

# Dementia

## 14 essentials of management

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### Key points

- When a patient is diagnosed with dementia, implement a detailed care plan as soon as possible and follow up regularly.
- Encourage patients and their families to address issues relating to work, driving, finances and legal responsibilities.
- Ensure the patient's environment is dementia-friendly.
- For patients with Alzheimer's disease, consider prescribing specific medication when appropriate.
- Manage neuropsychiatric symptoms and comorbidities with nonpharmacological approaches whenever possible. When psychotropic treatments are considered necessary, minimise dose and duration and evaluate regularly for benefits and side effects.
- Ensure patients and carers have appropriate assistance and support, including community, respite and residential care.
- Monitor carers' ability to cope and level of distress; refer if indicated.

Dementia places a great burden on patients and their families and the challenges vary considerably over the course of the illness. We describe 14 practical points to guide management.

**D**ementia, or 'major neurocognitive disorder,' is usually characterised by the progressive deterioration of cognitive and functional abilities. At early stages of dementia, those affected (hereafter termed patients) may experience only slight deficits in their cognitive abilities that interfere with their capacity to function in daily life. At late stages of dementia, patients may be totally dependent on carers to survive. The course of decline varies considerably across patients and different types of dementia. The time from diagnosis to death typically ranges from two to 10 years (see Table 1).<sup>1,3</sup>

In the previous issue of *Medicine Today*, we outlined 14 essentials of assessment and care planning for patients with dementia.<sup>4</sup> Here we focus on management and describe 14 practical points that clinicians can apply to patients across different stages and types of dementia. The business case for care planning and relevant Medicare item numbers are listed in the previous article.

### THE FOURTEEN ESSENTIALS

#### 1. Implement a detailed care plan and follow up regularly

When a patient is diagnosed with dementia, a comprehensive care plan should be developed and implemented as soon as possible. This care plan may need to be more detailed and wide-ranging than for some other conditions as it needs to address psychosocial issues and specify the involvement of many different personnel (e.g. carers, community services and medical, nursing, and allied health services).

As noted in our previous article, the care plan will evolve and requires regular review. It should include:

- strategies for compensating for and managing specific cognitive deficits, including medications if appropriate
- strategies for preventing and managing behavioural and psychological symptoms
- strategies for managing medical and

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**TABLE 1. TYPICAL PROGRESSION OF DEMENTIA<sup>3</sup>**

	Mild cognitive impairment	Mild dementia	Moderate dementia	Severe dementia
<b>Dementia severity scores*</b>	<ul style="list-style-type: none"> <li>• CDR 0.5</li> <li>• GDS 3</li> </ul>	<ul style="list-style-type: none"> <li>• CDR 1</li> <li>• GDS 4</li> </ul>	<ul style="list-style-type: none"> <li>• CDR 2</li> <li>• GDS 5</li> </ul>	<ul style="list-style-type: none"> <li>• CDR 3</li> <li>• GDS 6 to 7</li> </ul>
<b>Cognitive symptoms</b>	<ul style="list-style-type: none"> <li>• Mild subjective complaints</li> <li>• Objective memory loss</li> </ul>	<ul style="list-style-type: none"> <li>• Forgetfulness</li> <li>• Short-term memory loss</li> <li>• Loss of interests, hobbies</li> <li>• Repetitive questioning</li> <li>• Anomia</li> </ul>	<ul style="list-style-type: none"> <li>• Progression of cognitive deficits</li> <li>• Dysexecutive syndrome</li> <li>• Aphasia</li> </ul>	<ul style="list-style-type: none"> <li>• Profound cognitive deficits</li> </ul>
<b>Daily living</b>	<ul style="list-style-type: none"> <li>• No impairment</li> </ul>	<ul style="list-style-type: none"> <li>• Impaired function in instrumental activities of daily living (e.g. shopping, housework, managing finances)</li> </ul>	<ul style="list-style-type: none"> <li>• Impaired function in basic activities of daily living (e.g. bathing, dressing, eating)</li> <li>• Care transitions</li> </ul>	<ul style="list-style-type: none"> <li>• Total dependence on carers</li> </ul>
<b>Behavioural and psychological changes</b>	<ul style="list-style-type: none"> <li>• Subtle personality changes</li> </ul>	<ul style="list-style-type: none"> <li>• Mild apathy</li> <li>• Withdrawal</li> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Increasing apathy</li> <li>• Other disturbances (e.g. anxiety, depression, aggression, delusions, hallucination)</li> </ul>	<ul style="list-style-type: none"> <li>• Profound apathy</li> <li>• Agitation</li> <li>• Altered sleep patterns</li> </ul>
<b>Approximate time frame<sup>†</sup></b>	0 to 3 years	3 to 5 years	5 to 7 years	7 to 10 years

\* CDR = Clinical Dementia Rating Scale (range 0 to 3, where 0 = no symptoms, 3 = severe symptoms).  
 GDS = Global Deterioration Scale (range 1 to 7, where 1 = no cognitive decline, 7 = very severe cognitive decline).  
<sup>†</sup> Time frame may vary across patients, across different types of dementia and with the age of patients.

