

# Dementia: assessment, management and support for people living with dementia and their carers

NICE guideline

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## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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This guideline replaces CG42 and ESUOM41.

This guideline partially replaces TA217.

This guideline is the basis of QS30, QS50 and QS1.

## Overview

This guideline covers diagnosing and managing dementia (including Alzheimer's disease). It aims to improve care by making recommendations on training staff and helping carers to support people living with dementia.

NICE has also produced a guideline on [mid-life approaches to delay or prevent the onset of dementia](#).

## *Who is it for?*

- Healthcare and social care professionals caring for and supporting people living with dementia
- Commissioners and providers of dementia health and social care services
- Housing associations, private and voluntary organisations contracted by the NHS or social services to provide care for people living with dementia
- People living with dementia, their families and carers

## About this guideline

Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person's ability to carry out daily activities, such as shopping, washing, dressing and cooking. The most common types of dementia are: Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia. Dementia is a progressive condition, which means that the symptoms will gradually get worse. This progression will vary from person to person and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which these affect each person will vary ([Dementia Gateway](#), Social Care Institute for Excellence).

[A report published by the Alzheimer's Society](#) found that in 2013 there were approximately 815,000 people living with dementia in the UK. If current trends continue, this number is expected to increase to 1,143,000 by 2025. In England, the [National Dementia and Antipsychotic Prescribing Audit](#) found that approximately 31,000 people were newly diagnosed with dementia in 2011. This is an increase of 8% between 2006 and 2011. Finally, in December 2017, there were 456,739 people on GP registers with a formal diagnosis of dementia, up from approximately 290,000 people in 2009/10, with the majority of this difference accounted for by an increase in diagnosis rates.

The Alzheimer's Society report found that in 2013 the total cost of dementia in the UK was estimated to be £26.3 billion. Of this, approximately £4.3 billion consists of health care, and approximately £10.3 billion consists of social care. The remaining £11.6 billion accounts for estimated unpaid care contributions.

## *Why is it needed?*

Providing care and support is very complex, because of the number of people living with dementia and the variation in the symptoms each person faces. This has led to considerable variation in practice. Areas that pose particular challenges for services and practitioners may include:

- coordinating care and support between different services
- what support carers need, and how this should be provided
- staff training.

This guideline makes evidence-based recommendations aiming to support these areas of practice.

Dementia also has significant costs for health and social care services. Because of this, it is important to ensure that people living with dementia can get the care and support they need, and that services provide this in an efficient and cost-effective way.

In addition, new methods for diagnosing and assessing dementia have been developed. Amyloid imaging techniques have been licensed for use in the UK, and new evidence is available for cerebrospinal fluid examination. There is also evidence on different approaches to assess and diagnose dementia subtypes. The guideline makes new recommendations on dementia diagnosis, based on a review of the latest evidence.

### *What does it cover?*

This guideline addresses how dementia should be assessed and diagnosed. It covers person-centred care and support, tailored to the specific needs of each person living with dementia. As part of this, it can help professionals involve people living with dementia and their carers in decision-making, so they can get the care and support they need. It also addresses care coordination and staff training, and how dementia may impact on the care offered for other conditions.

The guideline does not cover every aspect of dementia care or support, or areas where recommendations would be the same for people with or without dementia. It focuses on areas where:

- there is variation in practice, and enough evidence is available to identify what works best
- people living with dementia need different care and support to people in the same situation who do not have dementia.

### *How has it been developed?*

This guideline has been developed by a multidisciplinary guideline committee, using an extensive review of research evidence. To ensure that the committee had the necessary social care expertise, a subgroup of social care practitioners was recruited to develop recommendations in this area.

Given the costs of dementia and the financial pressures facing health and social care services, the committee focused on making recommendations in areas where there is good evidence available. This will help services make the most of limited resources. For areas with a lack of evidence, the committee has made [recommendations for future research](#) (on health and social care topics) to address gaps in the evidence base. Future updates of the guideline will look at any relevant new research that has been published.

Some recommendations are made with more certainty than others. We word our recommendations to reflect this. In the sections on interventions we use 'offer' to reflect a strong recommendation, usually where there is clear evidence of benefit. We use 'consider' to reflect a recommendation for which the evidence of benefit is less certain. For more information see [making decisions using NICE guidelines](#).

### *How does it relate to statutory and non-statutory guidance?*

The guideline complements existing legislation and guidance. It describes how services and professionals can provide high-quality care and support.

The [Prime Minister's Challenge on Dementia 2020](#) sets out the UK Government's strategy for transforming dementia care within the UK. The aims of the strategy include:

- improving diagnosis, assessment and care for people living with dementia
- ensuring that all people living with dementia have equal access to diagnosis
- providing all NHS staff with training on dementia appropriate to their role
- ensuring that every person diagnosed with dementia receives meaningful care.

Since the 2006 NICE guideline on dementia was developed, key new legislation has been implemented. The [Care Act 2014](#) created a new legislative framework for adult social care, and also gives carers a legal right to assessment and support.

