

RACGP aged care clinical guide (Silver Book)

5th edition

Part A. Dementia



General principles

- Dementia affects a range of cognitive and physical functions, including memory, ability to initiate action, social function, activities of daily living and emotional control.
- Dementia is a chronic progressive disease that results in death.
- Diagnosis should include cognitive function testing, and exclusion of common differential diagnoses including delirium due to physical illness, depression and medication side effects; it is important to assess functional capacity, which is impaired in dementia.
- There is a range of anti-dementia medications available that may provide some modest delay in progression of symptoms.
- The mainstay of management is support of the person and their carers in maintaining dignity and independence as much as possible with non-pharmacological management.
- Behavioural and psychological symptoms of dementia, also known as responsive behaviours such as agitation, may also be assisted by non-pharmacological management.
- Short-term prescription of antidepressants (eg selective serotonin reuptake inhibitors [SSRIs]) may have a role.

Practice points

Practice points	References	Grade
Use the <i>Diagnostic and statistical manual of mental disorders</i> , fifth edition (DSM-5) to assist with the diagnostic criteria of dementia	2	Consensus-based recommendation
Apply a cognitive function test, and exclude depression, physical disorders and possible effects of medications before making a diagnosis of dementia	1, 6	Consensus-based recommendation

Conduct pathology tests to exclude a medical cause of the patient's cognitive decline	1	Consensus-based recommendation
Conduct imaging to exclude brain tumour or other rare physical brain pathology (eg chronic subdural haematoma)	1	Consensus-based recommendation
Assess for depression as it may mimic dementia (ie pseudodementia), and may also accompany dementia	12	Consensus-based recommendation
Undertake a full and comprehensive medication review to exclude medications that may be affecting brain function	15	Consensus-based recommendation
Conduct a functional assessment as a dementia diagnosis cannot be made unless there is interference with function	16	Consensus-based recommendation
Regularly review a patient's functional capacity	1	Consensus-based recommendation
Communicate the diagnosis of dementia using a gradual and individualised approach	1	Consensus-based recommendation
Consider a supported approach for more complex decision making	21	Consensus-based recommendation
Three acetylcholinesterase inhibitors are recommended as options for managing the symptoms of mild-to-severe Alzheimer's disease, Parkinson's disease dementia, Lewy body dementia, vascular dementia or mixed dementia:	1	Consensus-based recommendation
• donepezil		
rivastigmine		
• galantamine		
Be aware of adverse reactions, side effects and interactions between medications	1	Consensus-based recommendation

Introduction

Dementia is a clinical syndrome that is caused by a number of underlying diseases.¹ It may be associated with disorders as diverse as Parkinson's disease and multiple sclerosis, and may be classified into a number of discrete types, including the following four main types (or a mix of the four):

- · Alzheimer's disease
- vascular dementia
- · frontotemporal dementia
- dementia with Lewy bodies

The *Diagnostic and statistical manual of mental disorders*, fifth edition (DSM-5) refers to dementia under the heading of 'Major neurocognitive disorder'. The diagnostic criteria for dementia under DSM-5 include the following:²

- Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains
 (ie complex attention, executive function, learning and memory, language, perceptual-motor or social cognition –
 the role of cognition in understanding and responding appropriately to social interactions) based on
 - concern of the individual, a knowledgeable informant or the clinician that there has been a significant decline in cognitive function
 - a substantial impairment in cognitive performance, preferably documented by standardised neuropsychological testing or, in its absence, another quantified clinical assessment.
- The cognitive deficits interfere with independence in everyday activities (ie at a minimum, requiring assistance with complex instrumental activities of daily living such as paying bills or managing medications).
- The cognitive deficits do not occur exclusively in the context of a delirium.

The cognitive deficits are not better explained by another mental disorder (eg major depressive disorder, schizophrenia).

The implications for general practitioners (GPs) with the DSM-5 definition is that dementia may present with a number of cognitive changes apart from memory problems, including decline in planning, organisation and social cognition, and not involving memory. This may make it more challenging to diagnose dementia, especially in younger patients.

