CLINICAL PRACTICE GUIDELINES FOR DEMENTIA IN AUSTRALIA

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Members of the Guideline Adaptation Committee generously contributed their time to assist in the development of this Guideline.

This publication is an adaptation of 'Dementia: Supporting people with dementia and their carers in health and social care', published by the National Collaborating Centre for Mental Health (NCCMH, www.nccmh.org.uk) in 2006. The original publication is available from www.nice.org.uk/guidance/cg42/evidence. The NCCMH has not checked the adaptation to confirm that it accurately reflects the original NCCMH publication and no guarantees are given by the NCCMH in regard to the accuracy of the adaptation. The NCCMH guideline that this adaptation is based upon was prepared for the National Institute for Health and Care Excellence (NICE) for use by the National Health Service in England and Wales. NICE guidance does not apply to Australia and NICE has not been involved in the development or adaptation of this guidance for use in Australia.

Endorsements

A list of organisations formally endorsing the Guideline will be provided.
Plain English summary

Dementia is the name given to a number of conditions (including Alzheimer’s disease) that affect memory, thinking, behaviour and ability to perform activities of daily living.[1] People with dementia describe the condition as disabling, challenging, life changing and stressful.[2] The impact of dementia on carers is significant and caring for a person with dementia may lead to poor health, depression and social isolation.[3]

Approximately one in 10 Australians aged 65 and over have a diagnosis of dementia.[4] As Australia’s population ages, the number of people with dementia is expected to increase. Dementia has been named as a National Health Priority Area.

This Clinical Practice Guideline is written primarily for health and aged care staff (doctors, nurses, allied health and care workers) who work with people with dementia in community, residential and hospital settings. Health and aged care staff should apply the recommendations in their workplaces while also responding to the needs and preferences of the person with dementia and their carer(s) and families. The following key points are addressed within the recommendations.

- The symptoms of dementia should be investigated the first time they are reported and not dismissed as a ‘normal part of ageing’.
- Health and aged care professionals should talk to the person with dementia and their carer(s) and families about the symptoms of dementia, treatments and services, including those offered by Alzheimer’s Australia. Written information (such as brochures) should also be provided.
- Doctors, nurses, allied health and care workers should receive training in dementia care. They should be trained in how to communicate clearly with the person with dementia, their carer(s) and families and to provide person-centred care.
- The person with dementia should be encouraged to keep doing as much for themselves as possible and staff and carer(s) should be taught how to encourage independence.
- Medical practitioners should consider medication (acetylcholinesterase inhibitors or memantine) to manage the cognitive symptoms of dementia.
- Steps should be taken to prevent, recognise and manage common behavioural and psychological symptoms of dementia such as depression and agitation. In most cases, training the carer to provide care, forming specific strategies to address behaviours that are most upsetting, making small changes to the living environment and finding interesting and enjoyable activities for the person to do should be tried first. Medication to manage these symptoms should usually only be offered after these other strategies have been given an adequate trial.
- Carer(s) and families should be supported to care for the person with dementia. They should be offered education and training to enable them to develop skills in managing the symptoms of dementia and be offered respite when needed. Carers should be given information about coping strategies to maintain their own wellbeing and be supported to maintain their overall health and fitness.
- Care should be culturally appropriate. Professional interpreters should be involved, particularly at key points including during assessment, when communicating the diagnosis and when gaining consent.
EXECUTIVE SUMMARY

In Australia, approximately one in 10 older Australians have a diagnosis of dementia.[4] Dementia has a significant impact on the lives of people diagnosed with dementia, their carers and families. Dementia is a national health priority. Clinical Practice Guidelines have been shown to improve quality and consistency of care for people with a range of conditions.[5] To date, there have been no Australian dementia guidelines approved by the NHMRC.

The recommendations within this Clinical Practice Guideline were formed using the ADAPTE process [6] in which recommendations from an existing high quality guideline (the NICE Guideline developed by the National Collaborating Centre for Mental Health in the United Kingdom [7]) were adapted to suit the Australian context. The adaptation process included conducting systematic reviews to ensure that the Clinical Guideline reflects the most recent research evidence.

Recommendations are classed as ‘evidence-based recommendations’, ‘consensus based recommendations’ or ‘practice points’.

Table 1 Definitions of types of recommendations

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<tr>
<th>Type of recommendation</th>
<th>Description</th>
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<tr>
<td>Evidence-based recommendation (EBR)</td>
<td>Recommendation formulated after a systematic review of the evidence, with supporting references provided</td>
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<tr>
<td>Consensus based recommendation (CBR)</td>
<td>Recommendation formulated in the absence of quality evidence, when a systematic review of the evidence has failed to identify any quality studies meeting the inclusion criteria for that clinical question</td>
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<tr>
<td>Practice point (PP)</td>
<td>A recommendation that is outside the scope of the search strategy for the systematic evidence review and is based on expert opinion.</td>
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Each evidence based recommendation is supported by a grade reflecting the quality of the evidence. The grades range from very low to high and were assigned using the GRADE approach (Table 2).[8]
Table 2 Definitions of GRADE ratings of the quality of the evidence

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<th>GRADE of quality of the evidence</th>
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<tr>
<td>High</td>
<td>Further research is very unlikely to change our confidence in the estimate of effect</td>
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<tr>
<td>Moderate</td>
<td>Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate</td>
</tr>
<tr>
<td>Low</td>
<td>Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate</td>
</tr>
<tr>
<td>Very low</td>
<td>Any estimate of effect is very uncertain</td>
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The Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach is based on a sequential assessment of the quality of the evidence followed by judgement about the balance between desirable and undesirable effects and subsequent decisions about the strength of a recommendation.[8]

A strong recommendation implies that most or all individuals will be best served by the recommended course of action. Strong recommendations use the term ‘should’. A weak recommendation implies that not all individuals will be best served by the recommended course of action. There is a need to consider individual patients’ circumstances, preferences and values. Weak recommendations use the term ‘should/could be considered’ or ‘suggested’.

**PRINCIPLES OF CARE**

1. **PP** Health and aged care professionals should provide person-centred care, by identifying and responding to the individual needs and preferences of the person with dementia, their carer(s) and family. The 10 Principles of Dignity in Care should be used as the standard by which care is delivered and evaluated.

2. **PP** Improving quality of life, maintaining function and maximising comfort are appropriate for people living with dementia throughout the disease trajectory, with the emphasis on particular goals changing over time.

3. **PP** Health and aged care professionals should use language that is consistent with the Dementia Language Guidelines and the “Talk to me” good communication guide for talking to people with dementia to guide practice.

**ETHICAL AND LEGAL ISSUES**

4. **PP** Valid informed consent should always be sought from the person with dementia for decisions regarding financial affairs, health care and living arrangements. If the person lacks the capacity to make a decision, the regulations and guardianship laws that apply to the state or territory must be followed.
Health and aged care professionals should inform the person with dementia, their carer(s) and families about advocacy services and voluntary support, and should encourage their use. If required, such services should be available for both the person with dementia and their carer(s) and family independently of each other.

Health and aged care professionals should discuss with the person with dementia, while he or she still has capacity, and his or her carer(s) and family the use of:
- an Enduring Power of Attorney and enduring guardianship
- Advance Care Plans. Advance Care Plans should be revisited with the person with dementia and his or her carer(s) and family on a regular basis and following any significant change in health condition or circumstance. Advance Care Plans should be completed or updated at the time of assessment undertaken by the Aged Care Assessment Team.

Information provided by the person with dementia should be treated in a confidential manner. Health and aged care professionals should discuss with the person any need for information to be shared. Only in exceptional circumstances should confidential information be disclosed to others without the person’s consent. However, as the condition progresses and the person with dementia becomes more dependent on family or other carers, decisions about sharing information should be made in the context of the person’s capacity to make decisions. If information is to be shared with others, this should be done only if it is in the best interests of the person with dementia.

People with dementia should not be excluded from any health care services because of their diagnosis.

If language or culture is a barrier to accessing or understanding services, treatment and care, health and aged care professionals should provide the person with dementia and/or their carer and family with:
- information in the preferred language and in an accessible format
- independent interpreters
- interventions in the preferred language.

Health professionals should consider the needs of the individual and provide information in a format that is accessible for people with all levels of health literacy and considering the specific needs of people with dysphasia or an intellectual disability.

Hospitals should implement strategies to maximise independence and minimise the risk of harm for patients with dementia as identified by the Australian Commission on Safety and Quality in Health Care.

Organisations in primary, secondary and tertiary care settings should consider the needs of people with dementia when designing health and aged care services and facilities.
Clear communication pathways should be established across the continuum of dementia care.

Clear referral pathways should be established across the continuum of dementia care with transparent information regarding service eligibility.

**CONSIDERATIONS FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE**

Consultation with Indigenous community representatives and the local Indigenous medical service should occur in the development, implementation and review of any dementia initiative for Indigenous communities. The formation of an Indigenous advisory committee ensures ongoing consultation. Where appropriate, groups should consult with Alzheimer’s Australia’s National Indigenous and Torres Strait Islander Dementia Advisory Group and State or Territory Indigenous peak health bodies.

Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should utilise bilingual bicultural staff or professional interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent.

Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should employ Indigenous staff members at all levels to contribute actively to this goal.

Health and aged care professionals should consult with family and Indigenous community representatives when developing a culturally appropriate care plan. A case manager (who may be an Indigenous community-based staff member) can assist with accessing and coordinating services required and advocating for the person with dementia.

As the transition to residential care is a particularly difficult step for the person living with dementia, their family and community, health and aged care professionals should display sensitivity and could consider organising support from the community and Indigenous staff members at this time.

**CONSIDERATIONS FOR CULTURALLY AND LINGUISTICALLY DIVERSE POPULATIONS**

Consultation with culturally and linguistically diverse (CALD) community representatives should occur in the development, implementation and review of any dementia initiative for CALD communities. Appropriate CALD representation should be sought on an ongoing basis to ensure relevant consultation and support is provided. Where appropriate, groups should consult with Alzheimer’s Australia’s National Cross Cultural Dementia Network.

Health and aged care services need to acknowledge and be responsive to the cultural and linguistic needs of CALD people living with dementia, their carer(s) and family. Services should utilise bilingual bicultural staff or professional interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent.
CALD carers and family should receive support and education in a culturally and linguistically sensitive manner, through partnerships with ethno-specific and mainstream agencies and they should be delivered by bilingual, bicultural workers in the field.

**EARLY IDENTIFICATION**

23 CBR General population screening for dementia should not be undertaken.

24 PP Concerns or symptoms should be explored when first raised, noted or reported by the person, carer or family and should not be dismissed as ‘part of ageing’.

25 PP Medical practitioners working with older people should be alert to cognitive decline, especially in those aged 75 years and older.

**SPECIALIST ASSESSMENT SERVICES**

26 EBR Low People with a possible diagnosis of dementia should be referred to memory assessment specialists or services for a comprehensive assessment.

27 PP Memory assessment specialists and services should offer a responsive service to aid timely diagnosis and should be able to organise a full range of assessment, diagnostic, therapeutic and rehabilitation services to accommodate the needs of people with different types and severities of dementia as well as the needs of their families and carers living in the community.

28 PP Memory assessment specialists or services should ensure an integrated approach to the care of people with dementia and the support of their families and carers. Referrals for required health and aged care services should be made directly by the specialists or the memory assessment service.

29 PP All people seen by a memory assessment specialist or service should be provided with written and verbal information regarding relevant services such as Alzheimer’s Australia, Carers Australia and Aged Care Assessment Teams.

30 CBR Memory assessment services that identify people with Mild Cognitive Impairment should typically offer follow-up either at the memory assessment service or with a general practitioner or other medical practitioner after six to 18 months to monitor cognitive changes and other signs of possible dementia.
**DIAGNOSIS OF DEMENTIA**

31 PP A diagnosis of dementia should be made only after a comprehensive assessment, which should include:
- history taking from the person
- history taking from a person who knows the patient well if possible
- cognitive and mental state examination with a validated instrument
- physical examination
- a review of medication in order to identify and minimise use of medications, including over-the-counter products, that may adversely affect cognitive functioning
- consideration of other causes (including delirium/depression).

32 PP At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of coexisting conditions.

33 PP A basic dementia screen should be performed at the time of presentation, usually within primary care. It should include the following blood tests:
- routine haematology
- biochemistry tests (including electrolytes, calcium, glucose, and renal and liver function)
- thyroid function tests
- serum vitamin B12 and folate levels.

34 PP Testing for syphilis serology or HIV should be undertaken only in those with histories suggesting they are at risk.

35 PP Clinical presentation should determine whether investigations such as chest X-ray or electrocardiogram are needed. An electrocardiogram should be considered if intending to prescribe acetylcholinesterase inhibitors.

36 PP Cerebrospinal fluid examination should not be performed as a routine investigation for dementia.

37 PP A diagnosis of subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria (see Appendix 2).

38 PP Cerebrospinal fluid examination is indicated if Creutzfeldt–Jakob disease or other forms of rapidly progressive dementia are suspected. Caution is required in obtaining cerebrospinal fluid from a person with possible Creutzfeldt–Jakob disease.

39 PP Electroencephalography should not be used as a routine investigation in people with dementia. Electroencephalography should be considered if a diagnosis of delirium or Creutzfeldt–Jakob disease is suspected, or in the assessment of associated seizure disorder in those with dementia.
Brain biopsy for diagnostic purposes should be considered only in highly selected people whose dementia is thought to be due to a potentially reversible condition that cannot be diagnosed in any other way.

Many new technologies including Positron Emission Tomography (PET) (with 18F-fluorodeoxyglucose [FDG], amyloid and tau ligands) are currently being evaluated and may prove to be useful in the assessment of dementia in the future.

**Cognitive Assessment**

Clinical cognitive assessment in those with suspected dementia should include examination using an instrument with established reliability and validity (suggested assessment tools are presented in Box 7, page 138). Health and aged care professionals should take full account of other factors known to affect performance, including age, educational level, non-English speaking background, prior level of functioning, language, hearing or visual impairments, psychiatric illness or physical/neurological problems when interpreting scores.

Formal neuropsychological testing may form part of the assessment in cases of questionable dementia.

The Kimberley Indigenous Cognitive Assessment (KICA-Cog) or KICA-Screen tool is recommended for use with remote living Indigenous Australians for whom the use of alternative cognitive assessment tools is not considered appropriate.

The modified KICA (mKICA) is recommended as an alternative to the Mini Mental State Exam (MMSE) in urban and rural Indigenous Australian populations when illiteracy, language or cultural considerations deem it appropriate.

The Rowland Universal Dementia Assessment Scale (RUDAS) should be considered for assessing cognition in CALD populations.

**Neuroimaging**

Structural imaging (with computed tomography [CT] or magnetic resonance imaging [MRI]) should usually be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis, unless contraindicated by good clinical judgement. Structural imaging may not always be needed in those presenting with moderate-to-severe dementia, if the diagnosis is already clear.

HMPAO SPECT should not be used in patients with Mild Cognitive Impairment (MCI) either for the differentiation of dementia from MCI or for the differentiation of progressive from non-progressive MCI.

**Communicating the Diagnosis**

The diagnosis of dementia should be communicated to the person with dementia by a medical practitioner.
The medical practitioner should be honest and respectful and use a gradual and individualised approach when communicating the diagnosis to the person with dementia and their carer(s).

The medical practitioner should recognise that people have the right to know their diagnosis and the right not to know their diagnosis. In rare cases where the person with dementia indicates that they do not wish to be told his or her diagnosis, this wish should be respected. The medical practitioner should ensure that carer(s) and family are supported to manage this situation and that the consequences of this decision are managed (e.g., driving). Conflicts, such as when the carer(s) and family request the diagnosis not be communicated to the person with dementia should be resolved by further discussions over time if necessary.

The medical practitioner should provide information about dementia in a clear manner and emphasise that progression is often slow, symptomatic treatments are available and that research is striving to find cures, though so far without success.

Medical practitioners should be aware that people with a history of depression and/or self-harm may be at particular risk of a catastrophic reaction to a diagnosis of dementia, particularly in the first few months post diagnosis. While such reactions are rare, counselling should be offered as an additional way to support the person during this time.

INFORMATION AND SUPPORT FOR THE PERSON WITH DEMENTIA

Health and aged care professionals should be aware that people with dementia, their carer(s) and family members may need ongoing support to cope with the difficulties presented by the diagnosis.

Following a diagnosis of dementia, health and aged care professionals should, unless the person with dementia clearly indicates to the contrary, provide them and their carer(s) and family with written information in an accessible format about:
- the signs and symptoms of dementia
- the course and prognosis of the condition
- treatments
- local care and support services
- sources of financial and legal advice, and advocacy
- medico-legal issues, including driving.

People with a diagnosis of dementia should be provided with information about how to join a social support group.

Health and aged care professionals should ensure that the person with dementia and his or her carer(s) and family are informed regarding appropriate services available in the community (including those offered by Alzheimer’s Australia). Any advice and information given should be recorded.
### ORGANISATION OF HEALTH SERVICES

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<td>58</td>
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<td>Health and aged care managers should coordinate and integrate working across all agencies involved in the assessment, treatment, support and care of people with dementia and their carer(s) and family, including jointly agreeing on written policies and procedures. People with dementia and their carer(s) and families should be involved in planning local policies and procedures.</td>
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<td>Health system planners should ensure that people with dementia have access to a care coordinator who can work with families and carers from the time of diagnosis. If more than one service is involved in the person’s care, services should agree on one provider as the person’s main contact, who is responsible for coordinating care across services at whatever intensity is required.</td>
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<td>Care coordinators should ensure that care plans are developed in partnership with the person and his or her carer(s) and family and based on a comprehensive assessment including the person with dementia’s life history, social and family circumstance, and goals and preferences, as well as the person’s physical and mental health needs and current level of functioning and abilities.</td>
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| 61   |     |          | Care coordinators should ensure the coordinated delivery of health and aged care services for people with dementia. This should involve:  
  - a care plan developed in partnership with the person and his or her carer(s) and family that takes into account the changing needs of the person  
  - assignment of named health and/or aged care staff to operate the care plan  
  - formal reviews of the care plan at a frequency agreed between professionals involved and the person with dementia and/or their carer(s) and family. |
| 62   |     |          | Local dementia pathways and decision support software to improve the diagnosis and management of dementia should be developed and training in their navigation widely available. |

### TRAINING FOR STAFF AND STUDENTS

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<td>63</td>
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<td>Health and aged care organisations should ensure that all staff working with people with dementia receive dementia-care training (attitude, knowledge and skill development) that is consistent with their roles and responsibilities. Training should reflect programs that have been shown to optimise care for people with dementia. Effective programs tend to be: delivered face-to-face by someone experienced in dementia care; scheduled over several training sessions; involve ongoing mentoring or support from someone experienced in dementia care; and, utilise active learning techniques such as problem solving, case based training and role plays.</td>
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Training programs should be comprehensive and have a strong focus on communicating effectively with the person with dementia and his or her carer(s) and family and recognising, preventing and managing behavioural and psychological symptoms of dementia. Staff should be trained in the principles of person-centred care and how these principles are applied in practice.

As people with dementia are vulnerable to abuse and neglect, all health and aged care staff supporting people with dementia should receive information and training about how to prevent and manage suspected abuse.

Education programs implemented in health and aged care settings should be evaluated for impact on staff practices and outcomes for people with dementia and their carer(s) and families in those settings.

All undergraduate curricula in the health sciences should contain significant stand-alone content about the assessment, treatment, support and care of people living with dementia. Content should include person-centred care and the health, social and legal implications of a dementia diagnosis for the person with dementia, their carer(s) and family.

**PROMOTING FUNCTIONAL INDEPENDENCE**

Health and aged care staff should aim to promote and maintain functional and social independence of people with dementia. Interventions should address activities of daily living that maximise independence, function and engagement. Intervention should include:
- consistency of care staff
- stability in living environment
- flexibility to accommodate fluctuating abilities
- support for people with dementia and their carer(s) and family to participate in tailored activities that are meaningful and enjoyable
- assessment and intervention, involving the carer(s) and family wherever possible, to promote independent self-care skills and prevent excess disability, in particular supporting the person with dementia to retain continence
- supporting the person with dementia to receive adequate nourishment and hydration.

People with dementia living in the community should be offered occupational therapy interventions which should include: environmental assessment and modification to aid independent functioning; prescription of assistive technology; and tailored intervention to promote independence in activities of daily living which may involve problem solving, task simplification and education and skills training for their carer(s) and family.

People with dementia should be encouraged to exercise. Physiotherapy assessment and advice may be indicated.
**ACETYLCHOLINESTERASE INHIBITORS AND MEMANTINE**

71 EBR Low Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) are recommended as options for managing the symptoms of mild-to-moderate Alzheimer’s disease. Any one of the three acetylcholinesterase inhibitors could be considered for managing the symptoms of severe Alzheimer’s disease†. Prior to initiation of treatment medical practitioners should consider performing an electrocardiogram (ECG), recording weight and undertaking a falls risk assessment. Concomitant administration of medications with anticholinergic effects should be avoided.

72 EBR Moderate Medical and nurse practitioners should be aware that the acetylcholinesterase inhibitors are associated with a number of adverse reactions that have a risk of harm. These include nausea, vomiting, diarrhoea, dizziness, falls, weight loss, anorexia, headache and insomnia.

73 EBR Moderate Memantine is recommended as an option for people with moderate-to-severe Alzheimer’s disease who are intolerant of or have a contraindication to acetylcholinesterase inhibitors. For people with severe renal impairment (creatinine clearance < 30ml/min) the dose of memantine should be halved.

74 EBR Low Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) could be considered for managing the symptoms of Dementia with Lewy Bodies, Parkinson’s Disease dementia, vascular dementia or mixed dementia.

75 PP People who have been prescribed an acetylcholinesterase inhibitor or memantine should be reviewed within six months to determine whether there is a clinically meaningful response to treatment.

76 PP Acetylcholinesterase inhibitors should not be prescribed for people with Mild Cognitive Impairment.

**NUTRITIONAL SUPPLEMENT**

77 EBR Moderate It is suggested that health care practitioners do not recommend the use of Souvenaid® in people with dementia.

**BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA**

78 PP Health and aged care staff and carers and family should identify, monitor and address environmental, physical health and psychosocial factors that may increase the likelihood of the person with dementia experiencing distressing behavioural and psychological symptoms. These factors include:

- unmet needs (e.g., pain, hunger, need to eliminate, lack of privacy, lack of meaningful activities)
- lowered stress threshold (e.g., conflicts or poor communication within the family or between staff, carer stress).
People with dementia who develop behavioural and psychological symptoms should be offered a comprehensive assessment at an early opportunity by a professional skilled in symptom assessment and management. This should involve their carer(s) and family as appropriate and include:

- analysis of the behaviours (e.g., antecedent [triggers], behaviour description and consequence [ABC approach]), frequency, timing and presentation
- assessment of the person with dementia's physical and mental health
- whether they are experiencing side effects of medication
- the influence of religious and spiritual beliefs and cultural norms
- physical environmental and interpersonal factors
- an assessment of carer(s) health and communication style when interacting with the person with dementia should also be undertaken
- understanding the behaviour as a form of communication.

People with dementia who develop behavioural and psychological symptoms of dementia should usually be treated using non-pharmacological approaches in the first instance. Pharmacological intervention should usually only be offered first if the person, their carer(s) or family is severely distressed, pain is the suspected cause, or there is an immediate risk of harm to the person with dementia or others (i.e., very severe symptoms). If pharmacological management is used, this should complement, not replace, non-pharmacological approaches.

The objective measurement of behavioural and psychological symptoms of dementia should be undertaken using tools with strong psychometric properties and used to monitor the type and patterns of behaviours.

If a person with dementia is suspected to be in pain due to their distress or behaviour, as indicated by responses on an observational pain assessment tool, analgesic medication should be trialled using a stepped approach.

Health and aged care staff should attempt to minimise the impact of behavioural and psychological symptoms of dementia by providing person-centred care (care that is consistent with the 10 Principles of Dignity in Care).

Health and aged care staff should be trained to develop individual care plans (in partnership with the person with dementia’s carer(s) and family) that provide a clear crises plan to anticipate severe behavioural and psychological symptoms of dementia and how to manage violence, aggression and extreme agitation, including de-escalation techniques.
For people with dementia who also have depression and/or anxiety or agitation, interventions should be tailored to the person’s preferences, skills and abilities. The response to each modality should be monitored and the care plan adapted accordingly. Multicomponent interventions that involve engagement in activities that are enjoyable for the person with dementia plus individualised support should be offered where available. Where multicomponent interventions are not available, the following individual therapies should be considered:

For depression and/or anxiety:
- therapeutic use of music and/or dancing
- support and counselling
- reminiscence therapy.

For agitation:
- behavioural management interventions
- therapeutic use of music and/or dancing
- massage
- reminiscence therapy.

To assist the carer(s) and families help the person with dementia who is experiencing behavioural and psychological symptoms of dementia, carer(s) and family should be offered interventions which involve:
- carer skills training in managing symptoms and communicating effectively with the person with dementia
- meaningful activity planning
- environmental redesign and modification to improve safety and enjoyment
- problem solving and management planning.

People with dementia who experience agitation should be offered selective serotonin reuptake inhibitors (SSRI) antidepressants (the strongest evidence for effectiveness exists for citalopram) if non-pharmacological treatments are inappropriate or have failed. The need for adherence, time to onset of action and risk of withdrawal effects and possible side effects should be explained at the start of treatment.

Antidepressant medications with anticholinergic effects (e.g., tricyclic antidepressants) should be avoided because they may adversely affect cognition.

Larger trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se. People with dementia who also have depression without agitation may not benefit from antidepressant medication.

People with Alzheimer’s disease, vascular dementia or mixed dementias with mild-to-moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications because of the possible increased risk of cerebrovascular adverse events and death.
People with Dementia with Lewy Bodies with mild-to-moderate behavioural and psychological symptoms of dementia, should not be prescribed antipsychotic medications, because those with Dementia with Lewy Bodies are at particular risk of extrapyramidal adverse reactions.

People with dementia and severe behavioural and psychological symptoms of dementia (i.e., psychosis and/or agitation/aggression) causing significant distress to themselves or others, may be offered treatment with an antipsychotic medication. Risperidone has the strongest evidence for treating psychosis. Risperidone and olanzapine have the strongest evidence for treating agitation/aggression, with weaker evidence for aripiprazole. The following conditions should also be met:

- There should be a full discussion with the person with dementia and their carers and family about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.
- Target symptoms should be identified, quantified and documented.
- The effect of comorbid conditions, such as depression, should be considered.
- The choice of antipsychotic should be made after an individual risk–benefit analysis.
- The dose should be initially low and titrated upwards if necessary.
- Monitoring for adverse effects including the metabolic syndrome should occur.
- Treatment should be time limited and regularly reviewed (at least every three months or according to clinical need). This should include regular assessment and recording of changes in cognition and target symptoms.

As far as possible, antipsychotics should be avoided in people with Dementia with Lewy Bodies due to the risk of severe untoward reactions, particularly extrapyramidal side effects. If antipsychotics are used, atypical or second generation antipsychotics with low propensity to cause extrapyramidal side effects should be used; olanzapine has the best evidence of efficacy and tolerability. Healthcare professionals should use low dosage and closely monitor for adverse effects.
Health professionals who use medication in the management of violence, aggression and extreme agitation in people with dementia should:

- be trained in the correct use of medications for behavioural control
- be able to assess the risks associated with pharmacological control of violence, aggression and extreme agitation, particularly in people who may be dehydrated or physically ill
- understand the cardiorespiratory effects of the acute administration of benzodiazepines and antipsychotics and the need to titrate dosage to effect
- recognise the importance of positioning people who have received these medications in the recovery position and of monitoring vital signs
- be familiar with and trained in the use of resuscitation equipment
- undertake annual retraining in resuscitation techniques
- understand the importance of maintaining a clear airway
- be knowledgeable about the laws for informed consent in their jurisdiction.

If medications are necessary for the control of violence, aggression and extreme agitation in people with dementia, oral medication should be offered before parenteral medication.

In certain rare situations, parenteral medication may be required for the management of people with dementia with extreme behavioural and psychological symptoms of dementia. Local guidelines addressing appropriate pharmacological agents for use should be followed in these situations (e.g., the Handbook for NSW Health Clinicians addressing assessment and management of behavioural and psychological symptoms of dementia [BPSD]).

If parenteral treatment is necessary for the control of violence, aggression and extreme agitation, intramuscular (IM) administration is preferable because it is safer than intravenous administration. Intravenous administration should be used only in exceptional circumstances. Vital signs should be monitored after parenteral treatment. Health professionals should be aware that loss of consciousness can be mistaken for sleep. If the person appears to be or is asleep, more intensive monitoring is required because of the risk of loss of consciousness.

People with dementia who have received involuntary sedation should be offered the opportunity, along with their carer(s) and family, to discuss their experiences and be provided with a clear explanation of the decision to use urgent sedation. This should be documented in their notes.

