

Using NICE Guidelines and Standards to Provide High-Quality Dementia Care

Jane Moore

Associate Director, NICE Field Team

jane.moore@nice.org.uk

Session outline

- NICE: who we are and what we do
- Dementia: assessment, management and support for people living with dementia and their carers (NG97)
- Dementia quality standard (QS184)
- Finding what you need
- Supporting tools and resources

About NICE

Who are we?

We are the experts in evidence-based best practice and value for money in the health and care system.

What do we do?



We balance the best care with value for money, delivering both for individuals and society



We drive innovation into the hands of health and care professionals to enable best practice



We are fiercely independent: our decisions are rigorous, transparent and based on evidence

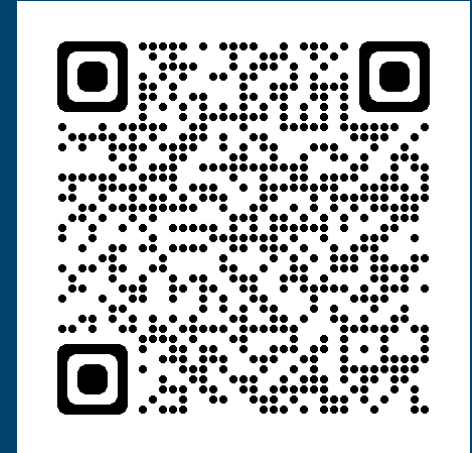
About NICE guidance

- Our guidance is based on the best available evidence. Our recommendations are put together by experts, people using services, carers and the public.
- NICE guidance makes **evidence-based recommendations** on a **wide range of topics**, from preventing and managing specific conditions, improving health, and managing medicines in different settings, to providing social care and support to adults and children, and planning broader services and interventions to improve the health of communities.
- Our guidance is used by a wide range of stakeholders across health and social care for a range of purposes including learning and development.
- It supports a shared view of quality across health and care

For more information please see Developing NICE guidelines: the manual:
<https://www.nice.org.uk/process/pmg20/chapter/introduction>



Dementia: assessment, management and support for people living with dementia and their carers (NG 97)



About the guideline NG97

Why is it needed?

How has it been developed?

How does it relate to statutory and non-statutory guidance?

What is the difference between offer and consider?

What is the status of NICE guidance?

When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Offer:
strong recommendation, clear evidence of benefit

Consider:
evidence of benefit is less certain


Do not offer:
evidence of lack of effectiveness or harm

NG97 Dementia – recommendations

- [1.1 Involving people living with dementia in decisions about their care](#)
- [1.2 Diagnosis](#)
- [1.3 Care coordination](#)
- [1.4 Interventions to promote cognition, independence and wellbeing](#)
- [1.5 Pharmacological interventions for dementia](#)
- [1.6 Medicines that may cause cognitive impairment](#)
- [1.7 Managing non-cognitive symptoms](#)
- [1.8 Assessing & managing other long-term conditions in people living with dementia](#)
- [1.9 Risks during hospital admission](#)
- [1.10 Palliative care](#)
- [1.11 Supporting carers](#)
- [1.12 Moving to different care settings](#)
- [1.13 Staff training and education](#)


NICE

Interventions to
promote cognition,
independence and
wellbeing



- Offer
 - a range of activities to promote wellbeing that are tailored to the person's preferences.
 - group cognitive stimulation therapy to people living with mild to moderate dementia.
- Consider
 - group reminiscence therapy for people living with mild to moderate dementia.
 - cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia.
- Do not offer
 - acupuncture to treat dementia.
 - ginseng, vitamin E supplements, or herbal formulations to treat dementia.
 - cognitive training to treat mild to moderate Alzheimer's disease.
 - interpersonal therapy to treat the cognitive symptoms of mild to moderate Alzheimer's disease.

Moving to different care settings




- 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 these guideline principles for transitions between other settings (for example from home to a care home or respite care)

- Review the person's needs and wishes (including any care and support plans and advance care and support plans) after every transition

Transferring information between services and care settings



- When developing care and support plans and advance care and support plans, request consent to transfer these to different care settings as needed
- 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)
- Deliver care and support maximising continuity and consistency of care. Ensure that relevant information is shared and recorded in the person's care and support plan.