The clinical picture should elicit any potential interference with activities of daily living, and GPs should monitor these as the patient's condition deteriorates by directly questioning the patient and talking to their carers. It is also important to ensure that functions related to the self-management of chronic disease (eg self-medication with asthma puffers) are maintained. GPs should be aware that some sort of cognitive function test should be applied (refer to Cognitive function test), and a diagnosis should not be made until depression, physical disorders (eg electrolyte disturbance, brain tumour) and the possible effects of medications are excluded.

Clinical context

The rate of dementia overall is 10% in those aged >75 years. Dementia is common in residents in residential aged care facilities (RACFs), and the rates of prevalence are often quoted to be above 50%.3 However, 70% of people with dementia live in the community.

In the community, the spectrum of dementia is more at the mild-to-moderate level, where a few people with severe dementia in the community are cared for by families. Many people with dementia will enter RACFs for respite or longterm care several years after onset, when they require additional support for impairment in activities of daily living or behavioural and psychological symptoms of dementia (BPSD; refer to Part A. Behavioural and psychological symptoms of dementia).

Dementia and BPSD can have a significant physical and emotional effect on the patient, families and carers. The process of moving to an RACF can be difficult, and requires understanding and support.⁴ Some older people may develop dementia while living in an RACF. Therefore, GPs are likely to see residents with the full spectrum of dementia.

There are risks associated with making a dementia diagnosis, including the possibility of an adverse emotional reaction from the patient and/or their family. However, there are also benefits associated with making a dementia diagnosis, including:

- access to additional medications that require a formal diagnosis
- access to services that may enhance independence
- an understanding by the patient, family and staff that this patient has a chronic and terminal deteriorating condition, and will require increasing support
- support from Dementia Australia and other organisations for the person with dementia, their family and carers with strategies to live positively with dementia and compensate for deficits
- better management of medications and life decisions
- preparing for transition from driving
- preparation of the family for the patient's ongoing cognitive deterioration, so that legal issues (eg will, power of attorney for financial affairs, documents to support designated people to make health-related decisions, advance care directives) can be attended while the person still has capacity
- communication of the diagnosis in transitions of care (eg hospitalisation) so that appropriate expectations and action for care can be taken (eg the increased possibility of delirium postoperatively will require additional nursing care).

In practice

Dementia is an insidious process, which usually starts while the person is living in the community. At this stage, it does not readily reveal itself in the GP's office. However, in order to provide support for the person living with dementia and their family, and to avoid health, safety and other problems caused by functional decline, it is important that this diagnosis is made earlier rather than later.

The RACF setting in itself speaks to a population that is not managing at home for one reason or other, and rates of cognitive impairment in RACF settings are high. Talking to the patient may reveal changes in memory and other cognitive deficits that should not simply be attributed to old age. Family and professional carers may also cast light on cognitive deficits. Different types of dementia have different patterns of cognitive change. Refer to Box 1 on the typical characteristics of cognitive impairment in early dementia with different causes.

Box 1. Typical characteristics of cognitive impairment in early dementia with different causes⁵

- Early Alzheimer's dementia is an insidious process of gradual cognitive decline that particularly affects the ability to store new memories.
- Early vascular dementia is classically a 'subcortical' picture, with general slowing of mental processing, and can be more varied in presentation than Alzheimer's disease, with scattered changes across multiple cognitive functions
- Lewy body dementia tends to affect visuospatial and attention functions early in the disease process, and may be accompanied by fluctuating confusion, visual hallucinations, Parkinsonism and rapid eye movement sleep behaviour disorder.
- Frontotemporal dementia tends to affect executive and language function early in the disease process, and thus usually presents with behavioural, language or personality changes.