Where people with dementia have moderate to severe BPSD that puts themselves or others at risk, referral to a specialist mental health service for older people should occur.
**SUPPORT FOR CARERS**

<table>
<thead>
<tr>
<th>Page</th>
<th>Level</th>
<th>Code</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>99</td>
<td>PP</td>
<td></td>
<td>Carer(s) and families should be respected, listened to and included in the planning, decision making and care and management of people with dementia.</td>
</tr>
<tr>
<td>100</td>
<td>PP</td>
<td></td>
<td>Health and aged care professionals should assess carer(s) and family for their emotional, psychological and social needs. Carer and family needs should be addressed regularly, including if the person with dementia has entered residential care, and after their death.</td>
</tr>
<tr>
<td>101</td>
<td>CBR</td>
<td></td>
<td>The person with dementia, their carer(s) and family should be offered respite appropriate to their needs. This may include in-home respite, day respite and residential respite.</td>
</tr>
<tr>
<td>102</td>
<td>EBR</td>
<td>Low</td>
<td>Carer(s) and family should have access to programs designed to provide support and optimise their ability to provide care for the person with dementia. Programs should be tailored to the needs of the individual and delivered in the home or at another accessible location. Programs should be delivered over multiple sessions and include: - education regarding dementia and its consequences - information regarding relevant services including respite - referral to support organisations such as Alzheimer’s Australia or Carers Australia - development of individualised strategies and building carer skills to overcome specific problems experienced by the person with dementia as reported by the carer - training in providing care and communicating most effectively with the person with dementia - support and information regarding coping strategies to maintain their own wellbeing including stress management - training in the use of pleasant and meaningful activities as a strategy to engage the person with dementia</td>
</tr>
<tr>
<td>103</td>
<td>PP</td>
<td></td>
<td>Consideration should be given to involving the person with dementia, as well as the carer and family, in carer programs.</td>
</tr>
<tr>
<td>104</td>
<td>EBR</td>
<td>Low</td>
<td>Health and aged care professionals should provide carer(s) and families with information regarding how to join a mutual support group. Individual preferences for group composition may vary and groups of the preferred composition should be available.</td>
</tr>
<tr>
<td>105</td>
<td>PP</td>
<td></td>
<td>Carer(s) and families of people with dementia should be supported to build resilience and maintain overall health and fitness. Where necessary, they should be offered psychological therapy, conducted by a specialist practitioner.</td>
</tr>
</tbody>
</table>

**PALLIATIVE APPROACH**

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<th>Level</th>
<th>Code</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>106</td>
<td>PP</td>
<td></td>
<td>Care for people with advanced dementia should be based on a palliative approach and involve a palliative care service if indicated.</td>
</tr>
</tbody>
</table>
Health and aged care staff and carer(s) and family should continue to offer people with dementia food and drink by mouth. Specialist assessment and advice concerning swallowing and feeding in dementia should be available. Professional dietary advice may also be beneficial. Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity. Ethical and legal principles should be applied when making decisions about introducing or withdrawing artificial nutritional support. Any decision about rehydration should be made in conjunction with the carer(s) and family after providing them with up-to-date information on the potential benefits and harm.

If a person with severe dementia has a fever, a clinical assessment should be undertaken. Simple analgesics, antipyretics and mechanical means of cooling the person may suffice. Antibiotics may be considered as a palliative measure in the terminal stages of dementia, but this needs an individual assessment.

In the absence of a valid and applicable advance directive to refuse resuscitation, the decision to resuscitate should take account of any expressed wishes or beliefs of the person with dementia, together with the views of the carer(s) and family and the multidisciplinary team. The decision should be made in accordance with the guidance developed by the Australian Resuscitation Council and, if the person with dementia lacks capacity, the provisions of state or territory based mental health and guardianship laws. Advance Care Plans must be recorded in the medical notes and care plans.
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### Abbreviations

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<th>Description</th>
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<td>3MS</td>
<td>Modified Mini Mental Exam</td>
</tr>
<tr>
<td>6-CIT</td>
<td>6-item cognitive impairment test</td>
</tr>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ACE-R</td>
<td>Addenbrooke’s Cognitive Examination—Revised</td>
</tr>
<tr>
<td>AD</td>
<td>Alzheimer’s Disease</td>
</tr>
<tr>
<td>ADAS-Cog</td>
<td>Alzheimer’s Disease Assessment Scale—Cognition</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>ADRDA</td>
<td>Alzheimer’s Disease and Related Disorders Association</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>AMTS</td>
<td>Abbreviated Mental Test Score</td>
</tr>
<tr>
<td>ATSI</td>
<td>Aboriginal and Torres Strait Islander peoples</td>
</tr>
<tr>
<td>AUC</td>
<td>Area Under the Curve</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and psychological symptoms of dementia</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and linguistically diverse</td>
</tr>
<tr>
<td>CBR</td>
<td>Consensus based recommendation</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>CT</td>
<td>Computed tomography</td>
</tr>
<tr>
<td>DBMAS</td>
<td>Dementia Behaviour Management Advisory Service</td>
</tr>
<tr>
<td>DEEP</td>
<td>Dementia Enabling Environments Project</td>
</tr>
<tr>
<td>DOMS</td>
<td>Dementia Outcomes Measurement Suite</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders—Text Revision</td>
</tr>
<tr>
<td>EBR</td>
<td>Evidence-based recommendation</td>
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<tr>
<td>EEG</td>
<td>Electroencephalography</td>
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<tr>
<td>FAB</td>
<td>Frontal Assessment Battery</td>
</tr>
<tr>
<td>FDA</td>
<td>Food and Drug Administration</td>
</tr>
<tr>
<td>FICA</td>
<td>Federal Insurance Contributions Act</td>
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<tr>
<td>Acronym</td>
<td>Full Form</td>
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<tr>
<td>FTD</td>
<td>Frontotemporal dementia</td>
</tr>
<tr>
<td>GPCOG</td>
<td>General Practitioner Assessment of Cognition</td>
</tr>
<tr>
<td>GRADE</td>
<td>Grading of Recommendations Assessment, Development and Evaluation</td>
</tr>
<tr>
<td>HTA</td>
<td>Health Technology Assessment</td>
</tr>
<tr>
<td>KGOWS</td>
<td>Koori Growing Old Well Study</td>
</tr>
<tr>
<td>(m)KICA</td>
<td>(modified) Kimberley Indigenous Cognitive Assessment</td>
</tr>
<tr>
<td>MBS</td>
<td>Medical Benefits Schedule</td>
</tr>
<tr>
<td>MCI</td>
<td>Mild Cognitive Impairment</td>
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<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
</tr>
<tr>
<td>MoCA</td>
<td>Montreal Cognitive Assessment</td>
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<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
</tr>
<tr>
<td>MSAC</td>
<td>Medical Services Advisory Committee</td>
</tr>
<tr>
<td>NARI</td>
<td>National Ageing Research Institute</td>
</tr>
<tr>
<td>NCCDN</td>
<td>National Cross Cultural Dementia Network</td>
</tr>
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<td>NCC-MH</td>
<td>National Collaborating Centre—Mental Health</td>
</tr>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NHPA</td>
<td>National Health Priority Area</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence (UK)</td>
</tr>
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<td>NINCDS</td>
<td>National Institute of Neurological and Communicative Disorders and Stroke</td>
</tr>
<tr>
<td>PAS</td>
<td>Psychogeriatric Assessment Scale</td>
</tr>
<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
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<tr>
<td>PP</td>
<td>Practice Point</td>
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<tr>
<td>PPV</td>
<td>Positive Predictive Value</td>
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<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
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<td>RUDAS</td>
<td>Rowland Universal Dementia Assessment Scale</td>
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<tr>
<td>SPECT</td>
<td>Single-photon emission computed tomography</td>
</tr>
<tr>
<td>SSRIs</td>
<td>Selective serotonin reuptake inhibitors</td>
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</table>
INTRODUCTION

Background

Types of dementia

The term ‘dementia’ is used to describe a number of conditions. The main types of dementia are presented in Box 1.

Box 1  Types of dementia

Alzheimer’s disease is the most common form of dementia and accounts for 50 per cent to 75 per cent of cases. People with Alzheimer’s disease often present with short-term memory loss, apathy and depression in the early stages. The onset of symptoms is gradual and Alzheimer’s is associated with progressive functional decline.

Vascular dementia is the second most common type of dementia and accounts for about 20 per cent to 30 per cent of cases. Vascular dementia is associated with cerebrovascular conditions (for example, stroke). The onset of vascular dementia can be sudden. Early symptoms are similar to those seen in Alzheimer’s disease however, memory loss may not be as evident and mood fluctuations may be more prominent. Functional decline is common although the course of decline is somewhat unpredictable and is more likely to be stepwise.

Frontotemporal dementia accounts for about five per cent to 10 per cent of cases. It tends to be more common in males with a younger onset of dementia. Personality and mood changes, disinhibition and language difficulties tend to be the first symptoms of frontotemporal dementia.

Dementia with Lewy Bodies (DLB) accounts for up to five per cent of cases and is associated with the development of abnormal cells, called Lewy bodies, in the brain. People with DLB often experience marked fluctuations in cognition. Visual hallucinations are common as are physical symptoms often seen in Parkinson disease such as tremor and rigidity.

Mixed dementia (for example Alzheimer’s - vascular dementia) is also common. There are other forms of dementia that are less common, including Parkinson’s disease dementia, Huntington’s disease and Creutzfeldt-Jakob disease.

Source: [Source: 4 9]

The symptoms of dementia range in severity; people are often described as being in a mild, moderate or severe stage of dementia. Typically, people with mild dementia experience some problems in managing everyday activities but require only minimal assistance. As dementia progresses and becomes moderate in nature, the person experiences more difficulties and increasing assistance is required to support the person to remain in their own home. People with severe dementia become almost completely dependent on others and most people with severe dementia live in residential care facilities.[10] There are a number of different approaches to classifying severity of dementia.[11] Classification can be difficult when stages overlap, however one of the values of staging is that it represents the ways in which the beginning and end of the condition are very different.

Prevalence of dementia in Australia

Dementia is increasingly common with age. As Australia’s population ages, the number of people with dementia in Australia will increase. It is estimated that there were 298,000 people living with a diagnosis of dementia in Australia in 2011; this is predicted to rise to about 900,000 in 2050.[4]
In 2011, about nine per cent of Australians aged 65 years and over had dementia. The prevalence increased from three per cent in people aged 65 to 74 years up to nearly 30 per cent in those aged 85 years and over. Dementia is slightly more common in women (10 per cent of those aged 65 years and over) than in men (seven per cent). Eight per cent of people living with dementia in Australia are aged less than 65 years.

Table 3 Estimated number of people with dementia, by age and sex, 2011

<table>
<thead>
<tr>
<th>Age</th>
<th>Males</th>
<th>Females</th>
<th>Persons</th>
<th>Males</th>
<th>Females</th>
<th>Persons</th>
<th>Per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>12,600</td>
<td>11,300</td>
<td>23,900</td>
<td>11.1</td>
</tr>
<tr>
<td>65–74</td>
<td>3.1</td>
<td>3.4</td>
<td>3.2</td>
<td>25,200</td>
<td>28,900</td>
<td>54,100</td>
<td>22.3</td>
</tr>
<tr>
<td>75–84</td>
<td>8.8</td>
<td>10.4</td>
<td>9.7</td>
<td>39,800</td>
<td>57,500</td>
<td>97,400</td>
<td>35.2</td>
</tr>
<tr>
<td>85+</td>
<td>24.4</td>
<td>32.3</td>
<td>29.5</td>
<td>35,600</td>
<td>87,000</td>
<td>122,600</td>
<td>31.5</td>
</tr>
<tr>
<td><strong>Total: 65+</strong></td>
<td><strong>7.1</strong></td>
<td><strong>10.3</strong></td>
<td><strong>8.8</strong></td>
<td><strong>100,700</strong></td>
<td><strong>173,400</strong></td>
<td><strong>274,100</strong></td>
<td><strong>88.9</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1.0</strong></td>
<td><strong>1.6</strong></td>
<td><strong>1.3</strong></td>
<td><strong>113,300</strong></td>
<td><strong>184,700</strong></td>
<td><strong>298,000</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

(a) Summary rates (per 100 population) were calculated using population data as at 30 June 2011 (ABS 2012a). See Table D2.4 in Appendix D for a complete list of the age-specific rates.

(b) Numbers may not sum to the total due to rounding.

Sources: Australian Institute of Health and Welfare (2012)

Risk factors for dementia

Researchers are increasingly discovering more information about risk factors for dementia and strategies that may be used to assist in the prevention of dementia. There is growing evidence that lifestyle and cardiovascular risk factors are associated with the development of dementia. However, there is currently insufficient information available from research studies to form specific recommendations regarding how to prevent dementia. In general, research suggests that all members of society should be encouraged to maintain good cardiovascular health and live a physically, socially and cognitively active life, particularly in middle age.

The main known risk factor for dementia is advancing age. The prevalence of dementia doubles every five years after the age of 65. In addition, there are a number of medical conditions thought to be associated with increased prevalence of dementia including diabetes, high cholesterol, hypertension in midlife, depression and brain injury. Lifestyle factors including smoking, physical inactivity, exposure to pesticides and a Body Mass Index in midlife outside of the normal range are also linked an increased risk of dementia. There are a number of studies that suggest that reduced social engagement is associated with an increased risk of dementia; the reasons for this are unclear.
Genetic factors also play a role in determining risk of dementia. The apolipoprotein E (APOE) gene is the only common genetic risk factor that has been found to be associated with non-familial, late-onset Alzheimer’s disease to date. [19] Presence of the APOE gene indicates susceptibility to Alzheimer’s disease and the mechanism for increasing the risk is unknown. [9] Hence, key organisations advise that there is currently no role for APOE genotyping in disease prediction or in the diagnosis of Alzheimer’s disease. [20] There are also several rare genes associated with the development of a small proportion of cases of younger onset dementia; dementia that is found to be caused by these deterministic genes is referred to as ‘familial Alzheimer’s disease’. [21]

Mild Cognitive Impairment

MCI is a state between normal ageing and early dementia in which there is an objective cognitive complaint for age in a person with essentially normal function in activities. [22] MCI may not necessarily involve memory loss. [22 23] Research suggests not all people with MCI will develop a diagnosis of dementia but that people with MCI are at greater risk of dementia.

Approach to Guideline development

Funding

The development, publication and dissemination of this Guideline was funded by the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People. The Partnership Centre receives support from the NHMRC and Funding Partners, including HammondCare, Alzheimer’s Australia, Brightwater Care Group and Helping Hand Aged Care.

Purpose of guideline

The purpose of this Guideline is to provide recommendations for the optimal diagnosis and management of dementia in Australia. The Guideline provides clear guidance that is relevant to Australian settings.

The intended users of the Guideline are staff working with people with dementia in the health and aged care sectors in Australia. This includes medical specialists (general physicians, general practitioners, geriatricians, neurologists, psychiatrists, psychogeriatricians, rehabilitation physicians), nurses, aged care workers and allied health professionals. The Guideline is also relevant to managers and administrators whose organisations provide services for people with dementia and their carers. People with dementia and their carer(s) and family will also find the Guideline highly useful.

As health and aged care services vary across Australia and different roles are completed by different health and aged care professionals in different settings, wherever possible individual health professions are not specified.

Scope

The Guideline addresses assessment and management of people with dementia in community, residential care and hospital settings. The Guideline does not provide recommendations regarding prevention of dementia. In recognition of the vital role of carers and family in providing care for
people with dementia, recommendations regarding support and interventions for carers and family are also provided.

As this Guideline was developed via the ADAPTE process (and therefore is an adaptation of an existing Guideline), the scope of the Guideline was bound by the scope of the NICE Guideline. Guideline Adaptation Committee members were presented with key clinical questions addressed within the NICE Guideline and identified the clinical questions that were of the highest priority for the Australian setting. The highest priority questions were addressed.

**Target population**

The population included within this Guideline are males and females of all ages with all the major forms of dementia, including Alzheimer’s disease, vascular dementia, Dementia with Lewy Bodies (DLB) and frontotemporal dementia. Where appropriate, the Guideline addresses the differences in treatment and care for people with mild, moderate and severe dementia. Dementia usually affects the whole family or household and the Guideline recognises the role of carers and family in the care and support of people living with dementia.

**Setting**

This Guideline applies to community (including care provided in the home), residential and hospital settings. It covers care provided by staff employed within the health and aged care sectors.
Clinical questions

The following clinical questions were prioritised by the Guideline Adaptation Committee and the evidence was examined by conducting systematic reviews. Additional background questions were addressed by non-systematic reviews (for details see Technical Report Volume 1).

Box 2  Clinical questions addressed by systematic review

1. Which interventions can reduce barriers to accessing optimal healthcare?
2. Are there any advantages/disadvantages to early identification?
3. For people with symptoms of dementia, does assessment from a memory assessment specialist or service provide benefits in comparison to attendance at another service?
4. How frequently should memory assessment services review people with Mild Cognitive Impairment (MCI) for progression to dementia?
5. What is the evidence for the validity of the Kimberley Indigenous Cognitive Assessment (KICA) and Rowland Universal Dementia Assessment Scale (RUDAS) cognitive assessment tools in Indigenous and Culturally and Linguistically Diverse (CALD) populations?
6. Does every person with dementia need structural imaging (with CT or MRI) of the brain?
7. Does the routine use of functional imaging (with SPECT) improve the diagnostic differentiation of dementia from MCI over and above that of standard comprehensive assessment?
8. For people with dementia, what type of information and support is beneficial?
9. For people with dementia, what is the best way of organising services in terms of integration of care, consumer directed care, multidisciplinary assessment and case management?
10. What models of training for health and aged care staff have positive outcomes for people with dementia?
11. For people with dementia, are there strategies for promoting independence that produce benefits?
12. For people with dementia, do non-pharmacological interventions aimed at improving cognitive function produce benefits?
13. For people with dementia, do acetylcholinesterase inhibiting drugs/memantine produce benefits/harms?
14. For people with dementia, does Souvenaid® produce benefits/harms?
15. For people with behavioural and psychological symptoms of dementia, do non-pharmacological interventions produce benefits?
16. For people with behavioural and psychological symptoms of dementia (BPSD), does appropriate drug treatment when compared to placebo/a comparator produce benefits/harm?
17. Does assessment or intervention for carers produce benefits?

Guideline development

Development of the Guideline is based on the ADAPTE process.[6] The ADAPTE process attempts to reduce duplication of effort by utilising existing high quality and current guidelines as the foundation for developing a local guideline. The NICE Guideline[7] was identified as being the most appropriate guideline to adapt. A Chairperson was appointed and the Guideline Adaptation Committee formed to adapt the NICE Guideline by updating and customising recommendations for the local context. Guideline customisation was informed based on a systematic search for evidence published following the searches conducted in 2005/2006 as part of the NICE Guideline. Full details of the
updated search are detailed in the Technical Report. Multiple databases were searched between April and December 2014. An additional search was conducted for literature relating to CALD and Indigenous populations to identify issues unique to Australia. This search included a number of databases and was not restricted by date. The application of the ADAPTE process in developing this Guideline is described in detail in the Technical Report.

A protocol was developed a priori to guide the evidence update. The protocol was reviewed by a methodologist with experience in clinical practice guideline development who provided feedback and recommended modifications. The evidence update involved conducting systematic reviews address the clinical questions and to summarise up-to-date information. For all questions, a hierarchical approach was used in the selection of the evidence; that is, only the highest level of evidence/best quality evidence addressing each outcome was included to answer each question. In some cases this meant that only randomised controlled trials were included while in other circumstances the evidence included cohort studies.

The Guideline Adaptation Committee discussed each recommendation at whole day face-to-face meetings held in October 2014 and February 2015. GRADE Evidence Profiles summarising the quality and findings of the body of literature were circulated to Committee members ahead of meetings. Recommendations were accepted, rejected or modified by the Committee and classed as evidence-based recommendations, consensus based recommendations or practice points using the definitions provided in the NHMRC 2011 Standards.[24] Modification was frequently required in order to ensure the recommendation fit the Australian context. In addition, there were occasions when recommendations were modified to reflect recent literature or to increase the specificity of the recommendation. Recommendations were reviewed to ensure that they reflected the strength of the body of evidence and were presented as strong (‘should’) or weak (‘should/could be considered’ or ‘suggested’) recommendations.

The draft Guideline was circulated to all Guideline Adaptation Committee members for further comment and refinement prior to release for public consultation in April 2015.

Finalisation

The Guideline will be released for public consultation for six weeks (April 2015 to May 2015). The Guideline will also be assessed by two reviewers who were not involved in guideline development using the AGREE II Instrument.[25]

Future updates of the Guideline

NHMRC recommends that clinical guidelines are reviewed and revised no more than five years after publication. Dementia research initiatives mean that the evidence in this field is likely to change within the next five years and the Guidelines will need to be updated.
PRINCIPLES OF CARE

Principles for providing effective care

Dignity in Care

These Guidelines are underpinned by the 10 Principles of Dignity in Care.[26] People with dementia and their carers and family should expect treatment that is provided according to these principles.

10 Principles of Dignity in Care

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<tbody>
<tr>
<td>1</td>
<td>Zero tolerance of all forms of abuse.</td>
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<tr>
<td>2</td>
<td>Support people with the same respect you would want for yourself or a member of your family.</td>
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<td>3</td>
<td>Treat each person as an individual by offering a personalised service.</td>
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<td>4</td>
<td>Enable people to maintain the maximum possible level of independence, choice and control.</td>
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<td>5</td>
<td>Listen and support people to express their needs and wants.</td>
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<tr>
<td>6</td>
<td>Respect people’s privacy.</td>
</tr>
<tr>
<td>7</td>
<td>Ensure people feel able to complain without fear of retribution.</td>
</tr>
<tr>
<td>8</td>
<td>Engage with family members and carers as care partners.</td>
</tr>
<tr>
<td>9</td>
<td>Assist people to maintain confidence and a positive self-esteem.</td>
</tr>
<tr>
<td>10</td>
<td>Act to alleviate people’s loneliness and isolation.</td>
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</tbody>
</table>

Health and aged care staff should apply the recommendations in their workplaces while also responding to the needs and preferences of the person with dementia and their carer(s) and families. Care should be person-centred; people with dementia should be valued, they must be treated as individuals and the perspective of the person with dementia must be understood.[27]

Health and aged care staff should identify the needs of people with dementia and their carer(s) and families arising from diversity including: gender, sexual orientation, cultural and linguistic background, age, religion and spirituality. Health and aged care staff should recognise the needs of people with social and environmental vulnerabilities including poverty, homelessness and imprisonment.
Principles of care

1  PP  Health and aged care professionals should provide person-centred care, by identifying and responding to the individual needs and preferences of the person with dementia, their carer(s) and family. The 10 Principles of Dignity in Care should be used as the standard by which care is delivered and evaluated.

2  PP  Improving quality of life, maintaining function and maximising comfort are appropriate for people living with dementia throughout the disease trajectory, with the emphasis on particular goals changing over time.

3  PP  Health and aged care professionals should use language that is consistent with the Dementia Language Guidelines and the “Talk to me” good communication guide for talking to people with dementia to guide practice.

Ethical and legal issues

There are a number of ethical issues that may arise when providing care for someone with dementia, their carer(s) and family. Many of these issues relate to autonomy.

The World Health Organization recommends that ethical issues in dementia care are considered in context with an understanding of the person, their family, culture, environment and the situation.[28] In some cases, conflicting principles may need to be balanced in order to make a decision regarding care.[29] Health and aged care professionals need to be aware of key ethical principles and the different guidelines and laws relating to ethical care in their organisation, profession and government. The World Health Organization states that education and support in ethical decision making should be essential for all involved in providing dementia care.[29]

How can it be ensured that people with dementia have a choice about their care environment?

Dementia is associated with gradual functional decline and increasing reliance on carers and aged care services. This increasing reliance sometimes means that people with dementia are dependent on other people to make decisions about their financial affairs, health care and living arrangements. The views of the person with dementia should always be sought, even when someone else is making decisions on their behalf. People with dementia and their families are encouraged to plan ahead so that the person’s wishes are carried out in the way that they would like.[30] The Start2Talk website provides information about how to plan ahead for people with dementia and their families (www.start2talk.org.au).

Families need to be aware that the laws relating to future care planning differ between states and territories and that a legal document from one state may not be recognised in another state. The Alzheimer’s Australia’s National Dementia Helpline (ph 1800 100 500) or the My Aged Care website (www.myagedcare.gov.au) provide information on how to make arrangements for an Enduring Power of Attorney or Advance Care Plan in each state or territory. The Advance Care Plan should be readily accessible as it may be needed quickly (e.g. by ambulance workers or emergency department staff).
Are there circumstances in which acting without/contrary to the consent of a person with dementia is appropriate?

The law states that an adult has capacity to make a particular decision when he or she can: understand the information being given; make a decision on the basis of the information given after having weighed and fully appreciated the positive and negative consequences of the decision; and, communicate that decision to another person.[31] Capacity is situation-specific, meaning that someone may have capacity to make some decisions but not others. Within Australia, it is usually the responsibility of the treating doctor to determine whether someone has capacity to make a particular decision. If the person with dementia does not have capacity to make a specific decision regarding their finances or care, this decision must be made by someone on their behalf; usually a family member.[31]

### Ethical and legal issues

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<td>7</td>
<td>PP</td>
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</table>
Barriers to care

Background

People with dementia often require health services for other primary medical conditions (for example, falls, stroke, critical illness, diabetes care). These other medical conditions or comorbidities may require a person with dementia to be admitted to hospital. People with dementia in hospitals are at increased risk of adverse events such as falls, delirium, infections and poor outcomes such as functional decline, mortality, readmission and entry to residential care.[32] Health practitioners need the knowledge and skills to identify cognitive impairment and to respond appropriately to minimise risks, in partnership with carers and families.[32]

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<th>Barriers to care</th>
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<td><strong>8</strong> PP</td>
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<td><strong>13</strong> PP</td>
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<td><strong>14</strong> PP</td>
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Summary of the NICE Guideline findings

The NICE Guideline Committee presented a narrative summary of local policies and documents that addressed principles of care and accessibility of services.

Evidence update

This evidence update involved a search for recent studies (2005–2014) that identified barriers to accessing services and healthcare disparities for people with dementia. The search failed to identify studies of any design that evaluated interventions designed to overcome barriers or to increase
access to healthcare among people with dementia. In lieu of this, studies describing the barriers to care for people with dementia were reviewed.

Australian studies

One study revealed differences in care among people with dementia. Certain groups (those living in rural and remote areas and those of lower socioeconomic status) were less likely to be prescribed acetylcholinesterase inhibitors than other groups (those in metropolitan areas and of higher socioeconomic status).[33] Another study, which involved surveys of public hospitals in New South Wales, demonstrated the reduced availability of specialist services and appropriate hospital wards for people with dementia in rural areas.[34]

Remote Aboriginal communities

Two studies have examined barriers to care for people living in remote Aboriginal communities.[35 36] Barriers included poor community awareness regarding dementia, lack of culturally appropriate services and poor links between service providers and the community. Within services, there was often high staff turnover and heavy workload.

CALD populations

A systematic review that examined dementia care in different cultural groups [37] found that people from culturally diverse backgrounds presented to diagnostic dementia services later and with more advanced cognitive decline. Use of community services following diagnosis did not differ between groups however, people from culturally diverse backgrounds were 40 per cent less likely to enter residential care.[37] This finding may reflect attitudes to the role of the family and views regarding care provision. An Australian study suggested that cultural background is associated with different attitudes to service use. People from Italian, Greek and Chinese backgrounds reported that they would be more likely than ‘third generation Australians’ to provide family based care for family members with dementia and less likely than ‘third generation Australians’ to use respite or residential care services.[38]

International studies

Studies conducted overseas have reported differences in care between people with dementia and people without dementia. A Canadian study reported that people with dementia living in the community were more likely to report unmet needs in regards to community care than people without dementia.[39] Another study, conducted in the United States, reported that among people with diabetes living in residential care, people with dementia received fewer diabetic treatments than those without dementia.[40]

A number of barriers to care have been identified when accessing primary care.[41] These are attributed to a variety of reasons including patient factors (such as perceived stigma), general practitioner factors (such as diagnostic uncertainty) and system characteristics (such as time constraints).
Considerations for Australia

Australia faces unique issues when attempting to ensure equitable access to health and aged care services. Approximately 30 per cent of people with dementia live in rural and remote areas and have reduced access to specialist care. Strategies to overcome these barriers should be investigated.

The recommendations highlight the need for clear communication pathways across the continuum of care and for clear referral pathways and transparent information regarding service eligibility. This requires the cooperation of a number of health and aged care agencies and should be addressed using a local approach as health and aged care arrangements differ between states.