### **Relevant legislation and statutory guidance**

- NHS England (2015) [Accessible Information Standard](#)
- [Care Act 2014](#)
- [Health and Social Care Act 2008 \(Regulated Activities\) Regulations 2014](#)
- Department of Health (2014) [Care Act 2014: Statutory Guidance for Implementation](#)
- Department of Health (2014) [Positive and Proactive Care: Reducing the need for restrictive interventions](#)
- [Health and Social Care Act 2012](#)
- [Equality Act 2010](#)



- [Mental Capacity Act 2005](#)
- [Human Rights Act 1998](#)

## Relevant policies and non-statutory guidance

- Information Commissioner's Office (2017) [Guide to the General Data Protection Regulation](#)
- NHS England (2017) [Dementia: Good Care Planning](#)
- NHS England (2015) [Implementation guide and resource pack for dementia care](#)
- Skills for Health, Health Education England and Skills for Care (2015) [Dementia Core Skills Education and Training Framework](#). This framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care
- Department of Health (2014) [NHS Outcomes Framework 2015 to 2016](#)
- Department of Health (2014) [Adult Social Care Outcomes Framework 2015 to 2016](#)

## More information

You can also see this guideline in the NICE Pathway on [dementia](#).

To find out what NICE has said on topics related to this guideline, see our web page on [dementia](#).

See also the guideline committee's discussion and the evidence reviews (in the [full guideline](#)), and information about [how the guideline was developed](#), including details of the committee.

## Person-centred care

This guideline offers best-practice advice on care and support for people living with dementia and their families and carers. The principles of person-centred care underpin good practice in dementia care, and they are reflected in the recommendations. These principles assert:

- the human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers
- the individuality of people living with dementia, and how their personality and life experiences influence their response to dementia
- the importance of the person's perspective
- the importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

Finally, the principles emphasise the importance of taking account of the needs of carers (whether they are family and friends or paid care-workers), and supporting and enhancing their input.

## Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

NICE has also produced:

- a guideline on [decision making and mental capacity](#), which provides further details on how practitioners can support decision-making for people who may lack capacity now or in the future
- patient decision aids on [antipsychotic medicines for treating agitation, aggression and distress in people living with dementia](#) and [enteral \(tube\) feeding for people living with severe dementia](#).

### 1.1 *Involving people living with dementia in decisions about their care*

#### Involving people in decision-making

- 1.1.1 Encourage and enable people living with dementia to give their own views and opinions about their care.
- 1.1.2 If needed, use additional or modified ways of communicating (for example visual aids or simplified text).
- 1.1.3 Consider using a structured tool to assess the likes and dislikes, routines and personal history of a person living with dementia.

#### Providing information

- 1.1.4 Provide people living with dementia and their family members or carers (as appropriate) with information that is relevant to their circumstances and the stage of their condition.
- 1.1.5 Be aware of the obligation to provide accessible information as detailed in the

NHS [Accessible Information Standard](#). For more guidance on providing information and discussing people's preferences with them, see the NICE [guidelines on patient experience in adult NHS services](#) and [people's experience in adult social care services](#).

1.1.6 At diagnosis, offer the person and their family members or carers (as appropriate) oral and written information that explains:

- what their dementia subtype is and the changes to expect as the condition progresses
- which healthcare professionals and social care teams will be involved in their care and how to contact them
- if appropriate, how dementia affects driving, and that they need to tell the Driver and Vehicle Licensing Agency (DVLA) and their car insurer about their dementia diagnosis
- their legal rights and responsibilities
- their right to reasonable adjustments (in line with the [Equality Act 2010](#)) if they are working or looking for work
- how the following groups can help and how to contact them:
  - local support groups, online forums and national charities
  - financial and legal advice services
  - advocacy services.

1.1.7 If it has not been documented earlier, ask the person at diagnosis:

- for their consent for services to share information
- which people they would like services to share information with (for example family members or carers)
- what information they would like services to share.

Document these decisions in the person's records.

1.1.8 After diagnosis, direct people and their family members or carers (as appropriate) to relevant services for information and support (see

recommendations 1.3.1 and 1.3.2 on care coordination).

- 1.1.9 For people who do not want follow-up appointments and who are not using other services, ask if they would like to be contacted again at a specified future date.
- 1.1.10 Ensure that people living with dementia and their carers know how to get more information and who from if their needs change.
- 1.1.11 Tell people living with dementia (at all stages of the condition) about research studies they could participate in.

## Advance care planning

- 1.1.12 Offer early and ongoing opportunities for people living with dementia and people involved in their care (see recommendation 1.1.7) to discuss:
  - the benefits of planning ahead
  - lasting power of attorney (for health and welfare decisions and property and financial affairs decisions)
  - an advance statement about their wishes, preferences, beliefs and values regarding their future care
  - advance decisions to refuse treatment
  - their preferences for place of care and place of death.

Explain that they will be given chances to review and change any advance statements and decisions they have made.

- 1.1.13 At each care review, offer people the chance to review and change any advance statements and decisions they have made.

## 1.2 *Diagnosis*

### Initial assessment in non-specialist settings

- 1.2.1 At the initial assessment take a history (including cognitive, behavioural and

psychological symptoms, and the impact symptoms have on their daily life):

- from the person with suspected dementia and
- if possible, from someone who knows the person well (such as a family member).

1.2.2 If dementia is still suspected after initial assessment:

- conduct a physical examination and
- undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline and
- use cognitive testing.

1.2.3 When using cognitive testing, use a validated brief structured cognitive instrument such as:

- the 10-point cognitive screener (10-CS)
- the 6-item cognitive impairment test (6CIT)
- the 6-item screener
- the Memory Impairment Screen (MIS)
- the Mini-Cog
- Test Your Memory (TYM).