Staff training and education



- 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, and the changes to expect as the condition progresses
 - 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
 - Principles of the Mental Capacity Act & the Care Act

Staff training and education



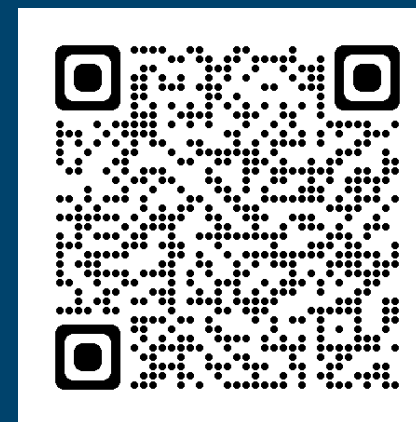
- Provide additional face-to-face training and mentoring to staff who deliver care and support to people living with dementia. This should include:
 - understanding the organisation's model of dementia care and how it provides care
 - how to monitor and respond to the lived experience of people living with dementia, including adapting communication styles
 - 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.

Staff training and education



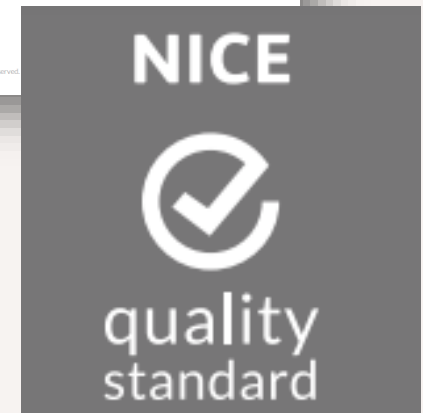
- Consider
 - giving carers and/or family members the opportunity to attend and take part in staff dementia training sessions.
 - training staff to provide multi-sensory stimulation for people with moderate to severe dementia and communication difficulties.
- Ensure that all health and social care staff are aware of:
 - the extent of their responsibility to protect confidentiality under data protection legislation
 - any rights that family members, carers and others have to information about the person's care
- Health and care professionals advising people living with dementia should be trained in starting and holding difficult and emotionally challenging conversations.

Dementia Quality standard (QS184)



NICE quality standards

- A prioritised set of statements designed to drive and measure quality improvement in specific areas of care
- They identify areas of health or care where there is unwarranted variation
- Developed by NICE's Quality Standard Advisory Committee (QSAC)



Dementia Quality standard (QS184)

NICE

Dementia

Quality standard [QS184] Published: 28 June 2019

Quality standard

Tools and resources

History

Overview

Quality statements

Quality statement 1: Raising awareness – health promotion interventions

Quality statement 2: Diagnosis

Quality statement 3: Advance care planning

Quality statement 4: Coordinating care

Quality statement 5: Activities to promote wellbeing

Quality statement 6: Managing distress

Quality statement 7: Supporting carers

Update information

Quality standard

[Download \(PDF\)](#)

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Quality statements

[Statement 1](#) People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can be reduced by making lifestyle changes. **[new 2019]**

[Statement 2](#) People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated. **[2010, updated 2019]**

[Statement 3](#) People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review. **[2010, updated 2019]**

[Statement 4](#) People with dementia have a single named practitioner to coordinate their care. **[2010, updated 2019]**

[Statement 5](#) People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences. **[2013, updated 2019]**

[Statement 6](#) People with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress. **[2010, updated 2019]**

[Statement 7](#) Carers of people with dementia are offered education and skills training. **[2010, updated 2019]**

Dementia

Quality standard [QS184] Published: 28 June 2019

Quality standard

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Quality statements

Quality statement 1: Raising awareness – health promotion interventions

Quality statement 2: Diagnosis

Quality statement 3: Advance care planning

Quality statement 4: Coordinating care

Quality statement 5: Activities to promote wellbeing

Quality statement 6: Managing distress

Quality statement 7: Supporting carers

Update information

About this quality standard

Quality standard

Quality statement 5: Activities to promote wellbeing

[Quality statement](#)

[Rationale](#)

[Quality measures](#)

[What the quality statement means for different audiences](#)

[Source guidance](#)

[Definitions of terms used in this quality statement](#)

[Equality and diversity considerations](#)

Quality statement

People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences. [2013, updated 2019]

Rationale

The symptoms of dementia make it harder for a person to take part in activities, to engage socially, to maintain their independence, to communicate effectively, to feel in control and to care for themselves. Providing enjoyable and health-enhancing activities that are suitable for the stage of dementia can help

Quality measures

Structure

a) Evidence of local arrangements to ensure that a range of activities are available that promote wellbeing for people with dementia.

Data source: Local data collection, for example, service specifications.

b) Evidence of local arrangements to ensure that people offering activities to promote wellbeing to people with dementia discuss the person's preferences with them and tailor the activities to these.

Data source: Local data collection, for example, service protocols.

c) Evidence of local arrangements to support access to a range of activities that promote wellbeing for people with dementia, such as transport options.

Data source: Local data collection, for example, service specifications.

Process

a) Proportion of people with dementia who discuss activities to promote wellbeing at a review of their care plan.

Numerator – the number in the denominator who discuss activities to promote wellbeing at a review of their care plan.

Denominator – the number of people with dementia.

Data source: Local data collection.

b) Proportion of people with dementia who discuss their preferences.

Numerator – the number in the denominator who discuss their preferences.

Denominator – the number of people with dementia.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as local authorities, community care providers, dementia adviser services, community old age psychiatry services and memory clinics) ensure that systems are in place for people with dementia to discuss their preferences and needs, to choose activities to promote wellbeing that are tailored to these, and to access the activities they have chosen.

Health and social care practitioners (such as occupational therapists, community psychiatric nurses, psychologists, care home nurses, healthcare assistants, activities coordinators, dementia advisers, wellbeing advisers and social workers) have a discussion with the person with dementia, and their families and carers if appropriate, about life experiences, circumstances, preferences, interests, strengths and needs. They are aware of the activities to promote wellbeing that are available locally and, based on this discussion, they help the person with dementia to choose activities that suit their preferences and needs.

Commissioners (such as local authorities and clinical commissioning groups) ensure that activities to promote wellbeing are available for people with dementia. They specify that providers offer people with dementia these activities based on a discussion of their preferences and needs.

People with dementia talk about their life experiences, circumstances, preferences, interests, strengths and needs with a professional and people involved in their care. They are told about suitable activities for improving their wellbeing, such as joining a local choir or walking group, and are supported to access the activities they choose.

Guidance

Evidence-based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders.

[View all guidance](#)

[Conditions and diseases](#)

[Health and social care delivery](#)

[Health protection](#)

[Lifestyle and wellbeing](#)

[Population groups](#)

[Settings](#)

Get involved

We want you to be involved in our work. There are many ways you can [get involved as a healthcare professional or a member of the public](#).

Tell us what matters to you, your organisation or your community and we'll share our latest news, features and guidance.

- [register as a stakeholder](#)
- [comment on a consultation](#)
- [join a committee](#)
- [come to a meeting](#)
- [come to an event](#)
- [subscribe to our newsletters](#).

About us

Find out more about

- [who we are](#)
- [what we do](#)

and how we support

- [social care](#)
- [life sciences](#)
- [the public](#)
- [international health organisations](#)

[The NICE strategy 2021 to 2025](#)
ambitious vision for our future.

Conditions and diseases

Health and social care delivery

Health protection

Lifestyle and wellbeing

Population groups

Settings

Conditions and diseases

Blood and immune system conditions

Cancer

Cardiovascular conditions

Chronic and neuropathic pain

Cystic fibrosis

Diabetes and other endocrinal, nutritional and metabolic conditions

Digestive tract conditions

Ear, nose and throat conditions

Eye conditions

Fertility, pregnancy and childbirth

Gynaecological conditions

Infections

Injuries, accidents and wounds

Kidney conditions

Liver conditions

ME/CFS

Mental health and behavioural conditions

Multiple long-term conditions

Musculoskeletal conditions

Neurological conditions

Oral and dental health

Neurological conditions

Brain cancers

Cerebral palsy

Delirium

Dementia

Epilepsy

Faecal incontinence

Headaches

Metastatic spinal cord compression

Motor neurone disease

Multiple sclerosis

Parkinson's disease, tremor and dystonia

Spasticity

Spinal conditions

Transient loss of consciousness

Urinary incontinence

Dementia

All NICE products on dementia. Includes any guidance and quality standards.

