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

NICE guideline: short version

Draft for consultation, January 2018

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.

Contents

About this guideline

Dementia is a term used to describe a collection of symptoms including memory loss, problems with reasoning and communication, and a reduction in a person's ability to carry out daily activities such as washing, dressing and cooking. The most common types of dementia are: Alzheimer's disease, vascular dementia, mixed dementia and dementia with Lewy bodies. 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.

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 to 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

- 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
- Mental Capacity Act 2005

Relevant policies and non-statutory guidance

- Department of Health (2014) NHS Outcomes Framework 2015 to 2016
- Department of Health (2014) Adult Social Care Outcomes Framework 2015 to 2016

More information

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

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.

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 guideline on patient experience in adult NHS 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 how it is likely to progress
- 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:

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

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

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

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.

Advance care planning

1.1.11 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 (health and welfare)
- 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.

1.1.12 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 and behavioural 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).

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

1.2.2 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).

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

1.2.4 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).

1.2.5 Refer the person to a specialist dementia diagnostic service if:

- reversible causes of cognitive decline (such as delirium or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated **and**
- dementia is still suspected.

1.2.6 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.

1.2.7 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.

Dementia diagnosis in specialist dementia diagnostic services

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

1.2.9 Consider structural imaging to rule out reversible causes of cognitive decline.

1.2.10 Diagnose a dementia subtype (if possible) if initial specialist assessment confirms cognitive decline and reversible causes have been ruled out.

1.2.11 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 (primary progressive 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 Recherché 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.

Diagnosing Alzheimer’s disease

1.2.12 If the diagnosis is uncertain and Alzheimer’s disease is suspected, consider either:

- examining cerebrospinal fluid for:
  - phosphorylated-tau 181 **and**
  - total tau **and**
  - either amyloid beta 1–42 or a ratio of amyloid beta 1–42 and amyloid beta 1–40

or

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

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

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

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

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

Diagnosing dementia with Lewy bodies

1.2.16 If the diagnosis is uncertain and dementia with Lewy bodies is suspected, use ^{123}I-FP-CIT SPECT.

1.2.17 If ^{123}I-FP-CIT SPECT is unavailable, consider ^{123}I-MIBG cardiac scintigraphy.

1.2.18 Do not rule out dementia with Lewy bodies based solely on normal results on ^{123}I-FP-CIT SPECT or ^{123}I-MIBG cardiac scintigraphy.

Diagnosing frontotemporal dementia

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

- FDG-PET **or**
- perfusion SPECT.

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

Diagnosing vascular dementia

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

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

Case finding

1.2.23 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

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

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

1.2.26 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

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

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

1.2.29 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 advocate 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.

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).

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 Consider providing structured group activities (including elements of cognitive stimulation and reminiscence therapy) to people living with mild to moderate dementia who are not already accessing them.

1.4.3 Consider providing a needs-based reablement programme (including elements of cognitive rehabilitation and/or occupational therapy) to people living with mild to moderate dementia who are not already accessing them.

1.4.4 Do not offer acupuncture to treat dementia.

1.4.5 Do not offer ginseng, vitamin E supplements, vitamin B and folic acid supplements, or herbal formulations to treat dementia.

1.4.6 Do not offer cognitive training to treat mild to moderate Alzheimer's disease.

1.4.7 Do not offer interpersonal therapies to treat the cognitive symptoms of mild to moderate Alzheimer's disease.

1.4.8 Do not offer non-invasive brain stimulation to treat mild to moderate Alzheimer's disease, except as part of a randomised controlled trial.

1.5 Pharmacological interventions for dementia

Pharmacological management of Alzheimer's disease

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

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

1.5.2 Memantine 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 1.5.4.

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

1.5.3 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.

1.5.4 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 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.

1.5.5 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 Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (NICE technology appraisal guidance 217).]

1.5.6 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 Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (NICE technology appraisal guidance 217).]

1.5.7 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 Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (NICE technology appraisal guidance 217).]

Slowing the progression of Alzheimer's disease

1.5.8 Do not offer the following 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

1.5.9 Offer donepezil or rivastigmine to people with mild to moderate dementia with Lewy bodies[1].

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

1.5.11 Consider donepezil or rivastigmine for people with severe dementia with Lewy bodies[1].

1.5.12 Consider memantine[3] for people with dementia with Lewy bodies if AChE inhibitors[4] are not tolerated or are contraindicated.

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

1.5.14 Do not offer AChE inhibitors or memantine to people with frontotemporal dementia.

---

[1] 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

[2] 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

[3] 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.

[4] 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

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

1.5.16 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 and distress

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

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[5,6] 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 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.

1.7.5 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.

1.7.6 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).

1.7.7 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.

1.7.8 Do not offer mood stabilisers to manage agitation or aggression in people living with dementia, unless they are indicated for another condition.

---

[5] 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.

[6] 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.

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

Depression and anxiety

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

1.7.11 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

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

1.7.13 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.

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 treatments and care 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.

Pain

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

1.8.3 Consider using a structured observational pain assessment tool 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 treating 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.

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.

1.10 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. 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 Practitioners must not hold a best interests discussion until a capacity assessment has been conducted, and a decision made and recorded that a person lacks capacity to make the decision in question (except in emergency situations). For more guidance, see the NICE guideline on decision-making and mental capacity[7].

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

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

---

[7] The NICE guideline on decision-making and mental capacity is in development and is due to be published in May 2018.

1.10.8 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.

1.10.9 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.

1.11 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 how it is likely to progress
- developing personalised strategies and building carer skills
- training in how to provide care, including how to understand and respond to changes in behaviour
- training in adapting communication styles to improve interactions with the person living with dementia
- how to look after their own physical and mental health and emotional wellbeing
- 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:

- 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.

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

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
- 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.

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
- 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 1.3.4 on information sharing between different care settings).

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

Terms used in this guideline

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 it addresses the disability resulting from 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.

Specialist clinician

Specialist clinicians are those with 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.

Putting this guideline into practice

[This section will be finalised after consultation]

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

June 2018

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

ISBN: