

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

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

Topic

This guideline will update the NICE guideline on Dementia (CG42) as set out in the [update decision](#).

Who the guideline is for

- People using NHS and social care services, their families and carers, and the public.
- Health and social care staff working in:
 - the NHS
 - integrated health and social care services
 - statutory social services
 - the voluntary and independent sectors.
- Commissioners, providers and regulators of dementia services.
- Health and social care staff who have direct contact with people living with dementia in:
 - hospitals
 - the community
 - home-based care
 - residential or specialist settings
 - secure environments.
- Housing associations, private and voluntary organisations contracted by the NHS or social services to provide care for people living with dementia.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope, if this was done.

1 What the guideline is about

1.1 Who is the focus?

Groups that will be covered

- People aged 40 and over living with dementia or suspected dementia
- Family members, informal and formal carers of people aged 40 and over living with dementia
- The guideline will give special consideration to:
 - the diverse attitudes and responses of different ethnic and cultural groups (including people who do not speak English as a first language)
 - people who cannot read English
 - people with different levels of educational attainment and people who have not had educational opportunities
 - people who are lesbian, gay, bisexual and/or transgender
 - people with sensory impairment
 - people with communication difficulties
 - people with difficulties eating, drinking or swallowing
 - people with comorbidities or conditions that may affect the treatment and management of dementia
 - people with learning disabilities
 - people who are at risk of social exclusion or isolation

- people aged 40–64 years with early onset dementia
- people with specific housing and supported living needs, including the need for a living environment adapted for people with cognitive impairment
- people in inpatient hospital settings.

Groups that will not be covered

- People with a confirmed diagnosis of mild cognitive impairment.
- People with juvenile onset dementia.

1.2 Settings

Settings that will be covered

All settings.

1.3 Activities, services or aspects of care

Key areas that will be covered

Note that when considering medication, the guideline recommendations will normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will assume that prescribers will use a medicine's summary of product characteristics to inform decisions made with individual patients.

Areas from the published guideline that will be updated

- 1 Principles of care for people living with dementia
 - Ethics, consent and advance decision-making
 - Training and development of health and social care staff
- 2 Risk factors and early identification
 - Recognition (signs and symptoms, risk factors)
 - Initial assessments for suspected dementia
 - Referral criteria for specialist dementia assessment
- 3 Slowing the progression of dementia
- 4 Diagnosing and assessing dementia

- Diagnosing dementia
 - Identifying dementia subtypes
 - Assessing the needs of people living with dementia
 - Specialist dementia assessment
 - Risk management and how it can support people living with dementia to avoid harm and maintain independence
- 5 Interventions to maximise the health and wellbeing of people living with dementia who experience changes in cognitive functioning
 - 6 Interventions to maximise the health and wellbeing of people living with dementia who experience non-cognitive symptoms of dementia, including changes in:
 - Behaviour
 - Physical functioning and ability to carry out activities of daily living
 - Mood and mental health
 - Physical symptoms such as incontinence and pain
 - 7 Interventions to maximise the health and wellbeing of family members and carers of people living with dementia, including:
 - Assessment of needs
 - Interventions
 - Advice and information
 - 8 Integrated health and social care
 - 9 Inpatient services
 - Experiences of people living with dementia and their informal carers
 - Arrangement of care
 - 10 Palliative care, pain relief and care at the end of life for people living with dementia.

Areas not in the published guideline that will be included in the update

- 1 Intercurrent illness and multimorbidities
 - Medical conditions that may mask, mimic or exacerbate a diagnosis of dementia (for example delirium, depression, or sensory impairments)
 - Managing multimorbidities that may affect the progression of dementia (for example diabetes mellitus or cardiovascular disease)

- How cardiovascular risk factors (for example hypertension and diabetes mellitus) affect the diagnosis and management of dementia
- Multimorbidities that may need to be treated differently in people living with dementia (for example incontinence or visual impairment).

Recommendations in areas that are not being updated may be edited to ensure that they meet current editorial standards, and reflect the current policy, practice and social context.