Considerations for Culturally and Linguistically Diverse populations

Aboriginal and Torres Strait Islander peoples

The prevalence of dementia among Aboriginal and Torres Strait Islanders (herein referred to as Indigenous Australians) in urban, regional and remote areas is much higher than the prevalence of dementia in non-Indigenous Australians [42-45]. Data from remote Indigenous communities in the Kimberley revealed a prevalence rate of 12.4 per cent in people aged over 45 years.[45] This is substantially higher than comparative rates of the general population in Australia (2.6 per cent). Recent data from urban and regional areas in Australia found a dementia prevalence rate of 13.4 per cent among Indigenous Australians aged 60 years and older, three times higher than in the general Australian population.[42] The most common type of dementia was Alzheimer’s disease.[42] Data from urban, regional and remote areas show that dementia due to alcohol abuse was uncommon.[42 45]

The reasons for increased prevalence in Indigenous Australians in urban and regional areas are currently being investigated as part of the Koori Growing Old Well Study.[43] Factors associated with dementia in the Kimberley study included: older age, male gender, no formal education, head injury, current smoking, previous stroke and epilepsy.[5]

Multiple barriers to health and aged care exist for Indigenous people. Indeed, few Indigenous Australians access formal respite or community care packages.[46] It is thought this may be related to a combination of factors including: reduced awareness of available services; services not meeting the needs of people with dementia, for example, lack of staff available that speak the local language; and lack of culturally appropriate care.[47]

Health and aged care professionals need to understand the cultural perspectives of the person with dementia and their families and carers and be aware of culturally-specific resources that may be available in their practice settings. State and territory offices of Alzheimer’s Australia have information about the resources available to enhance communication. Use of such resources can enrich the discussions that health care providers will need to hold with clients, their carers and community members about dementia. There is also a need for high-level skills in intercultural communication, which can be enhanced through access to training programs regularly offered in
various locations throughout Australia and by working closely with experienced cross cultural
dementia educators.

Historically, the term dementia has not commonly been used by Indigenous cultures. There is no
traditional explanation for dementia and therefore the condition may be associated with fear and stigma.[47-49] In addition, few Indigenous Australians consider themselves to be ‘carers’ although
many have caring responsibilities.[50] Similarly, care of older Indigenous people may be shared by a
number of people and the concept of a ‘primary carer’ may not apply. Person-centred care for
Indigenous Australians should take into account the cultural significance of connection to family,
networks and communities and to country.[50] Working with local Indigenous staff to translate
concepts of need into culturally appropriate care plans is recommended. This includes advocating for
a ‘whole of community’ approach to dementia awareness to ensure appropriate dementia pathways
and care.[11] A successful model of community care for Indigenous Australians in a remote area has
been demonstrated in a pilot study.[51]

There are existing guidelines for health professionals for the diagnosis and care of Indigenous
Australians with dementia in remote communities.[52] These guidelines were developed in Central
Australia and the process for their development is transferable to other settings. The guidelines
were guided by a steering committee of stakeholders in dementia care in Central Australia including
government, shire, Aboriginal community controlled organisations and non-government
organisations.[52] Another useful resource is the guide ‘Working with older Aboriginal and Torres
Strait Islander people’. [10] The guide was developed as part of the Koori Growing Old Well program.

The Alzheimer’s Association has a number of educational ‘help sheets’ that were developed to
inform Aboriginal and Torres Strait Islander people about dementia. The ‘help sheets’ cover:
information about dementia, diagnosis, information for family, memory changes and Alzheimer’s
disease. There are also a number of other educational tools including videos and presentations
available via the Alzheimer’s Association website (www.fightdementia.org.au).

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### Considerations for Aboriginal and Torres Strait Islander peoples

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<tr>
<td><strong>15</strong> PP</td>
<td>Consultation with Indigenous community representatives and the local Indigenous medical service should occur in the development, implementation and review of any dementia initiative for Indigenous communities. The formation of an Indigenous advisory committee ensures ongoing consultation. Where appropriate, groups should consult with Alzheimer’s Australia’s National Indigenous and Torres Strait Islander Dementia Advisory Group and State or Territory Indigenous peak health bodies.</td>
</tr>
<tr>
<td><strong>16</strong> PP</td>
<td>Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should utilise bilingual bicultural staff or professional interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent.</td>
</tr>
<tr>
<td><strong>17</strong> PP</td>
<td>Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should employ Indigenous staff members at all levels to contribute actively to this goal.</td>
</tr>
</tbody>
</table>
Considerations for Aboriginal and Torres Strait Islander peoples

18 PP  Health and aged care professionals should consult with family and Indigenous community representatives when developing a culturally appropriate care plan. A case manager (who may be an Indigenous community-based staff member) can assist with accessing and coordinating services required and advocating for the person with dementia.

19 PP  As the transition to residential care is a particularly difficult step for the person living with dementia, their family and community, health and aged care professionals should display sensitivity and could consider organising support from the community and Indigenous staff members at this time.

Culturally and Linguistically Diverse populations

Australia’s population is culturally diverse. People from CALD backgrounds make up a significant and growing proportion of the Australian population [53]. Approximately 20 per cent of people aged 65 years and over (600,000 people) were born outside Australia. [53] This proportion is increasing and, by 2021, more than 30 per cent of Australia’s older population will have been born outside Australia. [53]

There is significant diversity within Australia’s CALD community. Australians are linked to more than 300 ancestries and there are more than 260 different languages spoken in Australia today, including Indigenous languages. [53] The needs of communities and individuals within those communities vary considerably and these needs must be recognised and addressed in the health and aged care system to ensure that it has the capacity to provide optimal care for the individual person regardless of their cultural or linguistic background.

It is widely acknowledged that older people from CALD backgrounds face barriers when accessing health and aged care services. These barriers may be related to language, reduced awareness of services and lack of accessible information. [38] Research is now clarifying the specific issues that affect service utilisation. Factors affecting access include the type of service delivered, how the service is delivered and by whom. [54] Acceptability of services seems to be more likely to occur if the service is supporting care provided by the family; community care and respite services including residential respite are the most accessed services. [54] Services must be linguistically and culturally appropriate.

Symptoms of dementia present unique challenges for people from non-English speaking backgrounds, often causing them to revert to their primary language and past experiences. Such changes have a significant impact on family relationships and also create difficulties in service provision. [55] The English term ‘dementia’ may not always be appropriate when talking to people from CALD communities as it may be regarded as being offensive or disrespectful. The symptoms of dementia may be viewed as either a ‘normal’ part of ageing or as mental illness. These beliefs may lead to delay in seeking assistance from health and aged care services. Many communities are reluctant to admit to the illness because of the stigma associated with dementia within their
community. This may lead to the person (and their family) becoming isolated from family and friends. Levels of understanding about dementia vary across and within different cultural groups.\

Being aware of these issues is important when working with people living with dementia and their families.

Families from different cultural backgrounds may not associate with the term ‘carer’. There are strong cultural influences and the importance of family often influences the decision of taking on carer responsibilities. Life focus for many people from CALD backgrounds is family-centred and the role of the carer(s) is influenced by cultural expectations, financial issues and the relationship with the person with dementia. It is common to have multiple carers from different generations involved in different capacities and in some instances, critical decisions may involve family members living overseas. Hence, fulfilling the role of the carer(s) can be complex and challenging in CALD communities. Carers will often continue with the caring role even though they may be experiencing high levels of stress. They often feel that the ‘decision was out of their hands’ and that they had no choice but to care for the person with dementia, despite it having a significant impact on them physically and psychologically.

Guidelines exist for health professionals for the diagnosis and care of people with dementia from CALD backgrounds. Guidelines developed by the Alzheimer’s Australia - National Cross Cultural Dementia Network in collaboration with the National Ageing Research Institute (NARI) provide information for health professionals when they are planning to conduct assessment of a non-English speaking person. The Guidelines reflect good assessment principles in general, but have been written specifically with dementia-related assessments in mind. When undertaking cognitive assessment, tools specifically developed for use in CALD communities have been developed.

Alzheimer’s Australia has a number of educational ‘help sheets’ on dementia available in different community languages. There are also a number of other educational tools including videos and presentations available on the Alzheimer’s Association website.

<table>
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<th>Considerations for Culturally and Linguistically Diverse populations</th>
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<tr>
<td><strong>20   PP</strong> Consultation with culturally and linguistically diverse (CALD) community representatives should occur in the development, implementation and review of any dementia initiative for CALD communities. Appropriate CALD representation should be sought on an ongoing basis to ensure relevant consultation and support is provided. Where appropriate, groups should consult with Alzheimer’s Australia’s National Cross Cultural Dementia Network.</td>
</tr>
<tr>
<td><strong>21   PP</strong> Health and aged care services need to acknowledge and be responsive to the cultural and linguistic needs of CALD people living with dementia, their carer(s) and family. Services should utilise bilingual bicultural staff or professional interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent.</td>
</tr>
<tr>
<td><strong>22   PP</strong> CALD carers and family should receive support and education in a culturally and linguistically sensitive manner, through partnerships with ethno-specific and mainstream agencies and they should be delivered by bilingual, bicultural workers in the field.</td>
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</table>
DIAGNOSIS AND ASSESSMENT

Early identification

Background

A timely diagnosis is made when the person or someone that knows the person, first reports symptoms and the health professional responds to these concerns by promptly conducting or arranging further investigation. Symptoms of dementia are often reported by a family member or carer rather than the person experiencing the symptoms.[59] Symptoms may be also be noted by paid care workers or someone close to the person, such as a friend or neighbour. The general practitioner may first become aware of symptoms of cognitive impairment during the ‘Health assessment for people aged 75 years and older’. [60]

Research suggests that in current practice, there is a significant gap between onset of symptoms and diagnosis of dementia and a diagnosis of dementia is often missed.[61] In particular, people with younger onset dementia report barriers in obtaining a diagnosis. There is considerable debate regarding how to reduce this gap; one method suggested is to conduct population screening for cognitive impairment. The anticipated benefits of screening would be earlier diagnosis and reduced time delay between experiencing signs and symptoms and diagnosis. These would need to be balanced against potential harms, which may include anxiety, depression or earlier admission to care.[62] The debate regarding the benefits and harms of the timing of diagnosis is likely to change as new tests and treatments for dementia become available.

Some of the potential benefits are that receiving a diagnosis earlier in the course of the condition may make it easier for people with dementia and their carers to access services, make lifestyle changes and plans for the future, which can become more difficult as the condition progresses.

Clinical question

Are there advantages or disadvantages to early identification?

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<th>CBR</th>
<th>General population screening for dementia should not be undertaken.</th>
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<td>23</td>
<td>PP</td>
<td>Concerns or symptoms should be explored when first raised, noted or reported by the person, carer or family and should not be dismissed as ‘part of ageing’.</td>
</tr>
<tr>
<td>24</td>
<td>PP</td>
<td>Medical practitioners working with older people should be alert to cognitive decline, especially in those aged 75 years and older.</td>
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</table>

Summary of the NICE Guideline findings

The NICE Guideline Committee conducted a search for quantitative and qualitative evidence examining the advantages or disadvantages associated with early identification. They identified one systematic review that failed to identify any randomised controlled trials addressing this question.
They therefore concluded that there was insufficient evidence to justify population screening in primary care [63] and made a recommendation against population screening.

Evidence update
A recent high quality systematic review addressed the potential harms and benefits associated with screening for cognitive impairment [20]. The review failed to identify any studies that examined the direct effect or harms of screening. The Committee is aware of a large randomised controlled trial underway in the United States which is due to be completed in 2017 [64]. Results of this study will provide important information regarding the benefits and harms of early diagnosis.

Considerations for Australia
Health professionals should be aware that there is a higher prevalence of dementia in Indigenous Australians and that the symptoms of dementia may present at an earlier age. In addition, changes in cognitive function are perceived differently in some cultures, which may result in the person or their carer seeking a diagnosis later in the course of dementia.

Memory assessment services
Background
Memory assessment specialists or services have expertise in assessment, diagnosis, information and treatment for people with memory and related cognitive disorders with the focus being on timely assessment and intervention. Within Australia, specialists with expertise in memory disorders include geriatricians, neurologists, psychiatrists and psychogeriatricians. Memory assessment services may be staffed by these specialists and may include other medical, nursing and allied health staff. Patients are referred to memory assessment specialists or services by health professionals or in some cases via self-referral.
Clinical question

For people with symptoms of dementia, does attendance at a memory clinic provide benefits in comparison to attendance at another service?

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<th>26</th>
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<th>People with a possible diagnosis of dementia should be referred to memory assessment specialists or services for a comprehensive assessment.</th>
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<tr>
<td>27</td>
<td>PP</td>
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<td>Memory assessment specialists and services should offer a responsive service to aid timely diagnosis and should be able to organise a full range of assessment, diagnostic, therapeutic and rehabilitation services to accommodate the needs of people with different types and severities of dementia as well as the needs of their families and carers living in the community.</td>
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<tr>
<td>28</td>
<td>PP</td>
<td></td>
<td>Memory assessment specialists or services should ensure an integrated approach to the care of people with dementia and the support of their families and carers. Referrals for required health and aged care services should be made directly by the specialists or the memory assessment service.</td>
</tr>
<tr>
<td>29</td>
<td>PP</td>
<td></td>
<td>All people seen by a memory assessment specialist or service should be provided with written and verbal information regarding relevant services such as Alzheimer’s Australia, Carers Australia and Aged Care Assessment Teams.</td>
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Summary of the NICE Guideline findings

The NICE Guideline Committee conducted a broad search to develop recommendations relating to the optimal process of assessment for people with symptoms of dementia. They did not cite any studies reporting patient outcomes that evaluated the effects of memory assessment services relative to other service models.

Evidence update

This evidence update identified two randomised controlled trials. [65 66] The first randomised controlled trial was conducted in Australia by Logiudice and colleagues.[65] The intervention included specialist consultation, carer advice and counselling from a nurse specialist, neuropsychology assessment and family conference. The study focussed on outcomes for the family carer and found those who had attended a memory clinic had significantly improved psychosocial status at six months.

The second study was conducted in the Netherlands and compared the effects of memory clinic attendance versus general practitioner care in real life conditions.[66] The memory clinic involved specialist consultation, consideration of acetylcholinesterase inhibitor medication prescription and tailored non-pharmacological intervention (e.g., occupational therapy). The control group involved consultation with the general practitioner and care provided based on the Dutch general practice and homecare dementia guidelines. The study found no significant differences in patient outcomes at 12 months. There was no evidence of a significant difference in cost between memory clinics and general practitioner care.[66] Generalisability of these findings to the Australian setting is uncertain.
Evidence statements

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<th>Evidence statements</th>
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<td>One highly applicable RCT conducted in Australia found that carers who attended a memory clinic with someone with dementia reported improved psychosocial status at six months compared to those visiting the GP. [65]</td>
<td>Low</td>
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<tr>
<td>One RCT conducted in the Netherlands did not find a significant difference between memory assessment service and GP visits for quality of life of the person with dementia, ADL function or BPSD. The applicability of this trial to the Australian setting is uncertain. [66]</td>
<td>Moderate</td>
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</table>

Considerations for Australia

The Committee agreed that further research was needed to determine the effectiveness and costs of memory assessment services and to determine the optimal configuration including the health professionals that should be available within the service.

Access and referral to specialised memory assessment services varies through Australia, particularly in rural and remote areas of Australia. Existing memory assessment services often have long waiting lists and may not have capacity to accept all referrals in a timely manner. This was considered an important area for research translation and strategies to ensure access should be implemented.

Follow-up for people with Mild Cognitive Impairment

Background

People with MCI are at increased risk of developing dementia. Conversion rates of MCI differ between subtypes and different settings (specialist v. community). [67 68] There is currently no consensus on how frequently people with MCI should be assessed by memory assessment services.

Clinical question

How frequently should memory assessment services review people with mild cognitive impairment (MCI) for progression to dementia?

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| Memory assessment services that identify people with Mild Cognitive Impairment should typically offer follow-up either at the memory assessment service or with a general practitioner or other medical practitioner after six to 18 months to monitor cognitive changes and other signs of possible dementia.

Summary of the NICE Guideline findings

The NICE Guideline Committee recommended that people with MCI should be followed up in order to monitor cognitive decline. They did not provide guidance on how frequently reviews should occur; therefore, a review to address this question was conducted.
Evidence update

A systematic review of randomised controlled trials or other comparative studies published to November 2014 was completed. The search did not identify any studies that compared alternative assessment frequencies, or compared follow-up assessment to no review, for patients with MCI attending memory clinics.

Therefore, the Guideline Adaptation Committee decided to make a consensus based recommendation. The Committee used conversion rates of MCI to dementia to inform their decision making.

In a clinic (or specialist) setting, the annual conversion rate of MCI to Alzheimer’s disease across 13 studies was reported to be 10.2 per cent (range 5.9 per cent–18.8 per cent).[69] Annual conversion rates in studies that recruited subjects from the community were lower (median 6.0 per cent, range 4.3 per cent–11.5 per cent across 11 studies).

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>No studies were identified that compared outcomes for people with MCI attending memory clinics for review at alternative frequencies.</td>
<td>NA</td>
</tr>
</tbody>
</table>

NA – not applicable

Considerations for Australia

Access to specialised memory assessment services varies through Australia, particularly in rural and remote areas. However, follow-up may be conducted by general practitioners in consultation with specialists. The specification of a frequency for review may decrease the number of people being reviewed more frequently than necessary, making services more available to those in greater need.

Diagnosis of dementia

Background

Dementia is diagnosed on the basis of clinical criteria following comprehensive clinical assessment including history, cognitive and mental statement assessment, physical examination and medication review.[70 71]

Researchers have recently examined the amount of evidence available to inform the use of biomarkers for dementia.[72] At present, while there are many articles reporting on diagnostic accuracy studies of biomarkers for Alzheimer’s disease (including β-amyloid, tau, positron emission tomography using 18F- fluorodeoxy-glucose or ligands for amyloid), there are many limitations in the quality of the studies and overall the body of evidence for biomarkers for dementia diagnosis is not large.
## Diagnosis of dementia

### 31 PP
A diagnosis of dementia should be made only after a comprehensive assessment, which should include:

- history taking from the person
- history taking from a person who knows the patient well if possible
- cognitive and mental state examination with a validated instrument
- physical examination
- a review of medication in order to identify and minimise use of medications, including over-the-counter products, that may adversely affect cognitive functioning
- consideration of other causes (including delirium/depression).

### 32 PP
At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of coexisting conditions.

### 33 PP
A basic dementia screen should be performed at the time of presentation, usually within primary care. It should include the following blood tests:

- routine haematology
- biochemistry tests (including electrolytes, calcium, glucose, and renal and liver function)
- thyroid function tests
- serum vitamin B12 and folate levels.

### 34 PP
Testing for syphilis serology or HIV should be undertaken only in those with histories suggesting they are at risk.

### 35 PP
Clinical presentation should determine whether investigations such as chest X-ray or electrocardiogram are needed. An electrocardiogram should be considered if intending to prescribe acetylcholinesterase inhibitors.

### 36 PP
Cerebrospinal fluid examination should not be performed as a routine investigation for dementia.

### 37 PP
A diagnosis of subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria.

### 38 PP
Cerebrospinal fluid examination is indicated if Creutzfeldt–Jakob disease or other forms of rapidly progressive dementia are suspected. Caution is required in obtaining cerebrospinal fluid from a person with possible Creutzfeldt–Jakob disease.

### 39 PP
Electroencephalography should not be used as a routine investigation in people with dementia. Electroencephalography should be considered if a diagnosis of delirium or Creutzfeldt–Jakob disease is suspected, or in the assessment of associated seizure disorder in those with dementia.

### 40 PP
Brain biopsy for diagnostic purposes should be considered only in highly selected people whose dementia is thought to be due to a potentially reversible condition that cannot be diagnosed in any other way.
Diagnosis of dementia

Many new technologies including Positron Emission Tomography (PET) (with 18F-fluorodeoxyglucose [FDG], amyloid and tau ligands) are currently being evaluated and may prove to be useful in the assessment of dementia in the future.

Considerations for Australia

In current practice, the process for diagnosis of dementia is variable. These recommendations for the systematic assessment of dementia may increase consistency in approach across different practitioners and settings throughout Australia.

Cognitive assessment tools

Background

Cognitive assessment involves the assessment of many cognitive functions, including memory, orientation and executive function.

Cognitive assessment tools

Clinical cognitive assessment in those with suspected dementia should include examination using an instrument with established reliability and validity (suggested assessment tools are presented in Box 3). Health and aged care professionals should take full account of other factors known to affect performance, including age, educational level, non-English speaking background, prior level of functioning, language, hearing or visual impairments, psychiatric illness or physical/neurological problems when interpreting scores.

Formal neuropsychological testing may form part of the assessment in cases of questionable dementia.

The Dementia Outcomes Measurement Suite is a Federal Government initiative to assist health professionals in assessing dementia in all settings (www.dementia-assessment.com.au/index.html). The website has links to the assessment tools, manuals and scoring guides. The tools on the website have been appraised and have been presented as being current and suitable tools to use with people with dementia. The tools in Box 4 are recommended for assessment of cognitive function based on the appraisal in the Dementia Outcomes Measurement Suite.[73]
**Box 4: Measurement tools of cognitive function (adapted from the Dementia Outcomes Measurement Suite [DOMS: www.dementia-assessment.com.au])**

<table>
<thead>
<tr>
<th>RECOMMENDED TOOLS (for further detail see Appendix 1)</th>
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<tr>
<td>Modified Mini Mental Exam (3MS)</td>
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<tr>
<td>Mini Mental State Exam (MMSE)</td>
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<tr>
<td>The Alzheimer’s Disease Assessment Scale - Cognition (ADAS-Cog)</td>
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<tr>
<td>General Practitioner Assessment of Cognition (GPCOG)</td>
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<tr>
<td>Psychogeriatric Assessment Scale (PAS)</td>
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<tr>
<td>Montreal Cognitive Assessment (MoCA)</td>
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<td>Frontal Assessment Battery (FAB)</td>
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<td>EXIT 25</td>
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<tr>
<td>Addenbrooke’s Cognitive Examination (ACE-R now replaced by ACE-III)</td>
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</table>

Mental status tests are simple practical tests that assess specific aspects of cognitive function. As such, they act as initial tools for assessing cognition. Detection of cognitive impairment will lead to more comprehensive assessment. The Rowland Universal Dementia Assessment Scale (RUDAS) and the Kimberley Indigenous Cognitive Assessment (KICA-Cog) tool are both short mental status tests (cognitive assessment tools) that have been developed in Australia for use in specific subpopulations.

The KICA tool was developed in 2006 as a culturally appropriate tool for older Indigenous Australians living in remote and rural locations.[74] There are three individual parts to the complete tool: for cognitive assessment (the KICA-Cog), functional assessment and for the carer and family to complete. The tool is freely available online (at www.wacha.org.au/kica.html). The tool has a focus on memory and language skills and limited coverage of executive function. An adapted version of the tool (the modified KICA tool, mKICA) has also been developed for use with urban and regional Indigenous Australians.[75]

The RUDAS was designed in 2004 in Australia for use in culturally and linguistically diverse (CALD) populations.[76] Training is required to administer the tool, but the tool and training is freely available online (at https://fightdementia.org.au/about-dementia-and-memory-loss/cultural-diversity/culturally-appropriate-dementia-assessment-tools/RUDAS). An interpreter is used for people from non-English speaking backgrounds. The developers of the tool state that it can also be translated into other languages without other modifications.
Clinical question

What is the evidence for the validity of the Kimberley Indigenous Cognitive Assessment (KICA) in Indigenous Australian populations and the Rowland Universal Dementia Assessment Scale (RUDAS) in Culturally and Linguistically Diverse (CALD) populations?

44 EBR Low
The Kimberley Indigenous Cognitive Assessment (KICA-Cog) or KICA-Screen tool is recommended for use with remote living Indigenous Australians for whom the use of alternative cognitive assessment tools is not considered appropriate.

45 EBR Low
The modified KICA (mKICA) is recommended as an alternative to the Mini Mental State Exam (MMSE) in urban and rural Indigenous Australian populations when illiteracy, language or cultural considerations deem it appropriate.

46 EBR Very low
The Rowland Universal Dementia Assessment Scale (RUDAS) should be considered for assessing cognition in CALD populations.

Summary of the NICE Guideline findings

The NICE Guideline did not present the results of a systematic search for cognitive assessment tools. The KICA and RUDAS are relatively new cognitive assessment tools developed in Australia. They were not addressed in the NICE Guidelines.

Evidence update

A systematic review of accuracy studies of the KICA and RUDAS cognitive assessment tools was conducted. Studies were eligible for inclusion if they included all participants, including those with MCI, in the analysis of accuracy data as determined by the use of an appropriate reference standard.

Kimberley Indigenous Cognitive Assessment (KICA-Cog)

Remote Indigenous populations

As the KICA is the first cognitive assessment tool developed for use in remote Indigenous Australian populations, there is no appropriate alternative cognitive assessment tool for use in this population.[74] Therefore, included studies did not compare the accuracy of the KICA with other cognitive assessment tools. Two publications involving the KICA-Cog and KICA-Screen (a shortened version of the KICA-Cog) conducted in a remote population provided data on the accuracy of the tool for the diagnosis of dementia.[45 77] Additional data were provided by personal communication.[78] In one study conducted in remote Indigenous populations in the Kimberley, the sensitivity and specificity of the KICA-Cog for the diagnosis of dementia were high.[78] However, there are some limitations in the applicability of these accuracy data as it is a population-based, rather than a clinic based study. The prevalence and spectrum of cognitive function is likely to differ between these groups, which is likely to affect estimates of test accuracy. The KICA-Screen (a shortened, 10-item version of the KICA-Cog) was developed in this same population [77], and has high accuracy. The screening tool was then tested in 55 Indigenous Australians (including Torres...
Strait Islanders) from North Queensland and demonstrated a slightly lower, but moderately high sensitivity and specificity.[77]

Non-remote Indigenous populations

Two studies of a modified version of the KICA for urban dwelling Indigenous Australian populations (the mKICA) tested the tool against an alternative tool in non-remote (regional or urban) populations.[79 80] One high quality study was conducted in five urban and regional areas in NSW. In this study, diagnostic accuracy for the diagnosis of dementia was slightly higher for the mKICA and MMSE than the RUDAS.[80] At standard published cut-offs, the sensitivity of the tests were not significantly different, but were slightly higher for the MMSE (68 per cent) than for the mKICA (57 per cent) or the RUDAS (61 per cent). However, the specificities of the mKICA and MMSE were higher than that of the RUDAS and accuracy was good for both the MMSE and mKICA at 94 per cent, compared to 89 per cent for the RUDAS. A small pilot study of 19 subjects found similar accuracies for the mKICA, the MMSE and the RUDAS.[79]

Rowland Universal Dementia Assessment Scale

Four studies provided data on accuracy of the English version of the RUDAS in comparison to an alternative cognitive assessment tool.[81-84] All four studies compared the RUDAS to the MMSE; three of these provided data on sensitivity and specificity of the tests using a test cut-off score.[82-84] One of the studies also compared the RUDAS to the Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE) [82] and another to the General Practitioners Assessment of Cognition (GPCOG).[84]

In all four studies the accuracy as measured by the area under the ROC curve (AUC) did not significantly differ between the RUDAS and the MMSE.[81-84] The AUC did not significantly differ between the RUDAS and the IQ-CODE in one study [82] or the RUDAS and the GPCOG in another.[84] In two studies the results on the MMSE, but not the RUDAS, were affected by CALD status.[83 84]

Three studies reported the sensitivity and specificity of the RUDAS and MMSE in the study population.[82-84] In one study conducted in memory clinic patients, the sensitivity and specificity did not significantly differ between the tests [83] whereas in another the sensitivity of the MMSE was significantly higher than that of the RUDAS (sensitivity MMSE 83 per cent versus RUDAS 66 per cent).[82] However, both of these studies contain a high risk of bias as the cognitive assessment results for MMSE were considered as a component of the final consultant diagnosis (the reference standard) and some of the cut-off scores applied differed to that recommended in practice. In the third study conducted in people recruited from both memory and other clinics the accuracy of the RUDAS was slightly higher than that of the MMSE for the diagnosis of dementia at the recommended cut-off scores (sensitivity 88 per cent v. 79 per cent, specificity 77 per cent v. 79 per cent for RUDAS and MMSE, respectively).[84]

In summary, the RUDAS is considered likely to have a similar or slightly higher accuracy to that of the MMSE for the diagnosis of dementia in CALD populations; however, there is a high degree of uncertainty due to biases inherent in the studies. The RUDAS was less influenced by cultural background than the MMSE.
### Evidence statements

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
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</thead>
<tbody>
<tr>
<td>One diagnostic accuracy study of the KICA-Cog has demonstrated high accuracy for the diagnosis of dementia in a remote Indigenous Australian population.[45 78]</td>
<td>Low</td>
</tr>
<tr>
<td>The KICA-Screen had a high accuracy for dementia in one study in a remote Indigenous Australian population, in which the tool was developed.[77] Accuracy of the KICA-Screen was moderately high in a small study in a North Queensland remote Indigenous Australian population.[77]</td>
<td>Very low</td>
</tr>
<tr>
<td>A large accuracy study and a small pilot study of the mKICA have demonstrated comparable accuracy of the mKICA and the MMSE in urban and regional living Indigenous Australian populations.[79 80] The accuracy of the RUDAS was slightly lower than that of the mKICA and MMSE in this population.[80]</td>
<td>Low</td>
</tr>
<tr>
<td>The accuracy (as determined by the AUC) of the RUDAS and the MMSE did not significantly differ in four diagnostic accuracy studies.[81-84] Three diagnostic accuracy studies compared the sensitivity and specificity of the MMSE and the RUDAS, with inconsistent results.[82-84] There is a high degree of uncertainty due to biases inherent in the studies. The RUDAS was less influenced by cultural background than the MMSE in two studies.[83 84]</td>
<td>Very low</td>
</tr>
</tbody>
</table>

### Considerations for Australia

The KICA and RUDAS cognitive assessment tools were developed in Australia for specific Australian populations. Thus, they are expected to have good cultural acceptability in the populations for whom they are recommended and their use may improve the process of diagnosis of dementia in these populations.

