this information along with appropriate education may be required.

Helping GPs diagnose early-stage dementia

Lack of understanding of dementia and the diagnosis of dementia could be addressed through professional development workshops for GPs emphasising the benefits of early diagnosis, raising awareness of best practice guidelines, as well as establishing a structured approach to assessment – regularly monitoring borderline scores (e.g. three-monthly review of suspected dementia) with secondary referral incorporated (e.g. geriatrician, memory clinic) for equivocal cases could aid diagnosis. Also, guiding the person with early stage dementia and/or their carer to services (e.g. for legal or business issues) to help them plan for their life whilst they are able may be well met by other members of the multidisciplinary team (e.g. a social worker). As dementia progresses, multifaceted issues arise that require multidisciplinary assessment and the coordination of a range of health and community care interventions⁹⁴.

Dementia needs to be viewed as a chronic condition

In both the clinical consultation context and the broader community, dementia needs to be conceptualised as a chronic condition with a focal shift to preventative lifestyle measures. Campaigns are needed to raise both public and professional awareness of steps to good

health that may be beneficial to reduce the risk and progress of dementia and highlight the benefits of early diagnosis.

Change negative views of dementia

Training for GPs to enhance their competence as well as their general attitude towards dementia can have positive outcomes for patients with dementia and their caregivers. Research suggests GPs' self-estimated competence and general attitude towards caring for patients with dementia were both positively associated with an active approach to the care process.⁹⁵ Education through professional development initiatives, as noted above, could enhance GPs' knowledge, skills and confidence, change how they manage care of persons with dementia, and lead to a more proactive approach towards detection of dementia.

Communicating the diagnosis

Conveying the diagnosis of dementia is a particularly difficult aspect of the diagnostic process. Both GPs and medical specialists may be reluctant to convey the news; some GPs and medical specialists are not aware of the availability or the positive impact of support services, or where to refer to.⁹⁴ Hence, they may feel they have little to offer patients. GPs and medical specialists need to be informed about the services available and how to access them not only so they can give practical assistance to persons with dementia, and carers if available, but also to help normalise the notion that life goes on living with dementia – to offer persons with dementia a way forward. Being equipped to offer a way forward may make breaking the diagnosis less difficult.

Developing a communication model for GPs to ease the disclosure of the diagnosis of dementia may also be appropriate. Effective educational and support measures for GPs need to be put in place that will effect a change in their clinical practice. Possibly reframing dementia as a progressive disability (rather than a condition or disease) may make it more acceptable.¹⁰ Psychological support for the person with dementia and their carer, if there is one, may be appropriate through the Better Access to Mental Health Care Program under Medicare. Most importantly, the diagnosis of dementia should be communicated in a respectful, sensitive way that differentiates the syndrome from the person (i.e. the person is not the syndrome).

Systemic factors

Accessing assessment

There can be long waiting lists and 'closed books' constraining timely access to assessment and, combined with the prevailing stigma and attitudes towards dementia, this may disincline those in the early stages of dementia from attaining assistance. The public promotion of the importance of investigating concerns about declining abilities, instigating lifestyle changes to enhance brain health, the importance of timely recognition of dementia, and destigmatising dementia needs to be balanced with access to thorough assessment and subsequent care management. However, currently the pathways for specialist referral, diagnosis and assessment are neither clear or readily available, and access to dementia specialists varies with very limited access to medical specialists in rural areas.⁹⁴ Therefore, systemic changes need to be made that afford more equitable access to assessment and support in dementia care.

Research has identified expanding the role of the general practice nurses (PNs) to incorporate their role into the dementia assessment process – allowing screening for dementia by PNs or other nurses to become routine in primary care.⁸⁶ Piloting of models of dementia detection in Australian general practices using special memory trained nurses to assist in the detection of dementia in older people is in progress.⁹⁶ In one pilot study, GPs and PNs collaborated to refer patients to a specialist memory nurse (SMN) who conducted assessments and provided feedback, with a care plan developed based on the SMN's recommendations.

