

1           **Dementia: assessment, management and**  
2           **support for people living with dementia and**  
3           **their carers**

4  
5                           **NICE guideline: short version**

6                           **Draft for consultation, January 2018**

7  
**This guideline covers** diagnosing and managing dementia, and supporting people living with dementia and their carers. It aims to improve care by making recommendations on training staff and on helping carers to support people living with 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
- People living with dementia, their families and carers

This guideline will update and replace [NICE guideline CG42](#) (published November 2006), and recommendation 1.3 of [NICE technology appraisal guidance 217](#).

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the [guideline's page](#) on the NICE website. This includes the guideline committee's discussion and the evidence reviews (in the [full guideline](#)), the scope, and details of the committee and any declarations of interest.

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## 1 **About this guideline**

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

12 [A report published by the Alzheimer's Society](#) found that in 2013 there were  
13 approximately 815,000 people living with dementia in the UK. If current trends  
14 continue, this number is expected to increase to 1,143,000 by 2025. In England, the  
15 [National Dementia and Antipsychotic Prescribing Audit](#) found that approximately  
16 31,000 people were newly diagnosed with dementia in 2011. This is an increase of  
17 8% between 2006 and 2011.

18 The Alzheimer's Society report found that in 2013 the total cost of dementia in the  
19 UK was estimated to be £26.3 billion. Of this, approximately £4.3 billion consists of  
20 health care, and approximately £10.3 billion consists of social care. The remaining  
21 £11.6 billion accounts for estimated unpaid care contributions.

## 22 ***Why is it needed?***

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

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

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

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

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

### 13 ***What does it cover?***

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

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

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

### 27 ***How has it been developed?***

28 This guideline has been developed by a multidisciplinary guideline committee, using  
29 an extensive review of research evidence. To ensure that the committee had the

1 necessary social care expertise, a subgroup of social care practitioners was  
2 recruited to develop recommendations in this area.

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

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

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

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

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

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

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

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

- 29 • NHS England (2015) [Accessible Information Standard](#)

- 1 • [Health and Social Care Act 2008 \(Regulated Activities\) Regulations 2014](#)
- 2 • Department of Health (2014) [Care Act 2014: Statutory Guidance for](#)
- 3 [Implementation](#)
- 4 • Department of Health (2014) [Positive and Proactive Care: Reducing the need for](#)
- 5 [restrictive interventions](#)
- 6 • [Health and Social Care Act 2012](#)
- 7 • [Mental Capacity Act 2005](#)

## 8 **Relevant policies and non-statutory guidance**

- 9 • Department of Health (2014) [NHS Outcomes Framework 2015 to 2016](#)
- 10 • Department of Health (2014) [Adult Social Care Outcomes Framework 2015 to](#)
- 11 [2016](#)

## 12 **More information**

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

## 13 **Person-centred care**

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

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

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

## 4 **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.

### 5 **1.1 *Involving people living with dementia in decisions about*** 6 ***their care***

#### 7 **Involving people in decision-making**

- 8 1.1.1 Encourage and enable people living with dementia to give their own views  
9 and opinions about their care.
- 10 1.1.2 If needed, use additional or modified ways of communicating (for example  
11 visual aids or simplified text).
- 12 1.1.3 Consider using a structured tool to assess the likes and dislikes, routines  
13 and personal history of a person living with dementia.

#### 14 **Providing information**

- 15 1.1.4 Provide people living with dementia and their family members or carers  
16 (as appropriate) with information that is relevant to their circumstances  
17 and the stage of their condition.
- 18 1.1.5 Be aware of the obligation to provide accessible information as detailed in  
19 the NHS [Accessible Information Standard](#). For more guidance on

1 providing information and discussing people's preferences with them, see  
2 the NICE guideline on [patient experience in adult NHS services](#).

3 1.1.6 At diagnosis, offer the person and their family members or carers (as  
4 appropriate) oral and written information that explains:

- 5 • what their dementia subtype is and how it is likely to progress
- 6 • which healthcare professionals and social care teams will be involved  
7 in their care and how to contact them
- 8 • if appropriate, how dementia affects driving, and that they need to tell  
9 the [Driver and Vehicle Licensing Agency](#) (DVLA) and their car insurer  
10 about their dementia diagnosis
- 11 • their legal rights and responsibilities
- 12 • their right to reasonable adjustments (in line with the [Equality Act 2010](#))  
13 if they are working or looking for work
- 14 • how the following groups can help and how to contact them:
  - 15 – local support groups, online forums and national charities
  - 16 – financial and legal advice services
  - 17 – advocacy services.