1.2.4 Do not rule out dementia solely because the person has a normal score on a cognitive instrument.

1.2.5 When taking a history from someone who knows the person with suspected dementia, consider supplementing this with a structured instrument such as the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) or the Functional Activities Questionnaire (FAQ).

1.2.6 Refer the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service) if:

- reversible causes of cognitive decline (including delirium, depression, sensory

- impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated and
- dementia is still suspected.

1.2.7 If the person has suspected rapidly-progressive dementia, refer them to a neurological service with access to tests (including cerebrospinal fluid examination) for Creutzfeldt–Jakob disease and similar conditions.

1.2.8 For more guidance on assessing for dementia in people with learning disabilities, see the NICE guideline on mental health problems in people with learning disabilities.

## Diagnosis in specialist dementia diagnostic services

1.2.9 Diagnose a dementia subtype (if possible) if initial specialist assessment (including an appropriate neurological examination and cognitive testing) confirms cognitive decline and reversible causes have been ruled out.

1.2.10 If Alzheimer's disease is suspected, include a test of verbal episodic memory in the assessment.

1.2.11 Consider neuropsychological testing if it is unclear:

- whether the person has cognitive impairment or
- whether their cognitive impairment is caused by dementia or
- what the correct subtype diagnosis is.

1.2.12 Use validated criteria to guide clinical judgement when diagnosing dementia subtypes, such as:

- International consensus criteria for dementia with Lewy bodies
- International FTD criteria for frontotemporal dementia (progressive non-fluent aphasia and semantic dementia)
- International Frontotemporal Dementia Consortium criteria for behavioural variant frontotemporal dementia

- NINDS-AIREN criteria (National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherche et l'Enseignement en Neurosciences) for vascular dementia
- NIA criteria (National Institute on Aging) for Alzheimer's disease
- Movement disorders Society criteria for Parkinson's disease dementia
- International criteria for Creutzfeldt-Jakob disease.

1.2.13 Offer structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear.

1.2.14 Only consider further tests (recommendations 1.2.15–28) if:

- it would help to diagnose a dementia subtype and
- knowing more about the dementia subtype would change management.

### ***Further tests for Alzheimer's disease***

1.2.15 If the diagnosis is uncertain (see recommendation 1.2.14) and Alzheimer's disease is suspected, consider either:

- FDG-PET (fluorodeoxyglucose-positron emission tomography-CT), or perfusion SPECT (single-photon emission CT) if FDG-PET is unavailable

or

- examining cerebrospinal fluid for:
  - either total tau or total tau and phosphorylated-tau 181 and
  - either amyloid beta 1–42 or amyloid beta 1–42 and amyloid beta 1–40.

If a diagnosis cannot be made after one of these tests, consider using the other one.

1.2.16 Be aware that the older a person is, the more likely they are to get a false positive with cerebrospinal fluid examination.

1.2.17 Do not rule out Alzheimer's disease based solely on the results of CT or MRI



scans.

- 1.2.18 Do not use Apolipoprotein E genotyping or electroencephalography to diagnose Alzheimer's disease.
- 1.2.19 Be aware that young-onset Alzheimer's disease has a genetic cause in some people.

### ***Further tests for dementia with Lewy bodies***

- 1.2.20 If the diagnosis is uncertain (see recommendation 1.2.14) and dementia with Lewy bodies is suspected, use  $^{123}\text{I}$ -FP-CIT SPECT.
- 1.2.21 If  $^{123}\text{I}$ -FP-CIT SPECT is unavailable, consider  $^{123}\text{I}$ -MIBG cardiac scintigraphy.
- 1.2.22 Do not rule out dementia with Lewy bodies based solely on normal results on  $^{123}\text{I}$ -FP-CIT SPECT or  $^{123}\text{I}$ -MIBG cardiac scintigraphy.

### ***Further tests for frontotemporal dementia***

- 1.2.23 If the diagnosis is uncertain (see recommendation 1.2.14) and frontotemporal dementia is suspected, use either:
- FDG-PET or
  - perfusion SPECT.
- 1.2.24 Do not rule out frontotemporal dementia based solely on the results of structural, perfusion or metabolic imaging tests.
- 1.2.25 Be aware that frontotemporal dementia has a genetic cause in some people.

### ***Further tests for vascular dementia***

- 1.2.26 If the dementia subtype is uncertain and vascular dementia is suspected, use MRI. If MRI is unavailable or contraindicated, use CT.
- 1.2.27 Do not diagnose vascular dementia based solely on vascular lesion burden.
- 1.2.28 Be aware that young-onset vascular dementia has a genetic cause in some

people.

## Case finding

1.2.29 Only conduct [case finding](#) for suspected dementia as part of a clinical trial that also provides an intervention to people diagnosed with dementia.

## Telling the difference between delirium and dementia in people without a diagnosis of either

1.2.30 For people who are in hospital and have cognitive impairment with an unknown cause, consider using one of the following to find out whether they have delirium or delirium superimposed on dementia, compared with dementia alone:

- the long confusion assessment method (CAM)
- the Observational Scale of Level of Arousal (OSLA).

1.2.31 Do not use standardised instruments (including cognitive instruments) alone to distinguish delirium from delirium superimposed on dementia.

1.2.32 If it is not possible to tell whether a person has delirium, dementia, or delirium superimposed on dementia, treat for delirium first. For guidance on treating delirium, see [treating delirium](#) in the NICE guideline on delirium.