- psychiatric comorbidities
- strategies for promoting general health and wellbeing, social engagement and quality of life
- safety issues (e.g. driving, work, risk of falls)
- legal and financial planning and advance care directives
- sources of support, education, and counselling for patients and for carers (carers may need specific support for their own health and wellbeing)
- regular follow up.

Management should aim to ensure that patients and carers continue to participate in community life, thereby reducing the likelihood of social isolation, and to maintain their physical and emotional wellbeing

as far as possible. Some specific options for social support include Alzheimer’s Australia, which offers the *Living with Memory Loss* and other programs, and local community health services, which may hold lunches and other activities.

Health professionals should also attempt to anticipate challenges and minimise difficulties. As the symptoms associated with dementia change over its course, the care plan will need to be reviewed regularly. It is usually necessary to see patients every three to six months. More frequent appointments may be necessary when medications are started or when challenging symptoms emerge. These will need to be billed outside the normal care plan review process if a

three-month care plan review has already been completed.

**2. Make an assessment of the patient’s ability to drive or refer the patient for an on-road driving test**

*This test can be done either with an occupational therapist or at the state driving authority. Regardless of the outcome, tell patients of their responsibility to inform their state driving authority and insurance company of their diagnosis*

All patients with dementia will eventually need to stop driving, some immediately. When possible, it is important to discuss this with patients early on to prepare them. Although all patients with a dementia diagnosis must have a conditional licence,<sup>5</sup>

this does not mean they automatically lose their ability to drive. It can be helpful to consider patients in three groups as follows:

**Group 1. Patients who are clearly unsafe and should stop driving immediately.**

This may be obvious from the history given by the patient or family (e.g. accidents, near misses, traffic infringements, instances of becoming disoriented while driving) or from evidence of dementia severity, impaired visuospatial skills (which are often associated with Lewy body dementia or posterior cortical atrophy), impulsivity or poor judgement. Scratches or damage to the patient's car may also be evidence of unsafe driving; this may be noted, for example, by the practice nurse on a home visit.

**Group 2. Patients in the very early stages of dementia who can temporarily continue to drive.**

These patients require regular review (at least six-monthly) and should be encouraged to work gradually towards not driving. This involves restricting driving to shorter distances, familiar routes and particular times (daytime but not peak-hour), as well as increasingly allowing their partner to take over the wheel. Patients may also need to explore alternative community and public transport options. Taxi vouchers are available for some patients.

**Group 3. Patients for whom driving ability is unclear.**

These patients should be referred for a specialist occupational therapy assessment at a specialist-driving centre or with a private occupational therapist. If this is not available or if patients cannot afford it, patients could instead complete an on-road driving assessment at their state licensing authority, although this test may not be as stringent. Patients' self-evaluations of their driving ability, performance on standardised cognitive tests and testimonials from family members are not reliable indicators of accident risk.

*Managing the change to nondriving*

The issue of driving can cause conflict with patients. Indeed, many GPs report

that they do not wish to be responsible for preventing patients from driving. Patients with dementia who continue to drive, however, can pose a serious risk to others, and the issue should be seen as a matter of public safety. Consider discussing with patients the potential impact an accident could have.

In Australia, there are a number of legislative requirements.

- As noted above, individuals with dementia cannot hold an unconditional driver's licence.<sup>5</sup> Individuals may be granted a conditional driver's licence that is subject to review at least annually. The licence may also restrict individuals' driving to a specified radius around their home.
- All drivers in Australia with a condition that can affect their ability to drive are legally required to inform their state licensing authority.
- In South Australia and the Northern Territory, it is mandatory for GPs to report drivers with dementia. In other states and territories, discretionary reporting applies. Patients who present a safety risk to themselves or others need to be reported.

Patients who continue to drive despite being declared medically unfit to do so may not be covered by their car or life insurance policies. Inform patients that they could face civil or criminal prosecution if they have an accident. Remind patients that their insurance may be jeopardised if they do not inform their insurance company about their diagnosis. Given the possible legal implications, be sure to document all discussions.

**3. Encourage patients and their families to address the necessary legal and financial issues as soon as possible**

Dementia requires patients and families to address many important legal and financial issues. It is important that they do this as early as possible so that patients with dementia can still express their views.

*Legal issues*

Specific issues that need to be addressed for both the patient and their spouse or family carer include:

- wills
- enduring power of attorney for financial and legal matters
- enduring guardianship for medical matters and service provision (this is also known as a medical power of attorney in some states)
- advance care directives.

Specific requirements and terminology vary across states and territories. Family members, particularly spouses, need to address all the same issues for themselves as problems can arise if the healthy family member dies before the patient with dementia.

*Work*

Patients will need to cease working when their dementia becomes too severe. This transition from work should be gradual, if possible, to avoid the accompanying grief. In some occupations, however, particularly those involving the safety of others (e.g. machinery operators, pilots, surgeons), patients may need to give up work immediately. In these cases, psychological support may be particularly important. Consider referring patients with dementia to a psychologist or counsellor if they exhibit mental health problems such as depression or anxiety. Unpaid volunteer work, including grandparenting duties, may need review.

Working carers, who need to juggle their work and caring, can be encouraged to negotiate flexible work arrangements and to seek support services to enable them to continue working (see <http://www.workingcarers.org.au/>). They may also need to reduce the hours they work or stop altogether in order to care for family members.

*Financial assistance*

With both the patient and carer not earning their customary income, families can be under considerable financial pressure. Patients and their families may be eligible

**SUGGESTIONS FOR MAKING THE ENVIRONMENT DEMENTIA-FRIENDLY**

**Encourage patients and carers to make activities and routines visibly obvious and include aids for memory and orientation in the environment**

- Set up frequently used furniture and objects in places that are easy to find (e.g. on bench tops rather than in cupboards)
- Display analogue clocks and large wall calendars or electronic clocks that show time, day and date prominently
- Display a weekly routine of regular activities on a whiteboard
- Use colour-coded or graphic labels on drawers and cupboards to assist orientation

**Encourage patients and carers to make sure that the environment is safe and easy to navigate**

- Remove loose rugs, obtrusive cords, slippery floors, and low furniture (e.g. lounge chairs and coffee tables) that could cause falls
- Highlight step edges
- Install grab bars next to the toilet and in the shower
- Remove hazardous chemicals and medications
- Assess the adequacy of footwear and walking aids
- Assess the risk of falls in patients' typical activities and routines

**Encourage patients and carers to make sure that the environment is comfortable**

- Simplify the environment; avoid household clutter and put away items that are not regularly used
- Reduce excess visual and auditory stimulation, which can lead to agitation and disorientation (e.g. avoid glare from windows and mirrors, noise from radio and television)

for financial assistance. Patients may be eligible for:

- superannuation on medical grounds
- sickness allowance
- disability support pension

Carers may be eligible for either:

- carer's payment (if the carer would otherwise be able to work); this is equivalent to a pension (\$733 per fortnight for a single person as of May 2013) and is means tested, or
- carer's allowance (if the patient is looked after at either the patient's or carer's home and the patient needs care and attention on a daily basis); this is \$115 per fortnight (May 2013) and is not means tested (<http://australia.gov.au/topics/benefits-payments-and-services/carers-payments-and-services/carers-payments-and-allowances>).

GPs should inform patients and their carers of these possibilities. Further information can be obtained from Centrelink

(Disability, Sickness and Carers) (<http://www.humanservices.gov.au/customer/themes/carers>; telephone 132717).

**4. Encourage patients and carers to make the patient's environment dementia-friendly**

*A general rule where there is a conflict between the environment and the person is to change the environment, not the person* Encourage patients and carers to make the patient's home environment 'dementia friendly', such that it supports their everyday functioning and promotes their safety. Key principles are to make activities and routines visibly obvious and display memory aids, to make sure the environment is safe and easy to navigate, and to make sure the environment is comfortable.

It can be helpful to give patients and carers specific suggestions (see the box on this page). Patients and carers should also be referred to more detailed sources of information (e.g. Alzheimer's Australia).

It may be helpful for them to consult an occupational therapist.

**5. Promote the independence of patients with dementia for as long as possible**

*Use nonpharmacological approaches to compensate for the cognitive symptoms of dementia*

The cognitive deficits of dementia can present many challenges to patients. Where possible, use strategies and aids to compensate for these deficits. As noted above, environmental aids such as whiteboards and clocks can be helpful in this regard. Notepads, smartphones and tablet computers may be helpful to compensate for memory loss in the early stages of dementia. Some problems may require creative solutions; for example, using velcro instead of buttons to dress patients with dyspraxia, and photographing an item or person to be remembered using a mobile phone.

Engaging in physical, mental and social activities may help patients to maintain aspects of their functioning. Regular pleasant events can also help to improve patients' mood. Patients should be encouraged to continue hobbies or interests. Suggest new activities, particularly ones that create a sense of mastery, importance or feeling useful. Where possible, emphasise patients' abilities and strengths, and encourage them to maintain their autonomy when it is safe and realistic to do so. It is important that patients maintain a sense of control where possible, feel valued and continue to participate in activities that give their life meaning.

**6. For patients with Alzheimer's disease, prescribe medication where appropriate**

There are currently no drugs available to prevent dementia or modify the neuropathology of Alzheimer's disease. However, there are two types of medications available for Alzheimer's disease that may temporarily improve cognitive function or slow the rate of cognitive and functional decline. It is important to communicate the expected

**MEDICATIONS FOR ALZHEIMER'S DISEASE: CONTRAINDICATIONS AND ADVERSE EFFECTS**

**Acetylcholinesterase inhibitors (mild to moderate AD)**

**Relative contraindications include:**

- heart block
- bradyarrhythmias
- seizure disorder
- bronchospastic disease (e.g. asthma)
- active peptic ulcer
- obstructive urinary disease
- inability to ensure medication compliance

**Common adverse effects include:**

- nausea, vomiting, diarrhoea
- abdominal pain
- frequent urge to empty bladder or bowel
- bradycardia
- postural hypotension
- appetite and weight loss
- insomnia and nightmares
- muscle cramps
- skin reactions (with rivastigmine patch)

**Memantine (moderate to severe AD)**

**Contraindications include:**

- hypersensitivity to either the active ingredient or any of the excipients
- seizure disorder or history of seizures

**Common adverse effects include:**

- dizziness
- drowsiness
- headache
- constipation
- hypertension

ABBREVIATION: AD = Alzheimer's disease.

modest benefits of the medications – and that decline will continue despite the medication – to patients and their families.

*Mild to moderate Alzheimer's disease*

For mild to moderate Alzheimer's disease, acetylcholinesterase inhibitors are recommended. There are currently three acetylcholinesterase inhibitors available for

Alzheimer's disease:

- donepezil tablets, 5 mg and 10 mg
- galantamine prolonged release capsules, 8 mg, 16 mg and 24 mg
- rivastigmine transdermal patches, 4.6 mg per 24 hours and 9.6 mg per 24 hours; rivastigmine capsules and oral solutions continue to be available but are less often used.

Tacrine, an early acetylcholinesterase inhibitor, is no longer widely available. It has a short half-life requiring doses four times daily and is associated with liver damage.

There is no significant difference in effectiveness between the three available acetylcholinesterase inhibitors. Choice depends on availability, cost and side effects. Contraindications and common adverse effects are shown in the box on this page. Adverse effects can be minimised by titrating the dose up gradually and ensuring that patients take the medication with meals. Side effects usually resolve over time, or if necessary with dose reduction. Monitor patients who have a history of peptic ulcer or who are taking NSAIDs; monitor patients for bradycardia if they are taking  $\beta$ -blockers or other rate-slowng medications. If a patient has intolerable side effects, try a different acetylcholinesterase inhibitor. Patients who do not respond to one acetylcholinesterase inhibitor may respond to another.

Souvenaid is a recently released nutraceutical or 'medical food' combining vitamins and lipids. It contains a variety of nutrients, including uridine, choline, fish oil, phospholipids vitamins and minerals, at levels difficult to achieve from normal dietary intake alone. Souvenaid is intended to be used under medical supervision and is accessible over-the-counter from pharmacies. Two trials have shown modest improvement in memory but no improvement in global cognition or function. Another caveat is that it is unknown whether Souvenaid provides additional benefit for people with Alzheimer's disease already taking an acetylcholinesterase inhibitor as all trial participants were drug naive. Also, as the trial durations were

12 and 24 weeks, respectively, it is not known whether prolonged use is beneficial. Finally, the cost of Souvenaid (\$4.16 per day) is an important consideration.

*Moderate to severe Alzheimer's disease*  
Memantine is available for moderately severe to severe Alzheimer's disease. Contraindications and the more common side effects are shown in the box on this page. Memantine is usually well tolerated although the dose may need to be reduced in patients with renal impairment.

*Prescribing medication for Alzheimer's disease*

Common regimens for acetylcholinesterase inhibitors and memantine are shown in Table 2. After starting a medication, patients should be regularly reassessed. This should include standardised tests of cognition and function to determine the medication's effectiveness. Carers or family members can also be consulted.

Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive ability, functional ability or behavioural symptoms. If side effects develop, the dose should be reduced. If side effects do not resolve, the medication should be stopped.

Criteria for PBS subsidisation of Alzheimer's medications are as follows.

- Initial prescription requires documented confirmation of the diagnosis of Alzheimer's disease and the appropriateness of medication in consultation with a specialist/consultant physician (doctors, especially those in rural areas, can communicate with a specialist by telephone or electronically to obtain confirmation), a baseline score on the Mini-Mental State Examination (MMSE) and a written script to be submitted for authorisation.
- Continuation requires improvement as a result of the medication. From May 2013, clinicians need only certify that there has been a 'clinically meaningful improvement' (the previous

**TABLE 2. MEDICATIONS FOR ALZHEIMER'S DISEASE: COMMON REGIMENS**

Medication	Regimen
Donepezil	One-step titration <ul style="list-style-type: none"> <li>• Start with 5 mg once daily (morning or night after a meal)</li> <li>• After one month increase to 10 mg once daily after a meal</li> <li>• If side effects occur at any stage, halve the dose and try to increase again later</li> </ul>
Galantamine	One-step titration <ul style="list-style-type: none"> <li>• Start with 8 mg prolonged release capsule (PRC) in the morning (or 4 mg immediate release twice daily)</li> <li>• After one month, increase to 16 mg PRC in the morning (or 8 mg immediate release twice daily)</li> <li>• If side effects occur, reduce to previous level</li> </ul>
Rivastigmine	One-step titration <ul style="list-style-type: none"> <li>• Start with rivastigmine patch 5 – apply a new patch once daily to back, upper chest or outside of upper arms (in rotation) and remove previous day's patch</li> <li>• After one to two months, use rivastigmine patch 10 – apply once daily as above</li> </ul> Oral preparations are also available but are less often used; these require twice daily doses and a four-step titration
Memantine	Four-step titration over four weeks <ul style="list-style-type: none"> <li>• Start with 5 mg (half a 10 mg tablet) once a day after a meal for one week</li> <li>• Increase to 10 mg (one 10 mg tablet) daily for the second week</li> <li>• Increase to 15 mg (one and a half 10 mg tablets) daily for the third week</li> <li>• Maintain at 20 mg (two 10 mg tablets) daily for the fourth week and beyond</li> <li>• If side effects occur, reduce to previous level. Try to increase again later</li> </ul>

requirement that patients demonstrate improvement on a standardised cognitive test, such as the MMSE or the Alzheimer's Disease Assessment Scale – Cognitive Subscale, is no longer needed). Streamlined authorisation is available for a continuation script every six months if the clinician determines that the patient has demonstrated a clinically meaningful response to the treatment.

Acetylcholinesterase inhibitors and memantine are not approved by the TGA for patients at risk of dementia or patients with dementias other than Alzheimer's disease. GPs should ensure that all patients

with dementia and their families or carers are aware of opportunities to participate in research studies, particularly of dementia treatments.

**7. Manage the behavioural and psychological symptoms of dementia**

Almost all patients with dementia experience behavioural and psychological symptoms (BPSD; these are also referred to as neuropsychiatric or noncognitive symptoms). The symptoms vary between patients and over time and include:

- mood disturbances (e.g. anxiety, apathy, depression, euphoria)

- hyperactivity-type symptoms (e.g. aberrant motor behaviour, aggression, agitation, disinhibition, irritability, restlessness)
- psychotic symptoms (e.g. delusions, hallucinations, paranoia)
- other behavioural symptoms (e.g. changes in appetite, hoarding, night-time behaviour disturbances, wandering).

These symptoms become more common as dementia progresses and are a major cause of stress to carers.

*BPSD assessment*

When behavioural and psychological symptoms occur, assess factors that may cause, aggravate or reduce the behaviour. Assessment should first exclude physical causes, such as delirium (which is common in patients with dementia), urinary tract infection or a drug reaction. Other factors such as the environment and behaviour of others should then be considered.

The assessment should include:

- frequency of the behaviour over time
- the context and consequences of the behaviour (ABC: antecedents, behaviour description, consequences)
- mental health
- physical health
- medication side effects
- previous habits and beliefs
- psychosocial factors
- factors in the physical environment
- possible undetected pain or discomfort.

*BPSD management*

Interventions are not always needed, particularly if the behavioural and psychological symptoms are infrequent or mild. If intervention is deemed necessary, try nonpharmacological approaches before medication. Environmental modification can be helpful (e.g. secure grounds for people who wander). Aspects of patients' routines and their interactions with carers can also influence symptoms. Some general principles for carers to minimise disturbances are shown in the box on page 37.

Other nonpharmacological activities or therapies that may be helpful include animal-assisted therapy, aromatherapy, humour therapy, massage, multisensory stimulation, carer-administered therapy (e.g. tailored activities, problem solving, pleasurable events), music and dance. GPs can obtain advice about the availability of these activities and training sessions for carers from their local Dementia Behaviour Management Advisory Service (DBMAS; national 24-hour helpline 1800 699 799).

If other approaches are ineffective or the severity of the condition requires a quicker response, pharmacological interventions (usually in tandem with psychosocial strategies) may be necessary. Possible interventions are as follows.

- For depression and anxiety, short-acting selective serotonin reuptake inhibitors (SSRIs) such as citalopram and sertraline are usual first-line treatments.
- For agitation, paracetamol (1 g tablets three times daily) may be helpful.
- For psychotic symptoms or severe aggression, antipsychotic drugs can be considered, with stronger evidence for risperidone and some evidence for olanzapine. Antipsychotics should be avoided unless absolutely necessary because they are associated with increased risk of stroke and death in patients with dementia,<sup>6</sup> and have been associated with a faster rate of cognitive decline.
- In patients with Alzheimer's disease, acetylcholinesterase inhibitors may be helpful for some behaviours, such as apathy and hallucinations. Memantine has been reported to be of benefit for the cluster of agitation, aggression, hallucinations and delusions.<sup>7</sup>

All behaviours should be specifically documented (what, when, how often) before and after starting any intervention, and drugs should be used in conjunction with a behavioural intervention program.

For all medications, a general rule is to start on a low dosage and increase it slowly while monitoring frequency and severity

of target symptoms as well as adverse effects. After behavioural disturbances have been controlled for three to six months, the dosage of the medication should be reduced periodically to determine whether it is still needed. Depending on state laws, psychotropic interventions may require informed or proxy consent, verbally or in writing.

### **8. Manage physical and psychological comorbidities**

Comorbid conditions are common in older patients with dementia. Management of conditions such as depression and comorbid physical conditions can minimise disability and improve quality of life. It is important to consider the stage of dementia and how it might affect the benefits and risks of treatment, the patient's capacity to make informed decisions and adherence to treatment. In advanced dementia, for example, pain (such as from osteoarthritis) is often unrecognised because patients may not be able to communicate verbally. Observational pain assessment tools such as the Abbey Pain Scale can help to identify pain (it can be useful to ask carers – formal or informal – to complete these assessment tools).

Likewise, treatment and preventive options may be assessed differently in late stages of dementia because patients' quality of life may be more important than prolonging their survival. An implication is that it may be necessary to review the need for some preventive medications (e.g. statins, bisphosphonates, and anticoagulants for atrial fibrillation) for diseases that might occur in the future, particularly if taking oral medication is causing patients difficulties. Indeed, polypharmacy can directly contribute to dysphagia (pills are not treated by the oesophagus the same way as food), so there is a need to reduce patients' medications as dementia severity increases. It is important, however, to continue influenza vaccinations, particularly as dementia patients with influenza can infect other people. Given the ethical issues involved in withholding medications based on patients' quality of life, it is important

### **GENERAL PRINCIPLES FOR MINIMISING BEHAVIOURAL AND PSYCHOLOGICAL DISTURBANCES**

- Establish a simple, predictable routine
- Ignore unwanted behaviour or walk away (avoid arguing or scolding)
- Reinforce adaptive behaviour with compliments
- Use distraction to redirect patients' attention from distressing situations
- Avoid infantilising patients (e.g. offering sweets or saying 'I just told you that')
- Use humour and empathy
- Take things slowly; avoid any rush
- Simplify all tasks; break them into smaller steps
- Focus on one task or one concept at a time
- Before any activity, explain each step in simple language and repeat if necessary
- Ensure consistency and avoid change wherever possible

to discuss such decisions with patients and/or carers and to obtain informed consent.

As for all interventions, nonpharmacological approaches – if available – should be considered before medication. If medications are used, there should be a definite treatment goal and regular monitoring of their benefits and side effects. The number of medications should be limited as much as possible because of the potential for additive drug toxicity or complex interactions. Medications with anticholinergic effects, in particular, should be managed carefully and avoided if possible because they can exacerbate cognitive impairment and cause confusion and delirium (some common medications with anticholinergic effects are shown in the box on page 38). Similarly, benzodiazepines can exacerbate cognitive impairment and also impair gait and increase risk of falls.

### **9. Promote the general health and wellbeing of the patient**

It is important to promote the general

**EXAMPLES OF COMMON MEDICATIONS WITH ANTICHOLINERGIC EFFECTS\***

<b>Analgesics</b> Codeine	<b>Antihistamines</b> Chlorpheniramine <sup>†</sup> Cyproheptadine <sup>†</sup> Dexchlorpheniramine <sup>†</sup> Diphenhydramine <sup>†</sup>	Oxybutynin <sup>†</sup> Propantheline <sup>†</sup>
<b>Antidepressants</b> Amitriptyline <sup>†</sup> Clomipramine <sup>†</sup> Doxepin <sup>†</sup> Imipramine <sup>†</sup> Nortriptyline <sup>†</sup> Paroxetine Trimipramine <sup>†</sup>	<b>Antipsychotics</b> Chlorpromazine <sup>†</sup> Clozapine <sup>†</sup> Fluphenazine <sup>†</sup> Olanzapine	<b>Cardiovascular drugs</b> Digoxin Disopyramide
<b>Antiemetics</b> Prochlorperazine Promethazine <sup>†</sup>	<b>Antispasmodics</b> Belladonna alkaloids <sup>†</sup> Hyoscyamine <sup>†</sup>	<b>Diuretics</b> Frusemide
		<b>Gastrointestinal drugs</b> Atropine–diphenoxylate <sup>†</sup>
		<b>H<sub>2</sub>-blockers</b> Cimetidine Ranitidine

\* Many other medications not listed also have anticholinergic properties.<sup>9</sup>

<sup>†</sup> Indicates medications with particularly strong anticholinergic effects.

health of patients with dementia. General principles apply.

**Diet.** A healthy diet is important to ensure adequate hydration and intake of nutrients and vitamins. Dietary supplements may be considered if nutrition is poor. Meals-on-wheels should be considered for those living alone. However, it may be preferable to offer meals with other services, such as Community Aged Care Packages or day centres. Regular weighing of patients should be considered as part of the care plan.

**Exercise.** Patients should be encouraged to participate in physical activity appropriate to their interests and capabilities. It can be helpful to include exercise in their routine and to engage the carer in the program.

**Social engagement.** Patients should be encouraged to participate in social activities. Such activities can improve patients' mood and may help maintain cognitive function.

**Medication.** Patients should be discouraged from consuming excessive amounts of alcohol or from taking other potential drugs of abuse (especially tranquillisers). As dementia progresses, tolerance for drugs and alcohol often decreases.