18 1.1.7 If it has not been documented earlier, ask the person at diagnosis:

- 19 • which people they would like services to share information with (for  
20 example family members or carers)
- 21 • what information they would like services to share with these people
- 22 • for their consent for services to share this information.

23 Document these decisions in the person's records and tell all relevant  
24 services what the person has decided.

25 1.1.8 After diagnosis, direct people and their family members or carers (as  
26 appropriate) to relevant services for information and support.

27 1.1.9 For people who do not want follow-up appointments and who are not  
28 using other services, ask if they would like to be contacted again at a  
29 specified future date.



1 1.1.10 Ensure that people living with dementia and their carers know how to get  
2 more information and who from if their needs change.

### 3 **Advance care planning**

4 1.1.11 Offer early and ongoing opportunities for people living with dementia and  
5 people involved in their care (see recommendation 1.1.7) to discuss:

- 6 • the benefits of planning ahead
- 7 • lasting power of attorney (health and welfare)
- 8 • an advance statement about their wishes, preferences, beliefs and  
9 values regarding their future care
- 10 • advance decisions to refuse treatment
- 11 • their preferences for place of care and place of death.

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

14 1.1.12 At each care review, offer people the chance to review and change any  
15 advance statements and decisions they have made.

## 16 **1.2 *Diagnosis***

### 17 **Initial assessment in non-specialist settings**

18 1.2.1 At the initial assessment take a history (including cognitive and  
19 behavioural symptoms, and the impact symptoms have on their daily life):

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

23 If dementia is still suspected after this, use cognitive testing.

24 1.2.2 When using cognitive testing, use a validated brief structured cognitive  
25 instrument such as:

- 26 • the 10-point cognitive screener (10-CS)
- 27 • the 6-item cognitive impairment test (6CIT)

- 1           • the 6-item screener
  - 2           • the Memory Impairment Screen (MIS)
  - 3           • the Mini-Cog
  - 4           • Test Your Memory (TYM).
- 5   1.2.3    Do not rule out dementia solely because the person has a normal score
- 6           on a cognitive instrument.
- 7   1.2.4    When taking a history from someone who knows the person with
- 8           suspected dementia, consider supplementing this with a structured
- 9           instrument such as the Informant Questionnaire on Cognitive Decline in
- 10          the Elderly (IQCODE) or the Functional Activities Questionnaire (FAQ).
- 11   1.2.5    Refer the person to a specialist dementia diagnostic service if:
- 12           • reversible causes of cognitive decline (such as delirium or cognitive
  - 13            impairment from medicines associated with increased anticholinergic
  - 14            burden) have been investigated **and**
  - 15           • dementia is still suspected.
- 16   1.2.6    If the person has suspected rapidly-progressive dementia, refer them to a
- 17          neurological service with access to tests (including cerebrospinal fluid
- 18          examination) for Creutzfeldt-Jakob disease and similar conditions.
- 19   1.2.7    For more guidance on assessing for dementia in people with learning
- 20          disabilities, see the NICE guideline on [mental health problems in people](#)
- 21          [with learning disabilities](#).
- 22   **Dementia diagnosis in specialist dementia diagnostic services**
- 23   1.2.8    If Alzheimer’s disease is suspected, include a test of verbal episodic
- 24          memory in the assessment.
- 25   1.2.9    Consider structural imaging to rule out reversible causes of cognitive
- 26          decline.
- 27   1.2.10   Diagnose a dementia subtype (if possible) if initial specialist assessment
- 28          confirms cognitive decline and reversible causes have been ruled out.

1 1.2.11 Use validated criteria to guide clinical judgement when diagnosing  
2 dementia subtypes, such as:

- 3 • [International consensus criteria for dementia with Lewy bodies](#)
- 4 • [International FTD criteria for frontotemporal dementia](#) (primary  
5 progressive aphasia and semantic dementia)
- 6 • [International Frontotemporal Dementia Consortium criteria for](#)  
7 [behavioural variant frontotemporal dementia](#)
- 8 • [NINDS-AIREN criteria](#) (National Institute of Neurological Disorders and  
9 Stroke and Association Internationale pour la Recherche et  
10 l'Enseignement en Neurosciences) for vascular dementia
- 11 • [NIA criteria \(National Institute on Aging\) for Alzheimer's disease](#)
- 12 • [Movement disorders Society criteria for Parkinson's disease dementia](#)
- 13 • [International criteria for Creutzfeldt-Jakob disease](#).