Areas from the published guideline that will be removed

- 1 Pharmacological management of mild cognitive impairment in people living with dementia.
- 2 Pharmacological management of Parkinson's disease dementia

1.4 *Economic aspects*

We will review the economic evidence and carry out economic analyses using an appropriate perspective. For all questions, the perspective on outcomes will include direct health effects, whether for people using services or, when relevant, other people (principally family members or informal carers). For review questions that focus on health outcomes in NHS settings, an NHS and PSS perspective will be used for costs. For review questions that focus on social care, we may consider widening the perspective to capture non-health effects and/or a societal perspective on costs.

1.5 *Key issues and draft review questions*

While writing this scope, we have identified the following key issues, and key questions related to them:

- 1 Ethics, consent and advance decision-making
 - When a diagnosis of dementia is made, what interventions are most effective in enabling people living with dementia to anticipate and plan for their future needs?
 - How can it be ensured that people living with dementia can exercise choice in decisions about their care?

- How can it be ensured that people living with dementia are able to make use of advance decision-making (advanced care plans)?
- 2 Training and development of health and social care staff
 - What models of training for health and social care staff have positive outcomes for people living with dementia?
 - 3 Recognition (signs and symptoms, risk factors)
 - What are the signs and symptoms of dementia?
 - What are the risk factors for dementia?
 - 4 Assessments for suspected dementia
 - How useful are assessments for people with a suspected diagnosis of dementia?
 - 5 Diagnosing dementia
 - What are the most effective methods of diagnosing dementia?
 - What are the differential diagnoses of dementia (medical or psychiatric conditions) that may mask or mimic dementia?
 - How should the needs of people living with dementia be assessed?
 - 6 Slowing the progression of dementia
 - How can the progression of dementia be slowed (including by modifying cardiovascular risk factors)?
 - 7 Identifying dementia subtypes
 - What is the diagnostic accuracy of imaging to differentiate between dementia subtypes?
 - 8 Intercurrent illness in people living with dementia
 - What assessments should be done for people living with dementia who have a sudden deterioration in their health and wellbeing?
 - How should intercurrent illness (for example, infection) be managed in people living with dementia?
 - 9 Comorbidities and multimorbidities
 - How should medical comorbidities and multimorbidities be managed in people living with dementia?
 - How should psychiatric comorbidities and multimorbidities be managed in people living with dementia?

- 10 Risk management and how it can support people living with dementia to avoid harm and maintain independence
 - How should individual risks (for people living with dementia, their family members, carers, and health and social care staff) be assessed?
- 11 Interventions to maximise the health and wellbeing of people living with dementia who experience changes in cognitive function
 - What interventions (for example cognitive stimulation therapies, pharmacological interventions, assistive technologies or music therapy) are effective, when compared with placebo or usual care, in maximising the health and wellbeing of people living with dementia who experience changes in cognitive function?
 - Who should start and monitor the following pharmacological interventions for people with Alzheimer's disease;
 - donepezil,
 - galantamine,
 - rivastigmine
 - memantine
- 12 Interventions to maximise the health and wellbeing of people living with dementia who experience changes in non-cognitive symptoms of dementia
 - What interventions are effective in maximising the health and wellbeing of people living with dementia who experience changes in non-cognitive symptoms of dementia?
- 13 Assessing the needs of carers
 - How should the needs of informal and formal carers of people living with dementia be assessed?
- 14 Psychosocial interventions for carers of people living with dementia
 - What social interventions are effective for supporting informal and formal carers of people living with dementia?
 - What psychological interventions are effective for supporting informal and formal carers of people living with dementia?
- 15 Integrated health and social care

- What experiences do people living with dementia and their informal and formal carers have of integrated health and social care services?
 - How should care be arranged to optimise the health and wellbeing of people living with dementia and their informal carers?
- 16 Inpatient services
- How should people living with dementia in inpatient services be cared for?
- 17 Palliative care, pain relief and care at the end of life for people living with dementia
- What is best practice in palliative care for people with dementia?
 - How can it be ensured that end of life plans are acted upon?