### Neuroimaging

Neuroimaging is used primarily to identify potentially reversible causes of dementia due to underlying pathology, particularly those amenable to surgical intervention (e.g., intracranial masses, and normal-pressure hydrocephalus). It is estimated that of nine per cent of dementia cases that are identified as potentially reversible, only 0.6 per cent are partially or fully reversed.[85] Nevertheless, if a reversible cause is identified, the impact on outcomes for the person with dementia could be critical.

Neuroimaging may also be performed to aid in differentiating the dementia subtype. Diagnosis of subtype can be complex as many cases of dementia involve mixed pathology (for example, Alzheimer’s disease and vascular dementia or Alzheimer’s disease and DLB). The aim of diagnosis is to identify the predominant cause to inform management. Images from neuroimaging scans may also be of value when communicating the diagnosis to people with dementia and their carer(s) and family and explaining the pathological cause of the disease.
Structural imaging

Background

Structural imaging of the brain can be performed using CT or structural MRI. Such imaging can delineate body structures and provide information on structural abnormalities. Structural abnormalities, such as cerebrovascular disease or patterns of cerebral atrophy, may assist in the subtype diagnosis of dementia (e.g., atrophy of the medial temporal lobe may assist in the diagnosis of Alzheimer’s disease).[86] MRI has a higher resolution than CT and may detect more subtle anatomical and vascular changes.[87] However, a review of 38 studies, including four that directly compared the accuracy of MRI and CT, found a lack of evidence that MRI was superior to CT for the detection of a vascular component to dementia.[88] MRI is contraindicated in some patients, such as those with pacemakers, vagus nerve stimulators, implantable cardioverter-defibrillators, loop recorders, cochlear implants and insulin pumps.[89] MRI is also unsuitable for patients who are claustrophobic or unable to stay still for long periods.

Clinical question

Does every patient with dementia need structural imaging (with CT or MRI) of the brain?

Structural imaging (with computed tomography [CT] or magnetic resonance imaging [MRI]) should usually be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis, unless contraindicated by good clinical judgement. Structural imaging may not always be needed in those presenting with moderate-to-severe dementia, if the diagnosis is already clear.

The NICE Guideline Committee recommended the use of structural imaging in the assessment of people with suspected dementia to exclude other cerebral pathologies and help establish the subtype diagnosis. The results of a systematic search were not presented in their report.

Evidence update

This evidence update identified a Health Technology Assessment report that addressed a number of questions relating to neuroimaging.[87] This update considered evidence from three key questions addressed in the Health Technology Assessment: (1) ‘What are the indications for a structural imaging investigation for dementia diagnosis?’, (2) ‘What is the clinical utility or adjunctive value of neuroimaging for dementia diagnosis?’ and (3) ‘What is the diagnostic accuracy of neuroimaging for discriminating dementia types?’.

Nine studies provided data on the use of sets of clinical and/or demographic characteristics (e.g., age, condition severity, symptoms) to select patients for structural imaging. The accuracy of these groups of indications (clinical prediction rules) to predict abnormal scans showing potentially reversible causes of dementia varied highly between the different rules, and between studies.[90 91]. In a single study, single indications from clinical prediction rules did not predict the impact of test results on diagnosis or management.[92] Overall, clinical indications or prediction rules did not reliably predict the presence of abnormalities on structural imaging.
CT and MRI generally had good accuracy to discriminate dementia subtypes. Four studies indicated that structural imaging can have an impact on diagnosis in people with dementia; the magnitude of this effect varied depending on the dementia subtypes being detected. Two studies provided information on the accuracy of structural imaging in comparison to, or as an addition to, comprehensive clinical assessment. One of these found that in people with mixed dementia, the use of CT or MRI in addition to clinical diagnosis increased the detection of cerebrovascular disease, with an increase in sensitivity of 53 per cent and a decrease in specificity of 17 per cent.[22] The other study found that MRI had a high sensitivity for differentiating dementia subtype in memory clinic patients with clinically ambiguous dementia.[93] No studies provided information on the impact of structural imaging on patient outcomes.

The Guideline Adaptation Committee agreed that structural imaging was necessary to exclude cerebral pathologies in most people with suspected dementia and therefore, this was stated in a Practice Point. Evidence-based recommendations regarding the use of structural imaging in subgroups of people with dementia were therefore considered unnecessary.

### Evidence statements

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
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<tbody>
<tr>
<td>Evidence from nine accuracy studies indicated that clinical indications or prediction rules did not reliably predict the presence of abnormalities on structural imaging.[90 91] One accuracy study indicated that single indications from clinical prediction rules did not influence diagnosis or treatment.[92]</td>
<td>Very low</td>
</tr>
<tr>
<td>Six accuracy studies indicated that CT has moderate to high sensitivity and specificity for the diagnosis of Alzheimer’s disease.</td>
<td>Very low</td>
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<tr>
<td>Twenty-eight studies indicated that MRI has good sensitivity and specificity for the diagnosis of Alzheimer’s disease, with a wide range in the accuracy estimates.</td>
<td>Very low</td>
</tr>
<tr>
<td>Two accuracy studies indicated that MRI has a high specificity and moderate sensitivity for the diagnosis of Creutzfeldt-Jakob disease.</td>
<td>Low</td>
</tr>
<tr>
<td>One study indicated that when the subtype was unclear on comprehensive clinical assessment, MRI had a high sensitivity for differentiating subtypes, a moderate specificity for vascular dementia and a moderate sensitivity and high specificity for Alzheimer’s disease.</td>
<td>Very low</td>
</tr>
<tr>
<td>Four studies indicated that structural imaging can change the diagnosis in people with dementia; the magnitude of this effect varied depending on dementia subtypes. One of these studies indicated that structural imaging increased the number of diagnoses of cerebrovascular disease over and above that of clinical diagnosis, with an increase in sensitivity of 53 per cent and a decrease in specificity of 17 per cent.[94] One study indicated that CT changed treatment plans in approximately 10 per cent of dementia patients.[95]</td>
<td>Low</td>
</tr>
<tr>
<td>No studies reported on the impact of structural imaging on patient outcomes.</td>
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</table>

### Considerations for Australia

Structural imaging services may be limited in some rural and remote areas of Australia and general practitioners cannot order an MRI in Australia.
Functional imaging

Background

Functional neuroimaging depicts the changes in the functioning of the brain tissue. Single-photon emission computed tomography (SPECT) is performed with a variety of tracers including hexamethyl-propyleneamine oxime (99mTc-HMPAO), N-isopropyl-(iodine-123)p-iodoamphetamine (123I-IMP) and ethylene cysteinate dimer (99mTc-ECD) can be used. These tracers accumulate at sites with greater regional blood flow.

Functional imaging for the diagnosis of dementia can also be performed using PET. In Australia, availability of PET facilities is limited. The use of PET for the diagnosis of dementia is not reimbursed through the public insurer Medicare and is associated with significant out-of-pocket costs to the consumer. Thus, the use of PET for the diagnosis of dementia is not common in Australia. At the time of Guideline development, the Medical Services Advisory Committee (MSAC) was conducting an assessment of F-18 Flurodeoxyglucose (FDG) PET for the diagnosis of Alzheimer’s disease to determine whether it should be listed on the Medical Benefits Schedule (MBS).[96]

Clinical question

Does the routine use of functional imaging (with SPECT) improve the diagnostic differentiation of dementia from MCI over and above that of standard comprehensive assessment?

Secondary question

What is the accuracy of SPECT to predict progression of MCI to dementia?

48 EBR Very low HMPAO SPECT should not be used in patients with Mild Cognitive Impairment (MCI) either for the differentiation of dementia from MCI or for the differentiation of progressive from non-progressive MCI.

Summary of the NICE Guideline findings

The NICE Guideline Committee used evidence from an existing systematic review to inform a recommendation on the use of HMPAO SPECT in the differentiation of dementia subtypes.[97] Recent systematic reviews have reported similar accuracy values.[86 98] However, none of these reviews specifically consider the accuracy of SPECT over and above that of standard comprehensive assessment including structural imaging, nor do they exclude case control studies. Based on the paucity of evidence and clinical expert opinion, the Guideline Adaptation Committee considered that the additional value of SPECT to that of standard comprehensive assessment in the differentiation of dementia subtypes did not support a recommendation for its use in this context.

Evidence addressing the use of SPECT specifically for the differentiation of dementia (or AD) from MCI or for the prediction of MCI conversion to dementia was not presented in the NICE Guideline but was reviewed in this evidence update.
The NICE Guideline recommended the use of 2-[18F]fluoro-2-deoxy-D-glucose positron emission tomography (FDG PET) for differentiation of dementia subtypes when SPECT is not available. As accessibility of PET is highly limited in Australia, it was considered that investigating the evidence for PET was outside the scope of these Australian guidelines. It is recommended that evidence for the use of PET in the diagnosis of dementia be reviewed when these guidelines are next updated.

**Evidence update**

**Differentiation of mild cognitive impairment from dementia**

No studies reporting the accuracy of SPECT over that of clinical assessment in differentiating dementia from MCI were identified in a Health Technology Assessment published in 2006.[99] Three studies providing data on the value of SPECT over and above that of clinical assessment were identified in the evidence update.

Two studies provided some data on the accuracy of SPECT when used in addition to clinical assessment. One German study reported data from 12 memory clinic patients initially diagnosed with MCI.[100] SPECT changed the diagnosis from MCI to dementia in eight subjects, correctly in four of these cases (50 per cent). In this small study, SPECT was of no additional value overall, but there was considered to be a high risk of bias in these results. In another study, 99mTc-HMPAO SPECT was of little value in establishing a diagnosis in a group of young, cognitively impaired patients attending a memory clinic with diagnostic uncertainty following standard comprehensive assessment including structural imaging.[101]

A medical audit of SPECT referrals in rural NSW reported rates of concordance between SPECT, CT and neuropsychological assessment.[102] In this study, 31 per cent of referrals were from general practitioners and 98 per cent were referred for suspected dementia. In 76 per cent of people with a comparison to CT and neuropsychological assessment available, SPECT was either in agreement with the other test results or further studies were recommended. Thus, there is unlikely to have been any major impact on diagnosis or management for the majority of people, although there may have been increased confidence in diagnosis and treatment choice where results concurred.

**Prediction of progression of MCI to dementia**

A systematic review reporting the accuracy of SPECT to differentiate progressive MCI from non-progressive MCI found that that SPECT had only a moderate sensitivity and specificity in predicting conversion of MCI to Alzheimer’s disease.[103] A positive SPECT result did not provide good discrimination of patients who will progress to dementia from those who will not. In addition, the management and outcomes for people receiving a positive SPECT result for MCI that will progress to dementia are unclear.

<table>
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<tr>
<th><strong>Evidence statements</strong></th>
<th><strong>GRADE Quality</strong></th>
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<tr>
<td>Two accuracy studies indicated that SPECT has little additional value over that of standard comprehensive clinical assessment for differentiating dementia from MCI.[100 101]</td>
<td>Very low</td>
</tr>
<tr>
<td>Six studies indicated that SPECT does not provide good discrimination of patients who will progress to dementia from those who will not.[102]</td>
<td>Very low</td>
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</table>
Considerations for Australia

This recommendation against the routine use of SPECT in the process of diagnosis of dementia may reduce unnecessary testing and thereby decrease the costs of the diagnostic process for people with dementia or MCI.

Communicating the diagnosis

Background

Receiving a diagnosis of dementia has an enormous impact on the person with dementia, their carer(s) and families. Following diagnosis, people often report feelings of loss, anger, uncertainty and frustration.[59] Yet, some people report feelings of relief to have an explanation for their symptoms.[104]

Providing a diagnosis to a person with dementia is fundamental to the principle of personal autonomy and should be expected. Although a very small number of people may choose not to know the diagnosis, it is clear that the majority of people want to be informed and therefore, it is important that health professionals are honest and truthful when communicating the diagnosis to the person with dementia and families and carers. How and when that occurs must be managed with sensitivity to the person with dementia’s wishes, their relationship with the medical practitioner providing the diagnosis and the context of the discussion. The diagnosis of dementia is never provided without earlier discussion about memory and thinking difficulties. Medical practitioners should discuss the possibility of dementia as a diagnosis during the process of assessment, which may take three to six months to achieve. Discussion of the diagnosis and its consequences may occur gradually over several visits to the medical practitioner, but should occur as early as practicable.

<table>
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<th>Communicating the diagnosis</th>
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<td>49  PP</td>
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### Communicating the diagnosis

<table>
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<th>Notes</th>
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<td>51</td>
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<td>52</td>
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### Considerations for Australia

These recommendations promoted lengthy discussion among the Committee and there was debate about the wording of the final recommendations. The Committee agreed that all people with a diagnosis of dementia should have the opportunity to be told the diagnosis and that the diagnosis should not be withheld because of any discomfort in conveying the diagnosis on the part of the medical practitioner.

A recent initiative is to involve a Dementia Link Worker during and immediately after diagnosis. Piloting of the Dementia Link Worker program is underway in some areas of Australia and there is also a Dementia Key Worker program for people with younger onset dementia. The outcomes of these programs may provide further information about the best models of care for people upon diagnosis.

Medical practitioners working with people from CALD backgrounds should also be aware of particular issues in making a diagnosis. If the medical practitioner is not bilingual, a professional interpreter must be present. If there is a bilingual worker already involved with the person with dementia, they may be able to provide an important link by providing education and support. The western medical concept of dementia is not able to be simply translated into some languages and there is reduced understanding in some cultures regarding the condition. The term ‘dementia’ may not always be appropriate as it may be interpreted as offensive or disrespectful in some cultures and therefore it is important that medical practitioners understand the person, their families and carers and the communities they are a part of so that the most appropriate language can be used.
Information and support for the person with dementia

Background

Information and education is important for both the person with dementia and their carer(s) and families. Information needs will vary over the course of the disease. There are several organisations in Australia that provide high quality educational resources for both the person with dementia and their carer(s).

Alzheimer’s Australia (www.fightdementia.org.au) offers a range of resources including ‘help sheets’, books, videos, DVDs and useful websites. Help sheets are available in a number of languages and there is information developed for Indigenous people living in remote communities of the Northern Territory. People with a diagnosis of dementia are encouraged to contact Alzheimer’s Australia (phone 1800 100 500) for information about dementia, support groups and counselling services. The Living with Memory Loss Program is available in each state and territory. The program includes education and support groups specifically designed for people in the early stage of dementia, and their carer(s) and families.

MyAgedCare (www.myagedcare.gov.au) was established by the Australian Government to help consumers navigate the aged care system. It contains information regarding help at home and residential care.

Clinical question

For people with dementia, what type of information and support is beneficial?

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<td>Very low</td>
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<tr>
<td>57</td>
<td>PP</td>
</tr>
</tbody>
</table>
Summary of the NICE Guideline findings

The NICE Guideline Committee searched for studies that assessed the efficacy of educational interventions for the person with dementia. While it identified multifaceted interventions that included education as one component, it was unable to find any studies that evaluated information provision or educational programs alone.

Evidence update

This evidence update failed to identify any controlled trials or cohort studies that evaluated the effects of an information or education program for the person with dementia. Qualitative studies provide some useful information. Surveys, focus groups and interviews have revealed that people with dementia report that they have to ‘push’ to obtain information. Information that was provided in a ‘clear fashion’ or written in layman’s language was highly regarded whereas being provided with too much information was described as overwhelming. People commonly requested more information regarding cognitive testing, medications, disease progression, financial matters and behaviour change and management. Practical advice (addressing issues such as finances and Power of Attorney) was preferred once the person had time to come to terms with the diagnosis.

Boughtwood and colleagues looked specifically at the information needs of CALD Australians. It was recommended that information sessions for CALD communities regarding dementia be conducted regularly and locally and that services be widely promoted. Information regarding dementia was more highly regarded when it was provided in-person by someone credible (preferably a medical practitioner). Information needed to be tailored to the situation of the person with dementia and their families and carers. Other recommendations included the need for more written information in CALD languages and information beyond the basics of dementia.

This evidence update identified some evidence in favour of attending a support group for people with dementia. Leung and colleagues conducted a systematic review and identified two relevant randomised controlled trials that involved a social support group as a key component of the intervention. One of the studies evaluated a multifaceted program involving exercise, cognitive behavioural therapy and social support groups whereas the other study evaluated a structured social support group incorporating educational seminars, supportive discussion and strategies for enhancing communication. Both studies measured levels of depression at follow-up; one of the studies found a positive effect, with lower levels of depression in the intervention group, whereas the other study found no effect. One of the studies examined quality of life in the person with dementia and found that participants in the intervention group had significantly higher scores on a quality of life measurement tool than those in the control group.
### Evidence statements

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>No RCTs or cohort studies were identified that evaluated the effects of an education program alone for people with dementia.</td>
<td>NA</td>
</tr>
<tr>
<td>One RCT found that participation in a social support program led to increased quality of life (low). One of two RCTs found that participation in a social support group led to reduced levels of depression (very low). [106]</td>
<td>Very low-low</td>
</tr>
</tbody>
</table>

NA – not applicable

### Considerations for Australia

Within Australia, high quality consumer information is made available by Alzheimer’s Australia. There is a current trend towards providing information in an electronic format (e.g., health professionals providing links to websites). This method of providing information may be highly valued by some people; however, this may not suit the needs of others who prefer information in other formats.
TREATMENT

Models of care

Organisation of health services

Health and aged care services for people with dementia and their carers

Background

There are a number of different frameworks and pathways relevant to the organisation of care for people with dementia in Australia. The frameworks and pathways should be consulted when planning, developing and reviewing services.

Service guidance

The National Framework for Action on Dementia 2014–2018 is intended to guide the development and implementation of actions and policies to improve outcomes for people with dementia and their carers.[107] Seven priority areas for action are presented: (1) increasing awareness and reducing risk, (2) timely diagnosis, (3) care and support post diagnosis, (4) ongoing care and support, (5) care and support during and after hospital care, (6) end of life and palliative care, and (7) research. Policy makers and service providers should consult the framework for guidance in service delivery.

The National Dementia Services Pathways describes the timing and sequence of services required for people with dementia and their families and carers across the continuum.[108] The framework outlines principles of service delivery. Four management stages of dementia are presented: (1) awareness, recognition and referral, (2) initial assessment and diagnosis and post-diagnosis support, (3) management, care, support and review, and (4) end of life. People involved in planning services for people with dementia within jurisdictions should consult the Dementia Services Pathways for guidance.

In addition, there are existing state and territory frameworks designed to assist planning and development of dementia services and programs.[109] The frameworks should be consulted when establishing new services or reviewing existing services. The New South Wales Framework is comprehensive and practical and can be used as a checklist to review existing services and promote change to reflect best practice.[109]
### Clinical question

**For people with dementia, what is the best way of organising services in terms of integration of care, consumer directed care, multidisciplinary assessment and case management?**

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<tbody>
<tr>
<td><strong>58</strong></td>
<td>EBR</td>
<td>Very low Health and aged care managers should coordinate and integrate working across all agencies involved in the assessment, treatment, support and care of people with dementia and their carer(s) and family, including jointly agreeing on written policies and procedures. People with dementia and their carer(s) and families should be involved in planning local policies and procedures.</td>
</tr>
<tr>
<td><strong>59</strong></td>
<td>EBR</td>
<td>Very low Health system planners should ensure that people with dementia have access to a care coordinator who can work with families and carers from the time of diagnosis. If more than one service is involved in the person’s care, services should agree on one provider as the person’s main contact, who is responsible for coordinating care across services at whatever intensity is required.</td>
</tr>
<tr>
<td><strong>60</strong></td>
<td>PP</td>
<td>Care coordinators should ensure that care plans are developed in partnership with the person and his or her carer(s) and family and based on a comprehensive assessment including the person with dementia’s life history, social and family circumstance, and goals and preferences, as well as the person’s physical and mental health needs and current level of functioning and abilities.</td>
</tr>
</tbody>
</table>
| **61** | PP | Care coordinators should ensure the coordinated delivery of health and aged care services for people with dementia. This should involve:  
- a care plan developed in partnership with the person and his or her carer(s) and family that takes into account the changing needs of the person  
- assignment of named health and/or aged care staff to operate the care plan  
- formal reviews of the care plan at a frequency agreed between professionals involved and the person with dementia and/or their carer(s) and family. |
| **62** | PP | Local dementia pathways and decision support software to improve the diagnosis and management of dementia should be developed and training in their navigation widely available. |

### Summary of the NICE Guideline findings

The NICE Guideline Committee reported that few of the studies of services that looked at outcomes for people with dementia and/or their carers allowed inferences to be drawn about the most effective ways of planning and organising services. In addition, the NICE Guideline Committee felt that there were limitations in applying evidence from other countries due to different systems for organising and funding health and aged care services. It was decided that as ‘the evidence base for recommendations on the planning and organisation of services for people with dementia and their carers is small (or non-existent in relation to some services) and generally of a poor quality or not easily applicable to the United Kingdom, any service recommendations provided would be largely based on good practice, not good evidence’. [110] It therefore adopted a local policy document as the source of service guidance.
Evidence update

This evidence update examined the evidence for four models of care: integrated care, consumer directed care, multidisciplinary assessment and care coordination.

Integrated care

Integrated care (sometimes referred to as seamless care) is defined as the ‘bringing together of services across sectors or teams or the organisation of services to bring all services together at one time’. [111] This evidence update identified one relevant cluster randomised controlled trial evaluating the ‘Partners in Dementia Care’ intervention in the United States. [112] Care in the intervention group was integrated across the local Veterans Health medical centre and the partnering Alzheimer’s Association chapter. The services worked together using a shared electronic patient information system and regular case conferences. Following intervention, the intervention group reported reduced unmet need. Results suggested that a subgroup of participants with higher levels of cognitive impairment reported reduced levels of depression.

Consumer directed care

A systematic review of consumer directed care among older people with or without dementia in the community identified one non-randomised controlled trial. [113] The trial was conducted in Italy and compared a form of consumer directed care with usual care. [114] The intervention group received vouchers to purchase an additional four to 24 hours of care per day from health providers whereas the control group received usual care. Outcomes were similar at six and 12 months across trial arms. At 24 months, there were lower rates of mortality in the intervention group; however, the control group had lower levels of disability and depression. The high risk of bias in the study design and the differences in care (many hours of care v. usual care) means that the study provides little applicable information regarding the potential efficacy of consumer directed care models in Australia.

Multidisciplinary assessment

A systematic review identified five studies that assessed the value of multidisciplinary teams in comparison to monodisciplinary approaches for people with dementia. [115] The studies were not pooled and it was concluded that the added value of multidisciplinary assessment for people with dementia was unclear.

Three randomised controlled trials published subsequently evaluated different approaches to multidisciplinary assessment for people with dementia. These studies found mixed results. Bellantonio and colleagues [116] found that there were no significant benefits associated with multidisciplinary assessment for older people with dementia moving into assisted living. A large Swedish trial reported on the outcomes of multidisciplinary assessment (plus care on a specialised ward and early mobilisation) for people with dementia after hip fracture. [117 118] The intervention group had fewer complications such as falls, delirium and urinary tract infections and shorter stay on the ward (mean 20 versus 32 days). There were no differences in mortality between groups, however, at one year, people in the intervention group were more functionally independent. A third randomised controlled trial found no statistically significant differences in outcomes for people with dementia attending a multidisciplinary clinic compared with usual care. [119]
Case management
A review of non-pharmacological interventions identified four randomised controlled trials evaluating a case management intervention for people with dementia.[120] One additional randomised controlled trial was identified.[121] Across studies, case management was provided by different staff, however, the key elements of the intervention were consistent and involved assessing, planning, coordinating, monitoring and reviewing the person’s needs. The five trials examined different outcomes; one of two trials was associated with increased quality of life in the person with dementia and one of two studies reported a reduction in carer impact in the intervention groups.[120]

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
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<tbody>
<tr>
<td>One RCT evaluating the efficacy of an integrated care model found reduced levels of depression in a subgroup of participants with higher levels of cognitive impairment.[112]</td>
<td>Very low</td>
</tr>
<tr>
<td>One non-randomised controlled trial evaluating a form of consumer directed care found no significant differences between groups on quality of life for the person with dementia, ADL function or BPSD.[38]</td>
<td>Very low</td>
</tr>
<tr>
<td>Single RCTs evaluating the effects of multidisciplinary assessment found no difference between groups on ADL function (low), institutionalisation (low) or quality of life (low). [116-118]</td>
<td>Low</td>
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<tr>
<td>One (of two) RCTs evaluating the effects of case management found significantly improved quality of life in the person with dementia (very low).[120], [121] One (of two) RCTs reported a significant reduction in carer impact (very low).[120] One RCT found no significant difference between groups on institutionalisation (low).[120] A further two RCTs found no significant effect on the carer’s quality of life (low).[120], [121]</td>
<td>Low</td>
</tr>
</tbody>
</table>

NA – not applicable

Considerations for Australia
There is currently little evidence available to inform the best method of organising community services within Australia. This was identified as an area for further research by the Guidelines Adaptation Committee. The recommendation in favour of care coordinators has resource implications, as there is limited availability of this type of service in Australia.
Training for staff and students

Background

Within Australia, there have been calls for increased training for health and aged care professionals in the care of people with dementia.[107] The need for increased dementia care training for hospital staff [122] and training in a variety of settings on the management of BPSD have been highlighted as priority areas.[123]

Providing health and aged care professionals with training to increase knowledge and skills in the care of people with dementia is one strategy that may be used in an attempt to increase the quality of care and outcomes for people with dementia. However, training alone may not result in practice change. Other organisational, social or professional barriers to providing optimal care for people with dementia may be present.[124] In addition, one of the challenges associated with training is the high turnover of staff; hence, training needs to be conducted regularly and should be considered an ongoing process.

There is currently a range of educational resources freely available to health and aged care professionals. Training is available in a number of different formats, including seminars and online training modules. Organisations that provide training include the Australian Government funded Dementia Training Study Centres (www.dtsc.com.au/) and Alzheimer’s Australia (www.fightdementia.org.au/). In addition, training may also be offered through professional associations.

Clinical question

What models of training for health and aged care staff have positive outcomes for people with dementia?

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<tr>
<td>63</td>
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<td></td>
<td>Health and aged care organisations should ensure that all staff working with people with dementia receive dementia-care training (attitude, knowledge and skill development) that is consistent with their roles and responsibilities. Training should reflect programs that have been shown to optimise care for people with dementia. Effective programs tend to be: delivered face-to-face by someone experienced in dementia care; scheduled over several training sessions; involve ongoing mentoring or support from someone experienced in dementia care; and, utilise active learning techniques such as problem solving, case based training and role play.</td>
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<th>EBR</th>
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<tr>
<td>64</td>
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<td></td>
<td>Training programs should be comprehensive and have a strong focus on communicating effectively with the person with dementia and his or her carer(s) and family and recognising, preventing and managing behavioural and psychological symptoms of dementia. Staff should be trained in the principles of person-centred care and how these principles are applied in practice.</td>
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<tr>
<td>65</td>
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<tr>
<td></td>
<td>As people with dementia are vulnerable to abuse and neglect, all health and aged care staff supporting people with dementia should receive information and training about how to prevent and manage suspected abuse.</td>
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</tbody>
</table>
Clinical question

What models of training for health and aged care staff have positive outcomes for people with dementia?

<table>
<thead>
<tr>
<th>66</th>
<th>PP</th>
<th>Education programs implemented in health and aged care settings should be evaluated for impact on staff practices and outcomes for people with dementia and their carer(s) and families in those settings.</th>
</tr>
</thead>
<tbody>
<tr>
<td>67</td>
<td>PP</td>
<td>All undergraduate curricula in the health sciences should contain significant stand-alone content about the assessment, treatment, support and care of people living with dementia. Content should include person-centred care and the health, social and legal implications of a dementia diagnosis for the person with dementia, their carer(s) and family.</td>
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</table>

Summary of the NICE Guideline findings

The NICE Guideline Committee searched multiple databases for randomised controlled trials and qualitative research published up until 2006. They provided a narrative summary of studies and made several recommendations relating to staff training including that all staff working with people in community and residential care settings receive dementia-care training that is consistent with their roles and responsibilities.

Evidence update

Twenty-five randomised controlled trials examining staff training interventions were identified in this evidence update.[125-144]

The majority of studies were conducted with care staff in residential care facilities. No studies examining the efficacy of training hospital staff were identified. Overall, results of the studies suggest that staff training can result in reduced restraint use and reduced BPSD. Studies that reported positive outcomes tended to involve comprehensive training and focussed on teaching person-centred care, communicating effectively with the person with dementia and preventing and managing BPSD.