Published products on this topic (18)

Guidance

We use the best available evidence to develop recommendations that guide decisions in health, public health and social care.

Published guidance on this topic (4)

[New in the last 6 months \(2\)](#) | [Updated in the last 6 months \(0\)](#) | [In development \(2\)](#)

Quality standards

Set out priority areas for quality improvement in health and social care.

Published quality standards on this topic (2)

[New in the last 6 months \(0\)](#) | [Updated in the last 6 months \(0\)](#) | [In development \(0\)](#)

Products being developed or updated

[In development \(2\)](#)

Guidance, quality standards and advice being developed.

[Awaiting development \(2\)](#)

Guidance and quality standards awaiting development.

[Topic selection \(1\)](#)

Guidance in topic selection.

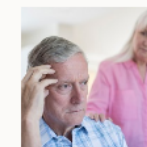
News on this topic



[New NICE guideline will help doctors recognise and refer people with suspected neurological conditions](#)

NICE's new guideline is the first to offer comprehensive information on neurological conditions to help non-specialist healthcare professionals to identify people who should be referred for specialist assessment and care.

Published: 01 May 2019



[People with dementia should be involved in discussions about their care, says NICE](#)

NICE has updated its guidance for the support of people living with dementia.

Published: 20 June 2018

Putting guidance into practice

Shared learning

Examples of how our guidance and standards have been put into practice in the NHS, local authorities, voluntary sector and a range of other organisations.

Showing 3 of 12 shared learning examples for this topic:

[Developing a 3Ds Clinical Framework in a Community Integrated Team](#)

Published date: June 2020

[Running Cognitive Stimulation Therapy \(CST\) groups as part of core Community Mental Health Team \(CMHT\) work](#)

Published date: April 2019

[STOP LOOK CARE](#)

Published date: March 2019

[View all 12 shared learning examples](#)

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

NICE guideline [NG97] Published: 20 June 2018

Guidance

Tools and resources

Information for the public

Evidence

History

Overview

About this guideline

Person-centred care

Recommendations

Putting this guideline into practice

Recommendations for research

Finding more information and committee details

Update information

Guidance

Recommendations

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- [1.2 Diagnosis](#)
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- [1.4 Interventions to promote cognition, independence and wellbeing](#)
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- [1.12 Moving to different care settings](#)
- [1.13 Staff training and education](#)
- [Terms used in this guideline](#)

Tools and resources

Tools to help you put the guidance into practice.

Implementation support

[Measuring the use of NICE guidance: NICE Impact dementia](#)

[Valproate in children, young people and adults: summary of NICE guidance and safety advice](#) PDF 134 KB
28 March 2019

Decision aids

[Antipsychotic medicines for treating agitation, aggression and distress in people living with dementia \(patient decision aid\)](#) PDF 454 KB
20 June 2018

[Antipsychotic medicines for treating agitation, aggression and distress in people living with dementia \(user guide and data sources\)](#) PDF 179 KB

Education

[Webinar: Using NICE guidance to improve and evidence quality in adult social care \(NICE/SCIE June 2019\)](#)

[Quick guide: Dementia, discussing and planning support after diagnosis - for people with dementia and their family and carers](#)

Shared learning

[Shared learning information](#)

Research recommendations

[Research recommendations information](#)

Resource impact

[Resource impact report](#)
PDF 360 KB
20 June 2018

[Resource impact template](#)
Excel 1.39 MB
20 June 2018

Audit and service improvement

[Baseline assessment tool](#)
Excel 423 KB
20 June 2018

Related news

[People with dementia should be involved in discussions about their care, says NICE](#)

Guidance into practice

Dementia quick guide




Dementia – discussing and planning support after diagnosis

A quick guide for people with dementia and their family and carers

QUICK GUIDE



“The right information and support will enable us to live better with dementia”
(Person living with dementia)

A diagnosis of dementia may create very mixed emotions. Coming to terms with it, making decisions and planning ahead are all part of living well with dementia.

Getting information and support when you need it from people working in health and social care can make a real difference.

What information to expect

When you are diagnosed with dementia you should be offered information relevant to the stage of your condition, including:

- Your type of dementia and how it will affect you
- Any further tests, treatment, activities or therapies that might help you
- Who will provide your care and how to contact them, including the professional who will coordinate your care
- Support groups and charities that can help you
- How dementia can affect your driving and what you need to do
- How your employer should support you if you work (or are looking for work)
- Any research studies you could take part in

This information should be explained to you and given to you in writing. You can ask for it to be provided in a format that you find easy to understand. If you don't need this information straight away you can ask for it when you do.

You should also have the chance to talk about:

- consent...** do you agree to services sharing information about you? Who can they share information with and what are you willing for them to share?
- information...** do you know who to contact for more advice if your needs change?
- future contact...** you may not need any help or further appointments now. If that is the case, would you like to be contacted again and if so, when?

Planning for now

After your diagnosis, you should be directed to the services that can give you more information and support. You should also be given the **name of a professional** who will co-ordinate any care and support you might need.

Help to express your wishes

You should be told about local advocacy services. An advocate can help you express your needs and wishes. They can help you to understand the different options and to make decisions. They can also help you find services, make sure the correct procedures are followed, and challenge decisions on your behalf.

The named professional should:

- Arrange a meeting to assess your needs
- Give you information about services and how to get in touch with them
- Involve your family or carers (if you wish)
- Help you make a plan for your care and support – they should give you a copy of this and agree how often to check it with you.

If you are unable to make decisions about your care, your views and wishes should still be taken fully into account. There is support available to help you with this.

Planning for your future

Thinking ahead may feel difficult but advance care planning can be helpful in making sure people are aware of your wishes for the future. When you feel ready for this discussion, you should be offered support and information to discuss:

- your wishes, preferences and beliefs for your future care (advance statement)
- whether you want to refuse any specific medical treatment at some time in the future (advance decision)
- why it's helpful to plan ahead
- making legal decisions about your health and welfare, and property and money if you can no longer make them yourself (lasting power of attorney)
- where you would prefer to be cared for, including at the end of your life

You should be offered the chance to check that any advance statements and decisions are still right for you each time your care and support is reviewed. You can change any decisions you wish to.

Support for carers

As a carer for a person living with dementia, you should be offered:

- training** to help you understand dementia, provide care and communicate with the person who has dementia, look after yourself, find out about services, plan activities and think about the future.
- support** that is flexible and right for you and what you want to achieve, that helps you support your relative or friend, and that is available when you need it. This may be as part of a group or online.
- advice** about how to get an assessment of your own needs (a 'carer's assessment') and about how to get a short break or respite care.

Further information

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

The dementia guide – Alzheimer's Society Telephone helpline 0300 222 1122

After diagnosis of dementia: what to expect from health and care services – Department of Health and Social Care

Living with young onset dementia – Young Dementia UK

Admiral Nurse Dementia Helpline – Telephone 0800 888 6678

Dementia – SCIE

Join dementia research – National Institute for Health Research

Making decisions – Office of the Public Guardian

Dementia Carers Count – Royal Surgical Aid Society

This content has been co-produced by NICE and SCIE and is based on NICE's guideline on dementia: assessment, management and support for people living with dementia and their carers.
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Social Care Institute for Excellence
www.scie.org.uk

Dementia - discussing and planning support after diagnosis, quick guide

Staying up to date

- Visit our website www.nice.org.uk
- Sign up for our [monthly newsletters](#) using the QR code
- Contact our enquiry team nice@nice.org.uk
- Contact the field team field.team@nice.org.uk
- Visit our social channels - Twitter, Facebook, LinkedIn, YouTube and Instagram



Thank you.