1.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

- 1 Signs and symptoms of dementia (including memory loss, communication and perceptual changes, behavioural or mood changes, and problems with cognitive reasoning)
- 2 Adaptive function (for example, social functioning)
- 3 Ability to carry out activities of daily living (for example physical functioning and activities of daily living)
- 4 Visual impairment
- 5 Changes in language and communication
- 6 Health-related quality of life of people living with dementia and their informal carers
- 7 Capability measures
- 8 Choice and autonomy for people living with dementia (including living well with dementia)
- 9 Need for extensive care
- 10 Informal carer health and wellbeing
- 11 Satisfaction of people living with dementia with the care they received
- 12 Informal carer satisfaction with the care the person living with dementia received

- 13 Informal carer satisfaction with the support they themselves received
- 14 Health and social care staff satisfaction
- 15 Health and social care service use (for example hospital admissions and re-admissions, primary care appointments, attendance at accident and emergency departments, and other planned and unplanned contacts with health and social care services)
- 16 Problematic polypharmacy (for example sub-optimal medicines use, over-prescribing and under-prescribing)
- 17 Medicines-related outcomes, including:
 - patient reporting outcomes such as concordance, compliance, patient experience and patient satisfaction
 - medicines-related problems such as potentially avoidable hospital admissions and re-admissions, errors, and potentially avoidable adverse effects
- 18 Mortality
- 19 Risk management
- 20 Resource use and cost

2 Links with other NICE guidance and NICE Pathways

2.1 NICE guidance

NICE guidance that will be updated by this guideline

- [Dementia: supporting people with dementia and their carers in health and social care](#) (2006) NICE guideline CG42
- [Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#) (2011) NICE technology appraisal guidance TA217
In line with the [review decision for this technology appraisal](#), only recommendation 1.3 in TA217 will be reviewed as part of this guideline update.

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to dementia care:

- [Medicines optimisation](#) (2015) NICE Guideline NG5
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76

NICE guidance in development that is closely related to this guideline

NICE is currently developing the following guidance that is closely related to this guideline:

- [Home care](#). NICE guideline. Publication expected September 2015
- [Social care of older people with complex care needs and multiple long-term conditions](#). NICE guideline. Publication expected October 2015
- [Care of the dying adult](#). NICE guideline. Publication expected December 2015
- [Mental health problems in people with learning disabilities](#). NICE guideline. Publication expected September 2016
- [Managing medicines for people receiving social care in the community](#). NICE guideline. Publication expected April 2017.
- [Parkinson's disease \(update\)](#). NICE guideline. Publication expected April 2017
- [Service user and carer experience](#). NICE guideline. Publication expected January 2018.
- [Disability, dementia and frailty in later life – mid-life approaches to prevention](#). NICE guideline. Publication date to be confirmed.

2.2 NICE Pathways

[NICE Pathways](#) bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

When this guideline is published, the recommendations will be added to a new NICE pathway. Other relevant NICE guidance will also be added to the NICE pathway, including:

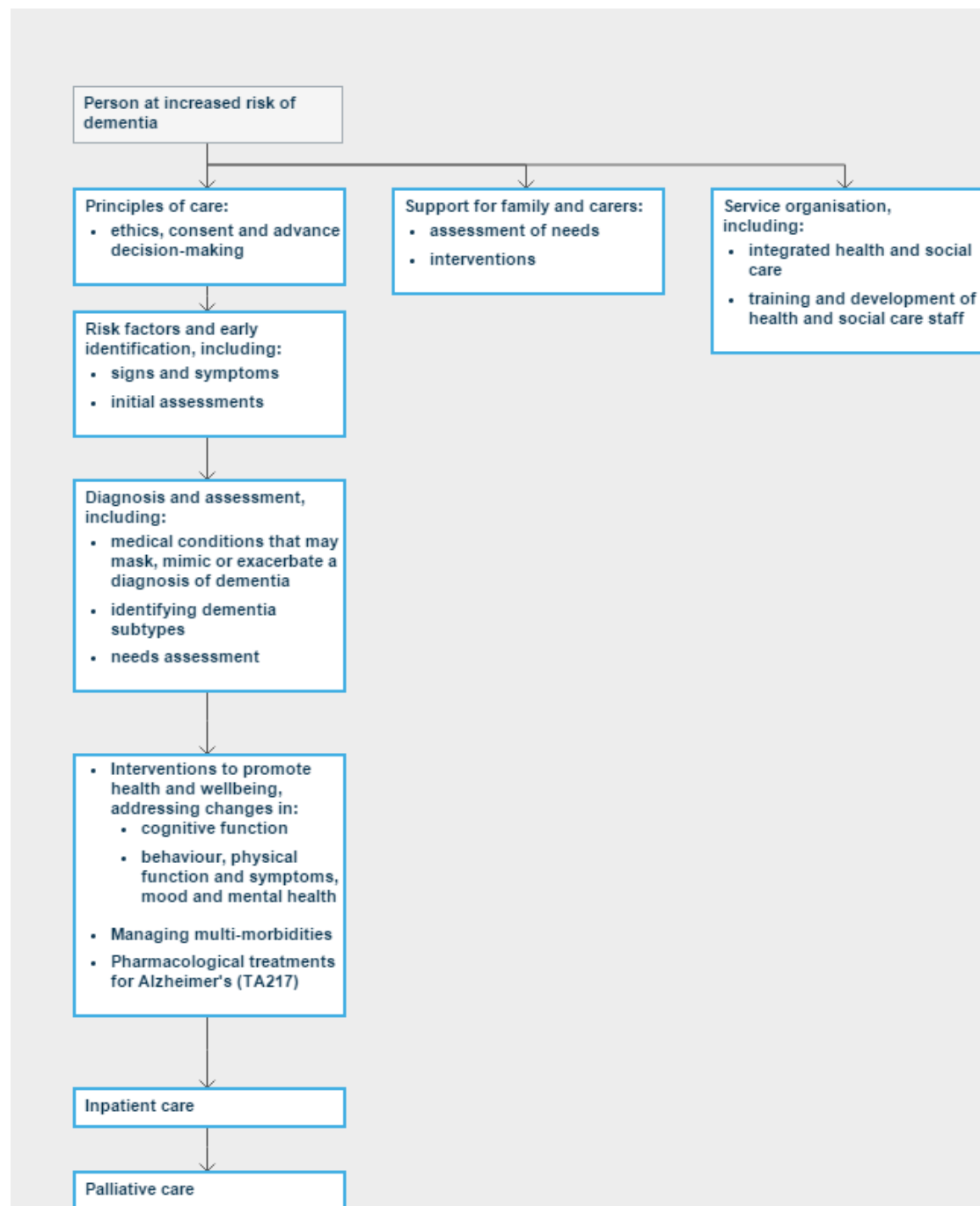
- [Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#) (2011) NICE technology appraisal guidance 217.

A draft pathway, based on the scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

This pathway will update and replace the existing pathway on [dementia](#). It will include links to patient experience pathways such as [medicines optimisation](#) and [service user experience in adult mental health services](#), and closely related pathways such as [delirium](#) and 'dementia, disability and frailty in later life – mid-life approaches to prevention' (publication date to be confirmed).

Links to pathways on [Parkinson's disease](#), 'mental health problems in people with learning disabilities' (publication expected September 2016) and on risk factors for dementia, for example cardiovascular conditions, will be added as needed.

Dementia overview



3 Context

3.1 *Key facts and figures*

Dementia is a progressive, variable and largely irreversible condition that covers a wide range of symptoms. It is characterised by widespread impairment of mental function, including some or all of the following:

- memory loss
- communication difficulties and sensory impairment
- disorientation
- personality change
- difficulties with activities of daily living
- self-neglect
- behaviour that is out of character (for example, sleep disturbance or sexual disinhibition).