Diagnosing dementia

It has been noted that GPs are not comfortable with diagnosing dementia themselves; however, in rural and remote communities, and in the RACF setting, it may be difficult to access a specialist. In any case, whether or not the GP is intending to refer on for a presumptive diagnosis, the following six steps should be included in consultation with the patient and family:

- Step 1. Cognitive function test
- Step 2. Pathology tests
- · Step 3. Imaging
- · Step 4. Assessment for depression
- · Step 5. Medication review
- Step 6. Functional assessment

Cognitive function test

The Royal Australian College of General Practitioners' (RACGP's) *Guidelines for preventive activities in general practice* (Red Book) recommends the following cognitive function tests for the diagnosis of dementia:⁶

- Standardised Mini-Mental State Examination (SMMSE)⁷
- General Practitioner assessment of Cognition (GPCog)⁸
- Clock drawing test⁹
- Rowland Universal Dementia Assessment Scale (RUDAS; for detection of dementia across cultures)¹⁰
- Kimberley Indigenous Cognitive Assessment (KICA) tool as a component of dementia assessment for Aboriginal and Torres Strait Islander peoples living in remote areas¹¹
- Modified KICA, which may be used as a component of dementia assessment in more urban Aboriginal and Torres Strait Islander peoples

As noted in the Red Book, the Mini-Mental State Examination (MMSE) is the most widely used and evaluated scale. However, it is now copyrighted, and it should be replaced by the SMMSE. Cognitive function tests may be best undertaken by the patient's multidisciplinary team, which can include GPs, nurses, RACF staff, other specialist medical practitioners, allied health professionals, family and carers.

Pathology tests

Pathology tests should be conducted to exclude a medical cause of the patient's cognitive decline. These should include:1

- routine haematology
- biochemistry, including electrolytes
- calcium
- glucose
- renal and liver function tests
- thyroid function test
- B12 and folate levels.

Syphilis serology and human immunodeficiency virus (HIV) testing may be considered in specific cases. Abnormalities should be investigated and treated as fully as possible before a dementia diagnosis can be made.

Imaging

Imaging should be conducted to exclude brain tumour or other rare physical brain pathology (eg chronic subdural haematoma). Imaging (eg chest X-ray) may also be necessary to exclude chest pathology causing delirium.¹

Assessment for depression

It is important to note that depression may mimic dementia (ie pseudodementia), and it may also accompany dementia. A trial of antidepressants or talking treatment (eg those available from a psychologist) may be warranted. Note also that antidepressants do not work well for depression in the presence of dementia, although they may be helpful for agitation. 12

Of the antidepressants, selective serotonin reuptake inhibitors (SSRIs) are commonly recommended for patients with dementia. Of the SSRIs, citalopram is regarded as being the most effective for the management of dementia. Start with half the usual adult dose and increase as tolerated by the older person. Assess serum sodium after a fortnight as hyponatremia is common. It is important to reassess the patient for a treatment response at four to six weeks. ^{13,14} Strongly anticholinergic antidepressants (eg tricyclics) should be avoided because of their adverse effect on cognition.

Refer to Part A. Mental health for more information.

Medication review

A full and comprehensive medication review needs to be undertaken to exclude medications that may be affecting brain function. Psychotropics, medicines for urinary incontinence (refer to Part A. Urinary incontinence) and anticholinergics are common culprits; however, a pharmacist may find that a combination of other medications (eq antihistamines) may also be contributing. ¹⁵ Deprescribing should be undertaken if possible, and before a dementia diagnosis is made (refer to Part A. Deprescribing). It is vital to do this slowly and monitor for adverse effects.

Refer to Part A. Medication management for more information.

Functional assessment

A dementia diagnosis cannot be made unless there is interference with a person's function. Functional decline will occur if dementia is present, although this is sometimes difficult to distinguish from physical decline and may be subtle (eg loss of executive function, associated apathy). 16

If the person still presents with symptoms of dementia following treatment of any treatable abnormalities, the diagnosis of dementia should be considered.

Table 1 includes a comparison of the clinical features of delirium, dementia and depression.

Table 1. Comparison of the clinical features of delirium, dementia and depression 16

Feature	Delirium	Dementia	Depression
Onset	Acute/sub-acute depends on cause, often twilight	Chronic, generally insidious, depends on cause	Coincides with life changes, often abrupt
Course	Short, diurnal fluctuations in symptoms; worse at night in the dark and on awakening	Long, no diurnal effects, symptoms progressive yet relatively stable over time	Diurnal effects, typically worse in the morning; situational fluctuations but less than acute confusion
Progression	Abrupt	Slow but even	Variable, rapid-slow but uneven
Duration	Hours to less than 1 month, seldom longer	Months to years	At least 2 weeks, but can be several months to years
Awareness	Reduced	Clear	Clear
Alertness	Fluctuates; lethargic or hypervigilant	Generally normal	Normal
Attention	Impaired, fluctuates	Generally normal	Minimal impairment but is distractible
Orientation	Fluctuates in severity, generally impaired	May be impaired	Selective disorientation
Memory	Recent and immediate impaired	Recent and remote impaired	Selective or patchy impairment, 'islands' of intact memory
Thinking	Disorganised, distorted, fragmented, slow or accelerated, incoherent	Difficulty with abstraction, thoughts impoverished, marked poor judgment, words difficult to find	Intact but with themes of hopelessness, helplessness or self deprecation
Perception	Distorted; illusions, delusions and hallucinations, difficulty distinguishing between reality and misperceptions	Misperceptions often absent	Intact; delusions and hallucinations absent except in severe cases
Stability	Variable hour to hour	Fairly stable	Some variability
Emotions	Irritable, aggressive, fearful	Apathetic, labile, irritable	Flat, unresponsive or sad; may be irritable
Sleep	Nocturnal confusion	Often disturbed; nocturnal wandering and confusion	Early morning awakening
Other features	Other physical disease may not be obvious		Past history of mood disorder

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Communicating the diagnosis

Like all medical bad news, communicating the diagnosis, or possibility, of dementia can be difficult. A gradual and individualised approach is recommended. If the person does not want to know the diagnosis, this should be respected. Family are usually keen to know, and the GP should take time to talk to them as well with the consent of the patient.

Ongoing management

Apart from diagnostic assessments, a number of other assessment steps are required, and many of them will need to be regularly reviewed.

Functional capacity

Functional capacity should be regularly reviewed, and steps should be taken to support this. An enablement approach may assist with this objective, in which the person with dementia is enabled to perform activities if given the appropriate supports. Examples include:

- person to accompany on activities (eg golf to keep score), or change of duties or better supervision to allow continued employment
- organising a family member to pay the grocery bills so that shopping can be continued without concerns about counting out money or remembering PIN numbers
- appropriate walking aids (including regular review of footwear)¹⁷
- signage to enable them to find the toilet easier¹⁸
- modification of eating utensils and food to allow for self-feeding 19
- regular reminders to enable them to structure their day.²⁰

In RACFs, staff input for these tasks can be very helpful, but does require training and takes time. The GP may be in a position to advocate for such training, which may be provided through Dementia Support Australia and is free to the RACF. In the community, psychosocial support provided by Dementia Australia and other local initiatives may assist with maintaining physical, emotional and social functioning.

Behavioural and psychological symptoms

It is important to note that these symptoms may be subtle (eg apathy). Refer to Part A. Behavioural and psychological symptoms of dementia for more information.

Decision-making capacity

A dementia diagnosis in itself is not a reason to assume the patient lacks the capacity for many decisions. A person with dementia may not be able to decide on their share trading, but may be more than capable of deciding which program they wish to watch on television. A supported decision-making approach may be used for more complex decisions (eg move to a higher level of care).²¹

There are strong arguments for supporting the 'dignity of risk' in some cases. For example, a person in the community may wish to leave the bathroom window open a little so the cat can get in, and the comfort provided by the pet needs to be weighed against the more remote risk of a break-in.

Physical comorbidities

There are a number of common physical comorbidities of dementia that are often not appreciated, including:22

- impaired vision dementia affects the visual cortex and not eye problems per se
- falls dementia impairs the ability to appreciate physical surroundings (refer to Part A. Falls)
- weight loss not due to lack of food intake
- poor oral health not necessarily due to a lack of teeth cleaning

seizures – minor absences or more major seizures; these occur in up to 10% of people living with dementia.

GPs should be aware of these common physical comorbidities and take steps to treat them if possible. A special diet may be necessary, especially if oral health is poor. Fall prevention measures should be instituted, and the environment should be uncluttered and clearly labelled if possible. Discussion with family members, or staff if in an RACF about these issues may be helpful.

It should be noted that there is growing evidence that good nutrition (eg Mediterranean diet), regular exercise and social contact may alleviate symptoms of dementia and slow progression (secondary prevention). ²³ As noted in the UK's National Institute for Health and Care Excellence (NICE) guidelines, cognitive stimulation may also be helpful. ²⁴ Family should be encouraged to incorporate these into the daily routine. Discussion with staff should take place to encourage the resident to participate in some of these recommended activities when they are available.

It is important that other geriatric syndromes are recognised and managed appropriately, as residents with dementia often may not report specific problems during routine care. The RACF setting provides opportunities for carefully targeted prevention and intervention programs for care of common conditions in people with dementia, ^{25,26,27} including:

- · routine assessment of swallowing difficulties
- · monitoring verbal and non-verbal pain behaviours
- prompting patients to visit the toilet on a regular basis.

In the community, speech pathologists often have an underestimated role in relation to swallowing and communication techniques. Family need support and education in relation to these interventions.

Palliative care

GPs have an important role in the palliative care of people with dementia, including in making decisions about when the principles of palliation should apply. Often the question 'Would you be surprised if this person died within a year?' may assist in this process. This decision should be made with the family and other carers, and informed if possible by an advance care directive. Discussion should occur about whether the family and the person would wish to die at home, and how best to support this if possible.

Refer to Part A. Palliative and end-of-life care for more information.

Medication

The National Health and Medical Research Council's (NHMRC's) *Clinical practice guidelines and principles of care for people with dementia* recommends any one of three acetylcholinesterase inhibitors for managing the symptoms of mild-to-severe Alzheimer's disease, Parkinson's dementia, Lewy body dementia, vascular dementia or mixed dementia:¹

- donepezil
- rivastigmine
- · galantamine.

These should not be used for frontotemporal dementia because of severe side effects, and may exacerbate BPSD in this condition.

Initial prescription of acetylcholinesterase inhibitors on the Pharmaceutical Benefits Scheme (PBS; only available on the PBS for Alzheimer's disease) must be done in consultation with a specialist physician geriatrician or psychiatrist. To continue the use of these medications, there needs to be evidence of clinical improvement during the first six months of therapy.

A Cochrane Review has shown some evidence of benefit of acetylcholinesterase inhibitors in managing the symptoms of dementia.²⁸ In particular there is evidence that acetylcholinesterase inhibitors improve cognitive function, function in activities of daily living, BPSD, and possibly quality of life and caregiver burden. Acetylcholinesterase inhibitors do not alter the course of the disease, which is one of progressive decline.

These medications are associated with a number of adverse reactions in people with dementia, and should be closely monitored. The adverse reactions include:¹

- nausea
- vomiting
- diarrhoea

- dizziness
- increased urinary incontinence and frequency
- muscle cramps
- weight loss
- anorexia
- headache
- insomnia.

Heart block is rare, but is a serious potential adverse event; an electrocardiography should therefore be performed prior to prescribing the medication. Thyroid function may need checking. GPs should be aware that increased incontinence may follow, and watch for a prescribing cascade. In particular, anticholinergic medications (eg for incontinence) should be avoided or deprescribed, as they counteract the effects of the cholinesterase inhibitors (refer to Part A. Deprescribing).²⁹

Memantine is an option for those with moderate-to-severe Alzheimer's disease, and may also have efficacy for moderate-to-severe vascular dementia.³⁰ It is an N-methyl-D-aspartate (NMDA) receptor antagonist, which may be prescribed under authority for moderately severe Alzheimer's disease and continued if a clinically meaningful response is shown.

There are case reports of adverse drug withdrawal reactions, including worsening of cognition, so a decision to cease these medications should involve a gradual withdrawal, and regular review (eg every four weeks).

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