Supporting people to live well with dementia

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Objectives

• About NICE – our role and organisation

• New developments at NICE – our new role in social care

• NICE quality standards – how to use them to commission services that promote independence and wellbeing

• Finding guidance and resources to support your work
• How are you using NICE quality standards now?

• Are you using them in contracts?

• Do you have examples of quality improvements as a result of specifying NICE guidance and quality standards in contracts
What is NICE?

The National Institute for Health and Care Excellence (NICE) is the independent organisation responsible for providing national guidance and advice to improve health and social care.
What we do

• Produce evidence-based guidance and advice for health, public health and social care practitioners

• Develop quality standards and performance metrics for those providing and commissioning health, public health and social care services

• Provide a range of information services for commissioners, practitioners and managers across health and social care
We produce national guidance covering…..

Health technologies:

• Technology appraisals
• Interventional procedures
• Medical technologies

NICE Guidelines (NG):

• Clinical guidelines
• Public health
• Social care topics

Quality standards
Our position in the social care sector

Social Care and Support White Paper “Caring for our Future”
NICE Guidelines

• NICE guidelines are comprehensive sets of recommendations based on the best available evidence
• They describe what is effective (what will result in the best outcomes)
• And what is cost effective (best value for money)
• They are developed to guide decisions made about health and care (for practitioners, providers, commissioners, service planners and users)
• Developed by independent committees with public involvement
• NICE consults on the scope and the draft of the guideline
• Open and transparent about decisions
Why use NICE guidance?

- Based on the best available research
  - Effectiveness: what works and in what population
  - Cost-effectiveness: value for money approaches to national and local priorities
- Reduce variation and inequalities
- Improve local services and accountability
- Improve health and wellbeing outcomes
- Supports the case for investment
- Supports local integration discussions and decisions with partners on investment and prioritisation
- Fit with broader policy agenda eg HWBS.
And the importance of NICE guidance to the public, service users, and carers

- “Having confidence in the staff looking after me ”
- “Understanding what treatment I can expect”
- “Being confident in the system”
- Better service user experience and outcomes
- Empowering people to make choices about their own care
- A constitutional right to receive treatment and medicines recommended by NICE
What are NICE guidance and quality standards?

A NICE quality standard is a concise set of statements designed to drive and measure priority quality improvements.

Evidence

Research studies - experimental and observational, quantitative and qualitative, process evaluations, descriptions of experience, case studies

Guidance

Quality Standards

A NICE quality standard is a concise set of statements designed to drive and measure priority quality improvements.
Typically 6–8 statements

Based on best available evidence such as NICE guidance and other evidence sources accredited by NICE

Define priority areas for quality improvement

Include measures to help inform local quality improvement work
Source guidance for QS50

- Dementia. NICE CG42 (2011)
- Delirium. NICE CG103 (2010)
- Social anxiety disorder. NICE CG159 (2013)
- Anxiety disorders. NICE quality standard (February 2014)
- Common mental health disorders. NICE CG123 (2011)
- Mental wellbeing and older people. NICE public health guidance 16 (2008)
- Dignity in Care. SCIE guide 15 (2010)
Potentially relevant guidelines & QS

- Dementia: supporting people with dementia and their carers in health and social care (CG42) Nov 2006
- Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset (NG16) Oct 2015
- Older people: independence and mental wellbeing (NG32) Dec 2015
- Mental wellbeing in over 65s: occupational therapy and physical activity interventions (PH16) Oct 2008
- Supporting people to live well with dementia (QS30)
- Mental wellbeing of older people in care homes (QS51)
Part 2:
How to use NICE quality standards to commission services that promote independence and wellbeing
How to use NICE quality standards

Help to identify local priorities for quality improvement

• NICE quality standards can highlight key areas for improvement. An initial assessment should consider: 
  * relevance to the organisation, how services compare, what evidence is available, actions to improve, risks of not improving

Driving quality improvement

• Once you have identified gaps and priorities, use quality standard measures to improve quality of services:
  * establish a project team, develop an action plan, assess cost and service impact, develop a business case, measure a baseline, deliver actions and evaluate success

• See Into Practice Guide www.nice.org.uk/intopracticeguide
Use NICE quality standards to….

