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Clinical Practice Guidelines and Principles of Care for People with Dementia

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Disclaimer:

This document is a general guide, to be followed subject to the clinician's judgment and person's preference in each individual case. The guideline is designed to provide information to assist decision making and is based on the best evidence available at the time of development of this publication.

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Publication Approval



Australian Government

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The guidelines (recommendations) on pages V-XVIII were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 1 February 2016 under section 14A of the *National Health and Medical Research Council Act 1992*. In approving the guidelines (recommendations), NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of five years.

NHMRC is satisfied that the guidelines (recommendations) are systematically derived, based on the identification and synthesis of the best available scientific evidence, and developed for health professionals practising in an Australian health care setting.

This publication reflects the views of the authors and not necessarily the views of the Australian Government.

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Members of the Guideline Adaptation Committee generously contributed their time to assist in the development of this Guideline. Consumers have played a key role in the development of this Guideline and their input has been critical to ensuring the document remains relevant to the needs of people with dementia and their carers.

This publication is an adaptation of 'Dementia: Supporting people with dementia and their carers in health and social care', published by the NCC-MH in 2006. The original publication is available from www.nice.org.uk/guidance/cg42/evidence. This adaptation has been reproduced with permission of the NCC-MH. The NCC-MH, however, has not checked the adaptation to confirm that it accurately reflects the original NCC-MH publication and no guarantees are given by the NCC-MH in regard to the accuracy of the adaptation. The NCC-MH 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. Throughout this document the NCC-MH publication will be referred to as the NICE Guideline.

Endorsements

- Alzheimer's Australia
- Australian and New Zealand Society for Geriatric Medicine
- The Royal Australian and New Zealand College of Psychiatrists
- Australian College of Rural and Remote Medicine
- Occupational Therapy Australia
- Exercise & Sports Science Australia
- Speech Pathology Australia

Plain English summary

Dementia is a clinical syndrome which can be caused by a number of underlying diseases (including Alzheimer's disease). Dementia can affect memory, thinking, behaviour, communication 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 nine per cent of Australians aged 65 and over have a diagnosis of dementia; in people aged 85 years and older this figure rises to 30 per cent. [4] As Australia's population ages, the number of people with dementia is expected to increase.

These Clinical Practice Guidelines and Principles of Care for people with dementia are 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 family. 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 family about the symptoms of dementia, treatments and services. Written information (such as brochures) should also be provided.
- 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(s) and family 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. Due to the increased risk of serious adverse events, people with mild-to-moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications.
- 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 family and to provide person-centred care.
- The person with dementia should be encouraged to exercise, eat well, keep doing as much for themselves as possible and stay socially connected in their local community. Staff and carer(s) should be taught how to encourage independence.
- Medical practitioners should consider medication (acetylcholinesterase inhibitors or memantine) to assist in the management of the cognitive symptoms of dementia.
- Carer(s) and family 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. Carer(s) and family should be given information about coping strategies to maintain their own wellbeing and be supported to maintain their overall health and fitness.

Clinical Practice Guidelines and Principles of Care for People with Dementia

Executive Summary

In Australia, approximately nine per cent of 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]

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

Type of recommendation	Description
Evidence-based recommendation (EBR)	Recommendation formulated after a systematic review of the evidence, with supporting references provided
Consensus based recommendation (CBR)	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
Practice point (PP)	A recommendation that is outside the scope of the search strategy for the systematic evidence review and is based on expert opinion

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 Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach (Table 2).[8]

Table 2 Definitions of GRADE ratings of the quality of the evidence

GRADE of quality of the evidence	Description
High	Further research is very unlikely to change our confidence in the estimate of effect
Moderate	Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate
Low	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
Very low	Any estimate of effect is very uncertain

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

Recommendations

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.

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 relevant state and territory laws in respect of substitute decision making for financial and personal and health matters must be followed.
- 5 PP Health and aged care professionals should inform the person with dementia, their carer(s) and family 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.
- 6 PP 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.
- 7 PP 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 (e.g., where the professionals has a duty of care) 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 (with other health professionals or substitute decision makers) should be made in the context of the person’s capacity to make decisions. If information is to be shared, this should be done only if it is in the best interests of the person with dementia.

Barriers to access and care

- 8 PP People with dementia should not be excluded from any health care services because of their diagnosis, whatever their age.
- 9 CBR 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(s) and family with:
- information in the preferred language and in an accessible format
 - professional interpreters
 - interventions in the preferred language.
- 10 PP 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.
- 11 PP 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.
- 12 PP 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. In particular, services should be structured to complement existing services in the local area.
- 13 PP People with younger onset dementia have unique needs; organisations should tailor their services in order to ensure that they are age appropriate and address the needs of the person with younger onset dementia and their carer(s) and family.

Considerations for Aboriginal and Torres Strait Islander people

- 14 PP Consultation with Indigenous community representatives and the local Indigenous medical service should occur in the development, implementation and review of any initiative intended for Indigenous communities. The formation of an Indigenous advisory committee or consultation with an existing committee ensures ongoing collaboration. Where appropriate, groups should consult with Alzheimer's Australia's National Aboriginal and Torres Strait Islander Dementia Advisory Group and State or Territory Indigenous peak health bodies.
- 15 PP Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should be culturally sensitive and informed and utilise translators and/or cultural interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent.
- 16 PP 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.
- 17 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.
- 18 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.

Considerations for culturally and linguistically diverse populations

- 19 PP Consultation with culturally and linguistically diverse (CALD) community representatives who have appropriate knowledge and skills 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 appropriate support is provided. Where appropriate, groups should consult with Alzheimer's Australia's National Cross Cultural Dementia Network. In the interest of accountability, feedback should be provided back to community.
- 20 PP Health and aged care services need to recognise and be responsive to the cultural and linguistic needs of CALD people living with dementia, their carer(s) and families. Services should utilise a range of communication tools, including working with bilingual bicultural staff or professional interpreters across the whole service pathway, particularly during assessment, when communicating the diagnosis and gaining consent.
- 21 PP CALD carers and families should receive support, education and information, through partnerships with ethno-specific and mainstream agencies and they should be delivered by bilingual, bicultural workers in the field.

Early identification

- 22 CBR General population screening for dementia should not be undertaken.
- 23 PP Concerns or symptoms should be explored when first raised, noted or reported by the person, carer(s) or family and should not be dismissed as 'part of ageing'.
- 24 CBR Medical practitioners working with older people should be alert to cognitive decline, especially in those aged 75 years and older.

Specialist assessment services

- 25 EBR
Low People with a possible diagnosis of dementia should be offered referral to memory assessment specialists or services for a comprehensive assessment.
- 26 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 carer(s) and families living in the community. Referrals for required health and aged care services should be made directly by the specialists or the memory assessment service.
- 27 CBR Memory assessment services or specialists that identify people with mild cognitive impairment should typically offer follow-up either at the memory assessment service or with a general practitioner, other medical practitioner or nurse practitioner after six to 18 months to monitor cognitive changes and other signs of possible dementia.

Diagnosis of dementia

- 28 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 person 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 and to simplify medication dosing
 - consideration of other causes (including delirium or depression).

- 29 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.
- 30 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.
- 31 PP Testing for syphilis serology or HIV should be undertaken only in those with histories suggesting they are at risk.
- 32 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.
- 33 PP Cerebrospinal fluid examination should not be performed as a routine investigation for dementia. Cerebrospinal fluid examination may be indicated if Creutzfeldt–Jakob disease is suspected or in rapidly progressive dementia.
- 34 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).
- 35 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.
- 36 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.
- 37 PP Many diagnostic technologies including biomarkers for β -amyloid or neuronal injury (e.g., 18F-fluorodeoxyglucose Positron Emission Tomography [FDG-PET] or CSF tau) are currently being evaluated and may prove to be useful in the assessment of dementia in the future. The routine use of these technologies in clinical practice is considered to be premature.

Cognitive assessment

- 38 PP Clinical cognitive assessment in those with suspected dementia should include examination using an instrument with established reliability and validity. 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, aphasia, hearing or visual impairments, psychiatric illness or physical/neurological problems when interpreting scores.
- 39 EBR
Low¹ 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.

¹ Quality of evidence is low for the KICA-Cog and very low for the KICA Screen

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| 40 | EBR
<i>Low</i> | 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. |
| 41 | EBR
<i>Very low</i> | The Rowland Universal Dementia Assessment Scale (RUDAS) should be considered for assessing cognition in CALD populations. |
| 42 | PP | Formal neuropsychological testing may form part of the assessment in cases where a dementia diagnosis is uncertain. |

Neuroimaging

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| 43 | PP | 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 clinical judgement indicates this inappropriate. Structural imaging may not always be needed in those presenting with moderate-to-severe dementia, if the diagnosis is already clear. |
| 44 | EBR
<i>Very low</i> | HMPAO SPECT should not be used in people 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

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| 45 | PP | The diagnosis of dementia should be communicated to the person with dementia by a medical practitioner. |
| 46 | PP | 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) and family. |
| 47 | PP | 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. |
| 48 | PP | 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. |
| 49 | PP | Medical practitioners should be aware that people with a history of depression and/or self-harm may be at particular risk of depression, self-harm or suicide following a diagnosis of dementia, particularly in the first few months post diagnosis. While such reactions are believed to be uncommon, counselling should be offered as an additional way to support the person during this time. |

Information and support for the person with dementia

- 50 PP 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.
- 51 CBR 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 and verbal information in an accessible format about:
- the signs and symptoms of dementia
 - the course and prognosis of the condition
 - treatments
 - sources of financial and legal advice, and advocacy
 - medico-legal issues, including driving.
- 52 EBR
Very low People with a diagnosis of dementia, particularly those living alone, should be provided with information about how to join a social support group.\
- 53 PP Health and aged care professionals should ensure that the person with dementia and his or her carer(s) and family are provided with written and verbal information regarding appropriate services available in the community (including those offered by Alzheimer's Australia, Carers Australia, Aged Care Assessment Teams and My Aged Care). Any advice and information given should be recorded.

Organisation of health services

- 54 EBR
Very low Health and aged care managers should coordinate and integrate, referral, transitions and communication across all agencies involved in the assessment, treatment, support and care of people with dementia and their carer(s) and families, including jointly agreeing on written policies and procedures. People with dementia and their carers and families should be involved in planning local policies and procedures.
- 55 EBR
Very low Health system planners should ensure that people with dementia have access to a care coordinator who can work with them and their carers and families 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.
- 56 PP 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, routines and current level of functioning and abilities.
- 57 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.
- 58 PP Health system planners should develop local dementia pathways and decision support software to improve the diagnosis and management of dementia.

Training for staff and students

- 59 EBR
Low 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.
- 60 EBR
Low 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.
- 61 PP 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.
- 62 PP 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.
- 63 PP 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.

Living well

- 64 PP Health and aged care professionals should support the person with dementia to receive adequate nourishment and hydration through maintaining a healthy, balanced diet. People with dementia should have their weight monitored and nutritional status assessed regularly. In cases of undernutrition, consultation with a dietitian and/or assessment by a speech pathologist may be indicated.
- 65 PP Dental and oral health personnel are an integral part of the health care team for people with dementia. Upon diagnosis, the medical practitioner should recommend the person with dementia (or their carer(s) or family) makes an appointment to see a dentist. The dentist should conduct an assessment and formulate a long term treatment plan.

Promoting functional independence

- 66 PP Health and aged care staff should aim to promote and maintain functional and social independence of people with dementia in community and residential care settings. 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 families 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

- 67 EBR
Low 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.
- 68 EBR
Low People with dementia should be strongly encouraged to exercise. Assessment and advice from a physiotherapist or exercise physiologist may be indicated.

Acetylcholinesterase inhibitors and memantine

- 69 EBR
Low Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) are recommended as options for managing the symptoms of mild to moderately severe Alzheimer's disease. Any one of the three acetylcholinesterase inhibitors could be considered for managing the symptoms of severe Alzheimer's disease.² 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.
- 70 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 (but are not limited to) nausea, vomiting, diarrhoea, dizziness, increased urinary incontinence and frequency, falls, muscle cramps, weight loss, anorexia, headache and insomnia. Heart block is a rare, but serious potential adverse event.
- 71 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.
- 72 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.³
- 73 EBR
Low The combination of an acetylcholinesterase inhibitor plus memantine could be considered for managing the symptoms of moderate-to-severe Alzheimer's disease.⁴
- 74 PP People who have been prescribed an acetylcholinesterase inhibitor or memantine should be reviewed within a short time (e.g., one month) for evaluation of adverse effects and dose titration and within six months, to determine whether there is a clinically meaningful response to treatment. Review and consideration of de-prescribing is recommended at regular intervals including at the time of admission to residential care.
- 75 EBR
Low Acetylcholinesterase inhibitors should not be prescribed for people with mild cognitive impairment.

² Not currently listed for severe Alzheimer's disease on the Pharmaceutical Benefits Scheme

³ Not currently listed for these indications on the Pharmaceutical Benefits Scheme

⁴ Listing on the Pharmaceutical Benefits Scheme is for single therapy

Nutritional supplement

76	EBR <i>Moderate</i>	A number of nutritional drinks are currently being investigated to reduce the symptoms of mild cognitive impairment or dementia, of which one (Souvenaid®) is marketed in Australia. There is currently insufficient evidence to recommend the routine use of Souvenaid® in people with mild Alzheimer's disease. Souvenaid® should not be recommended for people with moderate or severe Alzheimer's disease.
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Behavioural and psychological symptoms of dementia

77	PP	<p>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:</p> <ul style="list-style-type: none">• unmet needs (e.g., pain, hunger, need to eliminate, lack of privacy, lack of meaningful activities, communication)• lowered stress threshold (e.g., conflicts or poor communication within the family or between staff, carer stress).
78	PP	<p>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 families as appropriate and include;</p> <ul style="list-style-type: none">• 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.
79	PP	<p>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.</p>
80	PP	<p>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.</p>

81	EBR <i>Low</i>	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. The trial should be for a defined time period, particularly if opioids are used.
82	EBR <i>Low</i>	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).
83	PP	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.
84	EBR <i>Very low to Low</i>	<p>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:</p> <p>For depression and or/anxiety:</p> <ul style="list-style-type: none"> • therapeutic use of music and/or dancing • support and counselling • reminiscence therapy. <p>For agitation:</p> <ul style="list-style-type: none"> • behavioural management interventions • therapeutic use of music and/or dancing • massage • reminiscence therapy.
85	EBR <i>Low</i>	<p>To assist the carer(s) and family help the person with dementia who is experiencing behavioural and psychological symptoms of dementia, carer(s) and family should be offered interventions which involve:</p> <ul style="list-style-type: none"> • 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.
86	EBR <i>Moderate</i>	People with dementia who experience agitation should be offered a trial of selective serotonin reuptake inhibitor (SSRI) antidepressants (the strongest evidence for effectiveness exists for citalopram) if non-pharmacological treatments are inappropriate or have failed. Review with evaluation of efficacy and consideration of de-prescribing should occur after two months. 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.

87	PP	Antidepressant medications with anticholinergic effects (e.g., tricyclic antidepressants) should be avoided because they may adversely affect cognition.
88	EBR <i>Moderate</i>	The role of antidepressants in the treatment of depression in people with dementia is uncertain. Larger trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se. Nevertheless, it is considered that those with a pre-existing history of major depression (prior to developing dementia) who develop a co-morbid major depression should be treated in the usual way.
89	EBR <i>Moderate</i>	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 increased risk of cerebrovascular adverse events and death.
90	PP	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. Acetylcholinesterase inhibitors could be considered. If antipsychotics are used for severe behavioural and psychological symptoms of dementia, atypical or second generation antipsychotics with low propensity to cause extrapyramidal side effects should be used; quetiapine and olanzapine are considered to have the best tolerability ⁵ . Healthcare professionals should use low dosage and closely monitor for adverse effects.
91	EBR <i>Moderate</i>	<p>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 olanzapine¹ have the strongest evidence for treating agitation/aggression, with weaker evidence for aripiprazole⁵.</p> <p>The following conditions should also be met:</p> <ul style="list-style-type: none"> • 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. • If there is no efficacy observed within a relatively short timeframe (usually one to two weeks), treatment should be discontinued. <p>Treatment should be reviewed every four to 12 weeks, considering the need for antipsychotics and possible cessation of medication. Review should include regular assessment and recording of changes in cognition and target symptoms.</p>

⁵ The only antipsychotic that is currently listed for BPSD on the Pharmaceutical Benefits Scheme is risperidone.

