

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Guideline scope

### **Dementia: supporting people with dementia and their carers in health and social care**

#### ***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 these services for people receiving care for dementia.
- Health and social care staff who have direct contact with people with dementia in:
  - hospitals
  - the community
  - home-based care
  - group care
  - residential or specialist settings
  - secure environments.
- Housing associations and private organisations contracted by the NHS or social services to provide care for people 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 of all ages with dementia or suspected dementia
- Family members and carers of people with dementia
- The guideline will give special consideration to:
  - the diverse attitudes and responses 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 or who have not had educational opportunities.
  - people with HIV and other comorbidities or conditions that may affect the treatment and management of dementia.
  - people who are at risk of social exclusion.

### **Groups that will not be covered**

- People with mild cognitive impairment who are not suspected of having dementia

## **1.2 Settings**

### **Settings that will be covered**

All settings in which NHS-funded health and social care is received.

## **1.3 Activities, services or aspects of care**

### **Key areas that will be covered**

Note that 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 with dementia
  - Ethics, consent and advance decision-making
  - Supporting people with dementia to exercise choice
  - 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 Preventing dementia
- 4 Diagnosing and assessing dementia
  - Diagnosing dementia
  - Identifying dementia subtypes
  - Specialist dementia assessment
  - Multimorbidity in people with dementia
  - Risk management and how it can support people with dementia to avoid harm and stay independent
- 5 Managing dementia
  - Cognitive features
  - Emotional features

- Behavioural features
  - Functional features
- 6 Support for family members and carers of people with dementia
- Assessment of needs
  - Interventions
- 7 Integrated health and social care

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

- 1 Comorbidities
- Medical conditions that may mask a diagnosis of dementia (for example delirium or depression)
  - Managing comorbidities that may affect the progression of dementia (for example diabetes mellitus or cardiovascular disease)
  - How vascular risk factors (for example hypertension and diabetes mellitus) affect the diagnosis and management of dementia
  - Co-morbidities that may require treating differently because of the presence of dementia (for example incontinence or visual impairment).

**Areas that will not be covered**

- 1 Pharmacological management of Parkinson's disease dementia.

***Areas from the published guideline that will not be updated***

- 1 Palliative care, pain relief and care at the end of life for people with dementia.

***Areas from the published guideline that will be removed***

- 1 Inpatient dementia services.
- 2 Assessing and managing dementia for people who have learning disabilities.
- (N.B. It is proposed that this is covered by the guideline on mental health problems and learning disabilities currently in development.)

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

#### **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 for other people (usually 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 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
  - Is it ever appropriate to act when a person with dementia has not been able to give or has withheld consent?
- 2 Supporting people with dementia to exercise choice
  - How can it be ensured that people with dementia can exercise choice in decisions about their care?
  - How can it be ensured that people with dementia are able to make use of advance decision making (advanced care plans)?
- 3 Training and development of health and social care staff
  - What models of training for health and social care staff have positive outcomes for people with dementia?
- 4 Recognition (signs and symptoms, risk factors)
  - What are the signs and symptoms of dementia (including symptoms of differential diagnoses [medical or psychiatric] and co-existing medical conditions that may mask or mimic dementia)?
  - What are the risk factors for dementia?

- 5 Initial assessments for suspected dementia
  - What is the diagnostic accuracy of initial assessments?
- 6 Referral criteria for specialist dementia assessment
  - What are the indications for referral for specialist diagnostic assessment?
- 7 Preventing dementia
  - How can dementia be prevented (including modifying cardiovascular risk factors)?
  - What effect does managing cardiovascular risk factors have on the progression of dementia?
- 8 Diagnosing dementia
  - What are the most appropriate methods used to diagnose dementia?
  - What are the differential diagnoses of dementia (medical or psychiatric conditions that may mask dementia)?
- 9 Identifying dementia subtypes
  - What is the diagnostic accuracy of imaging to differentiate between dementia subtypes?
- 10 Multimorbidity in people with dementia
  - What assessments should be done for people with dementia who have a sudden deterioration in functioning?
  - How should intercurrent illness (for example, infection) be managed in people with dementia who have a sudden deterioration of functioning?
  - How should medical comorbidities be managed in people with dementia who have a sudden deterioration of functioning?
  - How should psychiatric comorbidities be managed in people with dementia who have a sudden deterioration of functioning?
- 11 Risk management and how it can support people with dementia to avoid harm and stay independent
  - How should individual risk (to people with dementia, their family members, carers, and health and social care staff) be assessed and managed?
- 12 Managing cognitive features