The format of training varied across the studies. Studies with positive results typically involved several training sessions, delivered over three to six months. The total duration of training in the studies was approximately eight hours of training. Training was commonly provided face-to-face and used interactive learning techniques such as role play. Many of the studies reported problems in uptake of the training, highlighting that compliance is an issue in staff training interventions.
Evidence statements

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two RCTs have found that providing broad but comprehensive training in dementia care can result in reduced restraint use in residential care facilities (moderate). [125 136] One RCT found that providing broad but comprehensive training in dementia care had no significant impact on BPSD or quality of life of the person with dementia (moderate). [125]</td>
<td>Moderate</td>
</tr>
<tr>
<td>Two (of six) RCTs have found that training staff in providing person-centred care and communicating effectively with the person with dementia can reduce BPSD (low) [127 128 145-148]. One (of two) RCTs found that training staff in providing person-centred care and communicating effectively with the person with dementia improved the quality of life of the person with dementia (proxy rated) (low). [128]</td>
<td>Low</td>
</tr>
<tr>
<td>Four (of 10) RCTs found that training staff to manage BPSD resulted in reduced BPSD (low). [129 133 140 142 143 149-152] Three RCTs found that training staff to manage BPSD resulted in reduced restraint use (low). [140 149 152] One RCT found no significant differences between groups on quality of life of the person with dementia (low). [143]</td>
<td>Low</td>
</tr>
</tbody>
</table>

Considerations for Australia

This was an area identified as a priority for research translation. It was also emphasised that training programs needed to be sufficiently comprehensive.

Promoting independence

Background

Functional decline is one of the key features of dementia and is associated with reduced quality of life for the person with dementia and increased impact on families and the health care system. [70]

People with dementia increasingly have difficulty performing activities of daily living; assistance is most frequently required for health care management, mobility, self-care and community transportation. [3]

Most people with dementia in Australia (88 per cent) live in private dwellings rather than residential care. [3] Australian data suggest that the majority of people with dementia (84 per cent) living in the community require assistance to manage at least one activity of daily living. [3] A large proportion of this assistance is provided informally, by family, friends or neighbours. Approximately three quarters of people with dementia living in the community are supported by a combination of formal and informal assistance and approximately one fifth of people with dementia receive informal care alone. [3]
Clinical question
For people with dementia, are there interventions for promoting independence that produce benefits/harms?

Health and aged care staff should aim to promote and maintain functional and social independence of people with dementia. Interventions should address activities of daily living that maximise independence, function and engagement. Intervention should include:

- consistency of care staff
- stability in living environment
- flexibility to accommodate fluctuating abilities
- support for people with dementia and their carer(s) and family to participate in tailored activities that are meaningful and enjoyable
- assessment and intervention, involving the carer(s) and family wherever possible, to promote independent self-care skills and prevent excess disability, in particular supporting the person with dementia to retain continence
- supporting the person with dementia to receive adequate nourishment and hydration.

People with dementia living in the community should be offered occupational therapy interventions which should include: environmental assessment and modification to aid independent functioning; prescription of assistive technology; and tailored intervention to promote independence in activities of daily living which may involve problem solving, task simplification and education and skills training for their carer(s) and family.

People with dementia should be encouraged to exercise. Physiotherapy assessment and advice may be indicated.

Summary of the NICE Guideline findings
The NICE Guideline Committee searched multiple databases for randomised controlled trials. It reported that there was little research from which to draw clear conclusions on specific interventions for promoting independence and therefore provided a summary of good practice. They recommended that interventions should be selected and implemented based on the needs and strengths of the individual and stated that any one person may benefit from any combination of strategies.

Evidence update
This evidence update involved searching for randomised controlled trials that assessed the efficacy of the following interventions: occupational therapy, exercise, technologies to promote functional independence in the person with dementia, and falls prevention intervention.

Occupational therapy
A systematic review examining the effects of non-pharmacological interventions to delay functional decline in people with dementia living in the community identified seven randomised controlled trials evaluating occupational therapy interventions.[153] An additional RCT published subsequent to
the review was also included in this evidence update.[154] One further study that evaluated the efficacy of an occupational therapy program for people with dementia in a residential care setting was also included.[155]

Interventions in the included studies ranged in dose from one to 10 consultations and commonly involved carer education and skills training, environmental modification, engagement of the person with dementia in meaningful activities, individualised problem solving and task simplification. When pooled, the studies involving community dwelling participants found that occupational therapy intervention resulted in improved ADL function and quality of life. Pooling of four studies did not detect a significant effect in reducing carer impact. The study conducted in a residential care setting found no significant differences in patient outcomes between groups.

Exercise

A Cochrane Review examining the efficacy of exercise for people with dementia included 16 randomised controlled trials.[156] A further two trials published subsequent to the review were included in the evidence update.[157 158] The majority of randomised controlled trials (14/18) took place in residential care settings while the remaining trials took place in the participants’ home setting. Participants in the included studies ranged from those with mild to severe dementia. The frequency of exercise intervention ranged from twice a week to daily and the duration ranged from two weeks to 12 months. Pooling of six studies found that exercise programs were associated with higher levels of independence in activities of daily living. Six of the studies reported that there were no adverse effects associated with the intervention. There were no clear differential effects in people with different severities of dementia. The most effective type of exercise or dose is currently unclear.

Technologies to promote functional independence in the person with dementia

Two randomised controlled trials evaluated the efficacy of assistive technologies designed to promote independence in people with dementia.[159 160] The technology in one of the trials included a falls prevention and management intervention and this is considered under falls prevention. The other trial examined the effects of using a monitoring platform that monitored the health status of the person with dementia and their family carer via self-reporting. There were no significant differences between groups in terms of carer impact.

Falls prevention

Two small randomised controlled trials involved interventions designed to reduce falls in people with dementia.[159 161] One of the studies examined the efficacy of an occupational therapy and physiotherapy program whereas the other study examined the efficacy of falls prevention and management technology (night light and personal call alarm). Both studies found that the intervention was associated with a reduced rate of falls.
Evidence statements

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
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<tbody>
<tr>
<td>Pooling of four RCTs demonstrated that occupational therapy was effective in improving ADL function (low) [162-165] and self-reported quality of life (moderate) [154 164-167] in community dwelling people with dementia. Pooling of four RCTs found no significant reduction in carer impact following occupational therapy (moderate).[162 163 166 168]</td>
<td>Low-moderate</td>
</tr>
<tr>
<td>Pooling of six RCTs evaluating an exercise intervention showed a significant improvement in ADL function (low).[156] One RCT found no significant differences between groups on self-reported quality of life after exercise intervention (low).[156] One (of two) RCTs found a significantly reduced carer impact following an exercise program for the person with dementia (very low).[156] Six RCTs that reported on harms associated with exercise did not report any adverse events associated with intervention (moderate).[156]</td>
<td>Low</td>
</tr>
<tr>
<td>One RCT evaluating a technology intervention using a health status monitoring platform found no significant differences between groups in terms of carer impact.</td>
<td>Low</td>
</tr>
<tr>
<td>One RCT evaluating a falls prevention intervention found no significant differences between groups on ADL function (low). Two RCTs found that falls prevention interventions led to reduced incidence of falls (low).</td>
<td>Low</td>
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Cognitive training and rehabilitation

Background

People with dementia typically experience a gradual decline in cognitive function, which increasingly impacts on their abilities to perform daily activities. Some aspects of cognitive function, such as executive function, tend to be impaired from the early stages of dementia whereas other aspects, such as memory for skills and routines, are relatively spared.[169] People with early stage dementia are capable of new learning and therefore rehabilitation interventions that aim to optimise independence may be appropriate.[170] Interventions that are targeted towards improving cognitive function and reducing the impact of cognitive impairment can be categorised into three approaches:

1. Cognitive stimulation therapy: Engagement in a ‘range of group activities and discussions aimed at general enhancement of cognitive and social functioning’. [169]

2. Cognitive training: Intervention ‘typically involves guided practice on a set of standard tasks designed to reflect particular cognitive functions, such as memory, attention, language or executive function’. [169]

3. Cognitive rehabilitation: An ‘individualised approach to helping people with cognitive impairments in which those affected, and their families, work together with health care professionals to identify personally-relevant goals and devise strategies for addressing these. The emphasis is not on enhancing performance on cognitive tasks but on improving functioning in the everyday context’. [169]
Summary of the NICE Guideline findings

The NICE Guideline Committee identified 19 randomised controlled trials evaluating programs designed to improve cognition. It recommended that people should be offered cognitive stimulation therapy but did not make a recommendation related to cognitive training or cognitive rehabilitation.

Evidence update

Cognitive stimulation therapy

A Cochrane review identified 15 randomised controlled trials that were generally low in quality and heterogeneous in terms of the participants involved and the intensity and duration of intervention provided.[171] Nine of the 15 studies were based in residential care or hospitals and the remaining six studies recruited people living in the community. The authors reported a benefit on cognitive function, associated with cognitive stimulation. However, the Committee indicated that there were significant flaws in the analysis of one of the main contributing trials in this review and that these flaws had affected the findings of the review. In view of these concerns and the effect on resources, it was decided that there was currently insufficient high quality evidence to make a recommendation.

Cognitive training

A Cochrane review included 11 randomised controlled trials evaluating cognitive training that were of low to moderate quality [172]. This evidence update identified one additional randomised controlled trial [173]. In general, participants were in the mild stages of dementia. Cognitive training was not associated with beneficial effects in relation to any of the reported outcomes. However, some of the trials did report statistically significant positive effects on specific measures of cognition.[174]

Cognitive rehabilitation

The Cochrane review that examined the efficacy of cognitive training also examined the efficacy of cognitive rehabilitation [172]. The authors included one randomised controlled trial (n=69) of high quality evaluating cognitive rehabilitation.[175] The intervention in the study focussed on addressing personally meaningful goals and delivering individualised intervention which involved providing practical aids and strategies, techniques for learning new information, practice in maintaining attention and techniques for stress management. The intervention was associated with improved performance of individual goals.

<table>
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<tr>
<th>Evidence statements</th>
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<tr>
<td>Pooling of 14 RCTs investigating cognitive stimulation therapy found a significant effect on global cognition (low). Pooling of four RCTs found no significant difference between groups on ADL function (mod). Pooling of four RCTs found a significant effect on quality of life (low).[171]</td>
<td>Low-moderate</td>
</tr>
<tr>
<td>Pooling of six RCTs investigating cognitive training found no significant effect on global cognition. Pooling of four RCTs found no significant effects on ADL function [172].</td>
<td>Low</td>
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### Evidence statements

| Evidence statements                                                                                   | GRADE  
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<tbody>
<tr>
<td>One RCT investigating cognitive rehabilitation found no significant differences between groups on ADL function, quality of life or carer impact.</td>
<td>Moderate</td>
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### Acetylcholinesterase inhibitors and memantine

#### Background

Medications subsidised through the Pharmaceutical Benefits Scheme (PBS) for people with Alzheimer’s disease include the acetylcholinesterase inhibitors donepezil, rivastigmine and galantamine and the N-methyl-D-aspartate receptor antagonist memantine. These medications do not provide a cure but may reduce symptoms.\(^{[176]}\)

The PBS has placed restrictions on the use of the subsidised medications. Donepezil, rivastigmine and galantamine may be prescribed for people with mild to moderately severe Alzheimer’s disease whereas memantine may be prescribed for people with moderate-to-severe Alzheimer’s disease. An initial trial of medication as a sole therapy (for six months) may be offered and a clinically meaningful response to treatment must be demonstrated before ongoing subsidy approval can be obtained. A clinically meaningful response is determined by assessment involving the person with dementia, their family or carer and the treating medical practitioner and must consider the person’s quality of life, cognitive functioning and behavioural symptoms.

During 2011, 46,183 people received a prescription for an acetylcholinesterase inhibitor or memantine and the Australian Government spent over 60 million dollars subsidising these medications.\(^{[177]}\) While government subsidy through the PBS is limited to mild to moderately severe Alzheimer’s disease for acetylcholinesterase inhibitors, benefits have been demonstrated in severe Alzheimer’s disease.\(^{[176\,178]}\) Subsidy is also limited to single therapies. A meta-analysis of findings from three trials showed that there may be a small benefits of combination therapy, however some data were not available for analysis so there was some uncertainty in the finding.\(^{[179]}\)
### Clinical question

**For people with dementia, do acetylcholinesterase inhibiting drugs/memantine produce benefits/harms?**

| 71 | EBR | Low | Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) are recommended as options for managing the symptoms of mild-to-moderate Alzheimer’s disease. Any one of the three acetylcholinesterase inhibitors could be considered for managing the symptoms of severe Alzheimer’s disease†. Prior to initiation of treatment medical practitioners should consider performing an electrocardiogram (ECG), recording weight and undertaking a falls risk assessment. Concomitant administration of medications with anticholinergic effects should be avoided. |
| 72 | EBR | Moderate | Medical and nurse practitioners should be aware that the acetylcholinesterase inhibitors are associated with a number of adverse reactions that have a risk of harm. These include nausea, vomiting, diarrhoea, dizziness, falls, weight loss, anorexia, headache and insomnia. |
| 73 | EBR | Moderate | Memantine is recommended as an option for people with moderate-to-severe Alzheimer’s disease who are intolerant of or have a contraindication to acetylcholinesterase inhibitors. For people with severe renal impairment (creatinine clearance < 30ml/min) the dose of memantine should be halved. |
| 74 | EBR | Low | Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) could be considered for managing the symptoms of Dementia with Lewy Bodies, Parkinson’s Disease dementia, vascular dementia or mixed dementia. |
| 75 | PP | People who have been prescribed an acetylcholinesterase inhibitor or memantine should be reviewed within six months to determine whether there is a clinically meaningful response to treatment. |
| 76 | PP | Acetylcholinesterase inhibitors should not be prescribed for people with Mild Cognitive Impairment. |

† Not currently listed for these indications on the Pharmaceutical Benefits Scheme

### Summary of the NICE Guideline findings

The NICE Guideline was amended in 2012 to reflect the updated NICE technology appraisal of donepezil, galantamine, rivastigmine and memantine for Alzheimer’s disease.[176] The review included four systematic reviews and 17 randomised controlled trials; the quality of trials ranged from low quality to high quality. The included studies were limited to those conducted in people with mild to moderately severe Alzheimer’s disease for the acetylcholinesterase inhibitors (with an MMSE score of 10 to 26) and to those conducted in moderate to severe Alzheimer’s disease for memantine (MMSE 0 to 20).
Evidence update

This evidence update identified a further nine randomised controlled trials published since the NICE health technology appraisal. One new trial examined the effect of donepezil v. placebo, [180] one new trial examined the effect of galantamine v. placebo, [181] one trial already included in the technology appraisal reported new data on rivastigmine patches [182] and six new trials examined the effects of memantine v. placebo.[183-187]

Donepezil

A total of 20 randomised controlled trials examined the efficacy of donepezil compared with placebo.[176 180] Overall, meta-analysis showed a significant benefit on cognitive function and ADL function at 24 weeks. Pooling of four trials found no significant improvement on global BPSD at 12 or 24 weeks. Only two RCTs measured effects on quality of life and findings were mixed with one study reporting significant improvement associated with donepezil and the other reporting no significant differences between groups. Adverse events associated with donepezil were common. The most frequently reported symptoms were nausea and vomiting (four to 24 per cent of participants), diarrhoea (four to 17 per cent), headache and dizziness (three to 13 per cent) and agitation (0 to 13 per cent). Three studies that compared 5mg and 10mg doses of donepezil found higher rates of withdrawal in the group receiving 10mg.

Rivastigmine

Seven randomised controlled trials investigated the efficacy of rivastigmine compared with placebo.[176] Overall, pooling of four studies showed a significant effect of rivastigmine on cognition at 24 weeks. There was also a positive effect on ADL function (based on pooling of three studies). There were mixed findings for the effect of taking rivastigmine on BPSD with one study reporting a significant effect and the other reporting no effect. Overall, there was a high percentage of adverse events, ranging from 51 per cent to 91 per cent in the treatment groups and from 46 per cent to 76 per cent in control groups. The main adverse events were gastrointestinal.

Galantamine

Nine randomised controlled trials compared galantamine with placebo.[176] Overall, meta-analysis of seven trials showed a significant effect on cognition at 12–16 weeks. Significant effects were also seen in improved ADL function (based on four studies) and reduced global BPSD (based on two studies). Overall, there was a high percentage of adverse events in both treatment and control groups although more people in the galantamine treatment group experienced adverse events. The main adverse events were gastrointestinal, dizziness and headaches. In the three studies reporting serious adverse event rates there was no statistically significant difference between treatment and control groups.

Memantine

Eight randomised controlled trials evaluated outcomes associated with taking memantine compared to placebo.[176] [183-187]. In an additional trial, subjects received memantine in addition to ongoing donepezil therapy.[188] While one trial reported that there was a significant effect of memantine on cognition at 12 weeks, six trials reported no significant differences between groups on cognition at follow-up assessments ranging from 24–52 weeks. Two studies were pooled and
found a significant effect on function at 24 weeks, whereas an additional study found no differences between groups on function. Six studies measured the effects of memantine on BPSD; findings were mixed. Pooling of three studies found a significant reduction in BPSD associated with memantine at 24 weeks, whereas two studies found no significant effect at follow-up over one to two years. Overall, the studies identified similar numbers and types of adverse events across groups. The main adverse events were agitation, hypertension, falls, dizziness and headache.

Comparisons of acetylcholinesterase inhibitors
While this evidence update did not include studies comparing the efficacy of the acetylcholinesterase inhibitors, the NICE technology appraisal identified seven randomised controlled trials that involved head-to-head comparisons and did not recommend use of one acetylcholinesterase inhibitor over another.[176]

Acetylcholinesterase inhibitors for people with severe Alzheimer’s disease
While acetylcholinesterase inhibitors are not listed on the Pharmaceutical Benefits Scheme for people with severe Alzheimer’s disease, there is some evidence to suggest that people with severe dementia may benefit from treatment.[189] A systematic review examining the efficacy of acetylcholinesterase inhibitors by dementia severity included six randomised controlled trials including people with severe dementia. The trials were generally large in terms of sample size and assessed as being at low risk of bias. All six trials found a positive effect on cognition. There were mixed results for impact on activities of daily living function and BPSD.

Acetylcholinesterase inhibitors for people with Parkinson’s disease dementia, Dementia with Lewy Bodies
The majority of studies examining the efficacy of acetylcholinesterase inhibitors have been conducted in people with Alzheimer’s disease. There is a smaller body of evidence for these medications in people with other types of dementia. A systematic review of the use of acetylcholinesterase inhibitors for people with Parkinson’s Disease Dementia or Dementia with Lewy Bodies included randomised controlled trials which found a statistically significant positive effects on cognition, when the results were pooled.[190] There was inconsistency in results in terms of impact on BPSD and a lack of evidence for impact on activities of daily living function, with only one study reporting outcomes although these were positive. There were more adverse events in the groups receiving the acetylcholinesterase inhibitors; these included anorexia, nausea, vomiting, diarrhoea, aggravation of Parkinson and psychiatric symptoms, tremor, fall, somnolence, insomnia, pain, hallucination, confusion, dizziness, urinary tract infection and respiratory tract infection.

Acetylcholinesterase inhibitors for people with vascular dementia
Three individual reviews examined the efficacy of donepezil, rivastigmine and galantamine for people with vascular cognitive impairment [191-193]. An additional trial published subsequent to these reviews was also included [194]. Use of acetylcholinesterase inhibitors was consistently associated with small but significant improvements in cognitive function and activities of daily living. There was little evidence for an effect on BPSD and people taking the drugs experienced significantly more adverse effects than those not taking the drugs. Adverse events were similar in frequency and type to those reported in people with Alzheimer’s disease.
### Evidence statements

<table>
<thead>
<tr>
<th>Evidence</th>
<th>GRADE Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pooling of nine studies (out of 10) found a significant effect on cognition at 24 weeks in people taking donepezil.[176]</td>
<td>Low</td>
</tr>
<tr>
<td>Pooling of four RCTs found that there was no significant improvement associated with donepezil on BPSD (measured using the Neuropsychiatric Inventory) at 12 weeks or 24 weeks.[176]</td>
<td>Moderate</td>
</tr>
<tr>
<td>Pooling of four RCTs of rivastagmine found a significant improvement in cognition at 24 weeks.[176]</td>
<td>Low</td>
</tr>
<tr>
<td>One small RCT of rivastagmine found a significant benefit on BPSD, while a larger RCT did not.[176]</td>
<td>Moderate</td>
</tr>
<tr>
<td>Pooling of seven RCTs of galantamine found a significant improvement in cognition at 12 to 16 weeks.[176]</td>
<td>Low</td>
</tr>
<tr>
<td>Two pooled studies of galantamine found a significant improvement in BPSD (measured using the Neuropsychiatric Inventory); this was not associated with an increase in the number of serious adverse events.[176]</td>
<td>Moderate</td>
</tr>
<tr>
<td>Pooled data from three RCTs of memantine found a significant improvement in BPSD (measured using the Neuropsychiatric Inventory) at 24 weeks; one RCT found a significant improvement at 12 weeks. Two RCTs reporting longer-term outcomes (at one to two years) did not find a significant effect. There were no significant differences in adverse events between memantine treatment and placebo .[176] [183-187]</td>
<td>Moderate</td>
</tr>
<tr>
<td>Six RCTs found that acetylcholinesterase inhibitors were associated with significantly improved cognitive function in people with severe Alzheimer’s disease. Two (of four) RCTs found a significant improvement on ADL function. One (of five) RCTs showed a significant reduction in BPSD [189].</td>
<td>Moderate</td>
</tr>
<tr>
<td>Pooling of nine RCTs showed a significant improvement in cognitive function amongst people with Dementia with Lewy Bodies and Parkinson’s Disease dementia taking acetylcholinesterase inhibitors. One of the RCTs measured impact on ADL function and found a significant improvement [190].</td>
<td>Low</td>
</tr>
<tr>
<td>Six (of eight) RCTs found a statistically significant improvement in cognition in people with vascular dementia taking acetylcholinesterase inhibitors compared to those taking a placebo. Three (of seven) RCTs found a positive impact on ADL function.</td>
<td>Low</td>
</tr>
</tbody>
</table>

### Considerations for Australia

Recent studies have shown inequities with regards to the prescription of acetylcholinesterase inhibitors in lower socioeconomic and rural populations within Australia.

The current recommendations suggest considering prescribing acetylcholinesterase inhibitors to people with severe dementia and to dementia subtypes not currently listed on the Pharmaceutical Benefits Scheme (eg., Dementia with Lewy Bodies). This has the potential to increase health inequities and out-of-pocket expenses. Health professionals should discuss the potential benefits, harms and costs associated with each prescription.
Nutritional supplement: Souvenaid®

Background
Souvenaid® is a dietary supplement that can be purchased from Australian pharmacies. The supplement is taken as a once-daily drink and contains a range of nutrients including omega-3 fatty acids, phospholipids, choline, uridine monophosphate, vitamins E, C, B12, B6, folic acid and selenium.[195] Souvenaid® is intended to provide nutrients to support synapse formation and function in the brain and thus lead to improved memory function.[196] The cost of Souvenaid® is around $130 per month (as at April 2014). There are no subsidies available so the full cost is paid by the consumer.

Clinical question
For people with dementia, does Souvenaid® produce benefits/harms?

<table>
<thead>
<tr>
<th>77</th>
<th>EBR</th>
<th>It is suggested that health care practitioners do not recommend the use of Souvenaid® in people with dementia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate</td>
<td></td>
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</tbody>
</table>

Summary of the NICE Guideline findings
The NICE Guideline Committee did not review the evidence for Souvenaid®; no randomised trials had been conducted at the time of their Guideline development.

Evidence update
This evidence update identified three randomised controlled trials comprising 1,011 patients, which were included in the review.[197-201] All three studies were sponsored by the manufacturer. Results of two studies in people with mild Alzheimer’s disease suggest that those who drank Souvenaid® were more likely to experience small improvements in tests of memory function; however, an effect on memory was not found in a study of people with mild-to-moderate Alzheimer’s disease. None of the studies found significant gains in global cognitive function, independence in activities of daily living or quality of life. The studies found that Souvenaid® was well tolerated and no significant adverse events were associated with taking the supplement.

Evidence statements

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
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</thead>
<tbody>
<tr>
<td>Three RCTs showed that there were no statistically significant benefits associated with taking Souvenaid® on quality of life (moderate), ADL function (moderate-high), cognition (low-moderate). A statistically significant benefit was found on memory function in people with mild Alzheimer’s disease (low). The total number of adverse events did not differ significantly between those taking Souvenaid® and those taking placebo (moderate).[197-201]</td>
<td>Moderate</td>
</tr>
</tbody>
</table>
Considerations for Australia

Souvenaid® is not listed on the Australian Therapeutic Goods Register and is not considered by any Australian regulatory body to be a therapeutic good. The Committee felt that, for many people, the possible small improvements in memory would be outweighed by the high cost of Souvenaid®.

Behavioural and Psychological Symptoms of Dementia (BPSD)

Background

People with dementia experience a gradual decline in their ability to communicate clearly with others. The person may have difficulty communicating their unmet needs and express these via behaviours. Behavioural and psychological symptoms of dementia (BPSD) such as depressive symptoms, anxiety, apathy, agitation, sleep problems, irritability and wandering, are very common in people with dementia. Studies suggest that at least 80 per cent of people with dementia have experienced at least one behavioural or psychological symptom from the onset of cognitive systems.[202] The most common symptoms are thought to be apathy, depression and agitation.[202]

Symptoms can be difficult to manage and the presence of symptoms is associated with reduced wellbeing in carers, higher costs of care [203] and earlier residential care placement.[204] Management of BPSD is thought to be particularly challenging in rural and remote areas due to reduced access to specialist services.[205] The earlier admission of people into residential care facilities in rural areas may reflect lack of specialist services to support BPSD in these settings.[206] A seven-tiered model of management of BPSD according to symptom severity has been proposed (see Figure 1).

Health and aged care professionals should attempt to prevent and minimise BPSD in the first instance by taking a supportive and proactive approach as there are ways to reduce BPSD.

The Dementia Behaviour Management Advisory Service is a program funded by the Australian Government (http://dbmas.org.au/). The aim of the program is to provide support for people caring for someone who is demonstrating BPSD that is affecting their care. The role of the program is to improve the quality of life of people with dementia and their carers. Clinicians within the service conduct individual assessments and care planning and assist carers to support the person with dementia.

Health and aged care professionals that work with people with dementia should also refer to resources specifically developed to improve the management of BPSD in Australia. The ‘Clinician’s Field Guide to Good Practice’ and associated free application available from the Dementia Collaborative Research Centre website (www.dementiaresearch.org.au/bpsdguide.html) provide information about the different behavioural and psychological symptoms that may present and the strategies that have been shown to be most effective for managing each symptom.
Symptoms can be managed with pharmacological or non-pharmacological treatments or a combination of both. Non-pharmacological interventions are typically recommended as first-line treatment.

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**Figure 1** Brodaty H, Draper BM, Low LF. Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. Med J Aust 2003; 178(5):231-234. © Copyright 2003 The Medical Journal of Australia - reproduced with permission
## Non-pharmacological interventions

### Behavioural and Psychological Symptoms of Dementia (BPSD)

<table>
<thead>
<tr>
<th>Page</th>
<th>PP</th>
<th>Note</th>
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<tbody>
<tr>
<td>78</td>
<td></td>
<td>Health and aged care staff and carers and family should identify, monitor and address environmental, physical health and psychosocial factors that may increase the likelihood of the person with dementia experiencing distressing behavioural and psychological symptoms. These factors include:</td>
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<td>- unmet needs (e.g., pain, hunger, need to eliminate, lack of privacy, lack of meaningful activities)</td>
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<td>- lowered stress threshold (e.g., conflicts or poor communication within the family or between staff, carer stress).</td>
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<tr>
<td>79</td>
<td></td>
<td>People with dementia who develop behavioural and psychological symptoms should be offered a comprehensive assessment at an early opportunity by a professional skilled in symptom assessment and management. This should involve their carer(s) and family as appropriate and include:</td>
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<td>- analysis of the behaviours (e.g., antecedent [triggers], behaviour description and consequence [ABC approach]), frequency, timing and presentation</td>
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<td>- assessment of the person with dementia’s physical and mental health</td>
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<td>- their level of pain or discomfort</td>
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<td>- whether they are experiencing side effects of medication</td>
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<td>- the influence of religious and spiritual beliefs and cultural norms</td>
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<td>- physical environmental and interpersonal factors</td>
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<td>- an assessment of carer(s) health and communication style when interacting with the person with dementia should also be undertaken</td>
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<td></td>
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<td>- understanding the behaviour as a form of communication.</td>
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<td>80</td>
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<td>People with dementia who develop behavioural and psychological symptoms of dementia should usually be treated using non-pharmacological approaches in the first instance. Pharmacological intervention should usually only be offered first if the person, their carer(s) or family is severely distressed, pain is the suspected cause, or there is an immediate risk of harm to the person with dementia or others (i.e., very severe symptoms). If pharmacological management is used, this should complement, not replace, non-pharmacological approaches.</td>
</tr>
<tr>
<td>81</td>
<td></td>
<td>The objective measurement of behavioural and psychological symptoms of dementia should be undertaken using tools with strong psychometric properties and used to monitor the type and patterns of behaviours.</td>
</tr>
<tr>
<td>84</td>
<td></td>
<td>Health and aged care staff should be trained to develop individual care plans (in partnership with the person with dementia’s carer(s) and family) that provide a clear crises plan to anticipate severe behavioural and psychological symptoms of dementia and how to manage violence, aggression and extreme agitation, including de-escalation techniques.</td>
</tr>
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</table>
Clinical question

For people with behavioural and psychological symptoms of dementia do non-pharmacological interventions produce benefits in the specified outcomes?