• Commission services based on evidence – by understanding what the evidence says is effective
• In service specifications, tender documents and contracts – specify what you want to see from providers
• Tender applications – are services monitoring and improving quality
• Develop metrics to monitor quality of providers which are evidence based and rigorous eg KPIs, dashboards
• Conduct quality surveillance and scrutinise or inspect services – turn QS statements into questions
• Market development – what does the evidence say works and is good quality
• Education and development
• Safeguarding
Quality Standard

List of quality statements

Statement 1. People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.

Statement 2. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

Statement 3. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

Statement 4. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

Statement 5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

Statement 6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Statement 7. People with dementia live in housing that meets their specific needs.

Statement 8. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

Statement 9. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
Source guidance

- Social Care Institute for Excellence (2011) IMCA and paid relevant person's representative roles in the Mental Capacity Act Deprivation of Liberty Safeguards. SCIE guide 41.
- NICE clinical guideline: CG42 Dementia (2006)
Quality Standard

List of quality statements

Statement 7. People with dementia live in housing that meets their specific needs.
Quality Standard

Quality statement 7: Design and adaptation of housing

What the quality statement means for each audience

Quality statement
People with dementia live in housing that meets their specific needs.

Rationale
Housing can be designed or adapted in a way that helps people with dementia manage their surroundings, retain their independence, and reduce feelings of confusion and anxiety.
What the quality statement means for each audience

People with dementia live in housing that is adapted to help them maintain their independence.

Carers of people with dementia are involved in helping to identify how the housing of the person they support may be adapted to help maintain their independence.

**Local authorities and others commissioning services** work with providers to ensure the housing they commission is designed or adapted to meet the specific needs of people with dementia and also commission services that can adapt the homes of people with dementia to better meet their specific needs.

Organisations providing care and support ensure housing is designed or adapted to meet the specific needs of people with dementia.

Social care staff ensure housing meets the specific needs of people with dementia.

Source guidance

*NICE clinical guideline 42* recommendations 1.1.10.1, 1.1.10.2 and 1.1.10.3.

*SCIE guide 15*: Practical assistance.

*SCIE guide 47*: Personalisation – a rough guide.

Data source

Structure: a) and b) Local data collection.

Process: a), b), c) and d) Local data collection.

Outcome: a) and b) Local data collection.

**Definitions**

**Housing**

This statement applies equally to people with dementia receiving care in their own homes or living in residential or care homes.
Definitions

Housing
This statement applies equally to people with dementia receiving care in their own homes or living in residential or care homes.

Design and adaptation
The design and adaptation of housing to help meet the needs of people with dementia could include changes to and use of:

- lighting
- colour schemes
- floor coverings
- assistive technology
- signage
- wide doorways
- flat gardens, low-wall flower beds
- glass-fronted cupboard doors in kitchens so people can see what is inside
- memory cues
- colour contrasts
- minimising reflections and glare
- notice boards.

Further suggestions are included in the King’s Fund document Developing supportive design for people with dementia. Any adaptation should take into account the preferences of the person with dementia.

Extra-care housing
There is some local variance in the specific features of extra-care housing. The National Dementia Strategy...
Suggested service review questions:

Are staff trained to recognise when adaptations to housing can help meet the specific needs of people with dementia?

1. Which roles would be well placed to recognise when housing adaptations would be beneficial?
2. Do these staff routinely access training to support them with this?
3. Is there a clear process for arranging housing adaptations?
4. Could more people benefit from housing adaptations to support them to live independently?
Andrea Sutcliffe, Chief Inspector for Adult Social Care at the CQC

“At the CQC we are asking the questions that matter to people. We’re asking whether services are safe, caring, effective, responsive to people’s needs, and well led.

“And the way that we can do this is by identifying key lines of enquiry – so the questions that we will ask when we go out on inspections. We will also identify what the characteristics are of the services that we see, so whether they are good, outstanding, require improvement or are inadequate.

“This quality standard will inform the questions that we ask, and help us to provide the understanding of what ‘good’ and ‘outstanding’ practice looks like in this area.”

https://www.youtube.com/watch?v=RxwHM0Jsdyl
Case study - NHS Stockport CCG & Stockport Metropolitan Borough Council

- Wanted to integrate quality agendas, with a systematic & evidence based approach to quality
- Designed a process & set up small steering group to evaluate all QS (tested it with QS1& 30 on dementia)
- Where indicated by initial assessment, set up small topic specific task & finish groups, which identified actions required to improve, and act upon them.
- Working together led to consistent approach, combined knowledge, avoided duplication, more powerful approach to change, feeds into formal structures.

http://www.nice.org.uk/localpractice/collection
Case study – Greater Manchester Sector Led Improvement

- NICE guidance & quality standards are pivotal to Greater Manchester's sector-led improvement approach to driving improvements in public health
- Process of self-assessment and peer review
- Local action plans are developed and reviewed regularly by LA peers to ensure that NICE guidance & quality standards are being implemented and that performance against PHOF (Public Health Outcomes Framework) measures improves in the long-term

http://www.nice.org.uk/localpractice/collection
Case study – Windsor & Maidenhead CCG & Royal Borough of Windsor and Maidenhead

- Use of NICE quality standard QS50 mental wellbeing of older people in care homes
- Consulted with older people, local agencies and charities, roundtable event with care home staff
- Developed dementia action plan including training on living with dementia, skin care, medication etc
- Led to re-design of services across all sectors, improved rate of early diagnosis, reduced admissions to hospital, better quality care provided in the community and 17 care homes

http://www.nice.org.uk/localpractice/collection
EG. Ensure wellbeing and safeguarding responsibilities are met

NICE Quality Standards can help organisations you commission to:

• Provide meaningful, person-centred activities
  – Supporting people to live well with dementia
  – Mental wellbeing of older people in residential care
• Reduce medication errors
  – Medicines management in care homes
• Monitor for malnutrition
  – Nutrition support in adults
• Prevent falls
  – Quality standard published in March 2015
• Reduce healthcare-related infections
  – Infection prevention and control
• Avoid delirium and monitor for depression
  – Delirium
  – Mental wellbeing of older people in residential care
QS30 – How will you use it for……..?

• Evidence base for commissioned services
• Service specs & contracts
• Tender applications – what would you expect to see
• Metrics to monitor provider quality
• Quality surveillance & scrutiny
• Market development
• Staff education
• Safeguarding
Part 3:
Finding guidance and resources to support your work
Improving health and social care through evidence-based guidance

Find NICE guidance

- NICE Pathways
  A visual, integrated view of everything NICE has said on a topic.
- Standards and indicators
  Short, evidence-based statements to help you deliver quality improvements at work.
Find guidance

Choose a category to find guidance in your area:

- Conditions and diseases
- Health protection
- Lifestyle and wellbeing
- Population groups
- Service delivery, organisation and staffing
- Settings

NICE guidance

Lists of NICE guidance, including published guidance, in development and consultations

- All NICE guidelines
- Clinical guidelines
- Public health guidelines
- Social care guidelines
- Safe staffing guidelines
- Medicines practice guidelines
- Quality standards
- Technology appraisals
- Interventionsal procedures
- Medical technologies
- Diagnostics
- Highly specialised technologies

NICE advice


- Evidence summaries: Unlicensed or off-label medicines
- Evidence summaries: New medicines
- Medtech innovation briefings
- Key therapeutic topics
- Local government briefings
- Evidence summaries: Medicines and prescribing briefings
# Dementia

Register as a stakeholder


## Guidance

### Resources
- [Home](#)
- NICE Guidance
- Conditions and diseases
- Mental health and behavioural conditions

### NICE Pathways - mapping our guidance

<table>
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<th>Pathway</th>
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<tbody>
<tr>
<td>Dementia</td>
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<tr>
<td>Dementia, disability and frailty in later life: mid-life approaches to delay or prevent onset</td>
<td>October 2015</td>
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### NICE guidelines

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### NICE quality standard

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<td>Dementia: independence and wellbeing (QS30)</td>
<td>April 2013</td>
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<td>Dementia: support in health and social care (QS1)</td>
<td>June 2010</td>
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### In development

<table>
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<tr>
<td>Dementia - assessment, management and support for people living with dementia and their carers</td>
<td>September 2017</td>
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<tr>
<td>NICE guidelines</td>
<td></td>
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<tr>
<td>Dementia (non-Alzheimer) - new pharmaceutical treatments</td>
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### NICE commissioning guides

- [Support for commissioning dementia care (CMG48)](#) April 2013

### NICE technology appraisal guidance

- [Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer’s disease (TA217)](#) March 2011

### NICE advice

- [Low-dose antipsychotics in people with dementia (KTT7)](#) January 2015
- [Management of aggression, agitation and behavioural disturbances in dementia: carbamazepine (ESUOM40)](#) March 2015
- [Management of aggression, agitation and behavioural disturbances in dementia: valproate preparations (ESUOM41)](#) March 2015
Mental wellbeing in over 65s: occupational therapy and physical activity interventions

NICE guidelines [PH16]  Published date: October 2008

Tools and resources
Tools to help you put the guidance into practice.

