

COGNITIVE DECLINE PARTNERSHIP CENTRE

Clinical Practice Guidelines for Dementia in Australia

Recommendations

Australian Government
National Health and Medical Research Council

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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

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The guidelines (recommendations) on pages 6-20 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

- 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

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 for Dementia in Australia

Recommendations

In Australia, approximately one in 10 older Australians have a diagnosis of dementia.[1] 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.[2]

The recommendations within this Clinical Practice Guideline were formed using the ADAPTE process [3] 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 [4]) 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 βamyloid 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 *Low*[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.

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

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

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 *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.

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.

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	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	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	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.

Behavioural and psychological symptoms of dementia

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: • 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; • 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.

81	EBR *Low*	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 *Low*	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 *Very low to Low*	For people with dementia who also have depression and/or anxiety or agitation, interventions should be tailored to the person's preferences, skills and abilities. The response to each modality should be monitored and the care plan adapted accordingly. Multicomponent interventions that involve engagement in activities that are enjoyable for the person with dementia plus individualised support should be offered where available. Where multicomponent interventions are not available, the following individual therapies should be considered: For depression and or/anxiety: • therapeutic use of music and/or dancing • support and counselling • reminiscence therapy. For agitation: • behavioural management interventions • therapeutic use of music and/or dancing • massage • reminiscence therapy.
85	EBR *Low*	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: • 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	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	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	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	People with dementia and severe behavioural and psychological symptoms of dementia (i.e., psychosis and/or agitation/aggression) causing significant distress to themselves or others, may be offered treatment with an antipsychotic medication. Risperidone has the strongest evidence for treating psychosis. Risperidone and olanzapine[1] have the strongest evidence for treating agitation/aggression, with weaker evidence for aripiprazole[5]. The following conditions should also be met: • There should be a full discussion with the person with dementia and their carers and family about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed. • Target symptoms should be identified, quantified and documented. • The effect of comorbid conditions, such as depression, should be considered. • The choice of antipsychotic should be made after an individual risk–benefit analysis. • The dose should be initially low and titrated upwards if necessary. • Monitoring for adverse effects including the metabolic syndrome should occur. • If there is no efficacy observed within a relatively short timeframe (usually one to two weeks), treatment should be discontinued. 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.

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

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: • 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.

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Appendix 1 Principles of Dignity in Care

This Guideline is underpinned by the 10 Principles of Dignity in Care. 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.

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.

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	Dementia Alzheimer's disease and other forms of dementia A form of dementia A type of dementia Symptoms of dementia	Dementing illness Demented Affliction Senile dementia Senility Going on a journey
TALKING ABOUT PEOPLE WITH DEMENTIA	A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia	Sufferer, Victim, Demented person, Dementing illness Dements, Afflicted, Offenders, absconders or perpetrators Patient (when used outside the medical context), Subject, Vacant dement, 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, Inmates (referring to people with dementia in care facilities) 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. 'They' (talking about all people with dementia rather than the individual)
A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About themselves)	Living alongside (someone/ a person/ my partner/my mother etc.) who has dementia Living with/caring for/supporting a person who has dementia Living with/caring for/supporting a person with a diagnosis of dementia Living with the impact of dementia	Person living with dementia

CONTEXT	PREFERRED TERMS	DO NOT USE
A CARER, FAMILY MEMBER OR FRIEND OF A PERSON WITH DEMENTIA (About someone else)	Family member(s) Person supporting someone living with dementia Wife/husband/partner Child/Son/Daughter Parent Friend Carer or care giver—not everyone will like to be referred to as a carer. If possible ask what the person's preference is before using this term	Person living with dementia
IMPACT OF CARING	Impact of supporting (someone/a person/my partner/my mother etc.) with dementia Effect of supporting (someone/a person/my partner/my mother etc.) with dementia	Carer burden Burden of caring
PEOPLE WITH DEMENTIA UNDER 65	Younger onset dementia	Pre-senile dementia Early onset dementia
THE IMPACTS OF DEMENTIA	Disabling Challenging Life changing Stressful	Hopeless Unbearable Impossible Tragic Devastating Painful
SYMPTOMS OF DEMENTIA	Describe the symptom itself. For example, reduced vision, hallucinations, difficulty communicating Describe the impact it is having. For example, difficulty communicating	

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.



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