Currently, a proposal is in place to extend this model and further explore a multidisciplinary approach to promote early detection and management of dementia by GPs in association with allied health practitioners in primary care. This proposal uses Primary Dementia/ Aged Care Nurse Practitioners (PDAC NP) working collaboratively with GPs and allied health practitioners in the Medicare Local setting. The PDAC NP is well placed as an autonomous practitioner to fulfil the dementia assessment role as they can act effectively in accord with the GP guidelines without the restrictions of the GP time-limited standard consultation context. Currently, there are a limited number of PDAC NP who can provide an advanced and extended clinical role.⁹⁴ Developing the PDAC NP role could enhance diagnosis, assessment and ongoing management of dementia in primary care.

Better integration and access to support services

Closer links and integration with other service providers (e.g. PNs, HACC services, and the aged care sector) need to be established. Also, increasing the availability of community-based support services for older people may serve to not only improve their quality of life, but may increase the rates of early diagnosis of dementia by bringing the person with dementia symptoms to medical attention.³⁹ This could be accomplished by a pathway being established for support service providers to report suspected dementia. Nonetheless, whilst carers have emphasised the importance of proactive follow-up, it is difficult for services to provide this due to the current demand.⁹⁴ Services need to be sufficient to meet the demand.

Whilst multidisciplinary teams can deliver support at an individual level, a key or lead worker must be identified as having overall responsibility for service coordination to avoid duplication – this is often the GP or social worker⁸⁶. Also, professional development workshops for GPs and the relevant health professionals focused on the team approach to management of dementia care and their role within a team management system need to be established.

Diagnosing those at risk

A system needs to be set in place to detect dementia and care for people who have no carer. Whilst population screening is not currently advocated to detect dementia, it has been considered as an inclusion in the annual health check of those aged 75 years and over.⁸⁶ Also, research suggests that there are populations that may benefit from screening, such as those most at risk of dementia being missed (e.g. people with Down syndrome, people living alone, older adults presenting with psychological or cognitive problems).⁸⁶ The absence of a carer also highlights the importance of establishing support service integration that can incorporate assessments and provide care that meets individual needs and enables the person with dementia to live and function independently of carer input if need be.

The role of community-based organisations

Good social networks can buffer the strain of the caring situation and carers need to be able to access social networks as the cognitive ability of the person they care for declines. Innovative proposals, such as funding aged care workers at major organisations (e.g. RSL clubs) to engage people with dementia in activities while carers participate in social activities may meet this need as well as serving to increase acceptance and understanding of dementia – making dementia familiar in the broader community.⁹² Also, an important source of support for people with dementia is access to others with dementia and their families for emotional peer support, information and practical advice.⁹⁷ Maintaining programs providing such support (e.g. the Living With Memory Loss Programs of Alzheimer's Australia), and raising public awareness of these initiatives, is imperative.

The role of front-line organisations

People with dementia and their carers interact with a range of front-line agencies, both public and private, Commonwealth and State funded health, community care, aged care– or dementia-specific services.⁹⁴ These include pharmacies, banks, solicitors, public housing and police; how these agencies respond influences the quality of life of the person with dementia and their carers.⁹⁴ For instance, should a person with dementia present to an after-hours medical centre with an infection (i.e. not see their usual GP), they may get a prescription for antibiotics, though an after-hours pharmacy may refuse to dispense the antibiotics in a Webster Pack (because they do not have the Patient Health Care Summary form), even though a Webster Pack is required for the person with dementia (or their carer) to dispense the medication. Thus, there is a need for better planned response from such agencies – an approach consistent with whole of community responses to substantive population health issues.⁹⁴

CONCLUSION

Dementia will be encountered more frequently in general practice as the population ages and the prevalence of dementia increases. Review of the guidelines and alignment of current practice with them is essential. This may be accomplished through multiprofessional team working practices. Integration of services is needed whereby GPs work with specialists and allied health professionals to diagnose and optimally manage care of the person with dementia. The development of models of working with multidisciplinary primary health teams to better identify and manage dementia needs to be addressed. Particular areas to focus improvements include early detection, communication of the diagnosis, and mobilisation of resources to assist the person with dementia to live safely in the community. Systems need to be developed with defined roles and responsibilities for GPs, specialists and community service workers to manage these issues to deliver best practice outcomes. Negative attitudes about dementia need to be addressed to break down the barriers hindering recognition/acknowledgement of dementia in the wider community.