<table>
<thead>
<tr>
<th>#</th>
<th>EBR</th>
<th>Health and aged care staff should attempt to minimise the impact of behavioural and psychological symptoms of dementia by providing person-centred care (care that is consistent with the 10 Principles of Dignity in Care).</th>
</tr>
</thead>
</table>
| 83 | Low | For people with dementia who also have depression and/or anxiety or agitation, interventions should be tailored to the person's preferences, skills and abilities. The response to each modality should be monitored and the care plan adapted accordingly. Multicomponent interventions that involve engagement in activities that are enjoyable for the person with dementia plus individualised support should be offered where available. Where multicomponent interventions are not available, the following individual therapies should be considered:  
For depression and/or anxiety:  
- therapeutic use of music and/or dancing  
- support and counselling  
- reminiscence therapy.  
For agitation:  
- behavioural management interventions  
- therapeutic use of music and/or dancing  
- massage  
- reminiscence therapy. |
| 85 | Very low to low | To assist the carer(s) and families help the person with dementia who is experiencing behavioural and psychological symptoms of dementia, carer(s) and family should be offered interventions which involve:  
- carer skills training in managing symptoms and communicating effectively with the person with dementia  
- meaningful activity planning  
- environmental redesign and modification to improve safety and enjoyment  
- problem solving and management planning. |

Summary of the NICE Guideline findings

The NICE Guideline Committee searched a number of databases for randomised controlled trials that assessed the efficacy of non-pharmacological interventions for the management of BPSD. It identified 19 trials meeting their criteria. Overall, it did not find strong evidence supporting a particular approach and highlighted the need for an individualised, tailored approach, given the range of behaviours and the many factors associated with it.
Evidence update

Our evidence update identified many studies and systematic reviews published since the NICE Guideline, addressing a wide range of interventions. Results are presented by intervention approach in the categories listed below.

Multicomponent interventions

Eleven randomised controlled trials examined the efficacy of non-pharmacological interventions that used a number of different approaches or strategies.[207-211] [212-217] Interventions that involved multiple components were frequently associated with positive results; five (of six) trials found a reduction in BPSD, four (of five) trials found significant reductions in depressive symptoms, two trials found reduced carer impact and four (of five) trials reported improved quality of life in the person with dementia. These findings suggest that an approach that is tailored to the abilities and preferences of the person with dementia and involves multiple intervention approaches may be most beneficial. Multicomponent interventions that were effective typically involved engagement in activities that are enjoyable for the person with dementia plus individualised support.

Behavioural management interventions

Behavioural management interventions tend to commence with a detailed assessment and individualised management plan which may include changes to the environment, the way in which care is delivered and training and support for carers or health and aged care staff. Ten randomised controlled trials evaluated this approach with mixed findings.[120] Of the nine trials that provided data on the impact of behavioural interventions on BPSD, three of these reported significant reductions in favour of the intervention group. Three (of seven) trials found a significant reduction in carer impact associated with the intervention.

Cognitive stimulation

A Cochrane review included 15 randomised controlled trials that examined the efficacy of cognitive stimulation therapy.[171] The results of the review suggested that cognitive stimulation was not associated with a reduction in global BPSD (based on eight studies) or mood (based on five studies).

Physical exercise

This evidence update identified 17 randomised controlled trials of exercise.[156] [157]. Pooled data from four trials found there was no significant effect on global BPSD. Pooling of six trials found a non-significant effect on reducing depression.

Music

A systematic review identified 10 randomised controlled trials examining the efficacy of music therapy which includes listening and singing.[218] The evidence update revealed a further six randomised controlled trials published subsequently.[219-226] Pooled analysis of six trials found that music was effective in reducing BPSD. A further three randomised controlled trials reported reduced levels of agitation associated with music therapy. Pooling of four trials found that music therapy was associated with reduced depressive symptoms in people with dementia. The review reported that music therapy was found to be particularly useful for people with anxiety and programs of longer duration appeared to be more beneficial.
Reminiscence
Nine randomised controlled trials evaluated the efficacy of reminiscence therapy.[120] [227-229] Two (of five) trials reported reduced global BPSD and two trials reported reduced levels of depression associated with intervention. Studies reporting beneficial effects tended to involve reminiscence groups, which were run by trained staff in residential care facilities.

Massage and touch
Seven randomised controlled trials evaluated the efficacy of massage and touch.[120] [230-232] Of the five studies reporting outcomes on agitation, all five reported significant reductions in BPSD. However, effects of the intervention were frequently assessed only in the short term.

Recreation therapy
Fifteen randomised controlled trials evaluated interventions of recreation therapy.[120] [142 225 226 233-242] Results were mixed; three (of 11) studies found reduced BPSD. Each of these studies reported benefits in different areas (apathy, anxiety and agitation). One (of six) trials reported significant reductions in levels of depression in people participating in recreation therapy.

Light therapy
A Cochrane review included six randomised controlled trials examining the efficacy of light therapy.[243] The review was unable to find any beneficial effects of light therapy on BPSD.

Aromatherapy
A Cochrane review identified two randomised controlled trials examining the effects of aromatherapy on BPSD.[244] The studies had mixed findings. One trial found that aromatherapy was associated with reduced global BPSD whereas the other trial found no significant effects.

Multisensory stimulation
Three randomised controlled trials examined the effects of multisensory stimulation for people with dementia.[120] While one small trial (n=24) reported reduced levels of agitation over time, a larger one (n=136) found no effects on BPSD.

Support and psychotherapy
Five randomised controlled trials examined the effects of support and psychotherapy on BPSD. [120] [245 246] Results were mixed. Of the three trials evaluating the impact on depression, one reported a significant reduction in depressive symptoms in the intervention group. This trial involved intensive counselling (30 minutes, three times a week for 16 weeks). Another trial, also involving intensive intervention, was associated with increased quality of life in participants.

Animal-assisted therapy
Although there appear to be a number of non-randomised studies exploring the effects of animal-assisted therapy, this evidence update included two recently published randomised controlled trials.[247 248] The quality of the studies was poor and findings were mixed and did not clearly identify benefits associated with animal-assisted therapy.
<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Five (of six) RCTs found that multicomponent interventions significantly reduced global BPSD (moderate).[120 247 248] Four (of five) RCTs found that multicomponent interventions significantly reduced levels of depression in the intervention group (low).[120 213 215 217]</td>
<td>Low-moderate</td>
</tr>
<tr>
<td>Three (of nine) RCTs found that behavioural management interventions reduced global BPSD (low). Three (of seven) RCTs reported reduced carer impact associated with the intervention (low).[120]</td>
<td>Low</td>
</tr>
<tr>
<td>Pooling of eight RCTs evaluating the effects of cognitive stimulation therapy found no significant overall effect on BPsd (low). Pooling of five RCTs found no significant effect on mood (very low).[229]</td>
<td>Very low-low</td>
</tr>
<tr>
<td>Pooling of four RCTs evaluating the effects of exercise on global BPSD found no significant effects (low). Pooling of seven RCTs found no significant effect on depression (low). One RCT reported a reduction in carer impact (moderate).[156]</td>
<td>Low-moderate</td>
</tr>
<tr>
<td>Pooling of six RCTs investigating the effects of music therapy found a significant reduction in global BPSD.[218] A further three RCTs also reported a reduction in agitation associated with music therapy [221 223 225] whereas two RCTs found no significant results (low). Pooling of four RCTs found a significant reduction in depression whereas a further study found no significant differences between groups (low).[218 219]</td>
<td>Low</td>
</tr>
<tr>
<td>Two (of five) RCTs found a significant reduction in global BPSD associated with reminiscence therapy (very low).[120] Two RCTs found significantly reduced levels of depression (low).[120 227]</td>
<td>Very low-low</td>
</tr>
<tr>
<td>Five RCTs reported reductions in agitation following massage (low).[231 232], [120]</td>
<td>Low</td>
</tr>
<tr>
<td>Three (of 11) RCTs found that recreation therapy led to reduced global BPSD (low).[225 226 235 236]. One (of six) RCT reported reduced levels of depression (low).[233]</td>
<td>Low</td>
</tr>
<tr>
<td>Pooling of six RCTs investigating light therapy found no significant effect on global BPSD (low) and pooling of five RCTs found no effect on depression (very low).[243]</td>
<td>Very low-low</td>
</tr>
<tr>
<td>One (of two) RCTs reported that aromatherapy was associated with reduced global BPSD (very low).[244]</td>
<td>Very low</td>
</tr>
<tr>
<td>One (of two) RCTs reported that multisensory stimulation was associated with reduced agitation (very low).[120]</td>
<td>Very low</td>
</tr>
<tr>
<td>One (of three) RCTs examining support and psychotherapy reported reduced levels of depression associated with the intervention (very low).[246] One RCT reported improved quality of life in the intervention group (low).[245]</td>
<td>Very low-low</td>
</tr>
<tr>
<td>One RCT reported no effect of animal-assisted therapy in reducing global BPSD whereas another study reported a trend towards reduced symptoms (very low).[247 248]</td>
<td>Very low</td>
</tr>
</tbody>
</table>
Pharmacological interventions may be prescribed to reduce BPSD but may also be associated with adverse events including increased confusion or acceleration of cognitive decline. They should be used in combination with non-pharmacological approaches. Medications that have been used in the management of BPSD include antipsychotics, acetylcholinesterase inhibitors, memantine, antipsychotics, antidepressants, mood stabilisers, benzodiazepines, melatonin and more recently analgesics.

BPSD may be an expression of underlying pain. Pain is common in people with dementia.[249-251] However, symptoms of pain such as verbalisations/vocalisations, noisy breathing, grimacing, restlessness, agitation and resistance to care may be dismissed as symptoms of dementia resulting in under treatment.[252 253] Multiple studies have shown that increased pain is associated with an increase in BPSD.[254 255]

Although non-pharmacological interventions are recommended as first-line treatment, the use of antipsychotics for people with dementia is relatively common.[256 257] In 2005, the United States Food and Drug Administration (FDA) issued a warning regarding an increased risk of mortality associated with the use of atypical antipsychotic drugs in this patient population. It has been suggested that the risks may be even greater with haloperidol use.[258] In certain emergency situations where a person with dementia has very severe BPSD, acute sedation may be necessary for safety reasons.[259]

This evidence update has only considered those categories of drugs with the most evidence available (i.e., antipsychotics, antidepressants, acetylcholinesterase inhibitors and memantine, anxiolytics, mood stabilisers and melatonin).

Recommendations regarding the use of pharmacological agents for the management of BPSD may not apply to those with pre-existing, comorbid serious mental illness.

### Clinical question

**For people with behavioural and psychological symptoms of dementia, does appropriate drug treatment when compared to placebo/non-pharmacological treatment produce benefits/harm?**

<table>
<thead>
<tr>
<th>Code</th>
<th>Evidence</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>82</td>
<td>Low</td>
<td>If a person with dementia is suspected to be in pain due to their distress or behaviour, as indicated by responses on an observational pain assessment tool, analgesic medication should be trialled using a stepped approach.</td>
</tr>
<tr>
<td>87</td>
<td>Mod</td>
<td>People with dementia who experience agitation should be offered selective serotonin reuptake inhibitors (SSRI) antidepressants (the strongest evidence for effectiveness exists for citalopram) if non-pharmacological treatments are inappropriate or have failed. The need for adherence, time to onset of action and risk of withdrawal effects and possible side effects should be explained at the start of treatment.</td>
</tr>
</tbody>
</table>
Clinical question
For people with behavioural and psychological symptoms of dementia, does appropriate drug treatment when compared to placebo/non-pharmacological treatment produce benefits/harm?

<table>
<thead>
<tr>
<th></th>
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<th>Clinical question</th>
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<tbody>
<tr>
<td>88</td>
<td>PP</td>
<td>Antidepressant medications with anticholinergic effects (e.g., tricyclic antidepressants) should be avoided because they may adversely affect cognition.</td>
</tr>
<tr>
<td>89</td>
<td>EBR</td>
<td>Larger trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se. People with dementia who also have depression without agitation may not benefit from antidepressant medication.</td>
</tr>
<tr>
<td>90</td>
<td>EBR</td>
<td>People with Alzheimer’s disease, vascular dementia or mixed dementias with mild-to-moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications because of the possible increased risk of cerebrovascular adverse events and death.</td>
</tr>
<tr>
<td>91</td>
<td>PP</td>
<td>People with Dementia with Lewy Bodies with mild-to-moderate behavioural and psychological symptoms of dementia, should not be prescribed antipsychotic medications, because those with Dementia with Lewy Bodies are at particular risk of extrapyramidal adverse reactions.</td>
</tr>
</tbody>
</table>
Clinical question

For people with behavioural and psychological symptoms of dementia, does appropriate drug treatment when compared to placebo/non-pharmacological treatment produce benefits/harm?

<table>
<thead>
<tr>
<th>92</th>
<th>EBR Mod</th>
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People with dementia and severe behavioural and psychological symptoms of dementia (i.e., psychosis and/or agitation/aggression) causing significant distress to themselves or others, may be offered treatment with an antipsychotic medication. Risperidone has the strongest evidence for treating psychosis. Risperidone and olanzapine have the strongest evidence for treating agitation/aggression, with weaker evidence for aripiprazole.

The following conditions should also be met:

- There should be a full discussion with the person with dementia and their carers and family about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed.
- Target symptoms should be identified, quantified and documented.
- The effect of comorbid conditions, such as depression, should be considered.
- The choice of antipsychotic should be made after an individual risk–benefit analysis.
- The dose should be initially low and titrated upwards if necessary.
- Monitoring for adverse effects including the metabolic syndrome should occur.
- Treatment should be time limited and regularly reviewed (at least every three months or according to clinical need). This should include regular assessment and recording of changes in cognition and target symptoms.

As far as possible, antipsychotics should be avoided in people with Dementia with Lewy Bodies due to the risk of severe untoward reactions, particularly extrapyramidal side effects. If antipsychotics are used, atypical or second generation antipsychotics with low propensity to cause extrapyramidal side effects should be used; olanzapine has the best evidence of efficacy and tolerability. Healthcare professionals should use low dosage and closely monitor for adverse effects.
**Clinical question**

For people with behavioural and psychological symptoms of dementia, does appropriate drug treatment when compared to placebo/non-pharmacological treatment produce benefits/harm?

<table>
<thead>
<tr>
<th>93</th>
<th>PP</th>
<th>Health professionals who use medication in the management of violence, aggression and extreme agitation in people with dementia should:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>- be trained in the correct use of medications for behavioural control</td>
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<tr>
<td></td>
<td></td>
<td>- be able to assess the risks associated with pharmacological control of violence, aggression and extreme agitation, particularly in people who may be dehydrated or physically ill</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- understand the cardiorespiratory effects of the acute administration of benzodiazepines and antipsychotics and the need to titrate dosage to effect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- recognise the importance of positioning people who have received these medications in the recovery position and of monitoring vital signs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- be familiar with and trained in the use of resuscitation equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- undertake annual retraining in resuscitation techniques</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- understand the importance of maintaining a clear airway</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- be knowledgeable about the laws for informed consent in their jurisdiction.</td>
</tr>
</tbody>
</table>

| 94  | PP | If medications are necessary for the control of violence, aggression and extreme agitation in people with dementia, oral medication should be offered before parenteral medication. |

| 95  | PP | In certain rare situations, parenteral medication may be required for the management of people with dementia with extreme behavioural and psychological symptoms of dementia. Local guidelines addressing appropriate pharmacological agents for use should be followed in these situations (e.g., the Handbook for NSW Health Clinicians addressing assessment and management of behavioural and psychological symptoms of dementia [BPSD]). |

| 96  | PP | If parenteral treatment is necessary for the control of violence, aggression and extreme agitation, intramuscular (IM) administration is preferable because it is safer than intravenous administration. Intravenous administration should be used only in exceptional circumstances. Vital signs should be monitored after parenteral treatment. Health professionals should be aware that loss of consciousness can be mistaken for sleep. If the person appears to be or is asleep, more intensive monitoring is required because of the risk of loss of consciousness. |

| 97  | PP | People with dementia who have received involuntary sedation should be offered the opportunity, along with their carer(s) and family, to discuss their experiences and be provided with a clear explanation of the decision to use urgent sedation. This should be documented in their notes. |

| 98  | PP | Where people with dementia have moderate to severe BPSD that puts themselves or others at risk, referral to a specialist mental health service for older people should occur. |
Summary of the NICE Guideline findings

The NICE Guideline Committee recommended that medications for BPSD should not be offered as a first-line treatment unless the person with dementia is severely distressed or there is an immediate risk of harm to the person or others. The NICE Guideline includes a large number of specific recommendations addressing the use of medications for BPSD. These are based upon both systematic evidence reviews and expert opinion.

Evidence update

This evidence update considered pharmacological interventions for BPSD in the following categories: antipsychotics, antidepressants (for both depression and agitation/psychosis), anxiolytics, mood stabilisers and melatonin. The update took the approach of including the most recent, comprehensive systematic review for each class and updating this with searches for additional studies. Studies included as the source of evidence for this review are summarised in the Technical Report Volume 1.

Analgesia

The use of analgesia to treat BPSD is a relatively new approach to care. The NICE Guideline Committee did not specifically look for evidence on the efficacy of analgesics for treating BPSD.

Three randomised controlled trials examined the effect of pharmacological treatment of pain on BPSD.[8-10] All three studies recruited participants with moderate-to-severe dementia residing in nursing homes. Two of the studies examined the effectiveness of regular paracetamol [8, 9] whereas the third study examined the effectiveness of analgesic medication prescribed based on the use of a step-wise protocol.[10] Two of the three studies reported improved outcomes for people with dementia.[9, 10]

Antidepressants

Dementia with concomitant depression

The NICE Guideline Committee considered evidence from a 2002 Cochrane systematic review.[260] The 2002 review included four small randomised controlled trials (two of selective serotonin reuptake inhibitors, two of tricyclic antidepressants) with six to 12 weeks treatment. Based on this review, NICE recommended that people with dementia who also have major depressive disorder should be offered antidepressant medication but also that antidepressant medications with anticholinergic effects (e.g., tricyclic antidepressants) should be avoided.

This evidence update considered a meta-analysis of five trials of novel antidepressants (selective serotonin reuptake inhibitors [SSRIs] and serotonin-noradrenaline reuptake inhibitors [SNRIs]) for people with Alzheimer’s disease and depression.[261] Evidence from the mirtazapine arm of one large, high quality trial included in the meta-analysis has also been considered here.[262 263] The identified trials of SSRIs (three randomised controlled trials and a small non-randomised trial) or mirtazapine failed to show a significant improvement in depression, global BPSD or quality of life in subjects with dementia and concomitant depression.[261 262] One included small randomised controlled trial demonstrated a significant improvement in depression according to one outcome
Overall, there was a lack of effectiveness of the antidepressants for treatment of depression in association with dementia.

Dementia with agitation/psychosis

This evidence update identified Seitz et al (2011) as the most recent, comprehensive systematic review of antidepressants for agitation in dementia. [265] In addition, the Citalopram for Agitation in Alzheimer Disease Study (CitAD) was identified in a search for more recent primary studies.[266] A significant improvement in reducing agitation was demonstrated in two of the large randomised controlled trials of SSRIs compared to placebo,[266 267] with no significant impact on serious adverse events or trial withdrawals. Evidence for the impact of SSRIs on global behavioural outcomes was less consistent; however, the most recent and highest quality trial did demonstrate a significant improvement over nine weeks of treatment with citalopram using a number of different outcome measures.[266] This recent trial also demonstrated an increase in some adverse events, including an increase in cognitive decline and of QT interval on ECG in the subjects treated with citalopram.[266]

Antipsychotics

Atypical antipsychotics:

The NICE Guideline Committee conducted a systematic review and identified 11 randomised controlled trials for their efficacy review and two meta-analyses for their safety review of atypical antipsychotics. Based on these trials, the Committee recommended that antipsychotics should not be prescribed to people with mild-to-moderate cognitive symptoms with Alzheimer’s disease, vascular dementia, mixed dementias or DLB. It was recommended that antipsychotics should only be offered to people with Alzheimer’s disease, vascular dementia, mixed dementias or DLB with severe non-cognitive symptoms following a number of specific procedures and assessments.

The current review identified a 2011 meta-analysis of 17 trials of atypical antipsychotics conducted over a six to 12 week follow-up.[268] The analysis demonstrated that atypical antipsychotics had small but statistically significant positive effects on BPSD overall, with the strongest evidence for risperidone, moderate evidence for aripiprazole and less evidence for olanzapine and quetiapine. Risperidone had the strongest evidence for decreasing psychosis symptoms. Olanzapine and risperidone had the strongest evidence for a small, but statistically significant improvement in agitation, with less evidence for aripiprazole. A large study reporting on the quality of life of people with dementia found no difference in carer-rated quality of life for subjects receiving atypical antipsychotic treatment compared to placebo (the Clinical Antipsychotic Trials of Intervention Effectiveness-Alzheimer’s Disease, CATIE-AD). [269 270] No additional studies of atypical antipsychotics for BPSD published to November 2014 were identified.

A 2005 meta-analysis of 15 published and unpublished studies of atypical antipsychotic use in dementia indicated a small but statistically significant increased risk of mortality (OR 1.54, 95 per cent CI 1.06 to 2.23).[271] This meta-analysis contains unpublished data not available to other authors and is therefore still considered the most comprehensive analysis available. The 2011 review found a statistically significant increased risk of cardiovascular events for olanzapine (OR 2.33, 95 per cent CI 1.08 to 5.61) and risperidone (OR 2.08, 95 per cent CI 1.38 to 3.22), but not quetiapine or
aripiprazole. The authors found consistency between this meta-analysis and FDA analyses as well as between published and unpublished trials.

**Intramuscular atypical antipsychotics:**

The NICE Guideline Committee recommended intramuscular olanzapine for behavioural control in situations where there is a significant risk of harm, based on one trial considered of moderate quality. One additional study of intramuscular aripiprazole was identified in this evidence update. As this antipsychotic is not available in this formulation in Australia, these data were not reviewed.

**Classical antipsychotics:**

The NICE Guideline Committee considered evidence for haloperidol compared to placebo from five studies of haloperidol for agitation in dementia.[272] No additional studies were identified. Haloperidol decreased behavioural symptoms, aggressive behaviour and agitation. A 2005 meta-analysis of published and unpublished studies showed haloperidol was associated with an increase in the risk of death at a rate similar to that of atypical antipsychotics, although it was not statistically significant.[271] Data from an observational study indicated no significant difference in the risk of cardiovascular events between haloperidol and atypical antipsychotics.[273] The overall quality of evidence was rated as moderate.

**Mood stabilisers**

The NICE Guideline Committee identified five randomised controlled trials that examined the effectiveness of mood stabilisers compared to placebo in people with dementia. The included studies demonstrated inconsistent effects for carbamazepine (two small studies). There was no significant improvement in BPSD for valproate, but adverse events were more frequent in the valproate group (three studies). No recommendations on the use of this class of medication were made by NICE.

This evidence update considered four randomised controlled trials of mood stabilisers administered in residential care settings.[274] One small, fair quality study of carbamazepine demonstrated a significant improvement in BPSD (Brief Psychiatric Rating Scale total) over six weeks. No significant change in BPSD was observed in studies of divalproex or oxcarbazepine. No additional trials of mood stabilisers for BPSD were identified. The body of evidence was considered too small to support a recommendation around this medication class.

**Anxiolytics/benzodiazepines**

The NICE Guideline Committee recommended the use of intramuscular lorazepam for behavioural control in situations where there is a significant risk of harm, based on a single study. [275] This trial was considered of moderate to high quality evidence of safety and effectiveness. The NICE Committee also recommended against the use of intramuscular diazepam for behavioural control. No additional randomised controlled trials of anxiolytics for BPSD were identified in this evidence update.
Melatonin

The NICE Guideline Committee did not review the evidence for the use of Melatonin for BPSD.

A Cochrane review of pharmacological treatments for sleep disorders in AD found that there were no significant effects on major sleep outcomes or adverse events in three studies of melatonin and one study of ramelteon, a melatonin receptor-agonist [276]. Another Cochrane review [277] of melatonin in dementia found positive effects on global BPSD across two studies. [278] However, some negative effects on mood were found in another trial. [280] The number of adverse events did not significantly differ between treatment arms. No additional randomised controlled trials of melatonin for dementia were identified. In summary, there is uncertainty in the overall body of evidence for melatonin effectiveness.

Parenterally administered medications

The NICE Guideline recommendations relating to the use of parenterally administered medications in emergency situations for very severe BPSD were based upon single studies of intramuscular lorazepam and olanzapine. This evidence update did not identify any additional studies for parenterally administered medications for BPSD. The Guideline Adaptation Committee decided that the evidence was inadequate to inform a recommendation that could apply in a range of settings and contexts (e.g., acute hospital settings, residential care), and that reference to local guidelines was more appropriate.

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
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<tbody>
<tr>
<td>One of two randomised controlled trials examining the efficacy of analgesia to manage agitation reported a significant reduction in agitation and pain, with no significant change in adverse event rates.</td>
<td>Low</td>
</tr>
<tr>
<td>A pooled analysis of five RCTs indicated that antidepressants (SSRIs or mirtazapine) do not have a statistically significant impact on depression in people with dementia overall.[261]</td>
<td>Low</td>
</tr>
<tr>
<td>Two of three RCTs demonstrated a significant reduction in agitation with the use of selective serotonin update inhibitors (SSRIs) in patients with dementia (Quality: moderate).[265-267] One high quality trial found that there was no significant difference in the number of serious adverse events between SSRIs and placebo (Quality: moderate).[266] This was associated with an increase in the QT interval on ECG, which is considered a surrogate outcome for adverse events (Quality: low).[266]</td>
<td>Moderate</td>
</tr>
<tr>
<td>A pooled analysis of 17 randomised controlled trials (RCTs) indicated that atypical antipsychotics are associated with a small but statistically significant improvement in global BPSD.[268] This is associated with a small but statistically significant increase in mortality, cardiovascular and cerebrovascular events.[271]</td>
<td>Moderate</td>
</tr>
<tr>
<td>A significant improvement in BPSD (as measured with the Brief Psychiatric Rating Scale) with carbamazepine was observed over six weeks (one RCT). No significant effect on BPSD was found with divalproex sodium (two RCTs) or oxcarbazepine (one RCT).</td>
<td>Low</td>
</tr>
</tbody>
</table>
Evidence statements

Pooled data from two small RCTs indicated that melatonin may be useful in BPSD.[278 279]. However there are also possible negative effects on mood (one RCT) [280] and unclear biological plausibility given the lack of effect on sleep (four RCTs). [276] Therefore, there is uncertainty in the overall body of evidence for melatonin effectiveness.

GRADE Quality
Low

Considerations for Australia

As the body of evidence for parenteral administration of medications in emergency situations is highly limited, the recommendation refers to appropriate local expert consensus guidelines. If local guidelines do not exist in some Australian settings where parenteral administration of medications for BPSD is occurring, they should be developed.

Support for carers

Background

Most people with dementia live in the community with the support of carers and family.[1] Carers are those individuals who provide the primary ongoing support and care in a non-professional, unpaid capacity for a person with dementia. The carer is generally a spouse/partner, child or other family member. Not everyone in this role likes to be referred to as a ‘carer’ and the person’s preference should be sought before using the term. The person’s support network may also include friends and neighbours.

In recognition of their vital role in the lives of people with dementia, carers have been labelled as ‘the primary therapeutic agent in dementia care’. [281] They have also been labelled as ‘the forgotten patient’ due to the impact of caring on the carer’s health. Carers are typically the first to notice symptoms of dementia.[59] They provide the support required for the person with dementia to remain at home and to maintain participation in daily activities and life roles. They monitor and support the person’s general ongoing state of health, including the presence or development of comorbidities, the signs and symptoms of which the person with dementia may not be able to identify, describe or discuss. In addition, they often assist with administration of medication and managing BPSD.[281]

There are approximately 200,000 Australians caring for a person with dementia living in the community.[4] Approximately two thirds of carers are women and approximately half are aged 65 or over.[4] Providing care is emotionally and physically demanding. Caring is associated with poor health, depression, social isolation and physical and emotional impact in carers.[3] Carers require support in order to maintain their own health and wellbeing and to provide the best support for the person for whom they care.