#### 14 ***Diagnosing Alzheimer's disease***

15 1.2.12 If the diagnosis is uncertain and Alzheimer's disease is suspected,  
16 consider either:

- 17 • examining cerebrospinal fluid for:
  - 18 – phosphorylated-tau 181 **and**
  - 19 – total tau **and**
  - 20 – either amyloid beta 1–42 or a ratio of amyloid beta 1–42 and amyloid  
21 beta 1–40

22 **or**

- 23 • FDG-PET (fluorodeoxyglucose-positron emission tomography-CT), or  
24 perfusion SPECT (single-photon emission CT) if FDG-PET is  
25 unavailable.

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

28 1.2.13 Be aware that the older a person is, the less accurate cerebrospinal fluid  
29 examination will be.

1 1.2.14 Do not rule out Alzheimer's disease based solely on the results of CT or  
2 MRI scans.

3 1.2.15 Do not use Apolipoprotein E genotyping or electroencephalography in the  
4 diagnosis of Alzheimer's disease.

#### 5 ***Diagnosing dementia with Lewy bodies***

6 1.2.16 If the diagnosis is uncertain and dementia with Lewy bodies is suspected,  
7 use <sup>123</sup>I-FP-CIT SPECT.

8 1.2.17 If <sup>123</sup>I-FP-CIT SPECT is unavailable, consider <sup>123</sup>I-MIBG cardiac  
9 scintigraphy.

10 1.2.18 Do not rule out dementia with Lewy bodies based solely on normal results  
11 on <sup>123</sup>I-FP-CIT SPECT or <sup>123</sup>I-MIBG cardiac scintigraphy.

#### 12 ***Diagnosing frontotemporal dementia***

13 1.2.19 If the diagnosis is uncertain and frontotemporal dementia is suspected,  
14 use either:

- 15 • FDG-PET **or**
- 16 • perfusion SPECT.

17 1.2.20 Do not rule out frontotemporal dementia based solely on the results of  
18 structural, perfusion or metabolic imaging tests.

#### 19 ***Diagnosing vascular dementia***

20 1.2.21 If the dementia subtype is uncertain and vascular dementia is suspected,  
21 use MRI. If MRI is unavailable, use CT.

22 1.2.22 Do not diagnose vascular dementia based solely on vascular lesion  
23 burden.

#### 24 **Case finding**

25 1.2.23 Only conduct case finding for suspected dementia as part of a clinical trial  
26 that also provides an intervention to people diagnosed with dementia.

## 1 **Telling the difference between delirium and dementia**

2 1.2.24 For people who are in hospital and have cognitive impairment, consider  
3 using the long confusion assessment method (CAM) or the Observational  
4 Scale of Level of Arousal (OSLA) to find out whether they have delirium or  
5 delirium superimposed on dementia, compared with dementia alone.

6 1.2.25 Do not use standardised instruments (including cognitive instruments)  
7 alone to distinguish delirium from delirium superimposed on dementia.

8 1.2.26 If it is not possible to tell whether a person has delirium, dementia, or  
9 delirium superimposed on dementia, treat for delirium first. For guidance  
10 on treating delirium, see [treating delirium](#) in the NICE guideline on  
11 delirium.

## 12 **Review after diagnosis**

13 1.2.27 After a person is diagnosed with dementia, refer them and their family  
14 members or carers (as appropriate) to a memory service or equivalent  
15 hospital- or primary-care-based multidisciplinary dementia service.

16 1.2.28 Memory services and equivalent hospital- and primary-care-based  
17 multidisciplinary dementia services should offer a choice of flexible access  
18 or prescheduled monitoring appointments.

19 1.2.29 When people living with dementia or their carers have a primary care  
20 appointment, assess for any emerging dementia-related needs and ask  
21 them if they need any more support.

## 22 **1.3 Care coordination**

23 1.3.1 Provide people living with dementia with a single named health or social  
24 care professional who is responsible for coordinating their care.

25 1.3.2 Named professionals should:

- 26 • arrange an initial assessment of the person's needs, which should be  
27 face to face if possible
- 28 • provide information about available services and how to access them

- 1           • involve the person’s family members or carers (as appropriate) in  
2           support and decision-making
- 3           • give special consideration to the views of people who do not have  
4           capacity to make decisions about their care, in line with the principles of  
5           the [Mental Capacity Act 2005](#)
- 6           • ensure that people are aware of their rights to and the availability of  
7           local advocate services, and if appropriate to the immediate situation  
8           an independent mental capacity advocate
- 9           • develop a care and support plan, and:
  - 10          – agree and review it with the involvement of the person, their family
  - 11          members or carers (as appropriate) and relevant professionals
  - 12          – specify in the plan when and how often it will be reviewed
  - 13          – evaluate and record progress towards the objectives at each review.

#### 14   **Transferring information between services and care settings**

15   1.3.3     When developing care and support plans and advance care and support  
16           plans, request consent to transfer these to different care settings as  
17           needed.

18   1.3.4     Service providers should ensure that information (such as care and  
19           support plans and advance care and support plans) can be easily  
20           transferred between different care settings (for example home, inpatient,  
21           community and residential care).

22   1.3.5     Staff delivering care and support should maximise continuity and  
23           consistency of care. Ensure that relevant information is shared and  
24           recorded in the person’s care and support plan.

#### 25   **Making services accessible**

26   1.3.6     Service providers should design services to be accessible to as many  
27           people living with dementia as possible, including:

- 28           • people who do not have a carer or whose carer cannot support them on  
29           their own

- 1           • people who do not have access to affordable transport, or find transport
- 2           difficult to use
- 3           • people who have other responsibilities (such as work, children or being
- 4           a carer themselves).

## 5   **1.4    Interventions to promote cognition, independence and**

## 6           **wellbeing**

- 7   1.4.1   Offer a range of activities to promote wellbeing that are tailored to the
- 8           person's preferences.
  
- 9   1.4.2   Consider providing structured group activities (including elements of
- 10           [cognitive stimulation](#) and reminiscence therapy) to people living with mild
- 11           to moderate dementia who are not already accessing them.
  
- 12   1.4.3   Consider providing a needs-based reablement programme (including
- 13           elements of [cognitive rehabilitation](#) and/or occupational therapy) to people
- 14           living with mild to moderate dementia who are not already accessing
- 15           them.
  
- 16   1.4.4   Do not offer acupuncture to treat dementia.
  
- 17   1.4.5   Do not offer ginseng, vitamin E supplements, vitamin B and folic acid
- 18           supplements, or herbal formulations to treat dementia.
  
- 19   1.4.6   Do not offer [cognitive training](#) to treat mild to moderate Alzheimer's
- 20           disease.
  
- 21   1.4.7   Do not offer interpersonal therapies to treat the cognitive symptoms of
- 22           mild to moderate Alzheimer's disease.
  
- 23   1.4.8   Do not offer non-invasive brain stimulation to treat mild to moderate
- 24           Alzheimer's disease, except as part of a randomised controlled trial.

## 1 **1.5 Pharmacological interventions for dementia**

### 2 **Pharmacological management of Alzheimer's disease**

3 1.5.1 The three acetylcholinesterase (AChE) inhibitors donepezil, galantamine  
4 and rivastigmine are recommended as options for managing mild to  
5 moderate Alzheimer's disease under all of the conditions specified in 1.5.4  
6 and 1.5.5.

7 [This recommendation is from Donepezil, galantamine, rivastigmine and  
8 memantine for the treatment of Alzheimer's disease ([NICE technology  
9 appraisal guidance 217](#)).]

10 1.5.2 Memantine is recommended as an option for managing Alzheimer's  
11 disease for people with:

- 12 • moderate Alzheimer's disease who are intolerant of or have a
- 13 contraindication to AChE inhibitors **or**
- 14 • severe Alzheimer's disease.

15 Treatment should be under the conditions specified in 1.5.4.

16 [This recommendation is from Donepezil, galantamine, rivastigmine and  
17 memantine for the treatment of Alzheimer's disease ([NICE technology  
18 appraisal guidance 217](#)).]

19 1.5.3 For people with an established diagnosis of Alzheimer's disease who are  
20 already taking an AChE inhibitor:

- 21 • consider memantine in addition to an AChE inhibitor if they have
- 22 moderate disease
- 23 • offer memantine in addition to an AChE inhibitor if they have severe
- 24 disease.

25 1.5.4 Treatment should be under the following conditions:

- 26 • For people who are not taking an AChE inhibitor or memantine,
- 27 prescribers should only start treatment with these on the advice of a



- 1 clinician who has the necessary knowledge and skills. This could  
2 include:
- 3 – secondary care medical specialists such as psychiatrists,  
4 geriatricians and neurologists
  - 5 – other healthcare professionals (such as GPs, nurse consultants and  
6 advanced nurse practitioners), if they have specialist expertise in  
7 diagnosing and treating Alzheimer’s disease.
  - 8 • Once a decision has been made to start an AChE inhibitor or  
9 memantine, the first prescription may be made in primary care.
  - 10 • For people with an established diagnosis of Alzheimer’s disease who  
11 are already taking an AChE inhibitor, primary care prescribers may  
12 start treatment with memantine without taking advice from a [specialist](#)  
13 [clinician](#).
  - 14 • Ensure that local arrangements for prescribing, supply and treatment  
15 review follow the NICE guideline on [medicines optimisation](#).
  - 16 • Do not stop AChE inhibitors in people with Alzheimer’s disease  
17 because of disease severity alone.