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- 92 PP Where people with dementia have moderate to severe behavioural and psychological symptoms that puts themselves or others at risk, referral to a specialist service for the management of behavioural and psychological symptoms should occur.
- 93 PP 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 any medications used 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.
- 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 There is a paucity of evidence regarding the efficacy and safety of parenteral medication in behavioural emergencies. However, in certain rare situations, parenteral medication may be required for the management of people with dementia with extreme behavioural and psychological symptoms of dementia. Because circumstances vary from setting to setting, local evidence-based guidelines should be developed to provide clinicians guidance about the appropriate use of parenteral medication in these situations for that setting (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 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 CBR If parenteral medication is necessary for the control of violence, aggression and extreme agitation in people with dementia, olanzapine or lorazepam are preferred. Wherever possible, a single agent should be used in preference to a combination.
- 98 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.

Support for carers

99	PP	Carers and families should be respected, listened to and included in the planning, decision making and care and management of people with dementia.
100	PP	Carers are at an increased risk of poor health and their needs should be assessed and reviewed regularly by their own health practitioner. Carer and family needs should be addressed regularly, including if the person with dementia has entered residential care, and after their death.
101	CBR	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, planned activity groups and residential respite.
102	EBR Low	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: <ul style="list-style-type: none">• 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 their carer(s) and family, in support programs.
104	EBR Low	Health and aged care professionals should provide carers 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	Carers 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.

Palliative approach

- 106 PP Care for people with advanced dementia should be based on a palliative approach and involve a palliative care service if indicated. Treatment and care should be provided as per the person's Advance Care Plans.
- 107 PP Health and aged care staff and carers and families should continue to offer people with dementia food and drink by mouth. Assessment of swallowing and feeding from a speech pathologist may be indicated. 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.
- 108 PP 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.
- 109 PP 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 and time should be taken to discuss these issues with the carer(s), family and support networks.

The Guideline Adaptation Committee identified recommendations that should be prioritised for research translation (see page 95).

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Abbreviations

3MS	Modified Mini Mental Exam	GPCOG	General Practitioner Assessment of Cognition
6-CIT	6-item cognitive impairment test	GRADE	Grading of Recommendations Assessment, Development and Evaluation
ABS	Australian Bureau of Statistics	HTA	Health Technology Assessment
ACE-R	Addenbrooke's Cognitive Examination—Revised	KGOWS	Koori Growing Old Well Study
AD	Alzheimer's Disease	(m)KICA	(modified) Kimberley Indigenous Cognitive Assessment
ADAS-Cog	Alzheimer's Disease Assessment Scale—Cognition	MBS	Medical Benefits Schedule
ADL	Activities of Daily Living	MCI	Mild Cognitive Impairment
ADRDA	Alzheimer's Disease and Related Disorders Association	MMSE	Mini Mental State Examination
AIHW	Australian Institute of Health and Welfare	MoCA	Montreal Cognitive Assessment
AMTS	Abbreviated Mental Test Score	MRI	Magnetic resonance imaging
ATSI	Aboriginal and Torres Strait Islander peoples	MSAC	Medical Services Advisory Committee
AUC	Area Under the Curve	NARI	National Ageing Research Institute
BPSD	Behavioural and psychological symptoms of dementia	NCCDN	National Cross Cultural Dementia Network
CALD	Culturally and linguistically diverse	NCC-MH	National Collaborating Centre—Mental Health
CBR	Consensus based recommendation	NHMRC	National Health and Medical Research Council
CBT	Cognitive Behavioural Therapy	NHPA	National Health Priority Area
CI	Confidence Interval	NICE	National Institute for Health and Care Excellence (UK)
CT	Computed tomography	NINCDS	National Institute of Neurological and Communicative Disorders and Stroke
DBMAS	Dementia Behaviour Management Advisory Service	PAS	Psychogeriatric Assessment Scale
DEEP	Dementia Enabling Environments Project	PBS	Pharmaceutical Benefits Scheme
DOMS	Dementia Outcomes Measurement Suite	PP	Practice Point
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4 th Edition	PPV	Positive Predictive Value
EBR	Evidence-based recommendation	RCT	Randomised controlled trial
ECG	Electrocardiogram	RUDAS	Rowland Universal Dementia Assessment Scale
EEG	Electroencephalography	SPECT	Single-photon emission computed tomography
FAB	Frontal Assessment Battery	SSRIs	Selective serotonin reuptake inhibitors
FDA	Food and Drug Administration	UK	United Kingdom
FICA	Federal Insurance Contributions Act		
FTD	Frontotemporal dementia		

Introduction

Background

Types of dementia

Dementia is a clinical syndrome which can be caused by a number of underlying diseases. The main types of dementia are presented in Box 1. Recent research suggests that pathologies are more often mixed than discrete.[9]

Box 1: Types of dementia

Dementia of the Alzheimer type 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: Alzheimer's Disease International [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. Dementia is a terminal condition, although the duration between diagnosis and death is highly variable.[12]

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] It is estimated that 70 per cent of people with dementia live in the community while the remainder live in residential care accommodation.[4] Of those living in private dwellings in the community, 88 per cent live with others while 12 per cent live alone. [4] People with mild dementia living in the community accounted for just over half of all people living with dementia in Australia in 2011.[4]

In 2011, about nine per cent of Australians aged 65 years and over had dementia.⁴ 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.⁴ 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, an estimated 23,900 Australians in 2011.[4]

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

Age	Summary age-specific rates (per 100 population)			Number		Per cent			
			Persons	Males	Females	Persons		Persons	
Under 65	0.1	0.1	0.1	12,600	11,300	23,900	11.1	6.1	8.0
65–74	3.1	3.4	3.2	25,200	28,900	54,100	22.3	15.6	18.1
75–84	8.8	10.4	9.7	39,800	57,500	97,400	35.2	31.1	32.7
85+	24.4	32.3	29.5	35,600	87,000	122,600	31.5	47.1	41.1
Total: 65+	7.1	10.3	8.8		173,400	274,100	88.9	93.9	92.0
All ages	1.0	1.6	1.3		184,700	298,000	100.0	100.0	100.0

Sources: Australian Institute of Health and Welfare (2012) [4]

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. [9,14] However, there is currently insufficient information available from research studies to form specific recommendations regarding how to prevent dementia. [15] 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. [16,17]

The main known risk factor for dementia is advancing age. The prevalence of dementia doubles every five years after the age of 65. [15] 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. [15,18,19] Lifestyle factors including smoking,[20] physical inactivity, [19] and a Body Mass Index in midlife outside of the normal range [21] are also linked to 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. [15]

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.[9] Presence of the APOE gene indicates susceptibility to Alzheimer's disease and the mechanism for increasing the risk is unknown.[22] Hence, key organisations advise that there is currently no role for APOE genotyping in disease prediction or in the diagnosis of Alzheimer's disease. [23] 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'. [24]

A recent report from Alzheimer's Disease International discussed findings from a randomised controlled trial of a multi-component intervention for the prevention of dementia.[9] The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) trial examined the effectiveness of a multi-domain lifestyle intervention of diet, exercise, cognitive training, and vascular risk monitoring to prevent cognitive decline in older people considered at risk. This trial suggested that lifestyle modification can have benefits for cognitive function in people from the general population over two years. The trial will determine whether or not there is an impact on dementia incidence over a period of seven years.

Mild Cognitive Impairment

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.[25] MCI may not necessarily involve memory loss.[25,26] Research suggests not all people with MCI will develop a diagnosis of dementia but that people with MCI are at greater risk of dementia.

Younger onset dementia

Younger onset dementia refers to dementia that develops prior to the age of 65 years. People with younger onset dementia present with different aetiologies and trajectories which may have implications for both diagnosis and management.[27] People with younger onset dementia have unique needs: they are more likely to still be employed; may still be raising a young family and are often otherwise physically strong and healthy.[28] The carers and families of people with younger onset dementia are also more likely to be working and raising young children. People with younger onset dementia often report that they experience delays in receiving an accurate diagnosis. Furthermore, obtaining appropriate community based services for their needs may be problematic as many health and aged care services are for people aged 65 years and over.[27,29,30] People with younger onset dementia and their carers and families may need ongoing counselling to adjust to their diagnosis. People with younger onset dementia are more likely to have forms of dementia other than Alzheimer's disease and the prevalence of behavioural and psychological symptoms of dementia may be higher. [4, 27, 29] As residential care settings tend to be designed for older people, those with younger onset dementia may have difficulty in this setting due to their need to be more active and engage in age-appropriate activities.

The Younger Onset Dementia Keyworker Program provides individualised information and support for people with younger onset dementia.[31] Information nights about services provided through this program and other support services available for people with younger onset dementia are listed on the Alzheimer's Australia website (see <https://fightdementia.org.au/>).

Public awareness regarding dementia

Within the general public, there is a lack of awareness and understanding of dementia; many people do not recognise the symptoms and dismiss these as a normal part of ageing.[31] For some people, a diagnosis of dementia is associated with a perception of stigma for the person with dementia, their carer(s) and family.³³ The combination of limited knowledge and perception of stigma may deter some people with symptoms of dementia from seeking a diagnosis.[34] Reduced awareness regarding dementia may be more evident in some cultural groups, including Indigenous Australians.[35-37] The consequences of perceived stigma may include isolation and exclusion from community, family or friendship groups or activities and may decrease the quality of life of people with dementia and their carers.[33] The World Health Organization suggests that improving public knowledge about dementia, valuing the work of carers and accepting people with dementia as a visible part of the community are necessary steps to combat stigma.[32]

Dementia care in Australia

Whilst there are a number of existing guidelines for aspects of dementia management in Australia (e.g., Guidelines for the Management of Behavioural and Psychological Symptoms of Dementia [38]), there are no current guidelines for the diagnosis and management of dementia that are utilised nationally and apply to all health and aged care professionals. Management and care of people with dementia in Australia appears to vary, with small audits suggesting that improvements in the consistency and quality of care are required. For example, studies have revealed lengthy gaps between the onset of symptoms and diagnosis.[39] Research suggests that legal matters are discussed with less than half of people with dementia in primary care settings.[40] Gaps between evidence and practice may be particularly apparent in rural and remote areas in which there is a lack of access to dementia care specialists.[41] Other research has suggested an overreliance on medications which are ineffective or potentially harmful in the management of behavioural and psychological symptoms of dementia. One Australian study estimated that 33 per cent of people in nursing homes were receiving antipsychotics, 11 per cent were receiving anxiolytics and 10 per cent were receiving hypnotics.[42] An Australian Government Senate Enquiry reported an overuse of restraint in the management of behavioural and psychological symptoms of dementia and that restraints were often used in the absence of protocols. The Enquiry also reported that only one-in-five people with dementia currently prescribed antipsychotics needed them.[43]

It is expected that the development and implementation of national guidelines for the diagnosis and management of dementia will improve the consistency and quality of care for people living with dementia and their carers and families in Australia.

Approach to Guideline development

Funding

The development, publication and dissemination of this Guideline was funded by the National Health and Medical Research Council (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. The views and interests of the funding bodies did not influence the final recommendations.

Purpose and impact 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, 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 carers and family will also find the Guideline useful as it provides guidance on the process of diagnosis and types of treatment that are beneficial.

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.

This Guideline is a source of systematically reviewed current evidence and, where there is insufficient evidence, expert opinion. It is hoped that the dissemination and implementation of the Guideline will improve consistency and quality of care, leading to improved outcomes for people with dementia and their carers and families.

Scope

Setting

The Guideline addresses assessment and management of people with dementia in community, residential care and hospital settings. In recognition of the vital role of carers and families in providing care for people with dementia, recommendations regarding support and interventions for carers and families 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 UK National Institute for Health and Care Excellence (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.

As there have been very few economic evaluations in dementia care conducted for the Australian setting [44], information regarding the health economic impact of assessment and treatment options was discussed when reported in the included studies, but specific searches for these types of studies were not conducted.

Target population

The population included within this Guideline are people of all ages with all the major forms of dementia, including Alzheimer's disease, vascular dementia, Dementia with Lewy Bodies, frontotemporal dementia and dementia with Parkinson's disease. 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 families in the care and support of people living with dementia.

In accord with the scope of the adapted NICE guideline, the following areas were not addressed: (a) Creutzfeldt-Jakob disease (CJD), Huntington's Chorea and Human Immunodeficiency Virus (HIV); (b) the physical treatments of organic disease sometimes associated with different forms of dementia, such as the treatment of convulsions or motor disorders; (c) the treatment of physical ill-health that is commonly encountered amongst elderly people, especially those with dementia, such as cardiovascular and neurological disease/disorders. In addition, delirium and dementia in people with an intellectual disability were also out of scope.

These Guidelines do not address the prevention of dementia in members of the general population or those at increased risk. A 2014 World Alzheimer Report analysing protective and modifiable factors for dementia stated that "There is no evidence strong enough at this time to claim that lifestyle changes will prevent dementia on an individual basis." [9] The report recommends improved management and detection of diabetes, hypertension and smoking cessation and increased physical activity. No definitive recommendations on the type or intensity of exercise were provided. Detailed discussion of risk and protective factors can be found in the 2014 World Alzheimer Report.[9]

Clinical questions

The following clinical questions were prioritised by the Guideline Adaptation Committee and the evidence was examined by conducting systematic reviews. Full details of the Population, Intervention, Comparator and Outcome (the PICO criteria) for each systematic review question are provided in the accompanying Technical Report, Volume 1. 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) in Indigenous Australian populations and the Rowland Universal Dementia Assessment Scale (RUDAS) in 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? What is the accuracy of SPECT to predict progression of MCI to dementia?
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/harms?
12. For people with dementia, does cognitive rehabilitation produce benefits?
13. For people with dementia/mild cognitive impairment, 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, does appropriate drug treatment when compared to placebo produce benefits/harm?
17. Does assessment and/or intervention for the carer(s) and families produce benefits when compared to usual care?

Please note that details of full PICO criteria are reported in the Technical Report.

Guideline development

Development of the Guideline is based on the ADAPTE process.[6] Further details of this process are provided in the Technical Report Volume 1. 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. Appraisal of existing guidelines using the Appraisal Of Guidelines For Research & Evaluation (AGREE) II instrument indicated that the NICE Guideline was the most appropriate guideline to adapt (see Technical Report Volume 1, Appendix 1). A Chairperson was appointed and the Guideline Adaptation Committee formed to adapt the NICE Guideline by updating and customising recommendations for the local context. Membership of the Guideline Adaptation Committee is provided on page 128. 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 culturally and linguistically diverse (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 Volume 1 and Volume 2.

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, systematic reviews and health technology assessment, who provided feedback and recommended modifications. The evidence update involved conducting systematic reviews to 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 (Table 4).[45] Evidence-based recommendations were formulated based upon the findings of the evidence update. Consensus-based recommendations were formulated when the findings of the systematic review were inconclusive or otherwise insufficient to inform a recommendation. Practice points were not formulated based upon systematic review of the evidence base. Evidence-based recommendations were associated with an overall rating of the quality of evidence identified in the evidence review using the GRADE system. This involves assessment of the criteria of risk of bias, directness, consistency of results, precision, publication bias, magnitude of effect and any other major considerations. These factors are then summarised into one overall rating, thus the quality of the evidence was rated as high, moderate, low or very low (Table 5). In contrast to consensus-based recommendations, evidence-based recommendations based on very low quality evidence are supported by the findings of the systematic review, however, the quality of the evidence is very low and further studies may change the estimate of effect. Nevertheless, the Guideline Adaptation Committee considered that the evidence, in combination with other considerations such as consumer values and clinical judgement justified evidence-based recommendations based on very low quality evidence.