## Review after diagnosis

1.2.33 After a person is diagnosed with dementia, ensure they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service.

1.2.34 Memory services and equivalent hospital- and primary-care-based multidisciplinary dementia services should offer a choice of flexible access or prescheduled monitoring appointments.

1.2.35 When people living with dementia or their carers have a primary care appointment, assess for any emerging dementia-related needs and ask them if they need any more support.

## 1.3 Care coordination

1.3.1 Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care.

1.3.2 Named professionals should:

- arrange an initial assessment of the person's needs, which should be face to face if possible
- provide information about available services and how to access them
- involve the person's family members or carers (as appropriate) in support and decision-making
- give special consideration to the views of people who do not have capacity to make decisions about their care, in line with the principles of the [Mental Capacity Act 2005](#)
- ensure that people are aware of their rights to and the availability of local advocacy services, and if appropriate to the immediate situation an independent mental capacity advocate
- develop a care and support plan, and:
  - agree and review it with the involvement of the person, their family members or carers (as appropriate) and relevant professionals
  - specify in the plan when and how often it will be reviewed
  - evaluate and record progress towards the objectives at each review
  - ensure it covers the management of any comorbidities
  - provide a copy of the plan to the person and their family members or carers (as appropriate).

## Transferring information between services and care settings

1.3.3 When developing care and support plans and advance care and support plans, request consent to transfer these to different care settings as needed.

1.3.4 Service providers should ensure that information (such as care and support

plans and advance care and support plans) can be easily transferred between different care settings (for example home, inpatient, community and residential care).

- 1.3.5 Staff delivering care and support should maximise continuity and consistency of care. Ensure that relevant information is shared and recorded in the person's care and support plan.

## Making services accessible

- 1.3.6 Service providers should design services to be accessible to as many people living with dementia as possible, including:

- people who do not have a carer or whose carer cannot support them on their own
- people who do not have access to affordable transport, or find transport difficult to use
- people who have other responsibilities (such as work, children or being a carer themselves)
- people with learning disabilities, sensory impairment (such as sight or hearing loss) or physical disabilities
- people who may be less likely to access health and social care services, such as people from black, Asian and minority ethnic groups.

## 1.4 *Interventions to promote cognition, independence and wellbeing*

- 1.4.1 Offer a range of activities to promote wellbeing that are tailored to the person's preferences.
- 1.4.2 Offer group cognitive stimulation therapy to people living with mild to moderate dementia.
- 1.4.3 Consider group reminiscence therapy for people living with mild to moderate dementia.
- 1.4.4 Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia.

- 1.4.5 Do not offer acupuncture to treat dementia.
- 1.4.6 Do not offer ginseng, vitamin E supplements, or herbal formulations to treat dementia.
- 1.4.7 Do not offer [cognitive training](#) to treat mild to moderate Alzheimer's disease.
- 1.4.8 Do not offer [interpersonal therapy](#) to treat the cognitive symptoms of mild to moderate Alzheimer's disease.
- 1.4.9 Do not offer non-invasive brain stimulation (including transcranial magnetic stimulation) to treat mild to moderate Alzheimer's disease, except as part of a randomised controlled trial.

## 1.5 *Pharmacological interventions for dementia*

### Managing medicines for all dementia subtypes

- 1.5.1 For guidance on managing medicines (including covert administration), see the NICE guidelines on [managing medicines for adults receiving social care in the community](#) and [managing medicines in care homes](#).

### Pharmacological management of Alzheimer's disease

- 1.5.2 The three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine as monotherapies are recommended as options for managing mild to moderate Alzheimer's disease under all of the conditions specified in 1.5.5 and 1.5.6.

This recommendation is from NICE technology appraisal guidance on [donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#).

- 1.5.3 Memantine monotherapy is recommended as an option for managing Alzheimer's disease for people with:
  - moderate Alzheimer's disease who are intolerant of or have a contraindication to AChE inhibitors or

- severe Alzheimer's disease.

Treatment should be under the conditions specified in 1.5.5.

This recommendation is from NICE technology appraisal guidance on [donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#).

1.5.4 For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor:

- consider memantine in addition to an AChE inhibitor if they have moderate disease
- offer memantine in addition to an AChE inhibitor if they have severe disease.

1.5.5 Treatment should be under the following conditions:

- For people who are not taking an AChE inhibitor or memantine, prescribers should only start treatment with these on the advice of a clinician who has the necessary knowledge and skills. This could include:
  - secondary care medical specialists such as psychiatrists, geriatricians and neurologists
  - other healthcare professionals (such as GPs, nurse consultants and advanced nurse practitioners), if they have specialist expertise in diagnosing and treating Alzheimer's disease.
- Once a decision has been made to start an AChE inhibitor or memantine, the first prescription may be made in primary care.
- For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor, primary care prescribers may start treatment with memantine (see recommendation 1.5.4) without taking advice from a specialist clinician.
- Ensure that local arrangements for prescribing, supply and treatment review follow the NICE guideline on [medicines optimisation](#).
- Do not stop AChE inhibitors in people with Alzheimer's disease because of disease severity alone.

1.5.6 If prescribing an AChE inhibitor (donepezil, galantamine or rivastigmine), treatment should normally be started with the drug with the lowest acquisition

cost (taking into account required daily dose and the price per dose once shared care has started). However, an alternative AChE inhibitor could be prescribed if it is considered appropriate when taking into account adverse event profile, expectations about adherence, medical comorbidity, possibility of drug interactions and dosing profiles.