**Routine immunisations.** Patients' immunisation history should be checked and vaccines administered if necessary (e.g. annual influenza immunisation).

**Prevention of falls.** Patients with dementia are at risk of falling. Prevention of falls involves assessing and modifying environmental risks and footwear, managing risky behaviours, and offering physical aids if appropriate.

**10. Facilitate more effective care by referring patients and carers to sources of information and support. Encourage carers to participate in carer training programs**

Facilitating more effective care can markedly improve the quality of life of both patients and their carers. Encourage patients and carers to obtain guidance and assistance, if available, and encourage carers to participate in carer training programs.

Useful resources include:

- the My Aged Care website and call centre (<http://www.myagedcare.gov.au>; 1800 200 422), which provides information on all aged care services in Australia

- Alzheimer's Australia, which can provide information and support for all types of dementia (<http://www.fightdementia.org.au>; 1800 100 500)
  - Carer's Australia (<http://www.carersaustralia.com.au>; 1800 242 636)
  - Commonwealth Respite and Carelink Centres (<http://www9.health.gov.au/ccsd/>; 1800 052 222)
  - the Dementia Behaviour Management Advisory Service, which can provide support for carers and professionals who are looking after patients with behavioural and psychological symptoms of dementia (<http://www.dbmas.org.au>; 1800 699 799)
  - local information services such as the Dementia Advisory Services in NSW.
- In later stages of dementia, patients become increasingly dependent, and carers may require help from a community nurse or personal care assistant.

Patients living at home usually require assistance with some activities. If they require only a small amount of assistance to stay at home, they can access services directly from local organisations through the Home and Community Care (HACC) program (local contact details are available from My Aged Care). Services include assistance with bathing, shopping, cooking, cleaning and transport.

If patients require more assistance at home, they may require a home care package. There are four levels of packages available reflecting different care needs (Level 1 for basic care needs, Level 2 for low-level care, Level 3 for intermediate care, and Level 4 for high-level care). Packages are tailored to the patient's needs and can range up to 21 hours per week. There is the possibility of a dementia supplement for each level for those with behavioural and psychological symptoms and for Department of Veterans' Affairs beneficiaries. All new packages are offered on a consumer-directed basis, in which patients (and their families) determine the level of assistance they would like (consumer-directed care packages will be mandated for all new and pre-existing packages from July 2015).

To obtain a home care package, patients first require approval from an Aged Care Assessment Team/Service (ACAT/ACAS; local contact details are available through My Aged Care). If approved, the ACAT/ACAS refers patients to home care providers in their area. It is useful to plan ahead as it may be necessary to wait first for assessment (depending on how the patient is prioritised by the ACAT/ACAS) and then for institution of services.

Management of dementia is often multidisciplinary and may involve allied health staff such as occupational therapists, physiotherapists, psychologists and social workers. Some of these services can be accessed through the HACC program or a home care package. Management of dementia may also involve staff outside the health system, including community workers, religious and cultural group workers. For patients without family carers, broader community resources and/or the paid social service system may be particularly important, although in many cases the GP will become aware of specific resources only through patients themselves or through local information services.

**11. Monitor how the carer is coping with their role and link them to resources for support**

Looking after patients with dementia is burdensome for carers, who are often referred to as ‘the second patient’. This level of burden does not necessarily correlate with the years spent as a carer or the severity of the patient’s dementia. Common issues faced by family carers are shown in the box on this page.

Carers may suffer from poor physical and mental health as a result and may require clinical attention. Many carers also derive satisfaction and feel rewarded for being able to reciprocate a lifetime of support from their loved one. Carers who see a different GP to the patient should be referred to their own GP with an offer of cooperation in management.

If the carer accompanies the patient with dementia to appointments, check on the

**COMMON ISSUES FACED BY FAMILY CARERS**

- Grief and bereavement at the gradual loss of parts of the patient (‘the long goodbye’)
- Anxiety over plans for the future
- Guilt
- Isolation and loneliness
- Intimacy and sexuality issues
- Stress coping with the burden of caring
- Stress coping with difficult behaviours
- Conflict with other family members
- Lack of time for themselves
- Lack of control over their lives, feeling trapped
- Depression and hopelessness
- Neglect of their own physical health

carer at each visit. Alternatively, a GP looking after a carer should monitor their caring responsibilities, even though they do not deal directly with the patient with dementia. Questions to ask the carer include:

- How are you coping with looking after ... [the patient]?
- What practical support do you have?
- What emotional support do you have?
- Do you need assistance or respite care?
- How is your health?
- How are you looking after yourself?

Monitor the carer at crisis points – for example, at diagnosis, during the patient’s transition from home to residential care, and when end-of-life decisions are made.

Encourage all carers to seek support for themselves. Alzheimer’s Australia coordinates a large number of support groups throughout Australia, offers free specialist counselling services and runs helpful training courses. Carers Australia and Commonwealth Respite and Carelink Centres also offer support services, including a national carer counselling program (this can be contacted on 1800 242 636 in business hours). A referral for psychological help under a Mental Health Care Plan is justifiable for a carer who is suffering from depression or anxiety.