A [report](#) published by the Alzheimers society found that in 2013 there were approximately 815,000 people living with dementia in the UK. The number of people living with dementia in the UK is expected to increase to 1,143,000 by 2025, if current trends continue.

According to the [National Dementia and Antipsychotic Prescribing Audit](#) (2012), there were approximately 31,000 people newly diagnosed with dementia in England in 2011. This is an increase of 8% between 2006 and 2011.

The Alzheimers 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.

The Prime Ministers Challenge on Dementia 2020 sets out the UK Government's long term strategy for transforming dementia care within the

UK. The strategy's aspirations include improving diagnosis, assessment and care for people with dementia. The aims of the strategy include, that by 2020, all people with dementia will have equal access to diagnosis, all NHS staff will receive training on dementia appropriate to their role, and every person diagnosed with dementia will receive meaningful care.

Since the NICE guideline on dementia was published, key new legislation has been implemented. The Mental Capacity Act 2005 created new systems for people living with dementia, their family members and carers, and health and social care staff to make decisions about care. The Care Act 2014 created a new legislative framework for adult social care, and also gives carers a legal right to assessment and support.

3.2 Current practice

Current options for managing the cognitive symptoms of dementia include the acetylcholinesterase (AChE) inhibitors (donepezil, rivastigmine and galantamine) and the N-methyl-D-aspartate (NMDA) receptor antagonist memantine. Antipsychotics licensed for short-term use (for example risperidone) are options in certain circumstances to manage the behavioural and psychological symptoms of dementia.

In addition, non-pharmacological treatment can help with the symptoms of dementia. These treatments include psychological and cognitive therapies (such as cognitive stimulation therapy), which can be used to improve memory skills in people living with dementia. Alternative therapies such as the therapeutic use of music or dancing, animal-assisted therapy, aromatherapy, massage and multi-sensory stimulation may help with the behavioural symptoms of dementia, and treatment can be tailored to individual needs.

According to the [National Dementia and Antipsychotic Prescribing Audit](#) (2012), the number of people living with dementia who are taking antipsychotic medication decreased from 17% in 2006 to 7% in 2011. There was little variation in the number of people taking donepezil, galantamine, rivastigmine or memantine during the audit period.

Since the NICE dementia guideline published in 2006, new methods for diagnosing and assessing dementia have been developed. Amyloid imaging techniques have been licensed for use in the UK, and new evidence has been identified on cerebrospinal fluid examination. There is also recent evidence on different approaches to assess and diagnose dementia subtypes.

3.3 Policy, legislation, regulation and commissioning Policy, legislation, regulation and commissioning

Policy

- Department of Health (2015) [Prime Ministers Challenge on Dementia 2020](#)
- Department of Health (2014) [NHS Outcomes Framework 2015 to 2016](#)
- Department of Health (2014) [Adult Social Care Outcomes Framework 2015 to 2016](#)
- Department of Health (2013) [2010 to 2015 government policy: dementia](#)
- Department of Health (2013) [Dementia care and support](#)
- Department of Health (2012) [Caring For Our Future: reforming care and support](#)
- Department of Health (2012) [Prime Minister's Challenge on Dementia](#)
- Department of Health (2009) [Living Well With Dementia: a national dementia strategy](#)

Legislation, regulation and guidance

- NHS England (2015) [Accessible Information Standard](#)
- Care Quality Commission (2015) [Guidance for service providers and managers](#)
- Care Quality Commission (2014) Our fundamental standards
- HM Government (2014) [Health and Social Care Act 2008 \(Regulated Activities\) Regulations 2014](#)
- HM Government (2014) [Care Act](#)
- 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](#)

- HM Government (2012) [Health and Social Care Act](#)
- HM Government (2009) [Care Quality Commission \(Registration\) Regulations \(2009\)](#).
- HM Government (2005) [Mental Capacity Act](#)

4 Further information

The guideline is expected to be published in September 2017.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.