18 1.5.5 If prescribing an AChE inhibitor (donepezil, galantamine or rivastigmine),  
19 treatment should normally be started with the drug with the lowest  
20 acquisition cost (taking into account required daily dose and the price per  
21 dose once shared care has started). However, an alternative AChE  
22 inhibitor could be prescribed if it is considered appropriate when taking  
23 into account adverse event profile, expectations about adherence,  
24 medical comorbidity, possibility of drug interactions and dosing profiles.

25 [This recommendation is from Donepezil, galantamine, rivastigmine and  
26 memantine for the treatment of Alzheimer’s disease ([NICE technology](#)  
27 [appraisal guidance 217](#)).]

28 1.5.6 When using assessment scales to determine the severity of Alzheimer’s  
29 disease, healthcare professionals should take into account any physical,  
30 sensory or learning disabilities, or communication difficulties that could  
31 affect the results and make any adjustments they consider appropriate.  
32 Healthcare professionals should also be mindful of the need to secure

1 equality of access to treatment for patients from different ethnic groups, in  
2 particular those from different cultural backgrounds.

3 [This recommendation is from Donepezil, galantamine, rivastigmine and  
4 memantine for the treatment of Alzheimer's disease ([NICE technology  
5 appraisal guidance 217](#)).]

6 1.5.7 When assessing the severity of Alzheimer's disease and the need for  
7 treatment, healthcare professionals should not rely solely on cognition  
8 scores in circumstances in which it would be inappropriate to do so.

9 These include:

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

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

24 [This recommendation is from Donepezil, galantamine, rivastigmine and  
25 memantine for the treatment of Alzheimer's disease ([NICE technology  
26 appraisal guidance 217](#)).]

### 27 ***Slowing the progression of Alzheimer's disease***

28 1.5.8 Do not offer the following to slow the progress of Alzheimer's disease,  
29 except as part of a randomised controlled trial:

- 1           • diabetes medicines
- 2           • hypertension medicines
- 3           • statins
- 4           • non-steroidal anti-inflammatory drugs (NSAIDs), including aspirin.

## 5 **Pharmacological management of non-Alzheimer's dementia**

- 6 1.5.9 Offer donepezil or rivastigmine to people with mild to moderate dementia  
7 with Lewy bodies<sup>1</sup>.
- 8 1.5.10 Only consider galantamine<sup>2</sup> for people with mild to moderate dementia  
9 with Lewy bodies if donepezil and rivastigmine<sup>1</sup> are not tolerated.
- 10 1.5.11 Consider donepezil or rivastigmine for people with severe dementia with  
11 Lewy bodies<sup>1</sup>.
- 12 1.5.12 Consider memantine<sup>3</sup> for people with dementia with Lewy bodies if AChE  
13 inhibitors<sup>4</sup> are not tolerated or are contraindicated.
- 14 1.5.13 Only consider AChE inhibitors<sup>4</sup> or memantine<sup>3</sup> for people with vascular  
15 dementia if they have suspected comorbid Alzheimer's disease,  
16 Parkinson's disease dementia or dementia with Lewy bodies.
- 17 1.5.14 Do not offer AChE inhibitors or memantine to people with frontotemporal  
18 dementia.

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<sup>1</sup> At the time of consultation (January 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 consultation (January 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 consultation (January 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 consultation (January 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

1 1.5.15 Do not offer AChE inhibitors or memantine to people with cognitive  
2 impairment caused by multiple sclerosis.

3 1.5.16 For guidance on pharmacological management of Parkinson's disease  
4 dementia, see [Parkinson's disease dementia](#) in the NICE guideline on  
5 Parkinson's disease.

## 6 **1.6 Medicines that may cause cognitive impairment**

7 1.6.1 Be aware that some commonly prescribed medicines are associated with  
8 increased anticholinergic burden, and therefore cognitive impairment.

9 1.6.2 Consider minimising the use of medicines associated with increased  
10 anticholinergic burden, and if possible look for alternatives:

- 11 • when assessing whether to refer a person with suspected dementia for  
12 diagnosis
- 13 • during medication reviews with people living with dementia.

14 1.6.3 Be aware that there are validated tools for assessing anticholinergic  
15 burden (for example, the Anticholinergic Cognitive Burden Scale), but  
16 there is insufficient evidence to recommend one over the others.

17 1.6.4 For guidance on carrying out medication reviews, see [medication review](#)  
18 in the NICE guideline on medicines optimisation.

## 19 **1.7 Managing non-cognitive symptoms**

### 20 **Agitation, aggression and distress**

21 1.7.1 Check for and address clinical or environmental causes (for example pain,  
22 delirium or inappropriate care) before starting non-pharmacological or  
23 pharmacological treatment for distress in people living with dementia.

24 1.7.2 As initial and ongoing management, offer psychosocial and environmental  
25 interventions to reduce distress in people living with dementia.

- 1 1.7.3 Only offer antipsychotics<sup>5,6</sup> for people living with dementia who are either:
- 2 • at risk of harming themselves or others **or**
- 3 • experiencing agitation, hallucinations or delusions that are causing
- 4 them severe distress.
- 5 1.7.4 Before starting antipsychotics, discuss the benefits and harms with the
- 6 person and their family members or carers (as appropriate). Consider
- 7 using a decision aid to support this discussion.
- 8 1.7.5 When using antipsychotics:
- 9 • use the lowest effective dose and use them for the shortest possible
- 10 time
- 11 • reassess the person at least every 6 weeks, to check whether they still
- 12 need medication.
- 13 1.7.6 Stop treatment with antipsychotics:
- 14 • if the person is not getting a clear ongoing benefit from taking them **and**
- 15 • after discussion with the person taking them and their family members
- 16 or carers (as appropriate).
- 17 1.7.7 Ensure that people living with dementia can continue to access
- 18 psychosocial and environmental interventions for distress while they are
- 19 taking antipsychotics and after they have stopped taking them.
- 20 1.7.8 Do not offer mood stabilisers to manage agitation or aggression in people
- 21 living with dementia, unless they are indicated for another condition.

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<sup>5</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>6</sup> At the time of consultation (January 2018), the only antipsychotic with a UK marketing authorisation for this indication was risperidone, and this marketing authorisation 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 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.

1 1.7.9 For people living with dementia who experience agitation or aggression,  
2 offer personalised activities to promote engagement, pleasure and  
3 interest.

#### 4 **Depression and anxiety**

5 1.7.10 For people living with mild to moderate dementia who have mild to  
6 moderate depression and/or anxiety, consider psychological treatments.

7 1.7.11 Do not routinely offer antidepressants to manage mild to moderate  
8 depression in people living with mild to moderate dementia, unless they  
9 are indicated for a pre-existing severe mental health problem.

#### 10 **Sleep problems**

11 1.7.12 Do not offer melatonin to manage sleep problems in people living with  
12 dementia.

13 1.7.13 For people living with dementia who have sleep problems, consider a  
14 personalised multicomponent sleep management approach that includes  
15 sleep hygiene education, exposure to daylight, exercise and personalised  
16 activities.

### 17 **1.8 *Assessing and managing other long-term conditions in*** 18 ***people living with dementia***

19 1.8.1 Ensure that people living with dementia have equivalent access to  
20 treatments and care for comorbidities to people who do not have  
21 dementia. For more guidance on assessing and managing multimorbidity,  
22 see the NICE guidelines on [multimorbidity](#) and [older people with social](#)  
23 [care needs and multiple long-term conditions](#).

#### 24 **Pain**

25 1.8.2 Consider using a structured observational pain assessment tool alongside  
26 self-reported pain and standard clinical assessment for people living with  
27 moderate to severe dementia.

1 1.8.3 Consider using a structured observational pain assessment tool alongside  
2 standard clinical assessment for people living with dementia who are  
3 unable to self-report pain.

4 1.8.4 For people living with dementia who are in pain, consider using a stepwise  
5 treatment protocol that balances pain management and potential adverse  
6 events.

7 1.8.5 Repeat pain assessments for people living with dementia:

- 8
- 9 • who seem to be in pain
  - 10 • who show signs of behavioural changes that may be caused by pain
  - 11 • after any pain management intervention.

## 11 Falls

12 1.8.6 For guidance on managing the risk of falling for people living with  
13 dementia (in community and inpatient settings), see the NICE guideline on  
14 [falls in older people](#). When using this guideline:

- 15
- 16 • take account of the additional support people living with dementia may  
17 need to participate effectively
  - 18 • be aware that multifactorial falls interventions may not be suitable for a  
19 person living with severe dementia.