**12. Consider respite care as part of the long-term management plan**

Respite care allows carers the opportunity to have a break. Given the stress that carers are under, consider respite care in any long-term management plan. Suggest it to carers early rather than waiting for them to raise the issue. Respite care may be regular or intermittent and is increasingly more flexible. It includes:

- in-home care, where a care worker comes into the patient’s home, including overnight care
- day programs and centre-based care, where the patient is taken to a day centre or individual or small group outings
- overnight respite cottages
- carer retreats, usually in holiday-like locations
- residential care, where patients are placed in an aged care facility for a period of time.

Residential respite care needs to be planned in advance as it is rarely available at short notice. It also needs to be planned carefully to maximise the possibility that the respite care will be compatible with patients and their needs.

Approval to stay in a residential aged care facility must be arranged through an ACAT/ACAS. Further information about respite care and access to these services is available through My Aged Care. Residential respite in some other settings, such as overnight cottages, is available through Commonwealth Respite and Carelink Centres, which can also arrange emergency respite (telephone 1800 052 222; and 1800 059 059 outside business hours).

**13. Consider whether some form of institutional care might better meet the needs of patients and their carers**

Dementia is characterised in its final stages by a loss of basic daily functional abilities. When the strain on carers becomes excessive or the person with dementia needs 24/7 care, some form of residential care may be necessary. Common tipping points for

carers to make the decision to seek residential care are when the patient becomes incontinent, stops recognising the carer or becomes too behaviourally disturbed. Permanent care requires prior ACAT/ACAS assessment and needs to be planned because it may take time to organise and for a place to become available. Patients and their families may need to visit several facilities and seek opinions from others in order to find a facility with which they are comfortable (information about local aged care facilities is also available through My Aged Care). Expectations about what is available need to be realistic: residential care, for example, will not prevent falls, and staffing ratios do not provide 24-hour one-on-one care.

Placing patients in residential care can be emotionally very difficult for family members. The decision is often associated with very strong feelings of guilt and grief. It can be helpful to acknowledge these feelings and to encourage the family members to seek counselling or support.

#### 14. Discuss end-of-life care with the patient and their family early on

About 50% of patients with dementia reach the terminal stage of their illness, with the remainder dying earlier from comorbidities. These terminal stages are often characterised by malnutrition, functional dependence, pressure areas, recurrent aspiration and dysphagia. In one large influential US study, 54.8% of nursing home residents with advanced dementia died within 18 months; the six-month mortality rate for residents who had pneumonia was 46.7%, a febrile episode, 44.5%, and an eating problem, 38.6%. Distressing symptoms were common at this stage of dementia, yet in the last three months of life, 40.7% of residents underwent at least one burdensome intervention, although this was less likely if families understood the prognosis.<sup>9</sup>

End-of-life care should aim to maximise the quality of life of patients and to support carers during their bereavement. It is important to discuss end-of-life care with patients and their families early on, and to understand and document their

preferences. This may be done, for example, as a case conference with a billable Medicare item number. Key issues to discuss about end-of-life care include artificial feeding, the use of antibiotics, and 'do not resuscitate' orders. It is usually best to avoid futile care that does not provide comfort and prolongs the dying process. It is important to obtain the patient's views early. All discussions should be documented.

When appropriate, discuss the clinical course of advanced dementia with patients and carers. Many symptoms of advanced dementia can be distressing and burdensome. These symptoms include the inability to communicate, to remember or recognise friends and family, or to recognise or use familiar objects, restlessness, agitation, incontinence and total dependence in basic activities of daily living. Possible comorbidities of advanced dementia can also be difficult to bear. These comorbidities include, for example, dyspnoea, pain, pressure ulcers, aspiration, sleep difficulties, pneumonia, fever and eating problems.

Patients should be encouraged to eat and drink by mouth for as long as possible. Artificial (tube) feeding is usually not advisable if dysphagia is stable or reflects end-stage dementia.<sup>10</sup> If patients in the terminal stages of dementia have a fever, it may be sufficient to offer simple analgesics, antipyretics and mechanical means of cooling.<sup>10</sup> Antibiotics should be considered on a case-by-case basis after discussion with the family. Good mouth care is also particularly important; poor mouth care with dry mouth can contribute, for example, to the perception of thirst and to considerable discomfort. Finally, as already noted, it is important to assess for and treat pain in patients with advanced dementia as many may not be able to communicate their pain verbally.

#### CONCLUSION

The primary care physician will need to respond to very different challenges across the course of dementia. A strong working relationship with patients, their carers and other health and aged care professionals is

crucial to meeting these challenges effectively, as is the ability to provide appropriate referrals. As for all patients, empathy and compassion within professional limits can make a significant difference to those who are suffering. **MT**

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A list of references is included in the website version (<http://www.medicinetoday.com.au>) and the iPad app version of this article.

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# Dementia

## 14 essentials of management

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