- What pharmacological interventions are effective for managing cognitive features in people with dementia?
  - What non-pharmacological interventions are effective for managing cognitive features in people with dementia?
- 13 Managing emotional features
- What pharmacological interventions are effective for managing emotional features in people with dementia?
  - What non-pharmacological interventions are effective for managing emotional features in people with dementia?
- 14 Managing behavioural features
- What pharmacological interventions are effective for managing behavioural features in people with dementia?
  - What non-pharmacological interventions are effective for managing behavioural features in people with dementia?
- 15 Managing functional features
- What pharmacological interventions are effective for managing functional features in people with dementia?
  - What non-pharmacological interventions are effective for managing functional features in people with dementia?
  - What medical conditions may affect progression of dementia?
- 16 Assessing the needs of carers
- How should the needs of carers be assessed?
- 17 Social interventions for carers
- What social care interventions are effective for supporting family members and carers of people with dementia?
  - What psychological interventions are effective for supporting carers of people with dementia?
- 18 Integrated health and social care
- What experiences do people with dementia and their family members and carers have of integrated health and social care?
  - What experiences do health and social care staff have of integrated health and social care?

- How should care be arranged to optimise the independence of people with dementia and their family members and carers?

The key questions may be used to develop more detailed review questions, which guide the systematic review of the literature.

## **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, language changes, behavioural or mood changes, and problems with cognitive reasoning)
- 2 Adaptive function (for example, social functioning and the ability to carry out activities of daily living)
- 3 Health and social care related quality of life
- 4 Mortality
- 5 Choice and control for people with dementia
- 6 Problematic polypharmacy
- 7 Rates of withdrawal
- 8 Adverse events
- 9 Family and carer wellbeing
- 10 Patient, family members and carers satisfaction and experience
- 11 Health and social care staff satisfaction and experience
- 12 Health and social care service use
- 13 Risk management
- 14 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  
N.B. In accordance with the [review decision](#), only recommendation 1.3 in TA217 will be considered for update within the update of the guideline.

#### **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:

- [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

- [Disability, dementia and frailty in later life – mid-life approaches to prevention](#) NICE guideline. Publication date to be confirmed.

## **2.2 NICE Pathways**

When this guideline is published, the recommendations will be added to [NICE Pathways](#). NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

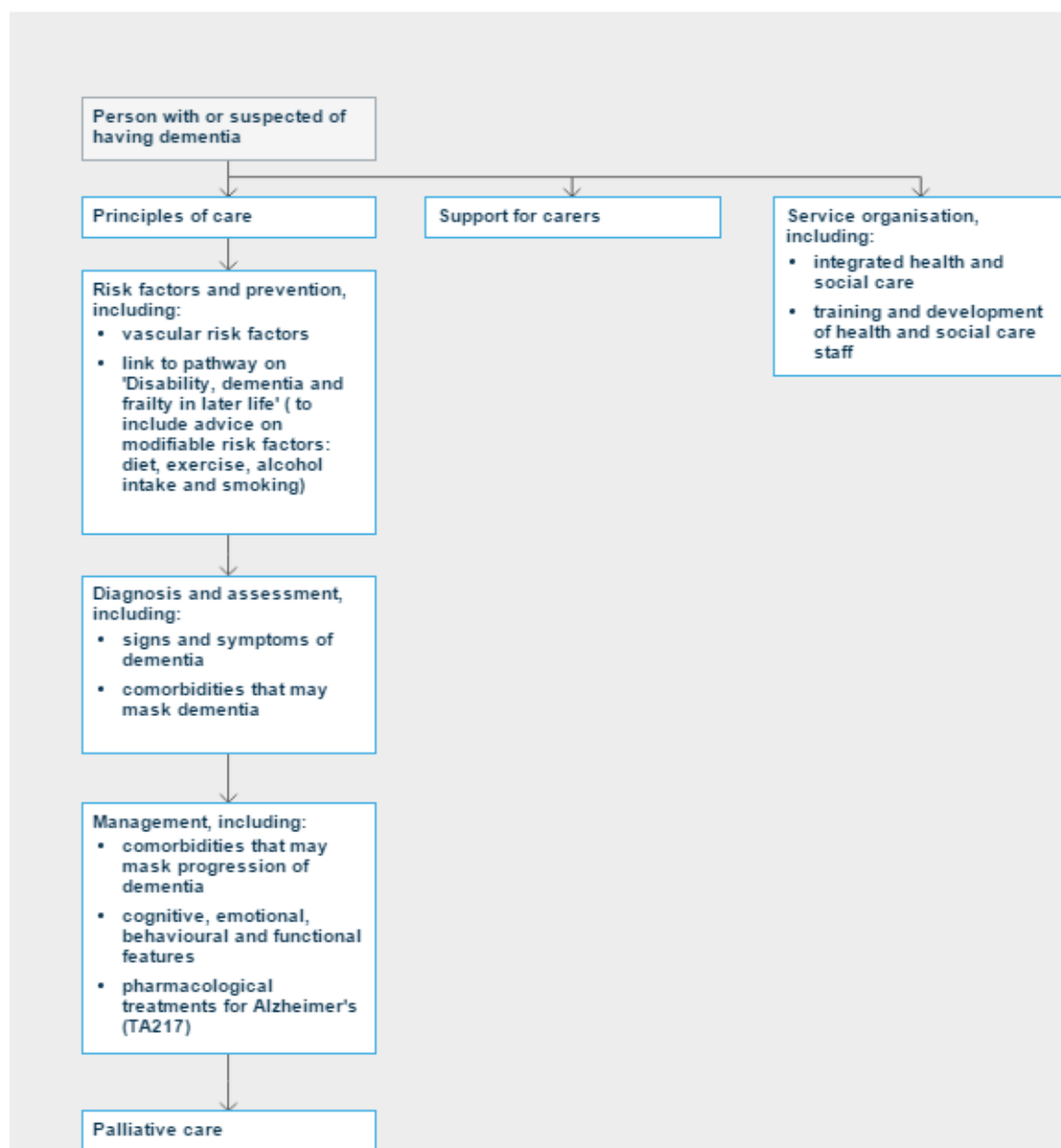
Other relevant NICE guidance will also be added to the NICE Pathway, including: [donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#) (2011) NICE technology appraisal guidance 217.

A draft pathway, based on the draft 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 the pathways covering cardiovascular conditions and lifestyle choices, 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
- language impairment
- disorientation

- personality change
- difficulties with activities of daily living
- self-neglect
- behaviour that is out of character (for example, aggression, sleep disturbance or sexual disinhibition).

A [recent report](#) published by the Alzheimers society found that in 2013 there were approximately 815,000 people with dementia in the UK. The number of people 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 the UK in 2011. This is an increase of 8% between 2006 and 2011.

[A report](#) by the Alzheimers society found that the total cost of dementia in the UK is 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.

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 management of 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 used to manage the behavioural and psychological symptoms of dementia.

According to the [National Dementia and Antipsychotic Prescribing Audit](#) (2012), the number of people 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 guideline on dementia published there have been various techniques identified as appropriate for diagnosing and assessing dementia. 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 currently used to assess and diagnose subtypes of dementia.

### ***3.3 Policy, legislation, regulation and commissioning Policy, legislation, regulation and commissioning***

#### **Policy**

- 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 (2009) [Living Well With Dementia: a national dementia strategy](#)

#### **Legislation, regulation and guidance**

- 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](#)
- 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

This is the draft scope for consultation with registered stakeholders. The consultation dates are 8 July to 5 August 2015.

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.