Health and aged care professionals should engage with family members and carers as care partners as described in the 10 Principles of Dignity in Care.
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<tbody>
<tr>
<td>99</td>
<td>PP</td>
<td>Carer(s) and families should be respected, listened to and included in the planning, decision making and care and management of people with dementia.</td>
</tr>
<tr>
<td>100</td>
<td>PP</td>
<td>Health and aged care professionals should assess carer(s) and family for their emotional, psychological and social needs. Carer and family needs should be addressed regularly, including if the person with dementia has entered residential care, and after their death.</td>
</tr>
<tr>
<td>101</td>
<td>CBR</td>
<td>The person with dementia, their carer(s) and family should be offered respite appropriate to their needs. This may include in-home respite, day respite and residential respite.</td>
</tr>
</tbody>
</table>
| 102  | EBR  | Carer(s) and family should have access to programs designed to provide support and optimise their ability to provide care for the person with dementia. Programs should be tailored to the needs of the individual and delivered in the home or at another accessible location. Programs should be delivered over multiple sessions and include:  
- education regarding dementia and its consequences  
- information regarding relevant services including respite  
- referral to support organisations such as Alzheimer’s Australia or Carers Australia  
- development of individualised strategies and building carer skills to overcome specific problems experienced by the person with dementia as reported by the carer  
- training in providing care and communicating most effectively with the person with dementia  
- support and information regarding coping strategies to maintain their own wellbeing including stress management  
- training in the use of pleasant and meaningful activities as a strategy to engage the person with dementia |
| 103  | PP   | Consideration should be given to involving the person with dementia, as well as the carer and family, in carer programs. |
| 104  | EBR  | Health and aged care professionals should provide carer(s) and families with information regarding how to join a mutual support group. Individual preferences for group composition may vary and groups of the preferred composition should be available. |
| 105  | PP   | Carer(s) and families of people with dementia should be supported to build resilience and maintain overall health and fitness. Where necessary, they should be offered psychological therapy, conducted by a specialist practitioner. |
Summary of the NICE Guideline findings

The NICE Guideline based its recommendations on the findings of two systematic reviews and an additional 25 randomised controlled trials. It also provided a summary of 20 qualitative studies to complement the findings from the trials. Based on the large body of evidence, it concluded that interventions for families and carers can be effective in carer wellbeing and in reducing the impact on carers; however, variability in the intervention meant that it was unclear as to which interventions were most helpful for which carers. The NICE Guideline Committee felt that multicomponent interventions offered the best chance of success.

Evidence update

A systematic review identified 71 studies published in English that evaluated the efficacy of interventions targeted towards helping the carer to manage care.[120] A search revealed a further 32 randomised controlled trials meeting the inclusion criteria [121 164 282-313] bringing the total number of randomised controlled trials considered in this evidence update to 103.

Interventions were categorised as follows: carer education; carer support; case management; respite care; multicomponent for the families and carers; multicomponent for the person with dementia and their families and carers. Within categories, the content of the intervention, type of health professional providing the intervention and dose of intervention varied.

While there were a number of large trials at low risk of bias, there were also many small trials at high risk of bias. When considered as a body of evidence, the overall quality was often low.

The body of evidence supports:

- carer education programs for increasing carer quality of life, reducing carer impact and increasing carer knowledge
- carer support programs for improving carer quality of life and reducing carer impact
- tailored multicomponent interventions for the carer for reducing behavioural and psychological symptoms in the person with dementia and delaying time until institutionalisation
- tailored multicomponent interventions involving both the carer and the person with dementia in improving the quality of life for both the carer and the person with dementia and reducing carer impact.
Evidence statements

<table>
<thead>
<tr>
<th>Evidence statements</th>
<th>GRADE Quality</th>
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<tbody>
<tr>
<td>There were no RCTs that looked at impact of respite on outcomes for the person with dementia. One RCT failed to show a significant reduction in carer impact associated with respite use.[120]</td>
<td>Very low</td>
</tr>
<tr>
<td>Five (of nine) RCTs investigating carer education programs reported a significant improvement on carer quality of life (low). Two (of four) reported a significant improvement in the quality of life of the person with dementia (low).[120 303]</td>
<td>Low</td>
</tr>
<tr>
<td>Pooling of three RCTs investigating carer support programs found a significant improvement in carer quality of life.[284 312 313] An additional two studies could not be pooled but reported no effect (low). One RCT reported a significant reduction in carer impact (low).[312] and two (of four) RCTs reported reduced rates of institutionalisation (low).[290 312]</td>
<td>Low</td>
</tr>
<tr>
<td>One RCT reported a significant reduction in BPSD following provision of a multicomponent intervention for carers (low).[310] Two (of six) RCTs reported improved quality of life for the carer (low).[120 297] Two (of four) RCTs reported a significant reduction in carer impact (very low).[120 310] One (of two) RCTs reported a significant improvement in quality of life for the person with dementia (very low).[120 310]</td>
<td>Very low-low</td>
</tr>
<tr>
<td>Five (of 13) RCTs investigating multicomponent interventions involving the person with dementia and their carer found significant reductions in BPSD (low).[120 164] Three (of seven) RCTs found an improvement in carer quality of life (low).[120] Three (of six) RCTs found improved quality of life for the person with dementia (moderate).[120] Three (of seven) RCTs reported a significant reduction in carer impact (low).[120 286 294]</td>
<td>Low-moderate</td>
</tr>
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</table>

Considerations for Australia

There are limited culture-specific carer support interventions in Australia. There was considerable discussion amongst the committee regarding use of the word ‘carer’. Many people who take on the role of ‘carer’ do not identify themselves as a ‘carer’ or like the term. Some consumers who provided feedback on drafts of the Guideline preferred the term ‘supporter’ or to be described as someone supporting the person with dementia. In the absence of a better term to describe the role the Guideline adopted the term ‘carer’ but noted that people should be asked as to their preference.

Environmental design

Background

The Dementia Enabling Environments Project (DEEP) is an Australian project funded by the National Quality Dementia Care Initiative that aims to facilitate the creation of supportive environments for people with dementia (www.enablingenvironments.com.au/). The DEEP project involves Australian experts in dementia environment design and draws on the latest research to provide architects, designers, landscapers, aged care providers and families with practical information and advice on how to create an enabling environment.
The website contains advice on adapting rooms within people’s homes and creating optimal care environments. For example, the website recommends that dining areas within residential care facilities should include small groups of tables in a variety of shapes to create an informal and non-institutionalised feel; small round tables are more intimate and can encourage conversation. There is also advice on creating garden areas. Links to audit tools that allow an individual or an organisation to audit their care environment are provided on the website.

**Box 5  Principles of creating a Dementia Enabling Environment**

The principles listed below are sourced directly from the DEEP website (www.enablingenvironments.com.au)

1. **Unobtrusively reduce risks**

   People with dementia require an internal and external environment that is safe, secure and easy to move around if they are to make the best of their remaining abilities. However, obvious safety features and barriers will lead to frustration, agitation and anger and so potential risks need to be reduced unobtrusively.

2. **Provide a human scale**

   The scale of a building will have an effect on the behaviour and feelings of a person with dementia. The experience of scale is determined by three factors: the number of people that the person encounters, the overall size of the building and the size of the individual components, such as doors, rooms and corridors. A person should not be intimidated by the size of the surroundings or confronted with a multitude of interactions and choices. Rather the scale should help the person feel in control.

3. **Allow people to see and be seen**

   The provision of an easily understood environment will help to minimise confusion. It is particularly important for people with dementia to be able to recognise where they are, where they have come from and what they will find if they head in a certain direction. When they can see key places, such as a lounge room, dining room, their bedroom, kitchen and an outdoor area they are more able to make choices and find their way to where they want to go. Buildings that provide these opportunities are said to have good visual access. Good visual access opens up opportunities for engagement and gives the person with dementia the confidence to explore their environment. It can also enable staff to see residents from where they spend most of their time. This reduces their anxiety and the anxiety of the residents.

4. **Reduce unhelpful stimulation**

   As dementia reduces the ability to filter stimulation and attend to only those things that are important, a person with dementia becomes stressed by prolonged exposure to large amounts of stimulation. The environment should be designed to minimise exposure to stimuli that are not helpful. The full range of senses must be considered. Too much visual stimulation is as stressful as too much auditory stimulation.

5. **Optimise helpful stimulation**

   Enabling the person with dementia to see, hear and smell things that give them cues about where they are and what they can do, can help to minimise their confusion and uncertainty. Consideration needs to be given to providing redundant cueing (i.e., providing a number of cues to the same thing), recognising that what is meaningful to one person will not necessarily be meaningful to another. A person may recognise their bedroom, for example, because of a view, the presence of furniture, the colour of the walls, the light fitting and/or the bedspread. Cues need to be carefully designed so that they do not add to unhelpful stimulation.

6. **Support movement and engagement**

   Aimless wandering can be minimised by providing a well-defined pathway, free of obstacles and complex decision points, that guides people past points of interest and opportunities to engage in activities or social interaction. The pathway should be both internal and external, providing an opportunity and reason to go outside when the weather permits.
7. Create a familiar space
The person with dementia is more able to use and enjoy spaces and objects that were familiar to them in their early life. The environment should afford them the opportunity to maintain their competence through the use of familiar building design (internal and external), furniture, fittings and colours. This will involve an understanding of the personal background of the people living in the environment. The involvement of the person with dementia in personalising the environment with their familiar objects should be encouraged.

8. Provide opportunities to be alone or with others
People with dementia need to be able to choose to be on their own or spend time with others. This requires the provision of a variety of spaces, some for quiet conversation with one or two others and some for larger groups, as well as spaces where people can be by themselves. These internal and external spaces should have a variety of characters (e.g. a place for reading, looking out of the window or talking) to cue the person to what is available and stimulate different emotional responses.

9. Provide links to the community
Without constant reminders of who they were, a person with dementia will lose their sense of identity. Frequent interaction with friends and relatives can help to maintain that identity. This is made easier when the person’s residential care facility is within their local community as friends and relatives are able to drop in easily. The environment must include spaces for the resident and their visitors to use within the building and in its immediate surrounds. These need to be attractive and comfortable to encourage visitors to come and spend time. Stigma remains a problem for people with dementia so the building should be designed to blend with the existing buildings and not stand out as ‘special’. Where possible a ‘bridge’ should be built between the building and the community by providing a space that is used by both the community and people with dementia. Where the unit is a part of a larger site, there should be easy access around the site so people with dementia, their families and friends can interact with other people who live there.

10. Respond to a vision for way of life
The environment should support the person with dementia to lead a life that has meaning and value to them. The choice of this lifestyle, or philosophy of care, will vary between facilities. Some will choose to focus on engagement with the ordinary activities of daily living and have fully functioning kitchens. Others will focus on the ideas of full service and recreation, while still others will emphasise a healthy lifestyle or, perhaps, spiritual reflection. The way of life offered needs to be clearly stated and the building designed both to support it and to make it evident to the residents and staff. The building becomes the embodiment of the philosophy of care, constantly reminding the staff of the values and practices that are required while providing them with the tools they need to do their job.

Palliative and end of life care

Background
In Australia in 2010 dementia was listed as the underlying cause of death or as an associate cause of death in 14 per cent of deaths. The duration from diagnosis of dementia to death is highly variable with a review finding that the average duration across studies ranged from 1.1 to 8.5 years.

As the condition progresses and the severity of dementia increases, the focus is increasingly on providing care using a palliative approach. Palliative care is described as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and
impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’. [316]

The focus of palliative care has traditionally been on people with advanced stage cancer and there has been less attention given to people with dementia. However, people with end-stage dementia frequently experience symptoms including pain, agitation and shortness of breath which should be managed using a palliative approach. [317] There are unique issues associated with providing a palliative approach for people with dementia. First, there is usually a long time period between diagnosis and death and the focus of treatment may vary over time. [318] Further, the prognosis for people with dementia is often unclear and clinicians may be reluctant or unable to provide a clear prognosis. [319] In addition, providing palliative care for people with dementia can be challenging as the presence of cognitive impairment may impact on the person’s ability to consent or adhere to treatment. [320] Clear communication between the health professional, the person and their family is essential to ensure that the most appropriate treatments are provided. Families need support to help them in their role as proxy decision-makers and to deal with their grief. [12] Specific decisions may need to be made regarding hydration, feeding, symptom management and the prescription of medications. [321]

The National Health and Medical Research Council has published a framework for integrating palliative care principles into the management of advanced chronic or terminal conditions. [29] The framework describes the principles of clinical integrity, justice, respect for persons and beneficence to the person and the relationship of the principles to each other. The framework is intended to guide palliative care policy development and service delivery across Australia.

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<th>Palliative approach</th>
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<td>In the absence of a valid and applicable advance directive to refuse resuscitation, the decision to resuscitate should take account of any expressed wishes or beliefs of the person with dementia, together with the views of the carer(s) and family and the multidisciplinary team. The decision should be made in accordance with the guidance developed by the Australian Resuscitation Council and, if the person with dementia lacks capacity, the provisions of state or territory based mental health and guardianship laws. Advance Care Plans must be recorded in the medical notes and care plans.</td>
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METHODOLOGICAL CONSIDERATIONS

This evidence update used a hierarchical approach in the selection of evidence, that is, only the highest level of evidence addressing each clinical question was used to answer each question. In some cases, this meant that only randomised controlled trials were included. This process may mean that studies of a lower level of evidence (i.e., of a study design that is more prone to bias) were excluded from review.

The overall quality of the evidence was assessed using GRADE methodology. This approach rates the quality of the evidence based on the domains: risk of bias, indirectness, imprecision and inconsistency. The quality of the evidence is downgraded where the outcome of interest is considered a ‘surrogate outcome’ (i.e., it is not a direct measure of a patient-important outcome such as quality of life, patient function or behaviour). As one of the main symptoms of dementia is cognitive impairment, research in the dementia field frequently measures cognition as a primary outcome. Cognition is considered by GRADE to be a surrogate outcome for function as the clinical relevance of a change on a cognitive assessment scale is not always clear. Therefore, the quality of evidence from some well conducted trials in dementia (i.e., with a low risk of bias) was downgraded on this basis.

Care for people with dementia often involves complex interventions, such as carer interventions or case coordination. These interventions can be difficult to categorise as they may vary in terms of the theoretical approach, content, dose and person delivering the intervention. Wherever possible, we examined which specific interventions had the strongest evidence of effectiveness or safety and considered the most appropriate population or subgroup with optimal effectiveness or safety. However, this was not always possible as there may not have been enough studies to enable such evaluations. For example, while exercise appears to be beneficial generally, there was not enough information to determine which type and dose was most effective and at which point in the course of dementia it is most effective.

In some areas, such as staff training and carer interventions, there are a number of large high quality studies. However, there is also a number of lower quality studies and therefore, when considered as a whole, the body of evidence is not as strong as may be expected.
Areas for further research

The National Health and Medical Research Council recently undertook consultation with stakeholders to understand dementia research priorities from a number of different perspectives [322]. The consultation included a national survey and focus groups and interviews with consumers, aged care providers, researchers and medical practitioners. The top research priorities identified included prevention and the development of new effective interventions to treat or delay the onset of dementia. The immediate priorities were to improve interventions for the BPSD and to increase the self-determination and independence of the person with dementia.

The Dementia Research Mapping Project (2010) summarises existing evidence and identifies gaps in dementia research [13]. The report identifies a number of areas for further research including techniques to enable early diagnosis and more effective treatments. Further qualitative research to understand the experience and needs of people with dementia was also recommended.

The process of developing these Clinical Practice Guidelines for Dementia in Australia identified a number of key areas in which further research is required. The areas prioritised by the Guideline Adaptation Committee are listed in Box 6. The areas for further research are presented in order of their appearance in the guideline.
Early identification: The potential benefits of early identification are often described but there is currently insufficient information to determine whether early diagnosis (through interventions such as population screening) results in improved outcomes for the person with dementia, their carer(s) and families and the health and aged care system.

Memory assessment services: More information is required to determine the potential benefits of attending a memory assessment service in comparison to attending an alternative service. In addition, more information is required to determine the optimal configuration of memory assessment services (for example, the type of staff involved and the types of services offered).

Cognitive assessment tools: Research is required to understand the availability, type and performance of cognitive assessment tools in both urban and rural areas of Australia.

Communicating the diagnosis: Qualitative research to obtain information that describes the person’s experience and preferences when receiving a diagnosis could improve guidance.

Organisation of services: There is currently a lack of research regarding the most effective and efficient way to organise services. Evaluation of models of care, including care coordination, consumer directed care, multidisciplinary care and integrated or seamless care, is required.

Transitions in care (e.g., moving from services appropriate to the early stages of dementia to those for later stages; home to residential care): little is known about the experience of the person with dementia, their carer(s) and families and how these transitions can best be supported.

Respite: More information is needed regarding how to provide flexible and innovative models of respite and the effects of these models on the person with dementia and their carer(s) and families.

Primary care: Further research regarding the role of general practitioners in dementia care in Australia and the way in which they collaborate with specialists and hospitals is required.

Physical and cognitive rehabilitation: More research is required to determine the optimal timing and approach to physical rehabilitation and maintaining independence. Cognitive rehabilitation interventions that adopt a compensatory approach also warrant further investigation. In addition, information on the best type of exercise for mild and severe dementia is required.

Driving: There is currently insufficient evidence to determine the best ways to support people with dementia to continue to drive when fit to do so and to manage the process of driving cessation.
Non-pharmacological interventions for behavioural and psychological symptoms of dementia: More high quality research regarding which non-pharmacological interventions most effectively promote independence and reduce the frequency or impact of behavioural and psychological symptoms of dementia is needed.

Carer support: Information is needed regarding how to best support carers in looking after someone with dementia and in how to build resilience.

Treatment of behavioural and psychological symptoms of dementia: While research tends to focus on managing agitation and depression, there is less research regarding treatment of other symptoms including apathy and anxiety.

Palliative care: Exploration of service models that allow people with dementia to remain at home or return home at the end of life when desired. Further research regarding how to best manage hydration and a palliative approach in residential care facilities.

Research that is inclusive of people of CALD backgrounds is needed. Australia is a multicultural society and yet people who do not speak English as a first language are often excluded from research studies.

The characteristics and needs of specific groups of people with dementia: These include Indigenous Australians; people from CALD backgrounds; people in rural and remote areas; gay, lesbian and bisexual people; people from low socioeconomic backgrounds. Research is required to determine how to improve accessibility of services to meet the needs of these groups.

Terminology: Development of a common and consistent language to describe the stages, severity and progress of dementia is needed, so that descriptors can be widely understood (e.g., descriptors for the severity of dementia or the severity of BPSD).

Consent and capacity assessment: Approaches to reliable assessment of capacity to make decisions for those without specialised dementia care skills are needed.
Areas for research translation

The Guideline Adaptation Committee identified recommendations that should be prioritised for research translation. The prioritised recommendations are presented in order of their appearance in the guideline.

Memory assessment services

Recommendation 26: People with a possible diagnosis of dementia should be referred to memory assessment specialists or services for a comprehensive assessment.

Communicating the diagnosis

Recommendation 50: The medical practitioner should be honest and respectful and use a gradual and individualised approach when communicating the diagnosis to the person with dementia and their carer(s).

Organisation of care

Recommendation 58: Health and aged care managers should coordinate and integrate working across all agencies involved in the assessment, treatment, support and care of people with dementia and their carer(s) and family, including jointly agreeing on written policies and procedures. People with dementia and their carer(s) and families should be involved in planning local policies and procedures.

Recommendation 59: Health system planners should ensure that people with dementia have access to a care coordinator who can work with families and carers from the time of diagnosis. If more than one service is involved in the person’s care, services should agree on one provider as the person’s main contact, who is responsible for coordinating care across services at whatever intensity is required.

Training for staff and students

Recommendation 63: Health and aged care organisations should ensure that all staff working with people with dementia receive dementia-care training (attitude, knowledge and skill development) that is consistent with their roles and responsibilities. Training should reflect programs that have been shown to optimise care for the person with dementia. Effective programs tend to be: delivered face-to-face by someone experienced in dementia care; scheduled over several training sessions; involve ongoing mentoring or support from someone experienced in dementia care; and, utilise active learning techniques such as problem solving, case based training and role play.

Recommendation 64: Training programs should be comprehensive and have a strong focus on communicating effectively with the person with dementia and his or her carer(s) and family and recognising, preventing and managing behavioural and psychological symptoms of dementia. Staff should be trained in the principles of person-centred care and how these principles are applied in practice.
Promoting independence

Recommendation 69: People with dementia living in the community should be offered occupational therapy interventions which should include: environmental assessment and modification to aid independent functioning; prescription of assistive technology; and tailored intervention to promote independence in activities of daily living which may involve problem solving, task simplification and education and skills training for their carer(s) and family.

Behavioural and psychological symptoms of dementia

Recommendation 79: People with dementia who develop behavioural and psychological symptoms should be offered a comprehensive assessment at an early opportunity by a professional skilled in symptom assessment and management. This should involve their carer(s) and family as appropriate and include;

- analysis of the behaviours (e.g., antecedent [triggers], behaviour description and consequence [ABC approach]), frequency, timing and presentation
- assessment of the person with dementia’s physical and mental health
- their level of pain or discomfort
- whether they are experiencing side effects of medication
- the influence of religious and spiritual beliefs and cultural norms
- physical environmental and interpersonal factors
- an assessment of carer(s) health and communication style when interacting with the person with dementia should also be undertaken
- understanding the behaviour as a form of communication.

Recommendation 83: Health and aged care staff should attempt to minimise the impact of behavioural and psychological symptoms of dementia by providing person-centred care (care that is consistent with the 10 Principles of Dignity in Care).

Reducing over-prescription of antipsychotics

Recommendation 90: People with Alzheimer’s disease, vascular dementia or mixed dementias with mild-to-moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications because of the possible increased risk of cerebrovascular adverse events and death.

Support for carers

Recommendation 101: The person with dementia, their carer(s) and family should be offered respite appropriate to their needs. This may include in-home respite, day respite and residential respite.

Recommendation 102: Carer(s) and family should have access to programs designed to provide support and optimise their ability to provide care for the person with dementia. Programs should be tailored to the needs of the individual and delivered in the home or at another accessible location. Programs should be delivered over multiple sessions and include:

- education regarding dementia and its consequences
- information regarding relevant services including respite
- referral to support organisations such as Alzheimer’s Australia or Carers Australia
- development of individualised strategies and building carer skills to overcome specific problems experienced by the person with dementia as reported by the carer
- training in providing care and communicating most effectively with the person with dementia
- support and information regarding coping strategies to maintain their own wellbeing including stress management
- training in the use of pleasant and meaningful activities as a strategy to engage the person with dementia
RELEVANT NHMRC DEVELOPED OR APPROVED GUIDELINES

Health and aged care professionals working with people with dementia and their carer(s) and families should refer to the following NHMRC approved guidelines:

An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions (2011)

Guidelines for the management of absolute cardiovascular disease risk (2012)
REFERENCES

2. Fratiglioni L, Qiu C. Prevention of cognitive decline in ageing: dementia as the target, delayed onset as the goal. Lancet Neurology 2011;10(9):778-79.
towards a consensus: report of the International Working Group on Mild Cognitive 
24. National Health and Medical Research Council. Procedures and requirements for meeting the 
2011 NHMRC standard for clinical practice guidelines. Melbourne: National Health and 
Medical Research Council, 2011.
and evaluation in healthcare. Canadian Medical Association Journal 
http://www.dignityincare.org.uk/.
priority, 2012.
29. National Health and Medical Research Council. An ethical framework for integrating palliative 
care principles into the management of advanced chronic or terminal conditions. Canberra: 
National Health and Medical Research Council, 2011.
32. Australian Commission on Safety and Quality in Health Care. Evidence for the safety and quality 
issues associated with the care of patients with cognitive impairment in acute care settings: 
a rapid review. Sydney, Australia, 2013.
34. Bail K, Hudson C, Grealish L, et al. Characteristics of rural hospital services for people with 
dementia: findings from the Hospital Dementia Services Project. Australian Journal of Rural 
35. Lindeman MA, Taylor KA, Kuipers P, et al. 'We don't have anyone with dementia here': a case for 
better intersectoral collaboration for remote Indigenous clients with dementia. The 
36. Smith K, Flicker L, Shadforth G, et al. 'Gotta be sit down and worked out together': views of 
Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal 
differences in use of dementia treatment, care, and research. American Journal of Geriatric 
38. Low LF, Anstey KJ, Lackersteen SM, et al. Help-seeking and service use for dementia in Italian, 
39. Forbes DA, Morgan D, Janzen BL. Rural and urban Canadians with dementia: use of health care 
40. Quinn CC, Gruber-Baldini AL, Port CL, et al. The role of nursing home admission and dementia 
status on care for diabetes mellitus. Journal of the American Geriatrics Society 
2009;57(9):1628-33.
41. Koch T, Iliffe S, project E-E. Rapid appraisal of barriers to the diagnosis and management of 
patients with dementia in primary care: a systematic review. BMC Family Practice 
2010;11:52.
42. Radford K, Mack HA, Draper B, et al. Prevalence of dementia in urban and regional Aboriginal 
46. AIHW. Older Aboriginal and Torres Strait Islander people. 2011.
52. Dementia Collaborative Research Centre Assessment and Better Care. Guidelines for diagnosis and care of Aboriginal people with dementia in remote communities.


113. Low L, Yap M, Brodaty H. A systematic review of different models of home and community care services for older persons. BMC Health Services Research 2011;11(93).


123. Commonwealth of Australia. Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia, 2014.


GLOSSARY

The following glossary is adapted from the glossary used with the NICE guideline [7], with additions and modifications as necessary.

Aboriginal
A term that is traditionally applied to the Indigenous inhabitants of Australia along with some of the adjacent islands.

Acetylcholinesterase inhibitors
Drugs that prevent the breakdown of acetylcholine, a neurotransmitter thought to be important in the chemical basis of a number of cognitive processes, including memory, thought and judgement. Acetylcholinesterase inhibitors used in clinical practice include rivastigmine, donepezil and galantamine.

Activities of daily living (ADL)
Everyday activities, for example, showering, dressing, shopping, cooking and toileting.

ADAPTE
An international collaboration of researchers, guideline developers, and guideline implementers who aim to promote the development and use of clinical practice guidelines through the adaptation of existing guidelines.

Advance care planning
Planning future care to ensure that your wishes are known when you can no longer make decisions for yourself or legally complete documents.

Adverse event
Any undesirable experience associated with an intervention. Regarded as serious if it results in death, inpatient hospitalisation or prolongation of existing hospitalisation, a persistent or significant disability/incapacity.

Aged care staff
Care workers with certificate level qualifications.

AGREE II
A checklist designed to assess the methodological rigour and transparency of a clinical practice guideline.

Alzheimer’s disease (AD)
Alzheimer’s disease is a condition with symptoms of impaired memory, thinking and behaviour. Alzheimer’s disease is a progressive dementia—caused by a progressive degeneration of brain cells. The brain degeneration that occurs in Alzheimer’s disease affects memory, thinking skills, emotions, behaviour and mood.
Antipsychotics
Antipsychotics (also known as neuroleptics or major tranquilizers) are a class of psychiatric medication primarily used to manage psychosis.

Assistive technology
An umbrella term that includes assistive, adaptive, and rehabilitative devices for people with disabilities.

Australian Commission on Safety and Quality in Health Care
The Commission is a government agency that leads and coordinates national improvements in safety and quality in health care across Australia.

Behavioural and psychological symptoms of dementia
This term describes a number of different symptoms of dementia. Behavioural symptoms may include aggression, vocalisations, restlessness, agitation, wandering, culturally inappropriate behaviours, sexual disinhibition, hoarding, cursing and shadowing. Psychological symptoms may include anxiety, depressive mood, hallucinations and delusions.

CALD
A term commonly used to describe people who have a cultural heritage different from that of people from the dominant Anglo-Australian culture.

Capacity
The law says an adult has the capacity to make a particular decision when he or she can:
1. understand the information being given,
2. make a decision on the basis of the information given after having weighed and fully appreciated the positive and negative consequences of the decision; and,
3. communicate that decision to another person.

Carer
Individuals who provide the primary ongoing support and care in a non-professional, unpaid capacity for a person with dementia. The carer is generally a spouse/partner, child, other family member, relative or friend. Not everyone in this role likes to be referred to as a ‘carer’ and the person’s preference should be sought before using the term. They are to be distinguished from ‘Care workers’.

Care workers
Individuals who are employed to provide support and care in a professional, paid capacity for a person with dementia in the community, in a residential aged care facility or other care home. They are to be distinguished from ‘carers’.

Case management
Care that may involve one or more of the following elements: entry screening, assessment, planning, coordination, monitoring, review and exit/case closure planning.

Cerebrospinal fluid (CSF)
A nutrient-rich fluid, continuously being produced and absorbed, that flows in the ventricles (cavities) within the brain and around the surface of the brain and spinal cord.
Clinical question
The key questions about treatment and care which were addressed by systematic reviews of the evidence.

Cochrane review
A systematic review conducted according to the methods described in The Cochrane Handbook and published in The Cochrane Library. The reviews are regarded as high in methodological quality.

Cognitive rehabilitation
An approach to helping people with cognitive impairments in which those affected, and their families, identify cognitive strategies for addressing these. The emphasis is not on enhancing performance on cognitive tasks but on improving function.

Cognitive stimulation therapy
Engagement in a ‘range of group activities and discussions aimed at general enhancement of cognitive and social functioning’.

Cognitive training
Intervention usually involves practice of a set of tasks designed to reflect particular cognitive functions, such as memory, attention, language or executive function.

Cohort study (also known as follow-up, incidence, longitudinal or prospective study)
An observational study in which a defined group of people (the cohort) is followed over time.

Computed tomography (CT)
A medical imaging method employing tomography (imaging by sections). A three-dimensional image of the area is generated from a large series of two-dimensional x-ray images taken around a single axis of rotation.