APPENDIX 1: THE SEARCH STRATEGY

A number of terms concerning primary care are used interchangeably in the literature. For instance, the terms 'general practice', 'family practice' and 'primary care' are used interchangeably here to variously describe primary care clinicians, physicians and practitioners. 'General practitioner' is a common term in Australasia, the UK, and some parts of Europe. The search strategy incorporated the various terms and is shown in Table 1.1. Databases searched were: Medline, PsycINFO, CINHAHL, PubMed, Scopus, MDConsult, Sociological Abstracts, EMBASE and Informit. At times, review of an article suggested other articles of possible interest and these were sought by title search using Google Advanced Scholar Search.

Table 1.1 General search strategy re the diagnosis and management of dementia

| Search No. | Keyword search |
|------------|---|
| 1 | general practitioners or family practice or primary health care physician or practice nurse or family physician or rural general practitioner or memory clinics |
| 2 | comprehensive care or collaborative care or management or best practice management or current practice management or patient care team or multidisciplinary approach or integrated delivery of health care or specialist referral or drug therapy or drug treatments or medications) and dementia |
| 3* | 1 and 2 |
| 4 | barriers to diagnosis or patient care planning or best practice or current practice or diagnosis or diagnostic process or disclosing diagnosis) and dementia |
| 5* | 1 and 4 |
| 6 | barriers to assessment or assessment instruments or screening or case-finding or differential diagnosis or cognitive evaluation or office practices or office visits or geriatric assessment or physician's practice patterns or practice guidelines or practice protocols) and dementia |
| 7* | 1 and 6 |
| 8*^ | barrier\$ or limit\$ or obstacle\$ or hinder\$ or impede\$ |
| 9^ | 6 and 8 |
| 10^ | 1 and 9 |

Note: Searches were not necessarily run in this order in each database.

*Searches 3, 5, 7 and 8 were limited to Human, English, and 2008 to current.

^ Search was run in Medline, PsycINFO and EMBASE and returned 10 relevant articles in Medline, 3 in PsycINFO, none in EMBASE.

The search strategy shown was used for the database searches except for MDConsult, PubMed and Scopus. In these databases, the search strategy was modified to suit the search platform. That is, in MDConsult, PubMed and Scopus the search terms were reduced. In MDConsult the terms “dementia assessment in primary care”, “dementia diagnosis in primary care”, “dementia management” and “primary care”, “dementia management” and “general practitioners”, “management of dementia” and “general practitioners” were searched. In PubMed, the terms “physicians, family or general practitioner” and “dementia” were searched with “and diagnosis” and then searched with “and assessment”. In Scopus, “assessment or diagnosis or management or screening or case-finding” and “dementia” and “general practice or general practitioners or practice nurse or memory clinics or family practice or family physician” were used. Title, abstract and keyword searches were executed for these phrases.

The search results

The search resulted in the retrieval of numerous articles concerning issues pertinent to dementia. There were many duplicate and irrelevant items (e.g. articles not applicable to primary care) returned across the databases. To maintain the search sensitivity, the terms were not refined. Rather, the titles of the articles retrieved were reviewed; the abstracts of articles sounding relevant were reviewed, and the articles of interest obtained. Articles with titles and abstracts of uncertain relevance were also obtained. Articles with titles and abstracts of no relevance were disregarded. Documents of interest that were duplicated in prior searches of different databases were only counted as retained once. Consequently, as Table 1.2 shows, there were many results reviewed though relatively low numbers of articles retained due to irrelevant or duplicate items.

Table 1.2 Articles reviewed and kept re GPs' diagnosis and management of dementia

| Database searched | Results reviewed | References retained |
|------------------------|------------------|---------------------|
| Medline | 288 | 63 |
| PsycINFO | 76 | 31 |
| CINAHL | 17 | 5 |
| PubMed | 111 | 11 |
| Scopus | 59 | 9 |
| MDConsult | 225 | 8 |
| Sociological Abstracts | 48 | 5 |
| Informit | 57 | 9 |
| EMBASE | 89 | 3 |
| Total | 970 | 144 |

The research evidence retrieved provided insight into the process of the diagnosis and management of dementia which, in turn, suggested ways of improving care and overcoming barriers to the delivery of ‘best practice’ care for community-based dementia patients.