This recommendation is from NICE technology appraisal guidance on [donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#).

- 1.5.7 When using assessment scales to determine the severity of Alzheimer's disease, healthcare professionals should take into account any physical, sensory or learning disabilities, or communication difficulties that could affect the results and make any adjustments they consider appropriate. Healthcare professionals should also be mindful of the need to secure equality of access to treatment for patients from different ethnic groups, in particular those from different cultural backgrounds.

This recommendation is from NICE technology appraisal guidance on [donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#).

- 1.5.8 When assessing the severity of Alzheimer's disease and the need for treatment, healthcare professionals should not rely solely on cognition scores in circumstances in which it would be inappropriate to do so. These include:

- if the cognition score is not, or is not by itself, a clinically appropriate tool for assessing the severity of that patient's dementia because of the patient's learning difficulties or other disabilities (for example, sensory impairments), linguistic or other communication difficulties or level of education or
- if it is not possible to apply the tool in a language in which the patient is sufficiently fluent for it to be appropriate for assessing the severity of dementia or
- if there are other similar reasons why using a cognition score, or the score alone, would be inappropriate for assessing the severity of dementia.

In such cases healthcare professionals should determine the need for initiation or continuation of treatment by using another appropriate method of assessment.

- This recommendation is from NICE technology appraisal guidance on [donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#).

1.5.9 Do not offer the following specifically to slow the progress of Alzheimer's disease, except as part of a randomised controlled trial:

- diabetes medicines
- hypertension medicines
- statins
- non-steroidal anti-inflammatory drugs (NSAIDs), including aspirin.

## Pharmacological management of non-Alzheimer's dementia

1.5.10 Offer donepezil or rivastigmine to people with mild to moderate dementia with Lewy bodies.<sup>[1]</sup>

1.5.11 Only consider galantamine<sup>[2]</sup> for people with mild to moderate dementia with Lewy bodies if donepezil and rivastigmine<sup>[1]</sup> are not tolerated.

1.5.12 Consider donepezil or rivastigmine for people with severe dementia with Lewy bodies<sup>[1]</sup>.

1.5.13 Consider memantine<sup>[3]</sup> for people with dementia with Lewy bodies if AChE inhibitors<sup>[4]</sup> are not tolerated or are contraindicated.

1.5.14 Only consider AChE inhibitors<sup>[4]</sup> or memantine<sup>[3]</sup> for people with vascular dementia if they have suspected comorbid Alzheimer's disease, Parkinson's disease dementia or dementia with Lewy bodies.

1.5.15 Do not offer AChE inhibitors or memantine to people with frontotemporal dementia<sup>[5]</sup>.

1.5.16 Do not offer AChE inhibitors or memantine to people with cognitive impairment caused by multiple sclerosis.

1.5.17 For guidance on pharmacological management of Parkinson's disease dementia,



see [Parkinson's disease dementia](#) in the NICE guideline on Parkinson's disease.

## 1.6 *Medicines that may cause cognitive impairment*

- 1.6.1 Be aware that some commonly prescribed medicines are associated with increased anticholinergic burden, and therefore cognitive impairment.
- 1.6.2 Consider minimising the use of medicines associated with increased anticholinergic burden, and if possible look for alternatives:
- when assessing whether to refer a person with suspected dementia for diagnosis
  - during medication reviews with people living with dementia.
- 1.6.3 Be aware that there are validated tools for assessing anticholinergic burden (for example, the Anticholinergic Cognitive Burden Scale), but there is insufficient evidence to recommend one over the others.
- 1.6.4 For guidance on carrying out medication reviews, see [medication review](#) in the NICE guideline on medicines optimisation.

## 1.7 *Managing non-cognitive symptoms*

### **Agitation, aggression, distress and psychosis**

- 1.7.1 Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to:
- explore possible reasons for their distress and
  - check for and address clinical or environmental causes (for example pain, delirium or inappropriate care).
- 1.7.2 As initial and ongoing management, offer psychosocial and environmental interventions to reduce distress in people living with dementia.
- 1.7.3 Only offer antipsychotics<sup>[6],[7]</sup> for people living with dementia who are either:
- at risk of harming themselves or others or

- experiencing agitation, hallucinations or delusions that are causing them severe distress.
- 1.7.4 Be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions. For more guidance, see the advice on [managing delusions and hallucinations](#) in the NICE guideline on Parkinson's disease. Be aware that interventions may need to be modified for people living with dementia.
- 1.7.5 Before starting antipsychotics, discuss the benefits and harms with the person and their family members or carers (as appropriate). Consider using a decision aid to support this discussion. NICE has produced a patient decision aid on [antipsychotic medicines for treating agitation, aggression and distress in people living with dementia](#).
- 1.7.6 When using antipsychotics:
- use the lowest effective dose and use them for the shortest possible time
  - reassess the person at least every 6 weeks, to check whether they still need medication.
- 1.7.7 Stop treatment with antipsychotics:
- if the person is not getting a clear ongoing benefit from taking them and
  - after discussion with the person taking them and their family members or carers (as appropriate).
- 1.7.8 Ensure that people living with dementia can continue to access psychosocial and environmental interventions for distress while they are taking antipsychotics and after they have stopped taking them.
- 1.7.9 For people living with dementia who experience agitation or aggression, offer personalised activities to promote engagement, pleasure and interest.
- 1.7.10 Do not offer valproate to manage agitation or aggression in people living with dementia, unless it is indicated for another condition.<sup>[8]</sup>

## Depression and anxiety

- 1.7.11 For people living with mild to moderate dementia who have mild to moderate depression and/or anxiety, consider psychological treatments.
- 1.7.12 Do not routinely offer antidepressants to manage mild to moderate depression in people living with mild to moderate dementia, unless they are indicated for a pre-existing severe mental health problem.