- **Clinical audit**
  - Audit support
    - Audit support
    - 14 January 2009  Word 486.5 KB

- **Costing report**
  - Costing report
    - 22 October 2008  PDF 133.46 KB

- **Slide set**
  - Slide set
    - 12 November 2008  PowerPoint 256 KB

- **Implementation advice**
  - Endorsed resource - Living well through activity in care homes

- **Shared learning**
  - Shared learning information

- **Guidance into practice**
  - About the Into practice guide
  - Using NICE guidance and quality standards to improve practice
Living well through activity in care homes - the toolkit

Free resource - Living well through activity in care homes: the toolkit
Click on the images to access the different sections of the toolkit.

For optimum use, download the section you require and click on File/Save As. By saving this resource to your own computer it will be easily to hand whenever it's needed.

It will also allow for changes to the audit and action planning forms to be made quickly and efficiently to record improvements in the care home.

Please ensure you are using Adobe Acrobat Reader and if you are using a tablet or mobile phone download the Adobe Reader mobile app.

This toolkit is endorsed by the following 10 organisations:

1. Alzheimer's Society
2. Care Inspectorate
3. Skills for Care
4. British Geriatrics Society
5. Age Cymru
6. NAPA Living Life
7. Carers Trust
8. Carers UK
9. Care England
10. Care Wales
eLearning: The Open Dementia Programme

Published: 2009

The Open Dementia elearning Programme is aimed at anyone who comes into contact with someone with dementia and provides a general introduction to the disease and the experience of living with dementia. This programme is designed to be accessible to a wide audience and to make learning as enjoyable as possible and so allows users to fully interact with the content and includes video, audio and graphics to make the content come alive. In particular the programme includes a considerable amount of new video footage shot by both the Alzheimer’s Society and SCIE where people with dementia and their carers share their views and feelings on camera.

What it is and what it isn't

Covers: Views of dementia in the media; Facts and common misconceptions about dementia; Common symptoms, clinical terminology and causes of symptoms.

- View elearning resource
- View text-only version
- View printable version
- Download the SCORM 1.2 version
- Download the SCORM 2004 version
- Learning record

Living with dementia

Covers: The person with dementia as a unique individual; The importance of knowing their background and life history; Abilities people with a dementia retain in spite of the difficulties they face; How dementia impacts on families, friends and community and the support that is needed.

- View elearning resource
- View text-only version
- View printable version
- Download the SCORM 1.2 version
- Download the SCORM 2004 version
- Learning record

What do you think?

Please send us your comments and suggestions about ‘The Open Dementia elearning programme’. It will help us to continue to improve our work in the future.

Complete our feedback form.
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<td>Medication Monitoring for People with <strong>Dementia</strong> in Care Homes: Clinical Impact of Nurse-led monitoring</td>
<td>Shared Learning</td>
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<td>Living with <strong>Dementia</strong> - Improving Home Care</td>
<td>Shared Learning</td>
<td>June 2015</td>
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<tr>
<td>The role of Private domiciliary care for <strong>dementia</strong> care</td>
<td>Shared Learning</td>
<td>January 2014</td>
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<tr>
<td>Derby <strong>Dementia</strong> Support Service</td>
<td>Shared Learning</td>
<td>September 2013</td>
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<tr>
<td>Service redevelopment: Integrated whole system services for people with <strong>dementia</strong></td>
<td>QP Case Study</td>
<td>May 2012</td>
</tr>
<tr>
<td>Dancing down Memory Lane: Circle Dancing as a Psychotherapeutic Intervention in <strong>Dementia</strong></td>
<td>Shared Learning</td>
<td>January 2011</td>
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<td>Psychotherapy Service Provision for Carers of People with <strong>Dementia</strong></td>
<td>Shared Learning</td>
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<tr>
<td>Implementation and audit of Cognitive Stimulation Therapy on an acute admission/ assessment unit for people with <strong>dementia</strong></td>
<td>Shared Learning</td>
<td>September 2009</td>
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<td>Implement shared care guideline for drugs for <strong>dementia</strong></td>
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Dementia

http://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions

NICE commissioning guides
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Dementia: support in health and social care (QS1)
June 2010

In development
Dementia - assessment, management and support for people living with dementia and their carers
NICE guidelines
September 2017

Dementia (non-Alzheimer), non-pharmaceutical treatments
Support for commissioning dementia care

“Summarises the key commissioning issues and the resource impact that will arise from implementing the recommendations in NICE guidance and other NICE accredited guidance…”

- **Assessing service levels**
  - 4.1 Epidemiology of dementia
  - 4.2 Early identification, assessment and diagnosis of people with dementia
  - 4.3 Supporting people to live well with dementia
  - 4.4 Assessing service levels for end of life care for people with dementia
- **Living well with dementia**
  - 5.2.1 Promoting choice
  - 5.2.2 Promoting independence
  - 5.2.3 Providing support
  - 5.2.4 Palliative and end of life care
Commissioners may find the following resources useful when commissioning care and support for people to live well with dementia in their home and the community:

- The [SCIE dementia gateway](#) has examples of environmental improvements to support people with dementia.
- The King's Fund [developing supportive design for people with dementia](#).
- [Improving care in care homes in the South West – self assessment tool for commissioners](#).
- [Extra care housing and dementia commissioning checklist](#).
- [Community support services for people with dementia](#) outlines the costs and benefits of specialist and generic domiciliary care services.
- [Occupational Therapy evidence fact sheet - dementia and carers](#).
- The Department of Health's [dementia commissioning pack](#) includes resources for community-based services for people living with dementia.
- Joseph Rowntree Foundation [designing and managing care homes for people with dementia](#).
- Alzheimer's Society [assistive technology – devices to help with everyday living](#).
Dementia

NICE Pathways - mapping our guidance

- Dementia
- Dementia, disability and frailty in later life: mid-life approaches to delay or prevent onset

NICE guidelines
- Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset (NG16) October 2015
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- Dementia (non-Alzheimer): new pharmacological treatments
Dementia, disability and frailty in later life: mid-life approaches to delay or prevent onset overview

Strategy, policy and commissioning to delay or prevent onset of dementia, disability and frailty

Raise awareness

Public Health England, Health Education England and NHS England should:

- Commission national, regional and local campaigns aimed at the public and health and social care professionals to show how the risk of dementia, disability and frailty can be reduced and to promote the concept of keeping mentally and physically healthy. Campaigns should use a range of media and formats to reach as many people as possible. See information on population and community interventions in the NICE pathway on preventing type 2 diabetes.

- Use the campaigns to provide messages such as:
  - Sustained ill health in old age is not inevitable. The risk of developing dementia, disability and frailty may be reduced and, for some, onset can be delayed and the severity of the conditions reduced.
  - Smoking, lack of physical activity, alcohol consumption, poor diet, being overweight or obese and loneliness are all avoidable risk factors for dementia, disability and frailty.
  - The earlier in life that healthy changes are made, the greater the likelihood of reducing the risk of dementia, disability and frailty.
  - There are health gains that can be made by changing behaviours even in mid-life.
  - Healthy behaviours are more likely to be maintained if they are built into everyday life.

- Ensure messages do not stigmatise people by suggesting that people who develop dementia, disability or frailty are at fault. Tell people that although some important risks can be reduced, there may be others such as genetic susceptibility that cannot be changed.
Get involved with NICE

Comment on draft guidance and standards
All draft guidance and quality standards are consulted on prior to final publication. **Register as a stakeholder to comment.**

Join a working committee
Contribute to the production of guidance and quality standards. Vacancies are advertised on our website.

Become a NICE Fellow or NICE Scholar
Join us for a fixed period, for a day or more each month, to share your expertise, enthuse your colleagues or work upon an agreed research project of mutual interest. In return benefit from NICE’s expertise, mentorship and support.

Getting involved with NICE encourages local engagement with relevant topics, fosters a culture of using evidence based guidance, and supports individual professional development. [www.nice.org.uk/getinvolved](http://www.nice.org.uk/getinvolved)
Staying up to date with NICE

- Website [www.nice.org.uk](http://www.nice.org.uk)
- **NICE News** - monthly e-newsletter keeping you up to date consultations, published and forthcoming guidance
- 96,000+ people now follow us on Twitter for guidance updates [@NICEcomms](https://twitter.com/NICEcomms)
- General inquiries [nice@nice.org.uk](mailto:nice@nice.org.uk)
- Field team [fieldteam@nice.org.uk](mailto:fieldteam@nice.org.uk)