Modification from the NICE recommendation was frequently required in order to ensure the recommendation fitted 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 available information and were presented as strong ('should' or 'should not') or weak ('should/could be considered' or 'suggested') recommendations. The strength of the recommendation reflects the quality of the body of evidence in addition to values, preferences and resource use. A strong recommendation indicates that there will generally not be variation in implementation of the recommendation between individuals and

settings.[46] A weak recommendation indicates that there may be variation in implementation of the recommendation between individuals or settings, that is, that the balance of benefits and harms may depend on patient preferences or values.[46] Thus, while high quality evidence is more likely to lead to a strong recommendation this is not necessarily the case, and vice-versa with low quality evidence.

Table 4: Definitions of types of recommendations

Type of recommendation	Description
Evidence-based recommendation (EBR)	Recommendation formulated after a systematic review of the evidence, with supporting references provided
Consensus based recommendation (CBR)	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
Practice point (PP)	A recommendation that is outside the scope of the search strategy for the systematic evidence review and is based on expert opinion

Table 5 Definitions of GRADE ratings of the quality of the evidence

GRADE of quality of the evidence	Description
High	Further research is very unlikely to change our confidence in the estimate of effect
Moderate	Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate
Low	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
Very low	Any estimate of effect is very uncertain

The NICE Guideline included 128 recommendations. Prioritisation and adaptation resulted in 109 recommendations presented within this Guideline.

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. The recommendations that the Guideline Adaptation Committee considered should be prioritised for research translation are listed on page 95.

Stakeholder involvement

Consumers have played a key role in the development of this Guideline and their input has been critical to ensuring the Guideline is relevant to the needs of people with dementia and their carers and families. The Guideline Adaptation Committee included three carer representatives (see page 128). Carer representatives were sought via the Consumer Dementia Research Network (within Alzheimer's Australia), which contributes to the work of the NHMRC Cognitive Decline Partnership Centre. In addition to carer representation on the Guideline Committee, three additional people provided comments on drafts of the Guideline from the perspective of the consumer (two people living with a diagnosis of dementia and a carer). Additional input from stakeholders, people with dementia and carers was received during the public consultation phase.

Consumer representatives on the Guideline Adaptation Committee took a lead role in developing the recommendations relating to considerations for Aboriginal and Torres Strait Islander peoples and for culturally and linguistically diverse populations.

The Guideline document (including some of the systematic reviews) incorporated literature that captured the views of people with dementia and their carers. For example, the recommendations relating to early identification and barriers to care drew on qualitative studies involving interviews and focus groups conducted with people with dementia and their carers.

The Guideline was released for public consultation for six weeks (April 2015 to May 2015). The Guideline was assessed by two reviewers who were not involved in guideline development using the AGREE II Instrument.[47]

Future updates of the Guideline

NHMRC recommends that clinical guidelines are reviewed and revised no more than five years after publication. Dementia research initiatives, both within Australia and internationally, mean that the evidence in this field is likely to change within the next five years and the Guideline will need to be updated by January 2021. It is recommended that the methodology used in the development of this guideline be replicated in any future update.

Principles of Care

Principles for providing effective care

Dignity in Care

This Guideline is underpinned by the 10 Principles of Dignity in Care.[48] These Principles were developed by the Social Care Institute for Excellence in the UK based on consultation with consumers. People with dementia and their carers and family should expect treatment that is provided according to these principles. Health and aged care professionals are obligated to deliver care in line with Commonwealth, State and Territory regulatory frameworks such as the 'Quality of Care Principles 2014' (under section 96-1 of the Aged Care Act 1997) and relevant Commonwealth, State and Territory health professional regulations.

10 Principles of Dignity in Care

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

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 family. 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.[49]

Health and aged care staff should identify the needs of people with dementia 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.

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.[32] In some cases, conflicting principles may need to be balanced in order to make a decision regarding care.[50] 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.[32]

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. 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.[51] The views of the person with dementia should always be sought, even when someone else is making decisions on their behalf.

The terminology for legal issues and substitute decision making varies throughout the different states and territories. Advance care planning refers to the process of planning for future health and care in which the person's values, beliefs and preferences are made known so that they can be used to guide future decision making. An advance care planning discussion will often result in an advance care plan. Advance care plans state the person's preferences for health and care. Advance Care Directives are one way of formally recording an advance care plan. Advance Care Directives are a type of written advance care plan that are recognised by common law. Medical practitioners should be aware of the relevant terminology and documents used in each state. General practitioners can assist the person and their family to develop their advance care plans. Information regarding the process for advance care planning in each state is available via websites listed in Appendix 5 (page 142). Families need to be aware that the laws differ between states and territories and that a legal document from one state may not be recognised in another state. Documents detailing advance care plans should be readily accessible as they may be needed quickly (e.g., by ambulance workers or emergency department staff).

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 relevant state and territory laws in respect of substitute decision making for financial and personal and health matters must be followed.
5	PP	Health and aged care professionals should inform the person with dementia, their carer(s) and family 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.
6	PP	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: <ul style="list-style-type: none">– 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.
7	PP	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 (e.g., where the professionals has a duty of care) 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 (with other health professionals or substitute decision makers) should be made in the context of the person's capacity to make decisions. If information is to be shared, this should be done only if it is in the best interests of the person with dementia.

Barriers to accessing services and 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.[53 54] Health practitioners need the knowledge and skills to identify cognitive impairment and to respond appropriately to minimise risks, in partnership with carers and families.[53 54]

People with younger onset dementia, in particular, often report barriers to accessing services due to their age and diagnosis. As responsibility for providing services to people with younger onset dementia may fall between the aged and disability care sectors, this can increase difficulties in timely access to services for this group.[27 29].

People living alone with dementia may not be able to access the necessary levels of support and assistance to remain at home and may therefore require residential care earlier than people with dementia who live with a carer [55]. Health and aged care professionals may need to take on a larger role in the initiation and coordination of services for people living alone.

Barriers to access and care		
8	PP	People with dementia should not be excluded from any health care services because of their diagnosis, whatever their age.
9	CBR	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(s) and family with: <ul style="list-style-type: none">– information in the preferred language and in an accessible format– professional interpreters– interventions in the preferred language.
10	PP	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.
11	PP	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.
12	PP	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. In particular, services should be structured to complement existing services in the local area.
13	PP	People with younger onset dementia have unique needs; organisations should tailor their services in order to ensure that they are age appropriate and address the needs of the person with younger onset dementia and their carer(s) and family.

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 in the UK.

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 (non-systematically) to inform a consensus based recommendation.

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).[56] 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.[57]

Remote Aboriginal communities

Two studies have examined barriers to care for people living in remote Aboriginal communities.[58,59] 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.

Culturally and Linguistically Diverse populations

A systematic review that examined dementia care in different cultural groups [60] 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.[60] 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.[61]

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. [62] 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.[63]

A number of barriers to care have been identified when accessing primary care.[34] 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).

Evidence statements	GRADE Quality	Related
No studies were identified that evaluated interventions designed to overcome barriers to accessing optimal health care in people with dementia.	Not Applicable	CBR 9

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 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.[64-67] Data from remote Indigenous communities in the Kimberley revealed a prevalence rate of 12.4 per cent in people aged over 45 years.[67] 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.[64] The most common types of dementia are Alzheimer's disease and dementia of unknown cause.[64,67]

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.[65] Factors associated with dementia in the Kimberley study included: older age, male gender, no formal education, head injury, current smoking, previous stroke and epilepsy.[68]

Multiple barriers to health and aged care exist for Indigenous people. 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.[35]

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 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.

The literature suggests that in some Aboriginal cultures the term dementia has not commonly been used. In general, there is no traditional explanation for dementia and therefore the condition may be associated with fear and stigma.[35-37] Historically, few Indigenous Australians have identified with the term 'carer' despite having caring responsibilities although the number of people identifying themselves as a carer is growing.[69-70] 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.[69] 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.[71]

Assessing cognitive function in Indigenous people can be difficult, due to differing definitions, manifestations and conceptualisations of mental health in Indigenous Communities. Misunderstanding, by the clinician, of what constitutes normal or abnormal behaviours can lead to misdiagnosis and incorrect treatment.[72] There are existing guidelines for health professionals for the diagnosis and care of Indigenous Australians with dementia in remote communities.[73] These guidelines were developed in Central Australia and the process for their development is transferable to other settings. The guidelines were overseen by a steering committee of stakeholders in dementia care in Central Australia including government, shire, Aboriginal community controlled organisations and non-government organisations.[73]

A cognitive assessment tool (Kimberley Indigenous Cognitive Assessment or KICA-Cog) has been developed specifically for use in older Indigenous Australians living in remote locations and a modified KICA (mKICA) is available for use in urban and rural Indigenous Australian populations.[74-75] The KICA tool was developed with extensive involvement of Indigenous organisations and community members in the Kimberley region and has good acceptability in this population.⁷⁶ There are also sections of the tool

for the evaluation of emotional wellbeing, behavioural and psychological symptoms of dementia and functional ability; the latter two assessed by carer report.[77] A detailed discussion of the KICA-Cog and the mKICA is provided under 'Cognitive assessment tools' (page 31). 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.

Alzheimer's Australia 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 Australia website (www.fightdementia.org.au).

A systematic search of databases containing literature relevant to Aboriginal and Torres Strait Islander peoples was undertaken in order to inform the recommendations. A narrative summary of all identified studies was provided to the Committee to inform development of recommendations.

Considerations for Aboriginal and Torres Strait Islander peoples

14	PP	Consultation with Indigenous community representatives and the local Indigenous medical service should occur in the development, implementation and review of any initiative intended for Indigenous communities. The formation of an Indigenous advisory committee or consultation with an existing committee ensures ongoing collaboration. Where appropriate, groups should consult with Alzheimer's Australia's National Aboriginal and Torres Strait Islander Dementia Advisory Group and State or Territory Indigenous peak health bodies.
15	PP	Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should be culturally sensitive and informed and utilise translators and/or cultural interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent.
16	PP	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.
17	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.
18	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.

Considerations for 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.[78] Approximately 20 per cent of people aged 65 years and over (600,000 people) were born outside Australia.[78] This proportion is increasing and, by 2021, more than 30 per cent of Australia's older population will have been born outside Australia.[78]

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.[78] 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.[61] 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.[79]

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.[79]

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.[80] 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.[81] 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

Considerations for Culturally and Linguistically Diverse populations

19	PP	Consultation with culturally and linguistically diverse (CALD) community representatives who have appropriate knowledge and skills 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 appropriate support is provided. Where appropriate, groups should consult with Alzheimer's Australia's National Cross Cultural Dementia Network. In the interest of accountability, feedback should be provided back to community.
20	PP	Health and aged care services need to recognise and be responsive to the cultural and linguistic needs of CALD people living with dementia, their carer(s) and families. Services should utilise a range of communication tools, including working with bilingual bicultural staff or professional interpreters across the whole service pathway, particularly during assessment, when communicating the diagnosis and gaining consent.
21	PP	CALD carers and families should receive support, education and information, through partnerships with ethno-specific and mainstream agencies and they should be delivered by bilingual, bicultural workers in the field.

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.[87] Symptoms may 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'.[88]

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.[89] 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. This may make it easier for people with dementia and their carers and families to access information, advice and support services and treatments. It would also enable earlier planning (including early retirement, financial planning, safety and security issues) which can become more difficult as the condition progresses. These benefits would need to be balanced against potential harms, which may include anxiety, depression and earlier admission to care.[90] 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.

Clinical question		
Are there advantages or disadvantages to early identification?		
22	CBR	General population screening for dementia should not be undertaken.
23	PP	Concerns or symptoms should be explored when first raised, noted or reported by the person, carer(s) or family and should not be dismissed as 'part of ageing'.
24	CBR	Medical practitioners working with older people should be alert to cognitive decline, especially in those aged 75 years and older.

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 [91] 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.[23] The review failed to identify any studies that examined the direct effect or harms of screening. The Guideline Adaptation Committee is aware of a large randomised controlled trial underway in the United States which is due to be completed in 2017.[92] Results of this study will provide important information regarding the benefits and harms of early diagnosis.

Evidence statements	GRADE Quality	Related recommendation
No studies were identified that evaluated screening for cognitive impairment in the general population.	Not Applicable	CBR 22,24

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/specialists

Background

Memory assessment specialists or services have expertise in assessment, diagnosis, information provision 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. Specialist assessment may be conducted by a dedicated service (e.g., a memory clinic) or by a practitioner with expertise in memory assessment (e.g., a geriatrician, neurologist or psychiatrist working in public or private practice). Memory assessment services may be multidisciplinary and include other medical, nursing and allied health staff. People with symptoms of dementia 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?

25	EBR Low	People with a possible diagnosis of dementia should be offered referral to memory assessment specialists or services for a comprehensive assessment.
26	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 carer(s) and families living in the community. Referrals for required health and aged care services should be made directly by the specialists or the memory assessment service

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.[93,94] The first randomised controlled trial was conducted in Australia by Logiudice and colleagues.[93] 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 carer and found those who had attended a memory clinic with someone with dementia 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.[94] 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.[94] Generalisability of these findings to the Australian setting is uncertain.

Evidence statements	GRADE Quality	Related recommendation
One RCT conducted in Australia found that carers who attended a memory clinic with someone with dementia reported improved quality of life (psychosocial status) at six months compared to those visiting the GP.[93]	Low	EBR 25
One RCT conducted in the Netherlands did not find a significant difference between memory assessment service and GP visits (in which care was delivered based on local guidelines for GPs) for quality of life of the person with dementia, ADL function or BPSD.[94]	Moderate	EBR 25

See Table 24 in Technical Report for GRADE Evidence Profile

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 and specialists varies throughout 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. The Guideline Adaptation Committee considered that all Australians should have access to memory assessment services (whether through a memory clinic or a practitioner with specialised training) and that this is an important area for research translation; strategies to ensure access should be implemented.

While the committee agreed there was value in assessment by a specialist the role of the general practitioners in the diagnosis and management of dementia was acknowledged. Carers and families typically report symptoms of dementia and seek advice from the general practitioner in the first instance. The general practitioner assesses whether or not referral to specialist memory assessment services or specialists is indicated and provides ongoing support and management. This may be particularly complex in people with multimorbidity.

While one solution appears to be increasing training for general practitioners in diagnosis, research suggests that improving timely diagnosis of dementia in primary care settings is complex and that short training programs alone have limited efficacy.[95,96] Innovative approaches to improving diagnosis in primary care settings should be trialled.

Follow-up for people with Mild Cognitive Impairment

Background

People with mild cognitive impairment (MCI) are at increased risk of developing dementia. Conversion rates of MCI differ between subtypes and different settings (specialist v. community).[97,98] 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?		
27	CBR	Memory assessment services or specialists that identify people with mild cognitive impairment should typically offer follow-up either at the memory assessment service or with a general practitioner, other medical practitioner or nurse 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 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 to 18.8 per cent).[99] Annual conversion rates in studies that recruited subjects from the community were lower (median 6.0 per cent, range 4.3 per cent to 11.5 per cent across 11 studies).

Evidence statements	GRADE Quality	Related recommendation
No studies were identified that compared outcomes for people with MCI attending memory clinics for review at alternative frequencies.	Not applicable	CBR 27

Considerations for Australia

Access to specialists and 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 state assessment, physical examination and medication review (see Appendix 2, page 135).[100,101]

Researchers have recently examined the amount of evidence available to inform the use of biomarkers for dementia.[102] At present, while there are many diagnostic accuracy studies of biomarkers for Alzheimer's disease (including markers for β -amyloid, or markers of neuronal injury including CSF tau, decreased uptake of 18F-fluorodeoxy-glucose on positron emission tomography or atrophy on magnetic resonance imaging), there are many limitations in the quality of the studies and overall the body of evidence for biomarkers for dementia diagnosis is not large. Although recently developed criteria for the diagnosis of Alzheimer's disease provide a 'semantic and conceptual' distinction between Alzheimer's disease clinical syndromes and pathophysiological processes, the routine use of biomarkers for the diagnosis of Alzheimer's disease is not recommended at this time.[103,104] Many studies of biomarkers are concerned with their predictive value in determining whether mild cognitive impairment may progress to Alzheimer's disease dementia or other dementias.[105,106]

Diagnosis of dementia

28	PP	A diagnosis of dementia should be made only after a comprehensive assessment, which should include: <ul style="list-style-type: none"> – history taking from the person – history taking from a person who knows the person 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 and to simplify medication dosing – consideration of other causes (including delirium or depression)
29	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.
30	PP	A basic dementia screen should be performed at the time of presentation, usually within primary care. It should include the following blood tests: <ul style="list-style-type: none"> – routine haematology – biochemistry tests (including electrolytes, calcium, glucose, and renal and liver function) – thyroid function tests – serum vitamin B12 and folate levels.
31	PP	Testing for syphilis serology or HIV should be undertaken only in those with histories suggesting they are at risk.
32	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.
33	PP	Cerebrospinal fluid examination should not be performed as a routine investigation for dementia. Cerebrospinal fluid examination may be indicated if Creutzfeldt–Jakob disease is suspected or in rapidly progressive dementia.
34	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).
35	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.
36	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.
37	PP	Many diagnostic technologies including biomarkers for β -amyloid or neuronal injury (eg. 18F-fluorodeoxyglucose Positron Emission Tomography [FDG-PET] or CSF tau) are currently being evaluated and may prove to be useful in the assessment of dementia in the future. The routine use of these technologies in clinical practice is considered to be premature.

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 cognitive functions, including memory, orientation and executive function.

Cognitive assessment tools

38	PP	Clinical cognitive assessment in those with suspected dementia should include examination using an instrument with established reliability and validity. 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, aphasia, hearing or visual impairments, psychiatric illness or physical/neurological problems when interpreting scores.
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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). The website has links to recommended assessment tools and their associated 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 3 are recommended for assessment of cognitive function based on the appraisal in the Dementia Outcomes Measurement Suite.[107] Care must be taken when using assessment tools with people with low literacy levels and aphasia.

Box 3: Measurement tools of cognitive function

(adapted from the Dementia Outcomes Measurement Suite [DOMS: www.dementia-assessment.com.au])

RECOMMENDED TOOLS (for further detail see Appendix 1)

Modified Mini Mental Exam (3MS) Mini Mental State Exam (MMSE) The Alzheimer's Disease Assessment Scale - Cognition (ADAS-Cog) General Practitioner Assessment of Cognition (GPCOG) Psychogeriatric Assessment Scale (PAS) Rowland Universal Dementia Assessment Scale (RUDAS)	Kimberley Indigenous Cognitive Assessment (KICA-Cog) Montreal Cognitive Assessment (MoCA) Frontal Assessment Battery (FAB) EXIT 25 Addenbrooke's Cognitive Examination (ACE-R now replaced by ACE-III)
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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.

Assessing cognitive function in Indigenous Australians can be difficult, due to different definitions and understanding of mental health in Indigenous Communities.[72] The Kimberley Indigenous Cognitive Assessment (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.perkins.org.au/wacha/our-research/indigenous/kica). The tool has a focus on memory and language skills and limited coverage of executive function. The KICA tool was developed with extensive involvement from Indigenous organisations and community members in the Kimberley region. The tool is culturally sensitive to indigenous perspectives and has good acceptability among older Indigenous Australians.[76] Good reproducibility between raters has been demonstrated. [76] An adapted version of the tool (the modified KICA tool, mKICA) has also been developed for use with urban and regional Indigenous Australians.[108]

The RUDAS was designed in 2004 in Australia for use in culturally and linguistically diverse (CALD) populations.[109] It was designed to be a cognitive assessment tool which is less influenced by cultural background, language and education level. Training is required to administer the tool, but the tool and training is freely available online via the Alzheimer's Australia website. 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?

39	EBR <i>low</i> ¹	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.
40	EBR <i>low</i>	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.
41	EBR <i>very low</i>	The Rowland Universal Dementia Assessment Scale (RUDAS) should be considered for assessing cognition in CALD populations.
42	PP	Formal neuropsychological testing may form part of the assessment in cases where a dementia diagnosis is uncertain.

¹ Quality of evidence is low for the KICA-Cog and very low for the KICA Screen

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 Guideline.

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.[67, 110] Additional data were provided by personal communication.[111] 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.[111] However, there are some limitations in the applicability of the 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 population 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 [110], 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.[110]

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.[75, 112] 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. [75] 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.[112]

Rowland Universal Dementia Assessment Scale (RUDAS)

Four studies provided data on accuracy of the English version of the RUDAS in comparison to an alternative cognitive assessment tool.[113-116] 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.[114-116] One of the studies also compared the RUDAS to the Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE)[114] and another to the General Practitioners Assessment of Cognition (GPCOG).[116]

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.[113-116] The AUC did not significantly differ between the RUDAS and the IQ-CODE in one study [114] or the RUDAS and the GPCOG in another.[116] In two studies the results on the MMSE, but not the RUDAS, were affected by CALD status.[115,116]

Three studies reported the sensitivity and specificity of the RUDAS and MMSE in the study population. [114-116] In one study conducted in memory clinic patients, the sensitivity and specificity did not significantly differ between the tests [115] 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). [114] 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).[116]

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	GRADE Quality	Related recommendation
One diagnostic accuracy study of the KICA-Cog has demonstrated high accuracy for the diagnosis of dementia in a remote Indigenous Australian population. [67,111]	Low	EBR 39
The KICA-Screen had a high accuracy for dementia in one study in a remote Indigenous Australian population, in which the tool was developed.[110] Accuracy of the KICA-Screen was moderately high in a small study in a North Queensland remote Indigenous Australian population.[110]	Very low	EBR 39
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.[75,112] The accuracy of the RUDAS was slightly lower than that of the mKICA and MMSE in this population.[75]	Low	EBR 40
The accuracy (as determined by the AUC) of the RUDAS and the MMSE did not significantly differ in four diagnostic accuracy studies.[113-116] Three diagnostic accuracy studies compared the sensitivity and specificity of the MMSE and the RUDAS, with inconsistent results.[114-116] 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.[115 116]	Very low	EBR 41

See Tables 35-38 in Technical Report for GRADE Evidence Profiles

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.

In some cases, a carer, or someone that knows the person well, is asked to complete sections of the tool. Carer participation has been highlighted as problematic in General Practice in which time spent with the carer(s) of a person with dementia is not funded through the Medical Benefits Schedule (MBS).[43]

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.[117] 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 Dementia with Lewy Bodies). 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 a person 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).[118] MRI has a higher resolution than CT and may detect more subtle anatomical and vascular changes.[119] 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. [120] MRI is contraindicated in some patients, such as those with pacemakers, vagus nerve stimulators, implantable cardioverter-defibrillators, loop recorders, cochlear implants and insulin pumps.[121] MRI is also unsuitable for patients who are claustrophobic or unable to stay still for long periods. The NICE

Clinical question

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

43	PP	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 clinical judgement indicates this inappropriate. Structural imaging may not always be needed in those presenting with moderate-to-severe dementia, if the diagnosis is already clear.
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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. 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 in the absence of evidence of harms associated with structural imaging. Evidence statements and full details of the evidence review update are provided in the Technical Report Volume 1.

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) or positron emission tomography (PET) can be used to identify areas of reduced glucose metabolism or perfusion, indicating neuronal injury or loss. SPECT is performed with a variety of tracers including hexamethyl-propyleneamine oxime (99mTc-HMPAO), N-isopropyl-(iodine-123)p-iodoamphetamine (123I-IMP) and ethylene cysteinyl dimer (99mTc-ECD).

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. 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).[122] This review compared the performance of ¹⁸F-FDG-PET to that of SPECT for the diagnosis of AD where other diagnostic methods are inconclusive. The review found limited comparative clinical data and concluded that ¹⁸F-FDG-PET and SPECT had a similar diagnostic accuracy for detecting Alzheimer's disease; hence, public funding was not supported.[123] In addition, recent reviews have concluded that the evidence for the use of ¹⁸F-FDG-PET does not support routine use in the diagnosis of Alzheimer's disease or in people with mild cognitive impairment to predict conversion to Alzheimer's disease.[103,105,124]

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?

44	EBR very low	HMPAO SPECT should not be used in people with mild cognitive impairment (MCI) either for the differentiation of dementia from MCI or for the differentiation of progressive from non-progressive MCI.
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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.[125] Recent systematic reviews have reported similar accuracy values.[118,126] 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 this Australian Guideline. It is recommended that evidence for the use of PET in the diagnosis of dementia be reviewed when this Guideline is 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.[127] 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.[128] 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.[129]

A medical audit of SPECT referrals in rural NSW reported rates of concordance between SPECT, CT and neuropsychological assessment.[130] 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.[131] 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.

Evidence statements	GRADE Quality	Related recommendation
Two accuracy studies indicated that SPECT has little additional value over that of standard comprehensive clinical assessment for differentiating dementia from MCI.[128,129]	Very Low	EBR44
Six studies indicated that SPECT does not provide good discrimination of patients who will progress to dementia from those who will not.[130]	Very Low	EBR44

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 family. Following diagnosis, people often report feelings of loss, anger, uncertainty and frustration. [87] The term 'dementia' can be associated with stigma for the person with dementia, their carer(s), families, spouse and/or partner. This may be even greater in certain cultural groups.[35-37] Yet, some people report feelings of relief to have an explanation for their symptoms.[132]

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 those close to them. 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. The diagnosis should be communicated in a way that is understandable to the person with dementia with regard for their individual language and communication needs.

Communicating the diagnosis		
45	PP	The diagnosis of dementia should be communicated to the person with dementia by a medical practitioner.
46	PP	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) and family.
47	PP	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.
48	PP	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.
49	PP	Medical practitioners should be aware that people with a history of depression and/or self-harm may be at particular risk of depression, self-harm or suicide following a diagnosis of dementia, particularly in the first few months post diagnosis. While such reactions are believed to be uncommon, counselling should be offered as an additional way to support the person during this time.

Considerations for Australia

These recommendations promoted lengthy discussion among the Committee and much time was dedicated to determining 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. The Senate Community Affairs References Committee recently recommended that the Commonwealth consider increasing funding for this program to provide support to all people living with dementia.[29]

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 family context 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 family. Information provision is vital so that individuals have the opportunity to be proactive in terms of managing their diagnosis. Information needs and the way this information is conveyed will vary over the course of the disease. The general practitioner plays an ongoing role in providing information for the person with dementia and their carer(s) and family as needs change. There are several organisations in Australia that provide high quality educational resources for both the person with dementia and their carer(s) and family.

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 carers 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?		
50	PP	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.
51	CBR	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 and verbal information in an accessible format about: <ul style="list-style-type: none"> – the signs and symptoms of dementia – the course and prognosis of the condition – treatments – sources of financial and legal advice, and advocacy – medico-legal issues, including driving.
52	EBR <i>Very low</i>	People with a diagnosis of dementia, particularly those living alone, should be provided with information about how to join a social support group.
53	PP	Health and aged care professionals should ensure that the person with dementia and his or her carer(s) and family are provided with written and verbal information regarding appropriate services available in the community (including those offered by Alzheimer's Australia, Carers Australia, Aged Care Assessment Teams and My Aged Care). Any advice and information given should be recorded.

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.[133] 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.[133] 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.[134]

Boughtwood and colleagues looked specifically at the information needs of CALD Australians.[82] 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.[135] 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	GRADE Quality	Related recommendation
No RCTs or cohort studies were identified that evaluated the effects of an education program for people with dementia.	NA	CBR51
A systematic review[135] identified one RCT that found participation in a social support program led to increased quality of life (low). One of two RCTs included in the systematic review found that participation in a social support group led to reduced levels of depression (very low).[135]	Very Low - Low	EBR52

See Tables 62-63 in Technical Report for GRADE Evidence Profiles

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

Organisation of health services

Background

There are a number of different frameworks and pathways relevant to the organisation of care for people with dementia in Australia, i.e., different models of care. The frameworks and pathways should be consulted when planning, developing and reviewing services. Services for people with dementia are provided by private, government, profit making and non-profit organisations.

Service guidance

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.[136] 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.[137] 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.[137]

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?

54	EBR <i>Very low</i>	Health and aged care managers should coordinate and integrate, referral, transitions and communication across all agencies involved in the assessment, treatment, support and care of people with dementia and their carer(s) and families, including jointly agreeing on written policies and procedures. People with dementia and their carers and families should be involved in planning local policies and procedures.
55	EBR <i>Very low</i>	Health system planners should ensure that people with dementia have access to a care coordinator who can work with them and their carers and families 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.
56	PP	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, routines and current level of functioning and abilities.
57	PP	Care coordinators should ensure the coordinated delivery of health and aged care services for people with dementia. This should involve: <ul style="list-style-type: none">– 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.
58	PP	Health system planners should develop local dementia pathways and decision support software to improve the diagnosis and management of dementia.

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’.[138] 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’.[139] This evidence update identified one relevant cluster randomised controlled trial evaluating the ‘Partners in Dementia Care’ intervention in the United States.[140] 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.[141] The trial was conducted in Italy and compared a form of consumer directed care with usual care.[142] 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.[143] 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 colleagues¹⁴⁴ 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.[145,146] 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.[147]

Case management

A review of non-pharmacological interventions identified four randomised controlled trials evaluating a case management intervention for people with dementia.¹⁴⁸ One additional randomised controlled trial was identified.[149] 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.[148]

Evidence statements	GRADE Quality	Related recommendation
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.[140]	Very Low	EBR54
A systematic review[141] identified one non-randomised controlled trial evaluating a form of consumer directed care that found no significant differences between groups on quality of life for the person with dementia, ADL function or BPSD.[61]	Very Low	NA
Single RCTs evaluating the effects of multidisciplinary assessment found no difference between groups on ADL function (low), institutionalisation (low) or quality of life (low).[144-146]	Low	NA
A systematic review identified one RCT evaluating the effects of case management that showed significantly improved quality of life in the person with dementia (very low)[148] whereas an additional RCT found no effect on quality of life.[149] One (of two) RCTs included in a systematic review reported a significant reduction in carer impact (very low).[148] One RCT found no significant difference between groups on institutionalisation (low).[148]	Low	EBR55

NA – The Guideline Adaptation Committee decided not to form a recommendation based on the available evidence.

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.[150] The need for increased dementia care training for hospital staff ¹⁵¹ and training in a variety of settings on the management of behavioural and psychological symptoms of dementia have been highlighted as priority areas.[29]

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.[152] 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 workers. 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). Training may also be offered through professional associations. Due to the nature of dementia care an interdisciplinary approach to staff training is likely to be beneficial.

Clinical question

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

59	EBR <i>Low</i>	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.
60	EBR <i>Low</i>	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.
61	PP	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.
62	PP	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.
63	PP	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.

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.[153-181]

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 behavioural and psychological symptoms of dementia. 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 behavioural and psychological symptoms of dementia.

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	GRADE Quality	Related recommendation
Two RCTs have found that providing broad but comprehensive training in dementia care can result in reduced restraint use in residential care facilities (moderate).[153,164] 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).[153]	Moderate	EBR 59,60
Two (of six) RCTs [155,178] have found that training staff in providing person-centred care and communicating effectively with the person with dementia can reduce BPSD (low). [155,156,174,175 178,179] One (of two)[156] 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).[155,156]	Low	EBR 59,60, 81
Four (of 10) RCTs ^{157,168,177,180} found that training staff to manage BPSD resulted in reduced BPSD (low).[157,161,163,168,170,171, 176,177,180,181] Three RCTs found that training staff to manage BPSD resulted in reduced restraint use (low).[168,176,181] One RCT found no significant differences between groups on quality of life of the person with dementia (low).[171]	Low	NA

See Tables 80-82 in Technical Report for GRADE Evidence Profiles

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. The Committee agreed that in the absence of definitive treatments for symptoms of dementia there is a profound need to provide dementia-specific training for care staff. As described in these Guidelines, the initial approach for the management of behavioural and psychological symptoms of dementia is prevention and minimisation. Staff require the skills to understand symptoms and effectively apply non-pharmacological strategies in the first instance. The adequacy of staff training has been shown to have a direct impact on the quality of life and symptoms of people living with dementia and implementation of effective training programs is required.

Living well

It is important that people with dementia have a healthy and active lifestyle in order to maintain overall health and minimise co-morbidities and functional decline.

Epidemiological studies indicate that, in the general population, a Mediterranean diet, which contains cereals, fish, legumes, fruit and vegetables and is low in saturated fats, decreases the risk of cardiovascular disease, some cancers and overall mortality.[182-184] The person with dementia should visit their general practitioner regularly to ensure appropriate management of cardiovascular risk factors to reduce the risk of heart disease, stroke and vascular dementia. Specific guidance is provided in the NHMRC approved "Guidelines for the assessment and management of absolute cardiovascular disease risk".[185]

Nutrition

Undernutrition and weight loss are common amongst people with dementia.[186] In the community, 20 to 45 per cent of people with dementia experience clinically significant weight loss annually and food intake is considered to be inadequate in a similar proportion of people with dementia living in residential care.¹⁸⁷ Dietary habits in people with dementia can be influenced by changed appetite and taste, feeding and swallowing problems and difficulty in shopping for and preparing food.[186] Maintaining nutrition and hydration is critical in people with dementia to maximise their health and quality of life and reduce the risk of functional decline, falls, pressure sores and infection.[187] As there is currently insufficient evidence for nutritional micronutrient supplementation, the focus should be on maintaining a healthy diet.[187]

Nutrition

64	PP	Health and aged care professionals should support the person with dementia to receive adequate nourishment and hydration through maintaining a healthy, balanced diet. People with dementia should have their weight monitored and nutritional status assessed regularly. In cases of undernutrition, consultation with a dietitian and/or assessment by a speech pathologist may be indicated.
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Oral health

Advances in dentistry have seen an increase in the proportion of people retaining their natural teeth and carrying high levels of restorative dentistry into older age.[188] There are a number of factors which may lead to poorer oral health in people with dementia, including changed diet, reduced dental care, side effects of medications and reduced saliva.[189] Poor oral health may negatively impact comfort, nutrition, self-esteem, behaviour and general health of the person with dementia. The medical practitioner should emphasise the importance of good oral health following a diagnosis of dementia and encourage the person (and their carer and/or family) to make an appointment with a dentist (or dental hospital). The dentist should be made aware of the diagnosis of dementia and should undertake a thorough assessment of the person with the goal of developing a long term, uncomplicated treatment plan.[190] Regular check-ups should be arranged both for people with natural teeth and those with dentures. Carers have a role in supporting and assisting the person with dementia with oral health care. This role will change and increase as dementia progresses. Oral health professionals can assess and advise about the level of assistance required to maintain optimal oral health and provide technical advice.

Oral health

65	PP	Dental and oral health personnel are an integral part of the health care team for people with dementia. Upon diagnosis, the medical practitioner should recommend the person with dementia (or their carer(s) or family) makes an appointment to see a dentist. The dentist should conduct an assessment and formulate a long term treatment plan.
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Promoting functional 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.[100] 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.[4]

Most people with dementia in Australia live in private dwellings rather than residential care.[4] 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.[4] 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 (e.g., respite, information provision and advocacy) and informal assistance and approximately one fifth of people with dementia receive informal care alone.[4]

The needs of people with dementia vary widely and tailoring care to each person's circumstances can be complex. A multidisciplinary approach in which different health professionals work together is important. A number of different allied health professionals may be required at different points in time, including but not limited to: audiologists, dentists, dietitians, occupational therapists, orthoptists, physiotherapists, podiatrists, psychologists, social workers and speech pathologists.

A wellness approach in dementia care includes reablement and restorative care. Reablement includes time limited interventions targeted towards a person's specific goal to adapt to functional loss or regain confidence and capacity to resume activities.[191] Restorative care involves evidence based interventions led by allied health workers that allow a person to make a functional gain or improvement after a setback, or in order to avoid a preventable injury.[191]

Clinical question

For people with dementia, are there interventions for promoting independence that produce benefits/harms?

66	PP	Health and aged care staff should aim to promote and maintain functional and social independence of people with dementia in community and residential care settings. Interventions should address activities of daily living that maximise independence, function and engagement. Intervention should include: <ul style="list-style-type: none">– consistency of care staff– stability in living environment– flexibility to accommodate fluctuating abilities– support for people with dementia and their carer(s) and families 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
67	EBR Low	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.
68	EBR Low	People with dementia should be strongly encouraged to exercise. Assessment and advice from a physiotherapist or exercise physiologist 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.[192] An additional RCT published subsequent to the review was also included in this evidence update.[193] One further study that evaluated the efficacy of an occupational therapy program for people with dementia in a residential care setting was also included.[194]

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 (as described in the Technical Report). 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.[195] A further two trials published subsequent to the review were included in the evidence update.[196,197] 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. The effects of exercise on cognition and depression varied across studies with some studies reporting significant benefits associated with exercise and others unable to measure a significant effect. Pooling of these studies failed to identify a significant effect on cognition or depression.[195] There were no clear differential effects in people with different severities of dementia. The most effective type of exercise or dose is currently unclear. In the absence of clear evidence, health professionals should consider the advice provided in Australia's Physical Activity and Sedentary Behaviour Guidelines: Recommendations for Older Australians (presented in Box 4).

Box 4: Recommendations for physical activity for older Australians

1. Older people should do some form of physical activity, no matter what their age, weight, health problems or abilities.
2. Older people should be active every day in as many ways as possible, doing a range of physical activities that incorporate fitness, strength, balance and flexibility.
3. Older people should accumulate at least 30 minutes of moderate intensity physical activity on most, preferably all, days.
4. Older people who have stopped physical activity, or who are starting a new physical activity, should start at a level that is easily manageable and gradually build up the recommended amount, type and frequency of activity.
5. Older people who continue to enjoy a lifetime of vigorous physical activity should carry on doing so in a manner suited to their capability into later life, provided recommended safety procedures and guidelines are adhered to.

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.[198,199] 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 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. [198,200] 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	GRADE Quality	Related recommendation
Pooling of four RCTs demonstrated that occupational therapy was effective in improving ADL function (low) [201-204] and self-reported quality of life (moderate)[193,203-205] in community dwelling people with dementia. Pooling of four RCTs found no significant reduction in carer impact following occupational therapy (moderate).[201,202,205,206]	Low - Moderate	EBR67
A systematic review[195] pooled six RCTs evaluating an exercise intervention and showed a significant improvement in ADL function (low).[195] The systematic review[195] found one RCT that reported no significant differences between groups on self-reported quality of life after exercise intervention (low). [195] The systematic review found one (of two) RCTs associated with significantly reduced carer impact following an exercise program for the person with dementia (very low).[195] Six RCTs within the systematic review that reported on harms associated with exercise did not report any adverse events associated with intervention (moderate).[195]	Low	EBR 68
One RCT evaluating a technology intervention using a health status monitoring platform found no significant differences between groups in terms of carer impact.[199]	Low	NA
One RCT evaluating a falls prevention intervention found no significant differences between groups on ADL function (low). [200] Two RCTs found that falls prevention interventions led to reduced incidence of falls (low).[198,200]	Low	NA

NA – The Guideline Adaptation Committee decided not to form a recommendation based on the available evidence. See Tables 91-94 in Technical Report for GRADE Evidence Profiles

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.[207] People with early stage dementia are capable of new learning and therefore rehabilitation interventions that aim to optimise independence may be appropriate.[208] Interventions that are targeted towards improving cognitive function and reducing the impact of cognitive impairment can be categorised into three approaches [207]:

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

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.[209] 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.[210] This evidence update identified one additional randomised controlled trial. [211] 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.[212]

Cognitive rehabilitation

The Cochrane review that examined the efficacy of cognitive training also examined the efficacy of cognitive rehabilitation.[210] The authors included one randomised controlled trial (n=69) of high quality evaluating cognitive rehabilitation.[213] 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.

Evidence statements	GRADE Quality	Related recommendation
A systematic review [209] pooled 14 RCTs investigating cognitive stimulation therapy and found a significant effect on global cognition (low). Pooling of four RCTs in the review found no significant difference between groups on ADL function (mod).[209] Pooling of four RCTs found a significant effect on quality of life (low).[209]	Low - Moderate	NA
A systematic review [210] pooled six RCTs investigating cognitive training and found no significant effect on global cognition. Pooling of four RCTs within the review found no significant effects on ADL function.[210]	Low	NA
A systematic review [210] found one RCT investigating cognitive rehabilitation that reported no significant differences between groups on ADL function, quality of life or carer impact.[213]	Moderate	NA

NA – The Guideline Adaptation Committee decided not to form a recommendation based on the available evidence. See Tables 102-104 in Technical Report for GRADE Evidence Profiles

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.[214]

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 carer(s) or family and the treating medical practitioner and must consider the person's quality of life, cognitive functioning and behavioural symptoms. Acetylcholinesterase inhibitors and memantine are associated with potential adverse events and people prescribed these medications should be reviewed. In particular, health professionals should be aware of the increased risk of nocturnal falls associated with symptoms of increased urinary frequency and symptomatic bradycardia.

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.[215] 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 and other dementia subtypes in more recent trials.[214,216-221] Subsidy is also limited to single therapies, that is prescription of one acetylcholinesterase or memantine.

Clinical question

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

69	EBR Low	Any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) are recommended as options for managing the symptoms of mild to moderately severe Alzheimer's disease. Any one of the three acetylcholinesterase inhibitors could be considered for managing the symptoms of severe Alzheimer's disease. ⁶ 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.
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⁶ Not currently listed for severe Alzheimer's disease on the Pharmaceutical Benefits Scheme

Clinical question

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

70	EBR <i>Moderate</i>	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 (but are not limited to) nausea, vomiting, diarrhoea, dizziness, increased urinary incontinence and frequency, falls, muscle cramps, weight loss, anorexia, headache and insomnia. Heart block is a rare, but serious potential adverse event.
71	EBR <i>Moderate</i>	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.
72	EBR <i>Low</i>	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. ⁷
73	EBR <i>Low</i>	The combination of an acetylcholinesterase inhibitor plus memantine could be considered for managing the symptoms of moderate-to-severe Alzheimer's disease. ⁸
74	PP	People who have been prescribed an acetylcholinesterase inhibitor or memantine should be reviewed within a short time (eg. one month) for evaluation of adverse effects and dose titration and within six months, to determine whether there is a clinically meaningful response to treatment. Review and consideration of de-prescribing is recommended at regular intervals including at the time of admission to residential care.
75	EBR <i>Low</i>	Acetylcholinesterase inhibitors should not be prescribed for people with mild cognitive impairment.

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.[214] 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). Studies conducted in people with other types of dementia were excluded.

The original (2006) NICE Guideline conducted a systematic review of studies of acetylcholinesterase inhibitors and memantine for dementia and mild cognitive impairment to March 2006. Two randomised placebo controlled trials of donepezil and two trials of galantamine for the treatment of amnesic mild cognitive impairment were included. It was concluded that these studies failed to show benefits that outweighed potential adverse events for both of these drugs and it was recommended that acetylcholinesterase inhibitors should not be used in people with mild cognitive impairment. The 2012 NICE HTA did not assess the effectiveness of acetylcholinesterase inhibitors or memantine in people with mild cognitive impairment.[214]

Evidence update

This evidence update identified a further nine randomised controlled trials conducted in people with Alzheimer's disease published since the NICE health technology appraisal. One new trial examined the effect of donepezil v. placebo, [222] one new trial examined the effect of galantamine v. placebo, [223] one trial already included in the technology appraisal reported new data on rivastigmine patches [224] and six new trials examined the effects of memantine v. placebo.[225-229]

⁷ Not currently listed for these indications on the Pharmaceutical Benefits Scheme

⁸ Listing on the Pharmaceutical Benefits Scheme is for single therapy

This evidence update also identified and included recent systematic reviews of acetylcholinesterase inhibitors or memantine for people with severe Alzheimer's disease, Parkinson's disease dementia and Dementia with Lewy Bodies [217], vascular dementia [218-220], mild cognitive impairment [230], and combination therapy in people with moderate to severe Alzheimer's disease.[231]

Donepezil

A total of 20 randomised controlled trials examined the efficacy of donepezil compared with placebo. [214 222] Overall, meta-analysis showed a small significant benefit on cognitive function and ADL function at 24 weeks. Pooling of four trials found no significant improvement on global behavioural and psychological symptoms of dementia at 12 or 24 weeks. Only two randomised controlled trials 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 (up 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. [214] Overall, pooling of four studies showed a small significant effect of rivastigmine on cognition at 24 weeks. There was also a small positive effect on ADL function (based on pooling of three studies). There were mixed findings for the effect of taking rivastigmine on behavioural and psychological symptoms of dementia 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.[214] Overall, meta-analysis of seven trials showed a small significant effect on cognition at 12–16 weeks. Small significant effects were also seen in improved ADL function (based on four studies) and reduced global behavioural and psychological symptoms of dementia (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.[214] [225-229]. 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 ADL function at 24 weeks, whereas an additional study found no differences between groups on function. Six studies measured the effects of memantine on behavioural and psychological symptoms of dementia; findings were mixed. Pooling of three studies found a significant reduction in symptoms 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.[214]

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.[221] A systematic review examining the efficacy of acetylcholinesterase inhibitors by dementia severity included six randomised controlled trials including people with severe dementia. [221] The trials were generally large in terms of sample size and assessed as being at low risk of bias. All six trials found a small positive effect on cognition. There were mixed results for impact on activities of daily living function and behavioural and psychological symptoms of dementia.

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 effect on cognition, when the results were pooled.[217] There was inconsistency in results in terms of impact on behavioural and psychological symptoms of dementia 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.[218 232 233] An additional trial published subsequent to these reviews was also included.[234] 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 behavioural and psychological symptoms of dementia 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.

Acetylcholinesterase inhibitors used in combination with memantine

Evidence on the use of combination therapy (prescription of an acetylcholinesterase inhibitor plus memantine) in comparison to monotherapy (acetylcholinesterase inhibitor alone) was considered.

A meta-analysis of combination therapy in people with moderate to severe Alzheimer's disease included data from four large, high quality trials.[231] This meta-analysis pooled data to demonstrate significant benefits of combination therapy in comparison to monotherapy for cognition, behaviour and activities of daily living. The pooled estimate of serious adverse event rates was not significantly different between treatments. The overall quality of the evidence, based upon the lowest quality of the critical outcomes (as assessed using GRADE by the original authors), is considered to be low.

Acetylcholinesterase inhibitors or memantine for mild cognitive impairment

A systematic review of studies conducted in people with mild cognitive impairment included seven studies of the effectiveness of acetylcholinesterase inhibitors.[230] The use of acetylcholinesterase inhibitors did not significantly alter cognition, activities of daily living, behavioural and psychological symptoms of dementia, mortality or serious adverse events. Treatment was however associated with a significant increase in individual adverse event rates, including nausea and diarrhoea, vomiting and headache. The studies did not support a role for acetylcholinesterase inhibitors in treating people with mild cognitive impairment.