## 19 Diabetes

20 1.8.7 For guidance on setting HbA1c targets for people living with severe  
21 dementia who have type 2 diabetes, see [recommendation 1.6.9](#) in the  
22 NICE guideline on type 2 diabetes in adults.

## 23 Incontinence

24 1.8.8 For guidance on treating overactive bladder, see the NICE technology  
25 appraisal on [mirabegron for treating symptoms of overactive bladder](#).

26 1.8.9 For guidance on treating faecal incontinence, see [recommendations 1.7.2](#)  
27 [and 1.7.8](#) in the NICE guideline on faecal incontinence.

1 **1.9** ***Risks during hospital admission***

2 1.9.1 Be aware of the increased risk of delirium in people living with dementia  
3 who are admitted to hospital. See the NICE guideline on delirium for  
4 interventions to [prevent](#) and [treat](#) delirium.

5 **1.10** ***Palliative care***

6 1.10.1 From diagnosis, offer people living with dementia flexible, needs-based  
7 palliative care that takes into account how unpredictable dementia  
8 progression can be.

9 1.10.2 For people living with dementia who are approaching the end of life, use  
10 an anticipatory healthcare planning process. Involve the person and their  
11 family members or carers (as appropriate) as far as possible, and use the  
12 principles of best-interest decision-making if the person does not have  
13 capacity to make decisions about their care.

14 1.10.3 For standards and measures on palliative care, see the NICE quality  
15 standard on [end of life care for adults](#).

16 1.10.4 For guidance on care for people in the last days of life, see the NICE  
17 guideline on [care of dying adults](#).

18 1.10.5 Practitioners must not hold a best interests discussion until a capacity  
19 assessment has been conducted, and a decision made and recorded that  
20 a person lacks capacity to make the decision in question (except in  
21 emergency situations). For more guidance, see the NICE guideline on  
22 [decision-making and mental capacity](#)<sup>7</sup>.

23 1.10.6 Encourage and support people living with dementia to eat and drink if they  
24 wish to and can do so safely, taking into account their nutritional needs.

25 1.10.7 Do not routinely use enteral feeding in people living with severe dementia,  
26 unless indicated for a potentially reversible comorbidity.

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<sup>7</sup> The NICE guideline on [decision-making and mental capacity](#) is in development and is due to be published in May 2018.



1 1.10.8 When thinking about admission to hospital for a person living with severe  
2 dementia, carry out an assessment that balances their current medical  
3 needs with the additional harms they may face in hospital, for example:

- 4 • disorientation
- 5 • a longer length of stay
- 6 • increased mortality
- 7 • increased morbidity on discharge
- 8 • delirium
- 9 • the effects of being in an impersonal or institutional environment.

10 1.10.9 When thinking about admission to hospital for a person living with  
11 dementia, take into account:

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

## 14 **1.11 Supporting carers**

15 1.11.1 Offer carers of people living with dementia a psychoeducation and skills  
16 training intervention that includes:

- 17 • education about dementia, its symptoms and how it is likely to progress
- 18 • developing personalised strategies and building carer skills
- 19 • training in how to provide care, including how to understand and  
20 respond to changes in behaviour
- 21 • training in adapting communication styles to improve interactions with  
22 the person living with dementia
- 23 • how to look after their own physical and mental health and emotional  
24 wellbeing
- 25 • planning enjoyable and meaningful activities to do with the person they  
26 care for
- 27 • information about relevant services (including support services and  
28 psychological therapies for carers) and how to access them
- 29 • advice on planning for the future.

- 1 1.11.2 Ensure that the support provided to carers is:
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- designed to help them support people living with dementia
  - 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)
  - 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.

10 1.11.3 Be aware that carer interventions are likely to be most effective when  
11 provided as group sessions.

- 12 1.11.4 Advise carers about their right to the following and how to get them:
- 13
- 14
- 15
- 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.

16 1.11.5 Be aware that carers of people living with dementia are at an increased  
17 risk of depression. For guidance on identifying and managing depression,  
18 see the NICE guideline on [depression in adults](#).

## 19 **1.12 Moving to different care settings**

20 1.12.1 For guidance on managing transition between care settings for people  
21 living with dementia, see:

- 22
- 23
- 24
- 25
- 26
- 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.

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

1 1.12.2 Review the person's needs and wishes (including any care and support  
2 plans and advance care and support plans) after every transition.