Consensus based recommendation
Recommendation formulated in the absence of quality evidence, when a systematic review of the evidence has failed to identify any quality studies meeting the inclusion criteria for that clinical question.

Consumer directed care
Interventions where consumers were explicitly given choice and/or control of services.

Creutzfeldt-Jakob disease (CJD)
A rapidly progressing disease of the nervous system, which causes deterioration of brain tissue. There are several forms of the disease, the most common of which is sporadic CJD, which currently has no identifiable cause and which affects mostly middle-aged or elderly people.

Dementia with Lewy Bodies (DLB)
Dementia with Lewy Bodies (sometimes called Lewy Body Dementia) is a common form of dementia that shares characteristics with both Alzheimer’s and Parkinson’s diseases. Dementia with Lewy Bodies is a common neurodegenerative disease of ageing. This means that the disease causes
gradual brain damage. These abnormalities occur in specific areas of the brain, causing changes in movement, thinking and behaviour.

**Dysphagia**  
Difficulty swallowing.

**Dysphasia**  
Impaired ability to communicate due to damage to the brain.

**Effectiveness**  
The extent to which a specific intervention, when used under ordinary circumstances, does what it is intended to do.

**Efficacy**  
The extent to which an intervention produces a beneficial result under ideal (research) conditions. The randomised controlled trial is the accepted ‘gold standard’ for evaluating the efficacy of an intervention.

**Electroencephalogram (EEG)**  
A non-invasive, diagnostic technique that records the electrical impulses produced by brain-cell activity via electrodes attached to the scalp. An EEG reveals characteristic brain-wave patterns that may assist in the diagnosis of neurological conditions, such as seizure disorders, impaired consciousness, and brain lesions or tumours.

**Enduring Guardianship**  
Authority you invest in a trusted person to make health care decisions for you when you can no longer make those decisions for yourself.

**Enduring Power of Attorney**  
Authority you invest in a trusted relative or friend to deal with your financial affairs.

**Evidence-based recommendation**  
Recommendation formulated after a systematic review of the evidence, with supporting references provided.

**Frontotemporal dementia (FTD)**  
FTD is the name given to dementia due to progressive damage to the frontal and/or temporal lobes of the brain. The right and left frontal lobes are involved in mood, social behaviour, attention, judgement, planning and self-control. Damage can lead to reduced intellectual abilities and changes in personality, emotion and behaviour.

**GRADE**  
The Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach provides a system for rating quality of evidence and strength of recommendations that is explicit, comprehensive, transparent, and pragmatic and is increasingly being adopted by organisations worldwide.

**Health and aged care professionals**  
Doctors, nurses and allied health staff working in health and/or aged care settings.
Health Technology Appraisal
The process of determining the clinical and cost effectiveness of a health technology in order to develop recommendations on the use of new and existing medicines and other treatments.

Heterogeneity
A term used to illustrate the differences between studies in terms of participants, outcomes, interventions and results.

Indigenous
Indigenous peoples are peoples defined in international or national legislation as having a set of specific rights based on their historical ties to a particular territory, and their cultural or historical distinctiveness from other populations that are often politically dominant. In the Australian context this refers to Aboriginal and Torres Strait Islander Australians.

Integrated care
Bringing together of services across sectors or teams or the organisation of services to bring all services together at one time.

Magnetic resonance imaging (MRI)
A form of medical imaging used to visualise and evaluate an area of the patient’s body that is not externally visible. It uses radio frequency signals and a magnet to acquire its images and is best suited to soft tissue examinations. In clinical practice, MRI is used to distinguish pathological tissue (such as a brain tumour) from normal tissue.

Medicare Benefits Schedule (MBS)
The benefits received from Medicare are based on a Schedule of fees for medical services set by the Australian Government. The MBS lists a wide range of consultations, procedures and tests, and the Schedule fee for each of these items (for example, an appointment with a GP or blood tests to monitor cholesterol level).

Memory assessment services
Memory assessment specialists or services have expertise in assessment, diagnosis, information and treatment services for people with memory and related cognitive disorders with the focus being on timely assessment and intervention.

Multidisciplinary assessment
Assessment of the person with suspected dementia or dementia by a team comprising two or more different types of health professional.

Meta-analysis
The use of statistical techniques in a systematic review to integrate the results of several independent studies.

Mild cognitive impairment (MCI)
MCI is a state between normal ageing and early dementia in which there is an objective cognitive complaint for age in a person with essentially normal function in activities. MCI may not necessarily involve memory loss.
**National Institute for Health and Care Excellence (NICE)**
The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care in the United Kingdom. Set up in 1999, guidance and other recommendations are made by independent committees. NICE produces evidence-based guidance and advice for health, public health and social care practitioners; develops quality standards and performance metrics for those providing and commissioning health, public health and social care services; and provides a range of informational services for commissioners, practitioners and managers across the spectrum of health and social care.

**National Collaborating Centre for Mental Health (NCCMH)**
One of four centres established by the National Institute for Health and Care Excellence (NICE) to develop guidance on the appropriate treatment and care of people with specific diseases and conditions within the National Health Service in England and Wales. Established in 2001, the NCCMH is responsible for developing mental health guidelines, and is a partnership between the Royal College of Psychiatrists and the British Psychological Society. The aims of guidelines are to bring about genuine and lasting improvements in patient care.

**Parenteral medication**
Any non-oral means of administration, but is generally interpreted as relating to injecting directly into the body, bypassing the skin and mucous membranes. The common parenteral routes are intramuscular (IM), subcutaneous (SC) and intravenous (IV).

**Person-centred care**
A set of guiding principles for care that enable the person with dementia to be in a relationship with others. Guiding principles: Do my actions value and honour people living with dementia? Do I recognise the individual uniqueness of the people I work with? Do I make a serious attempt to see my actions from their perspective or stand point? Do my actions provide the support for people with dementia to feel socially confident and know they are not alone?

**Pharmaceutical Benefits Scheme (PBS)**
The PBS is the system that the Government uses to provide subsidies for prescription medication.

**Placebo**
A non-drug, or physically inactive substance (sugar, distilled water or saline solution) that is given as part of a clinical research trial.

**Positron emission tomography (PET)**
PET is a nuclear medicine (medicine in which radioactive substances are administered to the patient) medical imaging technique which produces a three-dimensional image or map of functional processes in the body. It is commonly used in the diagnosis of dementias.

**Practice point**
A recommendation that is outside the scope of the search strategy for the systematic evidence review and is based on expert opinion.

**Primary care**
Primary health care refers to a broad range of health services most often delivered in community
based settings. Primary health care services seek to intervene early to maximise health and wellbeing outcomes and prevent or slow the progression of ill health.

**Psychosis**
A condition in which an individual is not in contact with reality. This can include sensing things that are not really there (hallucinations), having beliefs that are not based on reality (delusions), problems in thinking clearly and not realising that there is anything wrong (called ‘lack of insight’).

**Quality of life (QoL)**
Used in some treatment studies to show improvement in a person’s condition beyond reduction in symptoms, measures of QoL can be defined broadly and include satisfaction, especially within important areas of one’s life, the level of functioning in different areas and the objective circumstances in which one lives.

**Randomised controlled trial (RCT)**
An experiment in which investigators randomly allocate eligible people into groups to receive or not to receive one or more interventions that are being compared. The results are assessed by comparing outcomes in the different groups. Through randomisation, the groups should be similar in all aspects, apart from the treatment they receive during the study.

**Residential care**
Refers to the care and services you receive when living in an aged care home.

**Reminiscence**
Involves the discussion of past activities, events and experiences, usually with the aid of tangible prompts (for example, photographs, household and other familiar items from the past, music and archive sound recordings). Reminiscence therapy in a group context has the aim of enhancing interaction in an enjoyable, engaging fashion.

**Selective serotonin reuptake inhibitors (SSRIs)**
A class of antidepressant medications that increase the level of serotonin (a neurotransmitter believed to influence mood) in the brain.

**Sensitivity**
Refers to the proportion of people with disease who have a positive test result.

**Specificity**
Refers to the proportion of people without disease who have a negative test result.

**Secondary care**
Refers to services provided by medical specialists who generally do not have the first contact with a patient, for instance a neurologist or a rehabilitation consultant.

**Single-photon emission computed tomography (SPECT)**
Single photon emission computed tomography (SPECT) is a nuclear medicine functional imaging technology which uses gamma rays to provide 3-dimensional images. A radioisotope that emits gamma rays must be administered to the patient, usually intravenously. SPECT is used in dementia to assess brain metabolism by using tracers that acculate at sites with the greatest regional blood
flow. The most commonly used radiotracer in dementia is hexamethyl-propyleneamine oxime (99mTc-HMPAO).

**Strong recommendation**
A strong recommendation implies that most or all individuals will be best served by the recommended course of action. Strong recommendations use the term “should”.

**Systematic review (SR)**
Research that summarises the evidence on a clearly formulated question according to a predefined protocol using systematic and explicit methods to identify, select and appraise relevant studies, and to extract, collate and report their findings.

**Tertiary care**
Tertiary care is specialised consultative health care, usually for inpatients and on referral from a primary or secondary health professional, in a facility that has personnel and facilities for advanced medical investigation and treatment, such as a tertiary referral hospital.

**Validated tool**
A survey or questionnaire that has been scientifically proven to measure what it was designed to measure. Validity may be demonstrated by conducting a number of different experiments.

**Vascular dementia (VaD)**
A general term describing problems with reasoning, planning, judgement, memory and other thinking skills that are significant enough to interfere with daily social or occupational functioning, and are caused by brain damage that has resulted from impaired blood flow in the brain.

**Weak recommendation**
A weak recommendation implies that not all individuals will be best served by the recommended course of action. There is a need to consider individual patient’s circumstances, preferences and values. Weak recommendations use the term “should be considered” or “it is suggested”.
Membership and acknowledgements

Efforts were made to invite individuals who (1) had relevant practical experience in the management of dementia in Australia, (2) were highly respected in their fields, (3) were skilled in the appraisal of scientific evidence, (4) represented the various geographical areas across Australia, and (5) were able to make the necessary time commitment. In addition, the organising committee approached the Australian Association of Social Workers for representation. Carer representatives were sought via the Consumer Dementia Research Network (within Alzheimer’s Australia), which contributes to the work of the NHMRC Partnership Centre.

We wish to thank Ms Joan Jackman, Ms Christine Bryden and Ms Kate Swaffer who commented on drafts of the guideline from the perspective of the consumer and the carer representative.

We also wish to thank Dr Owen Davies (geriatrician) and Ms Heather Forbes (pharmacist) who provided valuable advice on specific clinical issues during the process of guideline development. We thank Kate Smith and Melissa Lindeman for their input in developing recommendations relating to the care of Indigenous Australians.

We wish to thank Tamsin Maxwell for administrative support and Natalie May for research assistance. We thank Raechell Damarell for assistance in developing the search strategies.

<table>
<thead>
<tr>
<th>GUIDELINE ADAPTATION COMMITTEE</th>
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<tbody>
<tr>
<td><strong>Prof Robert Cumming</strong></td>
</tr>
<tr>
<td>Chairperson of the Guideline Adaptation Committee</td>
</tr>
<tr>
<td>Professor of Epidemiology</td>
</tr>
<tr>
<td>University of Sydney</td>
</tr>
<tr>
<td><strong>A/Prof Meera Agar</strong></td>
</tr>
<tr>
<td>Palliative Care</td>
</tr>
<tr>
<td>Director of Palliative Care, Braeside Hospital</td>
</tr>
<tr>
<td>Conjoint Associate Professor University of New South Wales</td>
</tr>
<tr>
<td><strong>Prof Kaarin Anstey</strong></td>
</tr>
<tr>
<td>Psychology</td>
</tr>
<tr>
<td>Director, Centre for Research on Ageing, Health and Wellbeing</td>
</tr>
<tr>
<td>Director, Dementia Collaborative Research Centre – Early Diagnosis and Prevention</td>
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<tr>
<td>The Australian National University</td>
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<tr>
<td><strong>Prof Elizabeth Beattie</strong></td>
</tr>
<tr>
<td>Anthropology and Sociology</td>
</tr>
<tr>
<td>Director, Dementia Collaborative Research Centre: Carers and Consumers</td>
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<tr>
<td>Queensland University of Technology</td>
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<tr>
<td><strong>Prof Henry Brodaty</strong></td>
</tr>
<tr>
<td>Psychogeriatrics</td>
</tr>
<tr>
<td>Director, Dementia Collaborative Research Centres (Assessment and Better Care)</td>
</tr>
<tr>
<td>Scientia Professor of Ageing and Mental Health, University of New South Wales</td>
</tr>
<tr>
<td>Consultant Psychogeriatrician, Aged Care Psychiatry and Head of the Memory Disorders Clinic, Prince of Wales Hospital</td>
</tr>
<tr>
<td><strong>Prof Tony Broe</strong></td>
</tr>
<tr>
<td>Geriatric Medicine</td>
</tr>
<tr>
<td>Senior Principal Research Fellow, NeuRA</td>
</tr>
<tr>
<td>Professor of Geriatric Medicine, UNSW</td>
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<tr>
<td>Scientific Director, Ageing Research Centre, Prince of Wales Hospital</td>
</tr>
<tr>
<td>Name</td>
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<tr>
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</tr>
<tr>
<td>Prof Lindy Clemson</td>
</tr>
<tr>
<td>Prof Maria Crotty</td>
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<tr>
<td>Margaret Dietz</td>
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<tr>
<td>Prof Brian Draper</td>
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<tr>
<td>Prof Leon Flicker</td>
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<tr>
<td>Meg Friel</td>
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<tr>
<td>Louise Heuzenroeder</td>
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<tr>
<td>A/Prof Susan Koch</td>
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<td>Prof Sue Kurrle</td>
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<tr>
<td>Prof Rhonda Nay</td>
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<tr>
<td>Prof Dimity Pond</td>
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<tr>
<td>Dr Jane Thompson</td>
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<tr>
<td>Yvonne Santalucia</td>
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<tr>
<td>A/Prof Craig Whitehead</td>
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<td>A/Prof Mark Yates</td>
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Terms of reference
The role of the Guideline Adaptation Committee was to:

- assist in refining the scope of the Guideline
- comment on the process of selection of Clinical Practice Guidelines to be adapted and clinical questions to be addressed within the new Guideline
- consider new evidence from updated literature searches
- review the evidence and develop recommendations
- refine and review the draft Guidelines before public consultation
- review public consultation comments and consider revising the Guidelines as necessary
- approve a final draft of the Guidelines to be submitted to the NHMRC for consideration of approval.

Purpose
The purpose of the Committee was to produce evidence-based guidelines for the diagnosis, management, treatment and care of people with dementia in Australia through the adaptation of existing evidence-based international guidelines.

The Guideline Adaptation Committee was supported by an organising committee. The organising committee was responsible for determining the scope of the guidelines, appointing a Chair and members of the Guideline Adaptation Committee and developing terms of reference for the committee.

The Guideline development project was funded by the NHMRC Cognitive Decline Partnership Centre. The project involves development of guidelines designed to meet the standards required for NHMRC approval and an implementation plan.

The role of the Guideline Adaptation Committee was to

- select Clinical Practice Guidelines to be adapted
- agree on the clinical questions to be addressed within the new Guideline
- identify and consider new evidence from updated literature searches
- review the evidence and develop recommendations that are clear and contextually appropriate
- participate in a formal consensus process for decision making where there is disagreement
- identify areas for further research
- draft, review and refine the Guideline ensuring that the document is useful and recommendations are amenable to implementation
- develop plans for implementation, review and update
- review public consultation comments and consider revising the Guidelines as necessary
- approve a final draft of the Guidelines to be submitted to the NHMRC Council and Chief Executive Officer to issue
- facilitate dissemination of the Guideline through professional bodies and organisations.

**Declaration of conflicts of interest policy**

Members of the Guideline Adaptation Committee were required to declare their conflicts of interest in writing, prior to appointment.

All members of the Guideline Adaptation Committee completed the NHMRC Form for Disclosure of Interests (Guideline Development) prior to the first committee meeting. This information was collated and checked for accuracy by Committee members at the first meeting.

The Chairperson considered all potential conflicts of interest. The Chairperson asked committee members to identify any new or changed conflicts of interest at each meeting.

Where a committee member was identified as having a real or perceived conflict of interest, the Chairperson asked the Committee Member to step out of the room during that particular conversation. The person had no subsequent input into the recommendation or presentation of information in the Guideline. Exclusion of committee members due to a potential conflict of interest occurred on one occasion. Three committee members were excluded from discussions on the use of Souvenaid®.

All disclosed interests are published in the Administration Report.
APPENDIX 1 MEASUREMENT TOOLS OF COGNITIVE FUNCTION

The Dementia Outcomes Measurement Suite is a Federal Government initiative to assist health professionals in assessing dementia in all settings (www.dementia-assessment.com.au/index.html). The website has links to the assessment tools, manuals and scoring guides. The tools on the website have been appraised and have been presented as being current and suitable tools to use with people with dementia. The following tools are recommended for assessment of cognitive function based on the appraisal in the Dementia Outcomes Measurement Suite.[73]

Box 7: Measurement tools of cognitive function (adapted from the Dementia Outcomes Measurement Suite [DOMS])

<table>
<thead>
<tr>
<th>RECOMMENDED TOOLS</th>
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<tbody>
<tr>
<td><strong>Modified Mini Mental Exam (3MS)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Purpose:</strong> The Modified Mini Mental (3MS) was designed and validated to replace the Mini Mental State Examination (MMSE). The Australian Government’s assessment of the MMSE in DOMS 2007 found there to be serious validity issues. The Modified Mini Mental (3MS) addresses those issues and is a longer form. It takes five more minutes to administer.</td>
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<tr>
<td><strong>Administration of the tool:</strong> Qualified health care professional (at least trained in the MMSE) interviews the patient using a standard set of questions.</td>
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<tr>
<td><strong>Time:</strong> Approximately 15 minutes to administer plus five minutes to score.</td>
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</tr>
<tr>
<td><strong>Most Appropriate Use:</strong> Acute, primary, community, and residential care to assess global cognitive status in older people. The 3MS can be used to track cognition trend over time. The 3MS can be used any time the MMSE is considered, and a valid measure of cognition is desired.</td>
<td></td>
</tr>
<tr>
<td><strong>Mini Mental State Exam (MMSE)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Purpose:</strong> The MMSE is the most widely used and well known cognitive assessment tool. It is recommended based on clinical expert opinion to enable consistency of use with existing research and practice. It is freely available in Australian hospitals.</td>
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</tr>
<tr>
<td><strong>Administration of the tool:</strong> Qualified health care professional trained in the use of the tool interviews the patient using a standard set of questions.</td>
<td></td>
</tr>
<tr>
<td><strong>Time:</strong> Approximately 10 to 15 minutes.</td>
<td></td>
</tr>
<tr>
<td><strong>Most Appropriate Use:</strong> Acute, Primary, Community, and Residential Care to assess global cognitive status in older people.</td>
<td></td>
</tr>
<tr>
<td><strong>The Alzheimer’s Disease Assessment Scale —Cognition (ADAS-Cog)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Purpose:</strong> To evaluate cognitive impairment in the assessment of Alzheimer’s disease. Recommended for second stage (specialist) or more detailed assessments and/or for particular research evaluations rather than for applications in routine care settings.</td>
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</tr>
<tr>
<td><strong>Administration of the tool:</strong> Staff with specialist qualifications - interviewer administered. Requires additional training.</td>
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<tr>
<td><strong>Time:</strong> 30—45 minutes.</td>
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<tr>
<td><strong>Most Appropriate Use:</strong> Usually administered by a neuropsychologist or psychologist with appropriate training.</td>
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</tbody>
</table>
General Practitioner Assessment of Cognition (GPCOG)
Recommended because of its usefulness in the primary care setting.
**Purpose:** The GPCOG is a reliable, valid and efficient instrument to screen for dementia in primary care settings.
**Administration of the tool:** General Practitioner, Practice Nurse or Nurse Practitioner.
**Time:** Less than four minutes to administer to a patient and two minutes to interview a family member or carer.
**Most Appropriate Use:** Primary and Residential Care.

Psychogeriatric Assessment Scale (PAS)
Added after the DOMS 2007 Project Final Report.
**Purpose:** Cognitive screening tool to assess level of cognitive impairment/decline. The Scale also assesses stroke and behaviour change.
**Administration of the tool:** Interviewer administered—data are routinely collected by nursing home staff trained in assessment as part of entry into care facilities as per the Aged Care Funding Instrument (ACFI). There are two scales—interview with resident and interview with care giver (informant or formal care giver).
**Time:** 10–20 minutes.
**Most Appropriate Use:** Nursing homes.

Montreal Cognitive Assessment (MoCA)
Is recommended because of its usefulness as a quick Mild Cognitive Impairment (MCI) assessment.
**Purpose:** It is a reliable, valid and efficient instrument to use for screening, diagnosis and tracking of mild cognitive impairment. Not as useful for assessing more advanced stages of Alzheimer’s disease.
**Administration of the tool:** Health professionals.
**Time:** Approximately 10–20 minutes to administer.
**Most Appropriate Use:** Primary, Acute and residential settings.
The MOCA was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuo-constructional skills, conceptual thinking, calculations and orientation. It has excellent psychometric properties and has become a widely used screening instrument for mild cognitive impairment. It is available in 31 languages.

Frontal Assessment Battery (FAB)
**Purpose:** The FAB provides an objective measure to distinguish Frontotemporal dementia (FTD) from Alzheimer’s disease (AD) in people with mild dementia. A bedside battery to assess the presence and severity of a dysexecutive syndrome affecting both cognition and motor behaviour.
**Administration of the tool:** Clinician structured interview with person being assessed.
**Time:** Less than 10 minutes.
**Most Appropriate Use:** Clinician at bedside. Poor performance on the FAB in conjunction with the presence of behavioural abnormalities could be an important factor in the diagnosis of FTD.

EXIT 25
**Purpose:** The EXIT 25 assesses executive cognitive function at bedside.
**Administration of the tool:** Administered and scored by any clinician.
**Time:** Approximately 15 minutes.
**Most Appropriate Use:** Higher EXIT 25 scores indicate greater executive dyscontrol. EXIT 25 scores have been specifically associated with left frontal system structural lesions by magnetic resonance imaging and with left mesiofrontal cerebral blood flow by single-photon emission computed tomography (SPECT).

Addenbrooke’s Cognitive Examination (ACE-R now replaced by ACE-III)
**Purpose:** The ACE-R is a brief cognitive test that assesses five cognitive domains, namely attention/orientation, memory, verbal fluency, language, and visuospatial abilities.
**Administration of the tool:** Interviewer with the person being assessed.

**Time:** Approximately 15 minutes.

**Most Appropriate Use:** A brief test sensitive to the early stages of dementia and capable of differentiating subtypes of dementia including Alzheimer’s disease, Frontotemporal dementia, progressive supranuclear palsy and other parkinsonian syndromes.

Scoring using the subscales: V= verbal fluency, L = Language, O=Orientation, M= Recall Memory, Ratio \((V+L)/(O+M)\), VLOM Ratio >3.2 differentiates AD from non-AD and a ratio of <2.2 differentiates FTD from non-FTD.
# APPENDIX 2 DIAGNOSTIC CRITERIA FOR DEMENTIA

International standardised criteria for subtype diagnosis of dementia.

<table>
<thead>
<tr>
<th>Type of dementia</th>
<th>Diagnostic criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>NINCDS/ADRA, ICD-10 and DSM-4</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>NINCDS/AIREN, ICD-10 and DSM-4</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>Consortium for DLB Diagnostic Criteria</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>Lund-Manchester Criteria, NINDS criteria for frontotemporal dementia</td>
</tr>
</tbody>
</table>

DSM-4 Diagnostic and Statistical Manual of Mental Disorders, fourth edition; ICD-10 International Classification of Diseases, 10th revision; NINCDS/ADRDA National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association; NINCDS/AIREN neuroepidemiology Branch of the National Institute of neurological Disorders and Stroke-Association Internationale pour la Recherche et l’Enseignement en Neurosciences
## APPENDIX 3 ALZHEIMER’S AUSTRALIA’S GUIDE TO DEMENTIA FRIENDLY LANGUAGE

Source: Alzheimer’s Australia (fightdementia.org.au/)

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>PREFERRED TERMS</th>
<th>DO NOT USE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TALKING ABOUT DEMENTIA</strong></td>
<td>Dementia</td>
<td>Dementing illness</td>
</tr>
<tr>
<td></td>
<td>Alzheimer’s disease and other forms of dementia</td>
<td>Demented</td>
</tr>
<tr>
<td></td>
<td>A form of dementia</td>
<td>Affliction</td>
</tr>
<tr>
<td></td>
<td>A type of dementia</td>
<td>Senile dementia</td>
</tr>
<tr>
<td></td>
<td>Symptoms of dementia</td>
<td>Senility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Going on a journey</td>
</tr>
</tbody>
</table>

| **TALKING ABOUT PEOPLE WITH DEMENTIA** | A person/people with dementia | Sufferer, Victim, Demented person, Dementing illness |
| | A person/people living with dementia | Demented illness |
| | A person/people with a diagnosis of dementia | Dements, Afflicted, Offenders, absconders or perpetrators |

Slang expressions that are derogatory, for example, delightfully dotty, away with the fairies, got a kangaroo loose in the back, paddock, a couple of cents short.

‘They’ (talking about all people with dementia rather than the individual)

| **A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About themselves)** | Living alongside (someone/ a person/my partner/my mother etc.) who has dementia | Person living with dementia |
| | Living with/caring for/supporting a person who has dementia | |
| | Living with/caring for/supporting a person with a diagnosis of dementia | |
| | Living with the impact of dementia | |

| **A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About someone else)** | Family member(s) | |
| | Person supporting someone living with dementia | |
| | Wife/husband/partner | |
| | Child/Son/Daughter | |
| | Parent | |
| | Friend | |
| | Carer or care giver—not everyone will like | |
to be referred to as a carer. If possible ask what the person’s preference is before using this term

| IMPACT OF CARING | Impact of supporting (someone/a person/my partner/my mother etc.) with dementia | Carer burden  
|                  | Effect of supporting (someone/a person/my partner/my mother etc.) with dementia | Burden of caring  

| PEOPLE WITH DEMENTIA UNDER 65 | Younger onset dementia | Pre-senile dementia  
|                                | Early onset dementia  

| THE IMPACTS OF DEMENTIA | Disabling  
|                         | Challenging  
|                         | Life changing  
|                         | Stressful  
|                         | Hopeless  
|                         | Unbearable  
|                         | Impossible  
|                         | Tragic  
|                         | Devastating  
|                         | Painful  

| SYMPTOMS OF DEMENTIA | Describe the symptom itself. For example, reduced vision, hallucinations, difficulty communicating  
|                     | Describe the impact it is having. For example, difficulty communicating  

| BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA | Changed behaviour(s)  
|                                                     | Expressions of unmet need  
|                                                     | Behavioural and psychological symptoms of dementia (in a clinical context)  
|                                                     | When talking about the symptoms  
|                                                     | Behaviour(s) of concern  
|                                                     | Challenging behaviours  
|                                                     | Difficult behaviours  
|                                                     | When talking about the person  
|                                                     | Difficult  
|                                                     | Faded away, empty shell or not all there  
|                                                     | Disappearing  
|                                                     | Aggressor  
|                                                     | Wanderer  
|                                                     | Obstructive  
|                                                     | Wetter  
|                                                     | Poor feeder  
|                                                     | Vocaliser  
|                                                     | Sexual disinhibitor  
|                                                     | Nocturnal  
|                                                     | Screamer  
|                                                     | Screamer  
|                                                     | Violent offender  

| IN RESEARCH | Dementia as a condition  
|             | A person/people with dementia  
|             | A person/people living with dementia  
|             | A person/people with a diagnosis of dementia  
|             | A participant (if in a research trial)  

| MEDICAL | Condition  
|         | Illness  
|         | Disease  


APPENDIX 4 ‘TALK TO ME’

Source: Alzheimer’s Australia (fightdementia.org.au/)

‘TALK TO ME’ Good communication tips for talking to people with dementia

THESE ARE PRINCIPLES OF COMMUNICATION THAT PEOPLE LIVING WITH DEMENTIA HAVE TOLD US WOULD MAKE A DIFFERENCE TO THEIR LIVES

TALK TO ME
Please talk to me, not my carer, family member or friend. Don’t pre-judge my level of understanding.

PLEASE SPEAK CLEARLY TO ME
Make eye contact and speak clearly. Use short sentences, with one idea at a time. Avoid jargon, as I might misunderstand.

PLEASE KEEP QUESTIONS SIMPLE
Make sure I am listening and use simple questions and/or repetition, offered with sensitivity. It’s easier for me to answer direct questions, rather than open-ended questions, such as saying ‘Wasn’t it lovely when we went out to the park yesterday?’ not just ‘Wasn’t it lovely yesterday?’.

TREAT ME WITH DIGNITY AND RESPECT
I am still a person, so don’t patronise me. Respect and empathy are important to everyone. If I act differently it may be because I am having difficulty communicating or because of my disease.

DON’T QUESTION MY DIAGNOSIS
The symptoms of dementia are not always obvious. Listen to me and don’t minimise my feelings.