Evidence statements	GRADE Quality	Related recommendation
Pooling of nine studies (out of 10) found a significant effect on cognition at 24 weeks in people taking donepezil.[214]	Low	EBR 69
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.[214]	Moderate	EBR 69
Pooling of four RCTs of rivastigmine found a significant improvement in cognition at 24 weeks.[214]	Low	EBR 69
One small RCT of rivastigmine found a significant benefit on BPSD, while a larger RCT did not.[214]	Moderate	EBR 69
Pooling of seven RCTs of galantamine found a significant improvement in cognition at 12 to 16 weeks.[214]	Low	EBR 69
Two pooled studies of galantamine found a significant improvement in BPSD (measured using the Neuropsychiatric Inventory) in people with mild to moderate Alzheimer's disease; this was not associated with an increase in the number of serious adverse events.[214]	Moderate	EBR 69
In people with moderately severe to severe Alzheimer's disease; pooled data from three RCTs of memantine found a significant improvement in BPSD (measured using the Neuropsychiatric Inventory) at 24 weeks.[214 228] Two RCTs reporting longer-term outcomes (at one to two years) did not find a significant effect. [226 235] There were no significant differences in adverse events between memantine treatment and placebo.[214] [225-229]	Moderate	EBR 71
Six RCTs found that acetylcholinesterase inhibitors were associated with significantly improved cognitive function in people with severe Alzheimer's disease.[221] Two (of four) RCTs found a significant improvement on ADL function.[221] One (of five) RCTs showed a significant reduction in BPSD.[221]	Moderate	EBR 69
Pooling of nine RCTs in a systematic review showed a significant improvement in cognitive function amongst people with Dementia with Lewy Bodies and Parkinson's Disease dementia taking acetylcholinesterase inhibitors [217]; one of the RCTs in the review measured impact on ADL function and found a significant improvement.[217]	Low	EBR 72
Systematic reviews [218-220] and one additional study [234] found that 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.[218-220 234]	Low	EBR 72
Pooled data from four RCTs of combination therapy of an acetylcholinesterase inhibitor and memantine, in comparison to acetylcholinesterase inhibitor monotherapy, found a significant improvement in cognition and behaviour, with no significant difference in activities of daily living or the rate of serious adverse events at 24 to 30 weeks.[231]	Low	EBR 73
A systematic review [230] reported that in people with mild cognitive impairment, pooled data from placebo-controlled RCTs of acetylcholinesterase inhibitors did not find any significant effect on cognition (eight RCTs), behaviour (one RCT), activities of daily living (two RCTs), overall mortality (three RCTs) or serious adverse events (four RCTs). Treatment was associated with a significant increase in the rates of nausea and diarrhoea (four RCTs), vomiting (three RCTs) and headache (two RCTs).[230]	Low	EBR 75

See Tables 112-121 in Technical Report for GRADE Evidence Profiles

Considerations for Australia

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

These recommendations suggest considering prescribing acetylcholinesterase inhibitors to people with severe dementia and to dementia subtypes not currently listed on the Pharmaceutical Benefits Scheme (e.g., Dementia with Lewy Bodies) as well as considering combination therapy. 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 supplements

Background

There are three medicinal foods specifically developed for people with cognitive symptoms (Axona®, Souvenaid® and CerefolinNAC®). No studies reporting the effectiveness of CerefolinAC® for treating cognitive decline have been reported.[187] Trials of Axona® have not shown a consistent or clinically significant benefit on cognition.[187] Axona® and CerefolinNAC® are not marketed in Australia and thus the evidence for these was not systematically reviewed.

Souvenaid®

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.[236] Souvenaid® is intended to provide nutrients to support synapse formation and function in the brain and thus lead to improved memory function in early Alzheimer's disease.[237]

Clinical question

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

76	EBR <i>Moderate</i>	A number of nutritional drinks are currently being investigated to reduce the symptoms of mild cognitive impairment or dementia, of which one (Souvenaid®) is marketed in Australia. There is currently insufficient evidence to recommend the routine use of Souvenaid® in people with mild Alzheimer's disease. Souvenaid® should not be recommended for people with moderate or severe Alzheimer's disease
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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.[238-242] Results from the two randomised controlled trials conducted in people with mild Alzheimer's disease found small but statistically significant improvements in memory function in some analyses but not in others.[240 241] Those with very mild Alzheimer's disease (MMSE 24-26) appeared most likely to benefit. One of these trials reported a statistically significant effect on global cognition whereas the other (using a different assessment tool) did not. The third randomised controlled trial conducted in people with mild-to-moderate Alzheimer's disease who were all taking cholinesterase inhibitors and/or memantine found no benefit on cognition. None of the studies reported significant gains in 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.

As studies have failed to demonstrate improvements in ability to perform activities of daily living or quality of life and there is uncertainty about the effect of Souvenaid® on memory in people with mild dementia the Guideline Adaptation Committee drafted a recommendation reflecting this. Further details are provided in the Technical Report.

Evidence statements	GRADE Quality	Related recommendation
One RCT showed that there were no statistically significant benefits associated with taking Souvenaid® on ADL function (high) or cognition (moderate) in patients with mild to moderately severe AD taking cholinesterase inhibitors and/or memantine.[242]	Moderate	76
There were no statistically significant benefits associated with taking Souvenaid® on quality of life (1 RCT, moderate) or ADL function (2 RCTs, high) in patients with mild Alzheimer's disease.[240 241] One RCT reported no significant effect on cognition in patients with mild Alzheimer's disease at 12 weeks, while another RCT reported a significant effect at 24 weeks (moderate).[240 241] A significant improvement in memory was demonstrated in a subgroup of people with very mild Alzheimer's disease (MMSE 24-26) in one RCT.[240] Amongst all patients with mild Alzheimer's disease, statistically significant differences were shown in some analyses of some memory outcome measures but not others in two RCTs.[240 241]	Moderate - High	76
In three RCTs, the total number of adverse events did not differ significantly between those taking Souvenaid® and those taking placebo (high).[238-242]	High	76

See Tables 126-127 in Technical Report for GRADE Evidence Profiles

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. There is no government subsidy available for Souvenaid, so the full cost must be borne by the consumer.

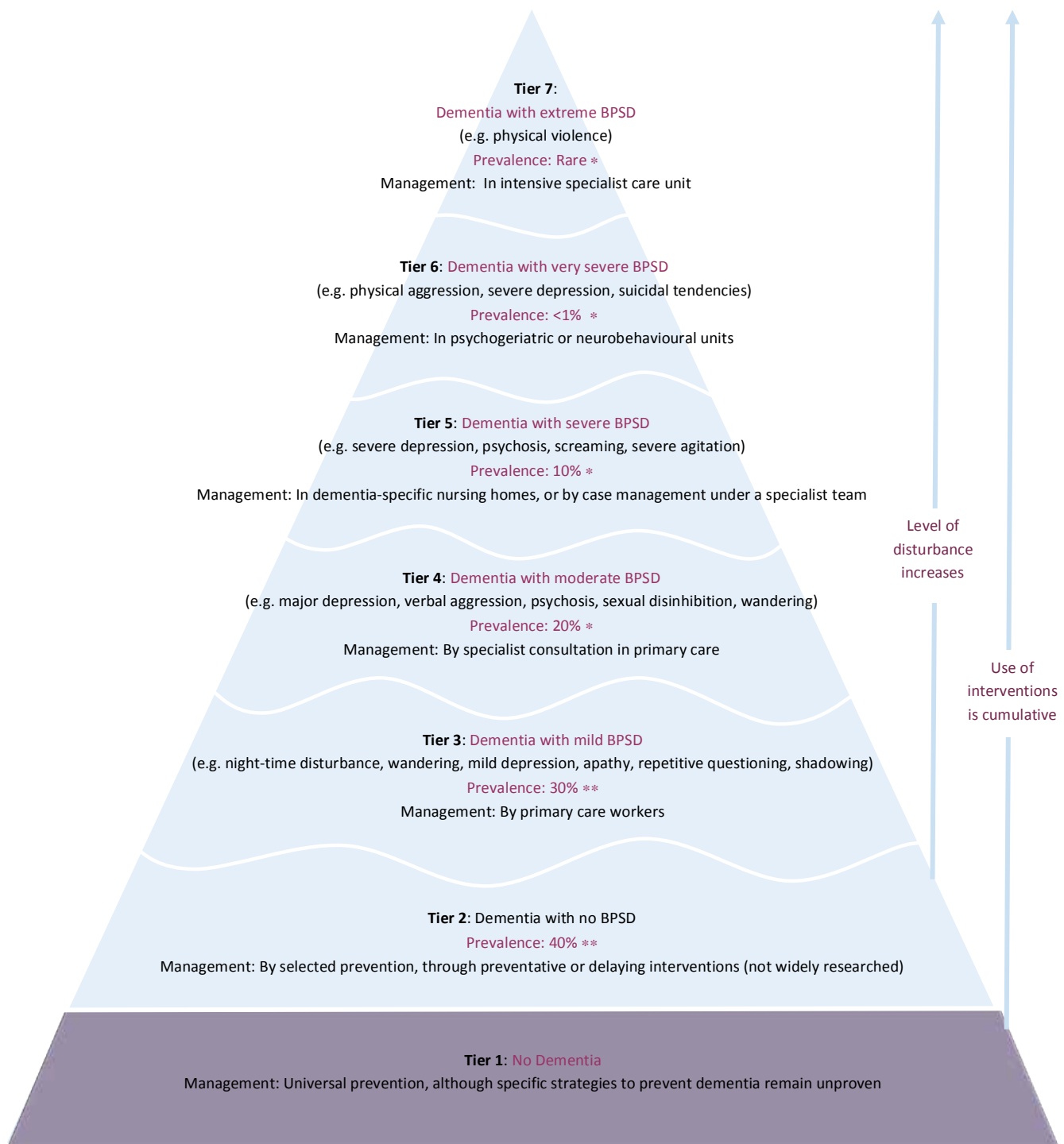
Behavioural and Psychological Symptoms of Dementia (BPSD)

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.[243] The most common symptoms are thought to be apathy, depression and agitation.[243] Behavioural and psychological symptoms of dementia refers to symptoms that emerge following the diagnosis and during the progression of dementia. Recommendations regarding the management of behavioural and psychological symptoms may not apply to those with pre-existing, comorbid serious mental illness.

Symptoms can be difficult to manage and the presence of symptoms is associated with reduced wellbeing in carers, higher costs of care [244] and earlier residential care placement.[245] Management of behavioural and psychological symptoms of dementia is thought to be particularly challenging in rural and remote areas due to reduced access to specialist services.[246] The earlier admission of people into residential care facilities in rural areas may reflect lack of specialist services to support behavioural and psychological symptoms of dementia in these settings.[254] Behavioural and psychological symptoms of dementia may be more prevalent in people with younger onset dementia, particularly as the proportion of people with non-Alzheimer's dementias is higher in this group.[29]

A seven-tiered model of management of behavioural and psychological symptoms of dementia according to symptom severity has been proposed by Brodaty and colleagues (see Figure 1).



Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category
* Estimate based on clinical observations ** Estimate based on Lyketsos et al

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

Health and aged care professionals should attempt to prevent and minimise behavioural and psychological symptoms of dementia in the first instance by taking a supportive and proactive approach as prevention can be effective.

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 behavioural and psychological symptoms of dementia that is affecting their care. Health professionals can also utilise the service. 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. Severe Behaviour Response Teams (SBRTs) are a national operation of mobile squads of clinical experts. The SBRTs are able to provide timely and expert advice and assessment to Commonwealth funded aged care providers that request assistance with addressing the needs of residents experiencing very severe behavioural and psychological symptoms of dementia.

Health and aged care professionals that work with people with dementia should also refer to resources specifically developed to improve the management of behavioural and psychological symptoms of dementia 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 non-pharmacological or pharmacological treatments or a combination of both. Non-pharmacological interventions are recommended as first-line treatment.

Non-pharmacological interventions

Clinical question		
For people with dementia, does Souvenaid® produce benefits/harms?		
77	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: <ul style="list-style-type: none"> – unmet needs (e.g., pain, hunger, need to eliminate, lack of privacy, lack of meaningful activities, communication) – lowered stress threshold (e.g., conflicts or poor communication within the family or between staff, carer stress).
78	PP	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 families as appropriate and include; <ul style="list-style-type: none"> – 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.
79	PP	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.
80	PP	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

Clinical question

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

82	EBR <i>Low</i>	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).
83	PP	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.
84	EBR <i>Very low to low</i>	<p>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:</p> <p>For depression and or/anxiety:</p> <ul style="list-style-type: none">- therapeutic use of music and/or dancing- support and counselling- reminiscence therapy. <p>For agitation:</p> <ul style="list-style-type: none">- behavioural management interventions- therapeutic use of music and/or dancing- massage- reminiscence therapy.
85	EBR <i>Low</i>	<p>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;</p> <ul style="list-style-type: none">- 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 behavioural and psychological symptoms of dementia. 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.[247-257] Interventions that involved multiple components were frequently associated with positive results; five (of six) trials found a reduction in behavioural and psychological symptoms of dementia, 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.[148] Of the nine trials that provided data on the impact of behavioural interventions on behavioural and psychological symptoms of dementia, 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.[209] The results of the review suggested that cognitive stimulation was not associated with a reduction in global behavioural and psychological symptoms of dementia (based on eight studies) or mood (based on five studies).

Physical exercise

This evidence update identified 17 randomised controlled trials of exercise.[195 196]. Pooled data from four trials found there was no significant effect on global behavioural and psychological symptoms of dementia. 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.[258] The evidence update revealed a further six randomised controlled trials published subsequently.[259-266] Pooled analysis of six trials found that music was effective in reducing behavioural and psychological symptoms of dementia. 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.[148 267-269] Two (of five) trials reported reduced global behavioural and psychological symptoms of dementia 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.[148 270-272] Of the five studies reporting outcomes on agitation, all five reported significant reductions in behavioural and psychological symptoms of dementia. However, effects of the intervention were frequently assessed only in the short term.

Recreation therapy

Fifteen randomised controlled trials evaluated interventions of recreation therapy.[148 170 265 266 273-282] Results were mixed; three (of 11) studies found reduced behavioural and psychological symptoms of dementia. 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.[283] The review was unable to find any beneficial effects of light therapy on behavioural and psychological symptoms of dementia.

Aromatherapy

A Cochrane review identified two randomised controlled trials examining the effects of aromatherapy on behavioural and psychological symptoms of dementia.[284] The studies had mixed findings. One trial found that aromatherapy was associated with reduced global behavioural and psychological symptoms of dementia whereas the other trial found no significant effects.

Multisensory stimulation

Three randomised controlled trials examined the effects of multisensory stimulation for people with dementia.[148] While one small trial (n=24) reported reduced levels of agitation over time, a larger one (n=136) found no effects on behavioural and psychological symptoms of dementia.

Support and psychotherapy

Five randomised controlled trials examined the effects of support and psychotherapy on behavioural and psychological symptoms of dementia.[155][293 294] 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.[285 286] The quality of the studies was poor and findings were mixed and did not clearly identify benefits associated with animal-assisted therapy.