## Sleep problems

- 1.7.13 Do not offer melatonin to manage insomnia in people living with Alzheimer's disease.
- 1.7.14 For people living with dementia who have sleep problems, consider a personalised multicomponent sleep management approach that includes sleep hygiene education, exposure to daylight, exercise and personalised activities.

## Parkinson's disease

- 1.7.15 For guidance on managing Parkinson's disease symptoms in people with Parkinson's disease dementia or dementia with Lewy bodies, see the NICE guideline on [Parkinson's disease](#). Be aware that interventions may need to be modified for people living with dementia.

## 1.8 *Assessing and managing other long-term conditions in people living with dementia*

- 1.8.1 Ensure that people living with dementia have equivalent access to diagnosis, treatment and care services for comorbidities to people who do not have dementia. For more guidance on assessing and managing multimorbidity, see the NICE guidelines on [multimorbidity](#) and [older people with social care needs and multiple long-term conditions](#).
- 1.8.2 For more guidance on providing support for older adults with learning disabilities, see the NICE guideline on [care and support of people growing older with learning disabilities](#).

## Pain

- 1.8.3 Consider using a structured observational pain assessment tool:
- alongside self-reported pain and standard clinical assessment for people living with moderate to severe dementia
  - alongside standard clinical assessment for people living with dementia who are unable to self-report pain.
- 1.8.4 For people living with dementia who are in pain, consider using a stepwise treatment protocol that balances pain management and potential adverse events.
- 1.8.5 Repeat pain assessments for people living with dementia:
- who seem to be in pain
  - who show signs of behavioural changes that may be caused by pain
  - after any pain management intervention.

## Falls

- 1.8.6 For guidance on managing the risk of falling for people living with dementia (in community and inpatient settings), see the NICE guideline on [falls in older people](#). When using this guideline:
- take account of the additional support people living with dementia may need to participate effectively
  - be aware that multifactorial falls interventions may not be suitable for a person living with severe dementia.

## Diabetes

- 1.8.7 For guidance on setting HbA1c targets for people living with severe dementia who have type 2 diabetes, see [recommendation 1.6.9](#) in the NICE guideline on type 2 diabetes in adults.

## Incontinence

- 1.8.8 For guidance on pharmacological treatment of overactive bladder, see the NICE technology appraisal on [mirabegron for treating symptoms of overactive bladder](#).
- 1.8.9 For guidance on treating faecal incontinence, see [recommendations 1.7.2 and 1.7.8](#) in the NICE guideline on faecal incontinence.

## Sensory impairment

- 1.8.10 For guidance on hearing assessments for people with suspected or diagnosed dementia, see [adults with suspected dementia](#) in the NICE guideline on hearing loss.
- 1.8.11 Encourage people living with dementia to have eye tests every 2 years. Consider referring people who cannot organise appointments themselves.

## 1.9 *Risks during hospital admission*

- 1.9.1 Be aware of the increased risk of delirium in people living with dementia who are admitted to hospital. See the NICE guideline on delirium for interventions to [prevent](#) and [treat](#) delirium.
- 1.9.2 When thinking about admission to hospital for a person living with severe dementia, carry out an assessment that balances their current medical needs with the additional harms they may face in hospital, for example:
- disorientation
  - a longer length of stay
  - increased mortality
  - increased morbidity on discharge
  - delirium
  - the effects of being in an impersonal or institutional environment.
- 1.9.3 When thinking about admission to hospital for a person living with dementia,

take into account:

- any advance care and support plans
- the value of keeping them in a familiar environment.

## 1.10 *Palliative care*

- 1.10.1 From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.
- 1.10.2 For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process (see [recommendation 1.1.12](#) on advance care planning). Involve the person and their family members or carers (as appropriate) as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.
- 1.10.3 For standards and measures on palliative care, see the NICE quality standard on [end of life care for adults](#).
- 1.10.4 For guidance on care for people in the last days of life, see the NICE guideline on [care of dying adults](#).
- 1.10.5 For guidance on best interests decision-making, see the NICE guideline on [decision-making and mental capacity](#).
- 1.10.6 Encourage and support people living with dementia to eat and drink, taking into account their nutritional needs.
- 1.10.7 Consider involving a speech and language therapist if there are concerns about a person's safety when eating and drinking.
- 1.10.8 Do not routinely use enteral feeding in people living with severe dementia, unless indicated for a potentially reversible comorbidity. NICE has produced a patient decision aid on [enteral \(tube\) feeding for people living with severe dementia](#).

## 1.11 *Supporting carers*

1.11.1 Offer carers of people living with dementia a psychoeducation and skills training intervention that includes:

- education about dementia, its symptoms and the changes to expect as the condition progresses
- developing personalised strategies and building carer skills
- training to help them provide care, including how to understand and respond to changes in behaviour
- training to help them adapt their communication styles to improve interactions with the person living with dementia
- advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing
- advice on planning enjoyable and meaningful activities to do with the person they care for
- information about relevant services (including support services and psychological therapies for carers) and how to access them
- advice on planning for the future.