3 **1.13 Staff training**

4 1.13.1 Care and support providers should provide all staff with training in person-  
5 centred and outcome-focused care for people living with dementia, which  
6 should include:

- 7 • understanding the signs and symptoms of dementia
- 8 • understanding the person as an individual, and their life story
- 9 • respecting the person's individual identity, sexuality and culture
- 10 • understanding the needs of the person and their family members or  
11 carers
- 12 • the principles of the [Mental Capacity Act 2005](#).

13 1.13.2 Care providers should provide additional face-to-face training and  
14 mentoring to staff who deliver care and support to people living with  
15 dementia. This should include:

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

- 1 1.13.3 Consider giving carers and/or family members the opportunity to attend  
2 and take part in staff dementia training sessions.
- 3 1.13.4 Consider training staff to provide multi-sensory stimulation for people with  
4 moderate to severe dementia and communication difficulties.
- 5 1.13.5 Ensure that all health and social care staff are aware of:
- 6 • The extent of their responsibility to protect confidentiality under data  
7 protection legislation **and**
- 8 • any rights that family members, carers and others have to information  
9 about the person's care (see recommendation 1.3.4 on information  
10 sharing between different care settings).
- 11 1.13.6 Health and social care professionals advising people living with dementia  
12 should be trained in starting and holding difficult and emotionally  
13 challenging conversations.

#### 14 ***Terms used in this guideline***

##### 15 **Cognitive rehabilitation**

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

##### 23 **Cognitive stimulation**

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

## 1 **Cognitive training**

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

## 5 **Specialist clinician**

6 Specialist clinicians are those with appropriate knowledge and skills and include  
7 secondary care medical specialists (for example psychiatrists, geriatricians and  
8 neurologists) and other healthcare professionals (for example GPs, nurse  
9 consultants and advanced nurse practitioners) with specialist expertise in diagnosing  
10 and treating Alzheimer's disease.

## 11 **Putting this guideline into practice**

12 **[This section will be finalised after consultation]**

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

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

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

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

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

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

- 1 1. **Raise awareness** through routine communication channels, such as email or  
2 newsletters, regular meetings, internal staff briefings and other communications with  
3 all relevant partner organisations. Identify things staff can include in their own  
4 practice straight away.
- 5 2. **Identify a lead** with an interest in the topic to champion the guideline and motivate  
6 others to support its use and make service changes, and to find out any significant  
7 issues locally.
- 8 3. **Carry out a baseline assessment** against the recommendations to find out  
9 whether there are gaps in current service provision.
- 10 4. **Think about what data you need to measure improvement** and plan how you  
11 will collect it. You may want to work with other health and social care organisations  
12 and specialist groups to compare current practice with the recommendations. This  
13 may also help identify local issues that will slow or prevent implementation.
- 14 5. **Develop an action plan**, with the steps needed to put the guideline into practice,  
15 and make sure it is ready as soon as possible. Big, complex changes may take  
16 longer to implement, but some may be quick and easy to do. An action plan will help  
17 in both cases.
- 18 6. **For very big changes** include milestones and a business case, which will set out  
19 additional costs, savings and possible areas for disinvestment. A small project group  
20 could develop the action plan. The group might include the guideline champion, a  
21 senior organisational sponsor, staff involved in the associated services, finance and  
22 information professionals.
- 23 7. **Implement the action plan** with oversight from the lead and the project group.  
24 Big projects may also need project management support.
- 25 8. **Review and monitor** how well the guideline is being implemented through the  
26 project group. Share progress with those involved in making improvements, as well  
27 as relevant boards and local partners.

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

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

## 6 **Recommendations for research**

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

### 9 **1 Case management**

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

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

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

### 21 **2 Staff training**

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

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

26 Robust evidence demonstrates the effectiveness of intensive training for staff heavily  
27 involved in providing care and support for people living with dementia. However, it is  
28 not clear if it is effective to provide basic training to all staff who come into contact  
29 with people living with dementia, or how this training should be provided. One

1 possibility is an expanded version of the Care Certificate that includes additional  
2 dementia-specific elements. Because this training would need to be given to a large  
3 number of staff, there needs to be good evidence of benefits, specifically in  
4 improving quality of life for people living with dementia and their carers, to justify the  
5 upfront costs.

### 6 **3 Anticholinergic burden**

7 Does actively reducing anticholinergic burden in people living with dementia improve  
8 cognitive outcomes compared with usual care?

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

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

### 18 **4 Managing delirium superimposed on dementia**

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

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

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



1 **5 Care and support planning**

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

4 **Why this is important**

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

10 **Update information**

11 **June 2018**

12 This guideline is an update of NICE guideline CG42 (published November 2006) and  
13 will replace it.

14 **ISBN:**