Evidence statements	GRADE Quality	Related recommendation
Five RCTs found that multicomponent interventions significantly reduced global BPSD (moderate)[247 250 254 256 257] whereas one RCT found no significant difference.[253] Four RCTs [249 251 255 257] found that multicomponent interventions significantly reduced levels of depression in the intervention group whereas one RCT found no effect (low).[248]	Low - Moderate	EBR 84
Three (of nine) RCTs included in a systematic review [148] found that behavioural management interventions reduced global BPSD (low). Three (of seven) RCTs reported reduced carer impact associated with the intervention (low).[148]	Low	EBR 84
A systematic review [209] which pooled 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).[269]	Very low - Low	NA
A systematic review [195] that pooled four RCTs evaluating the effects of exercise on global BPSD found no significant effects (low). Pooling of six RCTs found no significant effect on depression (low).[195] One RCT reported a reduction in carer impact (moderate).[195]	Low - Moderate	NA

Evidence statements	GRADE Quality	Related recommendation
A systematic review that pooled six trials investigating the effects of music therapy found a significant reduction in global BPSD. [258] A further three RCTs also reported a reduction in agitation associated with music therapy [261 263 265] whereas two RCTs found no significant results (low).[260 264] A systematic review which pooled four RCTs found a significant reduction in depression whereas a further study found no significant differences between groups (low).[258 259]	Low	EBR 84
Two (of five) RCTs included in a systematic review [148] found a significant reduction in global BPSD associated with reminiscence therapy (very low).[148] Two RCTs found significantly reduced levels of depression (low).[267 287]	Very low - Low	EBR 84
Five RCTs reported reductions in agitation following massage (low).[271 272 288-290]	Low	EBR 84
Three [265 266 275 276] (of 11) RCTs found that recreation therapy led to reduced global BPSD (low). One [273] (of six) RCTs reported reduced levels of depression (low).	Low	NA
A systematic review [283] which pooled 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).[283]	Very low - Low	NA
A systematic review [284] found that one (of two) RCTs reported that aromatherapy was associated with reduced global BPSD (very low).	Very low	NA
A systematic review [148] reported that one (of two) RCTs reported that multisensory stimulation was associated with reduced agitation (very low).	Very low	NA
One RCT [291] examining support and psychotherapy reported reduced levels of depression associated with the intervention (very low) whereas two other RCTs found no significant treatment effect.[292 293] One RCT reported improved quality of life in the intervention group (low).[293]	Very low - Low	EBR 84
One RCT reported no effect of animal-assisted therapy in reducing global BPSD [286] whereas another study reported a trend towards reduced symptoms (very low).[285]	Very low	NA

NA – The Guideline Adaptation Committee decided not to form a recommendation based on the available evidence.
See Tables 135-147 in Technical Report for GRADE Evidence Profiles

Pharmacological interventions

Pharmacological interventions may be prescribed to reduce behavioural and psychological symptoms of dementia 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 behavioural and psychological symptoms of dementia include acetylcholinesterase inhibitors, memantine, antipsychotics, antidepressants, mood stabilisers, benzodiazepines, melatonin and more recently analgesics.

Behavioural and psychological symptoms of dementia may be an expression of underlying pain. Pain is common in people with dementia.[294-296] 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.[297 298] Multiple studies have shown that increased pain is associated with an increase in behavioural and psychological symptoms of dementia. [299 300] Oral pain should be considered as a potential cause of behavioural and psychological symptoms of dementia.

Although non-pharmacological interventions are recommended as first-line treatment, the use of antipsychotics for people with dementia is relatively common.[41 301] 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.[302] In certain emergency situations where a person with dementia has very severe behavioural and psychological symptoms of dementia, acute sedation may be necessary for safety reasons.[303]

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 behavioural and psychological symptoms of dementia may not apply to those with pre-existing, comorbid serious mental illness. Potential side effects of medications should be explained to the person with dementia and their carer(s) and family.

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?

81	EBR <i>Low</i>	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. The trial should be for a defined time period, particularly if opioids are used.
86	EBR <i>Moderate</i>	People with dementia who experience agitation should be offered a trial of selective serotonin reuptake inhibitor (SSRI) antidepressants (the strongest evidence for effectiveness exists for citalopram) if non-pharmacological treatments are inappropriate or have failed. Review with evaluation of efficacy and consideration of de-prescribing should occur after two months. 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.
87	PP	Antidepressant medications with anticholinergic effects (e.g., tricyclic antidepressants) should be avoided because they may adversely affect cognition.
88	EBR <i>Moderate</i>	The role of antidepressants in the treatment of depression in people with dementia is uncertain. Larger trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se. Nevertheless, it is considered that those with a pre-existing history of major depression (prior to developing dementia) who develop a co-morbid major depression should be treated in the usual way.
89	EBR <i>Moderate</i>	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 increased risk of cerebrovascular adverse events and death.
90	PP	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. Acetylcholinesterase inhibitors could be considered. If antipsychotics are used for severe behavioural and psychological symptoms of dementia, atypical or second generation antipsychotics with low propensity to cause extrapyramidal side effects should be used; quetiapine and olanzapine are considered to have the best 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?

91	EBR <i>Moderate</i>	<p>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 olanzapine⁹ have the strongest evidence for treating agitation/aggression, with weaker evidence for aripiprazole.</p> <p>The following conditions should also be met:</p> <ul style="list-style-type: none"> – 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. – If there is no efficacy observed within a relatively short timeframe (usually one to two weeks), treatment should be discontinued. <p>Treatment should be reviewed every four to 12 weeks, considering the need for antipsychotics and possible cessation of medication. Review should include regular assessment and recording of changes in cognition and target symptoms.</p>
92	PP	Where people with dementia have moderate to severe behavioural and psychological symptoms of dementia that puts themselves or others at risk, referral to a specialist service for the management of behavioural and psychological symptoms should occur.
93	PP	<p>Health professionals who use medication in the management of violence, aggression and extreme agitation in people with dementia should:</p> <ul style="list-style-type: none"> – 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 any medications used 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.
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	There is a paucity of evidence regarding the efficacy and safety of parenteral medication in behavioural emergencies. However, in certain rare situations, parenteral medication may be required for the management of people with dementia with extreme behavioural and psychological symptoms of dementia. Because circumstances vary from setting to setting, local evidence-based guidelines should be developed to provide clinicians guidance about the appropriate use of parenteral medication in these situations for that setting (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 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	CBR	If parenteral medication is necessary for the control of violence, aggression and extreme agitation in people with dementia, olanzapine or lorazepam are preferred. Wherever possible, a single agent should be used in preference to a combination.

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?

98	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.
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Summary of the NICE Guideline findings

The NICE Guideline Committee recommended that medications for behavioural and psychological symptoms of dementia 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 behavioural and psychological symptoms of dementia. These are based upon both systematic evidence reviews and expert opinion.

Evidence update

This evidence update considered pharmacological interventions for behavioural and psychological symptoms of dementia 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 behavioural and psychological symptoms of dementia is a relatively new approach to care. The NICE Guideline Committee did not specifically look for evidence on the efficacy of analgesics for treating behavioural and psychological symptoms of dementia.

Three randomised controlled trials examined the effect of pharmacological treatment of pain on behavioural and psychological symptoms of dementia.[304-306] All three studies recruited participants with moderate-to-severe dementia residing in nursing homes. Two of the studies examined the effectiveness of regular paracetamol [304 305] whereas the third study examined the effectiveness of analgesic medication prescribed based on the use of a step-wise protocol [299]. Two of the three studies reported improved outcomes for people with dementia.[305 306]

Antidepressants

Dementia with concomitant depression

The NICE Guideline Committee considered evidence from a 2002 Cochrane systematic review.[307] 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.[308] Evidence from the third arm (examining mirtazapine) of one large, high quality trial included in the meta-analysis has also been considered.[309 310] Evidence for tricyclic antidepressants was not considered. The identified trials of SSRIs (four randomised controlled trials and a small pseudorandomised trial) or mirtazapine failed to show a significant improvement in

depression, global behavioural and psychological symptoms of dementia or quality of life in subjects with dementia and concomitant depression.[308 309] One included small randomised controlled trial demonstrated a significant improvement in depression according to one outcome measure (the Cornell Scale for Depression in Dementia), but not another (the Hamilton Depression Scale).[311] Overall, there was a lack of effectiveness of the antidepressants for treatment of depression in people with dementia.

Dementia with agitation/psychosis

This evidence update identified a review by Seitz and colleagues (2011) as the most recent, comprehensive systematic review of antidepressants for agitation in dementia.[312] Pooled data from two trials reporting the impact of SSRIs on agitation demonstrated a significant improvement in reducing agitation.[312] In addition, the Citalopram for Agitation in Alzheimer Disease Study (CitAD) was identified in a search for more recent primary studies.[313] This trial also demonstrated a significant improvement in reducing agitation. Thus, overall, two large randomised controlled trials of SSRIs compared to placebo have demonstrated a significant improvement in agitation,[313 314] 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.[313] 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.[313]

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 Dementia with Lewy Bodies. It was recommended that antipsychotics should only be offered to people with Alzheimer's disease, vascular dementia, mixed dementias or Dementia with Lewy Bodies 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.[315] The analysis demonstrated that atypical antipsychotics had small but statistically significant positive effects on behavioural and psychological symptoms of dementia 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).[316 317] No additional studies of atypical antipsychotics for behavioural and psychological symptoms of dementia published to November 2014 were identified.

A 2005 meta-analysis of 15 published and unpublished studies of atypical antipsychotic use in dementia indicated a statistically significant increased risk of mortality (3.5 per cent atypical antipsychotics vs 2.3 per cent placebo; OR 1.54, 95 per cent CI 1.06 to 2.23).[318] 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 United States Food and Drug Administration (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.[319] 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.[318] Data from an observational study indicated no significant difference in the risk of cardiovascular events between haloperidol and atypical antipsychotics.[320] 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 behavioural and psychological symptoms of dementia 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.[321] One small, fair quality study of carbamazepine demonstrated a significant improvement in behavioural and psychological symptoms of dementia (Brief Psychiatric Rating Scale total) over six weeks. No significant change in behavioural and psychological symptoms of dementia was observed in studies of divalproex or oxcarbazepine. No additional trials of mood stabilisers for behavioural and psychological symptoms of dementia 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.[322] 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 behavioural and psychological symptoms of dementia were identified in this evidence update.

Melatonin

The NICE Guideline Committee did not review the evidence for the use of Melatonin for behavioural and psychological symptoms of dementia.

A Cochrane review of pharmacological treatments for sleep disorders in Alzheimer's disease 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.[323] Another Cochrane review [324] of melatonin in dementia found positive effects on global behavioural and psychological symptoms of dementia across two studies.[325 326] However, some negative effects on mood were found in another trial.[327] 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 and the Guideline Adaptation Committee decided that the evidence was inadequate to inform a recommendation.

Parenterally administered medications

The NICE Guideline recommendations relating to the use of parenterally administered medications in emergency situations for very severe behavioural and psychological symptoms of dementia were based upon a single study of intramuscular lorazepam and olanzapine. This evidence update did not identify any additional studies for parenterally administered medications for behavioural and psychological symptoms of dementia. The Guideline Adaptation Committee decided that the evidence was inadequate to inform an evidence-based recommendation. These data were therefore used to inform a consensus-based recommendation, and a recommendation for the development of local guidelines that could apply in a range of settings and contexts (e.g., acute hospital settings, residential care) was made.

Evidence statements	GRADE Quality	Related recommendation
A systematic review [328] found that one of two RCTs examining the efficacy of analgesia to manage agitation reported a significant reduction in agitation and pain [306], with no significant change in adverse event rates in three RCTs.[304-306]	Low	EBR 81
A pooled analysis [308] of five studies (four RCTs and one pseudorandomised trial [308 309 311 329-331] indicated that antidepressants (SSRIs) do not have a statistically significant impact on depression in people with dementia overall. There were no significant effects on BPSD or quality of life (two RCTs). [309 332] Serious adverse event rates did not significantly differ in a pooled analysis of three RCTs. The systematic review [308] did not find a significant difference in cognition outcomes between SSRIs and placebo (five studies). The findings from an additional trial arm of mirtazapine were consistent.[309 310]	Low	EBR 88
Two large RCTs demonstrated a significant reduction in agitation with the use of selective serotonin reuptake inhibitors (SSRIs) compared to placebo in patients with dementia [313 314]; one additional very small RCT showed no significant difference [333] (Quality: moderate). One high quality RCT found that there was no significant difference in the number of serious adverse events between SSRIs and placebo (Quality: moderate).[313] Pooled data found no significant difference in trial withdrawals due to adverse events (four RCTs).[312] SSRI use was associated with a decrease in cognition (one point on the MMSE) and an increase in the QT interval on ECG, which is considered a surrogate outcome for adverse events (one RCT, Quality: low).[313]	Moderate	EBR 86
A pooled analysis of 17 RCTs indicated that atypical antipsychotics are associated with a small but statistically significant improvement in global BPSD.[315 334] In meta-analyses of individual medications, risperidone demonstrated a statistically significant positive effect on psychosis (five RCTs), but aripiprazole (three RCTs), olanzapine (five RCTs) and quetiapine (three RCTs) did not. Risperidone (six RCTs) and olanzapine (four RCTs) had a statistically significant positive effect on agitation, with weaker evidence of effectiveness for aripiprazole (two RCTs); no statistically significant difference was seen with quetiapine (five RCTs).[315 334] This is associated with a statistically significant increase in mortality (3.5% atypical antipsychotics vs 2.3% placebo) in a meta-analysis of 15 trials. [318] Separate meta-analyses demonstrated a significant increase in cardiovascular events with olanzapine (5 RCTs) and risperidone (6 RCTs) and cerebrovascular events with risperidone (3 RCTs).[315 334] There was no change in carer-rated quality of life in one RCT.[317]	Moderate	EBR 89,91
One RCT provided evidence that intramuscular olanzapine can improve agitation 2 hours after treatment.[322]	Moderate	CBR 97

Evidence statements	GRADE Quality	Related recommendation
A systematic review [321] found a significant improvement in BPSD (as measured with the Brief Psychiatric Rating Scale) with carbamazepine over six weeks [335] (one RCT; Quality: low). No significant effect on BPSD was found with divalproex sodium (two RCTs) [336 337] or oxcarbazepine (one RCT).[338]	Low	NA
No RCTs were identified that reported on the effectiveness of non-parenteral anxiolytics for BPSD (excluding intramuscular administration). One RCT reported that intramuscular lorazepam significantly improved BPSD two hours after treatment.[322]	Moderate	CBR 97
Pooled data from two small RCTs indicated that melatonin may be useful in BPSD.[325 326] There are also possible negative effects on mood (one RCT).[327] There is uncertainty in the overall body of evidence for melatonin effectiveness.	Low	NA

See Tables 156-166 in Technical Report for GRADE Evidence Profiles

Support for carers

Background

Most people with dementia live in the community with the support of carers and families.[4] 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. Support services need to be available for all those close to the person with dementia whether or not they see themselves as a carer. However, for simplicity the word 'carer' is used through this guideline to encompass all of these people who support the person with dementia.

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'.[339] Carers are typically the first to notice symptoms of dementia.[87] 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 behavioural and psychological symptoms of dementia.[339]

There are approximately 200,000 Australians caring for a person with dementia living in the community. [4] Approximately two thirds of these carers are women and approximately half are aged 65 or over. [4] Providing care and support for a person with any long term illness or disability is emotionally and physically demanding. Caring can be 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.

The carers and family of people with younger onset dementia are more likely than carers of older people with dementia to also be working, raising young children and have increased financial responsibilities. This can result in even greater physical and emotional demands of providing care and support.

Health and aged care professionals should engage with family members and carers of people with dementia of all ages as care partners as described in the 10 Principles of Dignity in Care.

Not all people with dementia have someone that they identify as a carer or someone that is able to provide regular support. The number of people without someone they identify as a carer is likely to increase due to increased divorce rates, delay in marriage and people choosing not to marry or have children.[340] The changing support and service considerations will be profound for people with dementia who would prefer to remain in their own home for as long as possible.

Clinical question		
Does assessment and/or intervention for carers produce benefits when compared to usual care?		
99	PP	Carers and families should be respected, listened to and included in the planning, decision making and care and management of people with dementia.
100	PP	Carers are at an increased risk of poor health and their needs should be assessed and reviewed regularly by their own health practitioner. Carer and family needs should be addressed regularly, including if the person with dementia has entered residential care, and after their death.
101	CBR	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, planned activity groups and residential respite.
102	EBR <i>Low</i>	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: <ul style="list-style-type: none"> – 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 their carer(s) and family, in support programs.
104	EBR <i>Low</i>	Health and aged care professionals should provide carers 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	Carers 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.[148] A search revealed a further 32 randomised controlled trials meeting the inclusion criteria [149 203 341-372] 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.