^d Best practice is defined internationally through clinical practice guidelines. Clinical practice guidelines are referred to here as ‘practice guidelines’ or ‘guidelines’. *Care of patients with dementia in general practice guidelines* can be accessed at <http://www.racgp.org.au/Content/NavigationMenu/ClinicalResources/RACGPGuidelines/CareofPatientswithDementia/20060413dementiaguidelines.pdf>.

APPENDIX 2: COMMON SCREENING TOOLS

The GPCOG, Mini-Cog and MIS have been identified as the most suitable dementia screening tools to use in the primary care setting.⁹⁸⁻¹⁰¹ Brief descriptions of these and other common screening tools follow:

- The General Practitioner Assessment of Cognition (GPCOG)¹⁰² is a quick efficient test for dementia screening in primary care that can use informant information if available. Scores appear to be independent of the patient’s Geriatric Depression Scale (GDS) score, a popular test for diagnosis of depression in the elderly; it takes about 5 to 7 minutes to complete.¹⁸
- The MiniCOG¹⁰⁰ is composed of a three item recall and clock drawing. It has been established as an effective routine screening test for use in primary care practice and takes about 3 minutes to administer.¹⁰³
- The Memory Impairment Screen (MIS)¹⁰⁴ is a four-item delayed free- and cued recall test of memory impairment that provides efficient, reliable and valid screening for dementia; it takes about 4 minutes to administer.
- The Rowland Universal Dementia Assessment Scale (RUDAS)¹⁰⁵ is a simple screening tool that tests multiple cognitive domains and appears unaffected by gender and years of education, and seems culturally fair. It was developed using culturally diverse study populations and advisory groups and takes about 10 minutes to complete.
- The Montreal Cognitive Assessment (MoCA)¹⁰⁶ is a brief cognitive screening test which has a high sensitivity and specificity for detecting Mild Cognitive Impairment (MCI) and early Alzheimer’ disease; it takes about 10 minutes to complete.
- The Kimberley Indigenous Cognitive Assessment¹⁰⁷ includes several subsections including a cognitive assessment section (KICA-Cog, which takes about 30 to 40 minutes to administer) and a briefer cognitive screen (KICA-Screen, which takes less than 10 minutes to administer¹⁰⁸) that can be used in conjunction with carer input. It is a valid dementia test for older rural and remote dwelling Indigenous Australians that does not appear to be affected by educational level.
- The Mini-Mental State Examination (MMSE) taps five areas: orientation (10 points), registration (3 points), attention and calculation (5 points), recall (3 points), and language (9 points) for a score out of 30. With widespread usage, a number of limitations have surfaced. High pre-morbid intelligence (e.g. high education level) shows a ceiling effect, thus leading to false negatives; great age, limited education, foreign culture and sensory impairment can produce false positives. It has limited sensitivity to frontal and subcortical changes.⁹⁸ It generally takes 5 to 10 minutes to complete, although it has been reported to take up to 20 minutes.⁷
- The clock-drawing test is a screening tool that has been suggested as a useful adjunct to the MMSE; it is quick and simple to use in general practice and detects cognitive impairment in older adults by testing visuoconstructive ability, executive function and numerical and verbal memory.¹⁰⁹ However, its complex nature tapping a wide range of intellectual and perceptual skills challenges scoring and interpretation.⁹⁸

ACRONYMS

| | |
|---------|---|
| ACAT | Aged Care Assessment Team |
| CAMCOG | Cambridge Cognitive Examination |
| EPC | Enhanced Primary Care |
| GP | general practitioner |
| HACC | Home and Community Care |
| IADL | Instrumental Activities of Daily Living |
| MMSE | Mini Mental Status Exam |
| NESB | Non English Speaking Background |
| PDAC NP | Primary Dementia/Aged Care Nurse Practitioners |
| PN | general practice nurse |
| RACGP | <i>The Royal Australian College of General Practice</i> |
| USPSTF | US Preventative Services Task Force |

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