1.11.2 Ensure that the support provided to carers is:

- tailored to their needs and preferences and to what they want it to achieve (for example, providing information on carer's employment rights for carers who work or want to work)
- designed to help them support people living with dementia
- available at a location they can get to easily
- provided in a format suitable for them (for example individual or group sessions, or online training and support)
- available from diagnosis and as needed after this.

1.11.3 Be aware that carer interventions are likely to be most effective when provided

as group sessions.

1.11.4 Advise carers about their right to the following and how to get them:

- a formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health
- an assessment of their need for short breaks and other respite care.

1.11.5 Be aware that carers of people living with dementia are at an increased risk of depression. For guidance on identifying and managing depression, see the NICE guideline on [depression in adults](#).

## 1.12 *Moving to different care settings*

1.12.1 For guidance on managing transition between care settings for people living with dementia, see:

- the NICE guideline on [transition between inpatient hospital settings and community or care home settings for adults with social care needs](#)
- the NICE guideline on [transition between inpatient mental health settings and community or care home settings](#)
- [section 1.2](#) of the NICE guideline on medicines optimisation.

Follow the principles in these guidelines for transitions between other settings (for example from home to a care home or respite care).

1.12.2 Review the person's needs and wishes (including any care and support plans and advance care and support plans) after every transition.

## 1.13 *Staff training and education*

1.13.1 Care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia, which should include:

- understanding the signs and symptoms of dementia, and the changes to expect as the condition progresses



- understanding the person as an individual, and their life story
- respecting the person's individual identity, sexuality and culture
- understanding the needs of the person and their family members or carers
- the principles of the [Mental Capacity Act 2005](#) and the [Care Act 2014](#).

1.13.2 Care providers should provide additional face-to-face training and mentoring to staff who deliver care and support to people living with dementia. This should include:

- understanding the organisation's model of dementia care and how it provides care
- how to monitor and respond to the lived experience of people living with dementia, including adapting communication styles
- initial training on understanding, reacting to and helping people living with dementia who experience agitation, aggression, pain, or other behaviours indicating distress
- follow-up sessions where staff can receive additional feedback and discuss particular situations
- advice on interventions that reduce the need for antipsychotics and allow doses to be safely reduced
- promoting freedom of movement and minimising the use of restraint
- if relevant to staff, the specific needs of younger people living with dementia and people who are working or looking for work.

1.13.3 Consider giving carers and/or family members the opportunity to attend and take part in staff dementia training sessions.

1.13.4 Consider training staff to provide multi-sensory stimulation for people with moderate to severe dementia and communication difficulties.

1.13.5 Ensure that all health and social care staff are aware of:

- the extent of their responsibility to protect confidentiality under data protection legislation and

- any rights that family members, carers and others have to information about the person's care (see [recommendation 1.3.5](#) on information sharing between different care settings).

1.13.6 Health and social care professionals advising people living with dementia (including professionals involved in diagnosis) should be trained in starting and holding difficult and emotionally challenging conversations.

## *Terms used in this guideline*

### **Case finding**

A strategy of actively assessing people who are at risk for a particular disease, before they present with symptoms and before there is clinical suspicion of the condition. It does not refer to situations such as assessing people for dementia after an acute episode of delirium, where clinical suspicion of dementia is likely to already be raised.

### **Cognitive rehabilitation**

Identifying functional goals that are relevant to the person living with dementia, and working with them and their family members or carers to achieve these. The emphasis is on improving or maintaining functioning in everyday life, building on the person's strengths and finding ways to compensate for impairments, and supporting independence. Cognitive rehabilitation does not aim to improve cognition, but addresses the disability resulting from the impact of cognitive impairment on everyday functioning and activity. Rehabilitation is sometimes referred to as 'reablement'.

### **Cognitive stimulation**

Engaging in a range of activities and discussions (usually in a group) that are aimed at general improvement of cognitive and social functioning.

### **Cognitive training**

Guided practice on a set of standard tasks that are designed to reflect particular cognitive functions. There may be a range of difficulty levels, to fit the tasks to each person's level of ability.

### **Interpersonal therapy**

Brief structured attachment-focused therapies for people with mild to moderate depression. These

therapies are based on the idea that difficulties interacting with other people can cause psychological symptoms such as depressed mood, which then make the difficulties with interaction worse, causing a cycle. Interpersonal therapies aim to help people interact more effectively with others, and through this improve the psychological symptoms. Therapy typically focuses on relationship issues such as conflict, difficulty starting or maintaining relationships, grief and loss, and life changes.

## Refer

A referral to a diagnostic service does not have to involve a clinic appointment. People can be seen in community settings (such as their home or a care home), or advice can be provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment. Specialists are those with the appropriate knowledge and skills and include secondary care medical specialists (for example psychiatrists, geriatricians and neurologists) and other healthcare professionals (for example GPs, nurse consultants and advanced nurse practitioners) with specialist expertise in assessing and diagnosing dementia.

## Social care terms

For social care terms see the Think Local, Act Personal [Care and Support Jargon Buster](#).

## Specialist clinician

Specialist clinicians (for the purpose of starting and monitoring treatment with cholinesterase inhibitors and memantine) are those with the appropriate knowledge and skills and include secondary care medical specialists (for example psychiatrists, geriatricians and neurologists) and other healthcare professionals (for example GPs, nurse consultants and advanced nurse practitioners) with specialist expertise in diagnosing and treating Alzheimer's disease.