Overall, 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	GRADE Quality	Related recommendation
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.[148]	Very Low	CBR 101
Two RCTs of six studies identified in an existing systematic review [148] plus two [354 359] of five additional studies [350 351 360] investigating carer education programs reported a significant improvement on carer quality of life (low). Two (of four) RCTs reported a significant improvement in the quality of life of the person with dementia (low).[148 350 351 362]	Low	EBR 102
Pooling of three RCTs investigating carer support programs found a significant improvement in carer quality of life.[343 371 372] An additional two studies within an existing systematic review [148] could not be pooled but reported no effect (low). One RCT reported a significant reduction in carer impact (low).[371]	Low	EBR 102
One RCT reported a significant reduction in BPSD following provision of a multicomponent intervention for carers (low).[369] One of three RCTs in a systematic review [148] reported improved quality of life for the carer; an additional study also reported a treatment effect.[356] One RCT (included in a systematic review [148]) reported a reduction in carer impact. An additional one [369] of three ([346 365 369] studies also found a reduction in carer impact (very low).	Very Low - Low	EBR 102, 85
Four RCTs included within a systematic review [148] and an additional study [373] investigating multicomponent interventions involving the person with dementia and their carer found significant reductions in BPSD whereas eight studies found no effect [148 203 345 359 370](low). Three RCTs included in a systematic review [148] of seven total studies found an improvement in carer quality of life (low).[148] Three RCTs included in a systematic review [148] of six total studies found improved quality of life for the person with dementia (moderate).[148]	Low - Moderate	EBR 102, 85

NA – The Guideline Adaptation Committee decided not to form a recommendation based on the available evidence. See Tables 173-178 in Technical Report for GRADE Evidence Profiles

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 their preference.

The Senate Community Affairs References Committee recently recommended that a review of the adequacy of respite services for people with younger onset dementia be carried out urgently and that the Commonwealth should fund the development of a pilot younger onset dementia specific respite facility.[29]

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 life style 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 2013 dementia was listed as the underlying cause of death in 7.4 per cent of all deaths. [374] 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.[12]

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'.[375]

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.[376] 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.[377] Further, the prognosis for people with dementia is often unclear and clinicians may be reluctant or unable to provide a clear prognosis.[378] 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.[379] Clear communication between the health professional, the person and their family is essential to ensure that the most appropriate treatments are provided. The health professional should convey to the family when palliative care is indicated, why it is recommended and what is involved. 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.[380]

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.[50] 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.

Palliative approach		
106	PP	Care for people with advanced dementia should be based on a palliative approach and involve a palliative care service if indicated. Treatment and care should be provided as per the person's Advance Care Plans.
107	PP	Health and aged care staff and carers and families should continue to offer people with dementia food and drink by mouth. Assessment of swallowing and feeding from a speech pathologist may be indicated. 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.
108	PP	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.
109	PP	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 and time should be taken to discuss these issues with the carer(s), family and support networks.

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.

Economic considerations

Despite the significant costs of providing health and aged care services for people with dementia, there are relatively few published cost-effectiveness studies within the field and even fewer conducted within Australia.[381] Most of the studies conducted to date have examined the cost-effectiveness of acetylcholinesterase inhibitors.[44] A recent review of economic evaluations of dementia care found two economic evaluations of non-pharmacological interventions conducted in Australia; one was a 1991 study of a multi-component residential training program for carers [382] and the other of the impact of care management arrangements on delayed institutionalisation.[383]

As there have been very few economic evaluations in dementia care conducted for the Australian setting [44], information regarding the health economic impact of assessment and treatment options was treated as secondary information. That is, this information is discussed when reported in the included studies, but specific searches for these types of studies were not conducted and studies only reporting these outcomes were not included.

Further research

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.[384] 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 behavioural and psychological symptoms of dementia and to increase the self-determination and independence of the person with dementia.

Several years ago, the Dementia Research Mapping Project (2010) summarised existing evidence and identified gaps in dementia research.[16] 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.

Box 6: Priority areas for further research

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 a priority. 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 behavioural and psychological symptoms of dementia).

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 25: People with a possible diagnosis of dementia should be offered referral to memory assessment specialists or services for a comprehensive assessment.

Communicating the diagnosis

Recommendation 46: 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) and family.

Organisation of care

Recommendation 54: Health and aged care managers should coordinate and integrate, referral, transitions and communication across all agencies involved in the assessment, treatment, support and care of people with dementia and their carer(s) and families, including jointly agreeing on written policies and procedures. People with dementia and their carers and families should be involved in planning local policies and procedures.

Recommendation 55: Health system planners should ensure that people with dementia have access to a care coordinator who can work with them and their carers and families 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 59: 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.

Recommendation 60: 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 functional independence

Recommendation 67: 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 78: 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 families 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 82: 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 89: 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 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, planned activity groups 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)

Available from: www.nhmrc.gov.au Reference number: REC31

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

Available from: www.nhmrc.gov.au Reference number: EXT10

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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.

Consumers

In the context of this Guideline, consumers are people with dementia and/or their carers.

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. In some jurisdictions it also gives authority to consent or refusal of medical treatment and blood, organ or tissue donation.

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 patients 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 accumulate 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" or "may be offered".

Guideline Adaptation Committee

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. Consumers have played a key role in the development of this Guideline and their input has been critical to ensuring the Guideline remains relevant to the needs of people with dementia and their carers. We wish to thank Joan Jackman, Christine Bryden and Kate Swaffer who commented on drafts of the guideline from the perspective of the consumer and the carer representative.

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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 Guideline before public consultation
- review public consultation comments and consider revising the Guideline as necessary
- approve a final draft of the Guideline 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 Guideline as necessary
 - approve a final draft of the Guideline 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 Administrative 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.[107] The Dementia Outcomes Measurement Suite website also includes a list of tools recommended for the assessment of functional independence, behavioural and psychological symptoms of dementia, delirium, depression, quality of life, frontotemporal dementia and recommended measures for individual symptoms.

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

RECOMMENDED TOOLS

Modified Mini Mental Exam (3MS)

Purpose: 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.

Administration of the tool: Qualified health care professional (at least trained in the MMSE) interviews the patient using a standard set of questions.

Time: Approximately 15 minutes to administer plus five minutes to score.

Most Appropriate Use: 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.

Mini Mental State Exam (MMSE)

Purpose: 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. The Standardised Mini-Mental State Examination is freely available in Australian hospitals.

Administration of the tool: Qualified health care professional trained in the use of the tool interviews the patient using a standard set of questions.

Time: Approximately 10-15 minutes.

Most Appropriate Use: Acute, Primary, Community, and Residential Care to assess global cognitive status in older people.

The Alzheimer's Disease Assessment Scale — Cognition (ADAS-Cog)

Purpose: 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.

Administration of the tool: Staff with specialist qualifications - interviewer administered. Requires additional training.

Time: 30–45 minutes.

Most Appropriate Use: Usually administered by a neuropsychologist or psychologist with appropriate training.

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.

Rowland Universal Dementia Assessment Scale (RUDAS)

Designed to enable the easy translation of the items into other languages and to be culture fair – it is recommended for use with those from culturally and linguistically diverse backgrounds.

Purpose: Short cognitive screening tool, for assessment of dementia.

Administration of the tool: Interviewer administered, patient response questionnaire.

Time: Approximately 10 minutes

Most Appropriate Use: Primary, Community and Residential Care. The respondent is encouraged to communicate in their first language. Therefore, the use of an interpreter is important. (The RUDAS, however, contains an item on judgement that may be inappropriate for remote Indigenous situations.)

Kimberley Indigenous Cognitive Assessment (KICA-Cog)

Purpose: The only validated dementia assessment tool for older indigenous Australians.

Administration of the tool: Interviewer administered, patient response questionnaire.

Time: Approximately 10 minutes

Most Appropriate Use: Primary, Community and Residential Care. In remote communities for those age 45 and older, when other instruments are not appropriate.

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), VL0M 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

Type of dementia	Diagnostic criteria
Alzheimer's disease	ICD-10 and DSM-4
Vascular dementia	ICD-10 and DSM-4
Dementia with Lewy bodies	Consortium for DLB Diagnostic Criteria
Frontotemporal dementia	Lund-Manchester Criteria, NINDS criteria for frontotemporal dementia
DSM-4 Diagnostic and Statistical Manual of Mental Disorders, fourth edition; ICD-10 International Classification of Diseases, 10th revision; NINCDS National Institute of Neurological and Communicative	

Although the DSM-4 has been superseded by the DSM-5, the literature and clinical practice that has informed this Guideline is based upon the definitions used in the DSM-4 and therefore this definition is used in the Guideline. The DSM-5 does not use the term dementia.

Appendix 3 Alzheimer's Australia's Guide to Dementia Friendly Language

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

CONTEXT	PREFERRED TERMS	DO NOT USE
TALKING ABOUT DEMENTIA	<p>Dementia</p> <p>Alzheimer's disease and other forms of dementia</p> <p>A form of dementia</p> <p>A type of dementia</p> <p>Symptoms of dementia</p>	<p>Dementing illness</p> <p>Demented</p> <p>Affliction</p> <p>Senile dementia</p> <p>Senility</p> <p>Going on a journey</p>
TALKING ABOUT PEOPLE WITH DEMENTIA	<p>A person/people with dementia</p> <p>A person/people living with dementia</p> <p>A person/people with a diagnosis of dementia</p>	<p>Sufferer, Victim, Demented person, Dementing illness</p> <p>Dements, Afflicted, Offenders, absconders or perpetrators</p> <p>Patient (when used outside the medical context), Subject, Vacant dement,</p> <p>He/she's fading away or disappearing, Empty shell, Not all there, Losing him/her or someone who has lost their mind, He/she's an attention seeker,</p> <p>Inmates (referring to people with dementia in care facilities)</p> <p>An onion with the layers peeling away, 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.</p> <p>'They' (talking about all people with dementia rather than the individual)</p>
A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About themselves)	<p>Living alongside (someone/ a person/ my partner/my mother etc.) who has dementia</p> <p>Living with/caring for/supporting a person who has dementia</p> <p>Living with/caring for/supporting a person with a diagnosis of dementia</p> <p>Living with the impact of dementia</p>	<p>Person living with dementia</p>

CONTEXT	PREFERRED TERMS	DO NOT USE
A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About someone else)	<p>Family member(s)</p> <p>Person supporting someone living with dementia</p> <p>Wife/husband/partner</p> <p>Child/Son/Daughter</p> <p>Parent</p> <p>Friend</p> <p>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</p>	Person living with dementia
IMPACT OF CARING	<p>Impact of supporting (someone/a person/my partner/my mother etc.) with dementia</p> <p>Effect of supporting (someone/a person/my partner/my mother etc.) with dementia</p>	<p>Carer burden</p> <p>Burden of caring</p>
PEOPLE WITH DEMENTIA UNDER 65	Younger onset dementia	<p>Pre-senile dementia</p> <p>Early onset dementia</p>
THE IMPACTS OF DEMENTIA	<p>Disabling</p> <p>Challenging</p> <p>Life changing</p> <p>Stressful</p>	<p>Hopeless</p> <p>Unbearable</p> <p>Impossible</p> <p>Tragic</p> <p>Devastating</p> <p>Painful</p>
SYMPTOMS OF DEMENTIA	<p>Describe the symptom itself. For example, reduced vision, hallucinations, difficulty communicating</p> <p>Describe the impact it is having. For example, difficulty communicating</p>	

CONTEXT	PREFERRED TERMS	DO NOT USE
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 Violent offender

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 prejudge 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.

Appendix 5 Useful Resources

Alzheimer's Australia

Alzheimer's Australia provide a number of services and fact sheets. They have specific information designed for people with younger onset dementia, for people of CALD background and Indigenous Australians.

<https://fightdementia.org.au/>

Assessing Fitness to Drive

A detailed document with guidance for health professionals regarding dementia and driving.

<https://www.onlinepublications.austroads.com.au/items/AP-G56-13>

Advance Care Planning Australia

Information on advance care planning and a step by step guide on how to develop a care plan.

<http://advancecareplanning.org.au/>

Assessment and Management of People with BPSD: A Handbook for NSW Health Clinicians

A practical resource designed to help health professionals understand, assessment manage BPSD using both non-pharmacological and pharmacological treatments.

https://www.ranzcp.org/Files/Publications/A-Handbook-for-NSW-Health-Clinicians-BPSD_June13_W.aspx

Australian Commission on Safety and Quality in Health Care

The Commission has developed three resources to guide health service managers, clinicians and consumers in improving care of people with cognitive impairment in hospital.

<http://www.safetyandquality.gov.au/our-work/cognitive-impairment/better-way-to-care/>

Carer's Australia

The national peak body representing Australia's carers, advocating on behalf of Australia's carers to influence policies and services at a national level. It works collaboratively with partners and its member organisations, the network of state and territory Carers Associations, to deliver a range of essential national carer services.

<http://www.carersaustralia.com.au/>

Dementia Behaviour Management Advisory Service

A service to assist carers and aged care workers by providing short term case management for each person to ensure that the best interventions/support have been implemented to manage BPSD.

<http://dbmas.org.au/>

Dementia Outcomes Measurement Suite (DOMS)

DOMS provides information about measurement tools that may be used with people with dementia. These include assessments of: global function, cognition, behavioural and psychological symptoms of dementia, depression, quality of life.

<http://www.dementia-assessment.com.au/>

Dementia Training Study Centre

The training centres aim to enhance the knowledge and skills base of the current and future dementia care workforce. A number of different educational and training programs can be accessed via the website.

<http://dtsc.com.au/>

Dignity in Care

Resources to promote practice of the Principles of Dignity in Care.

www.dignityincare.org.uk/

Guidelines for Diagnosis and Care of Aboriginal People with Dementia in Remote Communities

Australian developed guidelines which take into account specific cultural considerations.

<http://www.wacha.org.au/docs/misc/DSC-Guidelines-for-diagnosis-and-care-of-Aboriginal-people-with-dementia-in-remote-communities.pdf>

Kimberley Indigenous Cognitive Assessment

Information regarding the KICA and access to the assessment tool.

<http://www.wacha.org.au/kica.html>

Managing Behavioural and Psychological Symptoms of Dementia: A Clinician's Field Guide to Good Practice

The field guide provides initial points for consideration for clinicians in their role of assisting residential aged care facility staff, community care staff and family members caring for persons living with dementia, who present with behavioural and psychological symptoms of dementia.

www.dementiaresearch.org.au/bpsdguide.html

My Aged Care

The My Aged Care website was established by the Australian Government to help people to navigate the aged care system. The website includes information regarding help at home, aged care homes, respite, support for carers, therapy services and advocacy services.

www.myagedcare.gov.au/

NPS MedicineWise

NPS MedicineWise is an independent, not-for-profit organisation that provides practical tools and evidence based information to improve the way health technologies, medicines and medical tests are prescribed and used. NPS MedicineWise receives funding from the Australian Government Department of Health.

<http://www.nps.org.au/>

Palliative Care Australia

Information for people with a terminal illness, carers and health professionals about palliative care, how to access palliative care, and the types of care provided.

<http://palliativecare.org.au/>

Partners in Culturally Appropriate Care (PICAC)

Organisations within the PICAC program are funded to deliver culturally appropriate care to older people from CALD backgrounds.

<https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/older-people-their-families-and-carers/people-from-diverse-backgrounds>

Screening and Diagnostic Assessment of Non-English Speaking People with Dementia

Guidelines and recommendations for health professionals to assist in assessment developed for Alzheimer's Australia.

<https://fightdementia.org.au/sites/default/files/20101224-Nat-CALD-ScreeningGuidelines-07May.pdf>

Clinical Practice Guidelines and Principles of Care for People with Dementia



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