## Verbal episodic memory

Episodic memories include information about recent or past events and experiences (rather than factual knowledge, or habits and skills). They may be recent, or from the distant past (remote or long-term episodic memory). Tests to assess episodic memory may use either verbal or visual material. Examples of verbal episodic memory tests include reading the person a list of words or a short story and asking them to recall this information, both immediately and after a delay.

<sup>[1]</sup> At the time of publication (June 2018), donepezil and rivastigmine did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

<sup>[2]</sup> At the time of publication (June 2018), galantamine did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

<sup>[3]</sup> At the time of publication (June 2018), memantine did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

<sup>[4]</sup> At the time of publication (June 2018), the AChE inhibitors donepezil, rivastigmine and galantamine did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

<sup>[5]</sup> Note that logopenic aphasia, which has previously been included in some diagnostic guidelines for frontotemporal dementia, has now been shown to most commonly be caused by Alzheimer's disease.

<sup>[6]</sup> The MHRA (2012) has given [advice for health and social care professionals on prescribing antipsychotics to people living with dementia](#) to treat the behavioural and psychological symptoms of dementia.

<sup>[7]</sup> At the time of publication (June 2018), the only antipsychotics with a UK marketing authorisation for this indication were risperidone and haloperidol. The marketing authorisation for risperidone only covers short-term treatment (up to 6 weeks) of persistent aggression in people with moderate to severe Alzheimer's disease unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others. The marketing authorisation for haloperidol only covers treatment of persistent aggression and psychotic symptoms in people with moderate to severe Alzheimer's

dementia and vascular dementia when non-pharmacological treatments have failed and when there is a risk of harm to self or others. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

<sup>[8]</sup> If relevant, follow MHRA advice that [valproate medicines are contraindicated in women and girls of childbearing potential unless a Pregnancy Prevention Programme is in place.](#)

## Putting this guideline into practice

NICE has produced [tools and resources](#) to help you put this guideline into practice.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

- 1. Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.
- 2. Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.
- 3. Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.
- 4. Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. For **very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our [into practice](#) pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) [Achieving high quality care – practical experience from NICE](#). Chichester: Wiley.

## Recommendations for research

The guideline committee has made the following recommendations for research. The committee's full set of research recommendations is detailed in the [full guideline](#).

### *1 Case management*

What is the effectiveness and cost effectiveness of high-intensity case management compared with usual care on quality of life (for the person living with dementia and for their carers) and the timing of entry to long-term care?

#### **Why this is important**

There is evidence that case management is an effective intervention for people living with dementia. However, the effectiveness and cost effectiveness of high-intensity case management has not been tested in the UK. It has a high upfront cost, but there is some evidence from settings outside the UK that it may reduce the use of other services, leading to cost savings across the whole system. Because of the cost, robust evidence of effectiveness and cost effectiveness from a UK setting is needed.

### *2 Staff training*

What is the cost effectiveness of using a dementia-specific addition to the Care Certificate for community staff, including dementia-specific elements on managing anxiety, communication, nutritional status and personal care?

#### **Why this is important**

Robust evidence demonstrates the effectiveness of intensive training for staff heavily involved in providing care and support for people living with dementia. However, it is not clear if it is effective to provide basic training to all staff who come into contact with people living with dementia, or how this training should be provided. One possibility is an expanded version of the Care Certificate that includes additional dementia-specific elements. Because this training would need to be given to a large number of staff, there needs to be good evidence of benefits, specifically in improving quality of life for people living with dementia and their carers, to justify the upfront costs.

### *3 Anticholinergic burden*

Does actively reducing anticholinergic burden in people living with dementia improve cognitive



outcomes compared with usual care?

### **Why this is important**

Many people living with dementia are still prescribed medicines with a high anticholinergic burden (which can be caused by individual medicines or by combinations of medicines). It is often unclear if this prescribing is appropriate, or whether actively reducing the number of these medicines would improve cognition. Randomised controlled trials could be conducted, using structured tools to assess anticholinergic burden and actively switching medicines if possible. This would help to identify whether cognition can be improved without adversely affecting the management of the conditions these medicines are prescribed for.

## ***4 Managing delirium superimposed on dementia***

What are the most clinically and cost-effective non-pharmacological interventions for helping the long-term recovery of people with delirium superimposed on dementia?

### **Why this is important**

The acute management of delirium superimposed on dementia is likely to be similar to the management of delirium in people without dementia. However, there may be differences in the interventions needed to aid long-term recovery, particularly because people with different severities of dementia will have different baseline cognitive status. Research on the most effective non-pharmacological methods of promoting long-term recovery would help to identify whether alternative approaches are needed for people living with dementia.

## ***5 Care and support planning***

What are the most effective methods of care planning for people who do not have regular contact with an informal carer?

### **Why this is important**

Many randomised controlled trials of care planning or case management specifically exclude people without an informal carer. Conducting similar studies on case management and care planning for people without an informal carer would fill this gap in the evidence base, and help to identify whether these people have different needs.

## Update information

**October 2018:** Links have been added to patient decision aids from some recommendations.

**June 2018:** This guideline is an update of the NICE guideline on dementia (CG42, published November 2006) and replaces it. It also replaces recommendation 1.3 in the NICE technology appraisal guidance on [donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#) (TA217).

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## Accreditation

