

## Understanding NICE–SCIE guidance

Information for people who use NHS and social care services

# Dementia: supporting people with dementia and their carers

*NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The guideline on dementia also makes recommendations on social care.*

This booklet is about the support and treatment of people with dementia in the NHS and social care services in England and Wales. It explains a guideline from NICE (the National Institute for Health and Clinical Excellence) and SCIE (the Social Care Institute for Excellence). It is written for people with dementia and their carers, but it may also be useful for anyone with an interest in the condition.

The booklet aims to help you understand the support and treatment options that should be available in the NHS and social care. It does not describe dementia or the tests or treatments for it in detail. A member of your health and/or social care team should discuss these with you.

To help you, there are examples of questions you could ask your care team throughout this booklet. Some sources of further information and support are on page 20.

Words and phrases that may be unfamiliar to you appear in **bold type** and are explained in the glossary on pages 18–19.

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### **The advice in the NICE–SCIE guideline covers:**

- what support and treatment you can expect to be offered, including drugs and other therapies
- the services that are available to help people with dementia, including health and social care services
- how families and carers may be able to support people with dementia and get support for themselves.

## What is dementia?

Dementia is a disorder that affects how the brain works. Symptoms of dementia vary from person to person, but can include:

- loss of memory
- difficulty thinking things through and understanding
- problems with language (reading and writing)
- confusion and agitation
- **hallucinations** and **delusions**
- difficulty controlling movements of the body.

Symptoms of dementia usually get worse over time and can become very severe, so that it is difficult for the person to do many daily activities or to care for him or herself.

Dementia is more likely to affect older people, but younger people can also develop the condition.

## Types of dementia

There are different types of dementia; the most common are:

- Alzheimer's disease
- vascular dementia
- dementia with Lewy bodies
- frontotemporal dementia.

Dementia with Parkinson's disease is similar to dementia with Lewy bodies and some of the recommendations on dementia with Lewy bodies may be relevant to it as well. NICE has also produced a guideline specifically on Parkinson's disease (see [www.nice.org.uk/CG35](http://www.nice.org.uk/CG35)).

There are also other types of dementia, but these are not covered specifically by the NICE–SCIE guideline or this booklet.

*The guideline on dementia was developed in partnership with SCIE. SCIE's aim is to improve the experience of people who use social care by developing and promoting knowledge about good practice.*

## What happens when you are first diagnosed

If your GP or another healthcare professional thinks that you have problems with your memory, with language, or with planning daily activities, you may be offered a memory test at a memory clinic. If tests show that you do have a problem, you should be offered additional tests to look for signs of dementia so that care can be planned at an early stage.

It can sometimes be difficult to tell whether a person has dementia. If your doctor thinks that you have the condition, you should be offered further tests of your memory, your ability to pay attention and concentrate, and your use of language. You should also be offered:

- a brain scan called a CT or MRI scan (other types of scan may also sometimes be used if the diagnosis is unclear)
- a physical examination and other tests.

If you are tested for possible dementia, your doctor should ask you if you wish to know the diagnosis and which relatives or carers should be told.

Finding out you have dementia can be extremely upsetting for you and your family. Your doctor should explain what having dementia might mean. He or she should offer you further support and advice if you want to talk more about the condition.

When you are first diagnosed with dementia, and regularly after that, your doctor should talk to you about any physical illnesses or mental health problems you may have so that you can be helped with these as well.

Your doctor should check whether you have other conditions such as diabetes or high blood pressure, whether you are very overweight or have high cholesterol levels, and whether you smoke or drink a lot of alcohol. You should be offered treatment and help for any of these.

### Questions you might like to ask about finding out what is wrong (diagnosis)

- Please tell me about the type of dementia that I may have.
- Please give me more details about the tests or investigations I should have.
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?
- What will happen after I get the results?

## Your care

### Respect and an equal right to care

Health and social care staff should treat you with respect at all times. You should not be excluded from any services because you have dementia, because of your age, or because of any learning disability you may have. If it is thought that you may have dementia but you have not been diagnosed with the condition, you should still be able to use any dementia support services.

*If you think that your care does not match what is described in this booklet, please talk to a member of your care team.*

### Information and helping you make decisions

You have the right to be fully informed about your care and to make decisions in partnership with your care team. Unless you decide otherwise, your care team should explain to you and your family:

- the type of dementia that you have
- details about symptoms and how the illness might develop
- treatments
- care and support services in your area
- support groups and voluntary organisations for people with dementia and their families and carers
- **advocacy services**
- where you can find financial and legal advice.

You should also be given written information about dementia. This should be in your preferred language and in a format (for example in large print or Braille) that you and your family and carers can understand. Your care team should be able to arrange an interpreter if needed. Any **psychological treatment** should also be given in your preferred language.

You should be told about the possible benefits and risks of particular treatments. You can ask any questions you wish and can always change your mind about your care as your treatment progresses or your condition or circumstances change.

## Consent and capacity

Your own preferences for care and treatment are important, and your care team should support your choices wherever possible. Your care team will always seek your consent (agreement) about your care. They should explain the options available to you and make sure that you understand what has been said.

However, as your circumstances change, you may no longer be able to make specific decisions (this is called no longer having 'capacity') and you may not be able to communicate your needs. If this happens, your care team must follow the advice set out in the Mental Capacity Act 2005 (information about this is available from the Department of Health; [www.dh.gov.uk](http://www.dh.gov.uk)).

If you are worried about being able to make important decisions about your care in the future, you can make a set of written instructions (called advance decisions and advance statements) saying what treatments and other help you do and do not want in the future. These instructions may include a **lasting power of attorney** and a record of your **preferred place of care**. Your care team should discuss these with you while you are still able to make decisions and can help you write these instructions.

## Confidentiality

You should have the opportunity to discuss matters in private with your care team at every stage of your illness. Your care team should explain that some information might need to be shared with other professionals or services. Only in very unusual circumstances, for example if there are serious concerns about your safety, will private information be discussed with other people without your agreement.

As the illness worsens, your care team may need to share some information with your carers. They will only do this with your best interests in mind and it should be done according to the Mental Capacity Act 2005.

## Carers and relatives

If you agree, your carers and family members should have the chance to be involved in decisions about your care. Carers and relatives also have the right to receive the information and support they need in their role as carers. There is more information for carers on pages 16–17.

Your care team should talk to you sensitively about the effects of the illness on your relationships with your relatives and friends, including, if you have a partner, your sexual relationship. You and your partner, and your family or carers, should be given information about local support services.

## Personal preferences

Your care should be suited to your individual needs. Your care team should take account of your sex and age and any religious or cultural needs you or your carers may have. They should also consider factors such as your physical health, whether you have a physical or learning disability, sight or hearing problems, and difficulties with English.

It is also important that the care team takes account of your life history, your family and other relationships, and your likes and dislikes (for example, with regard to food). Your needs and preferences should be written into your care plan (see next section, 'Planning your care').

## Planning your care

Because of the nature of dementia and because your condition may change over time, you may need support from the NHS and social services.

Your care plan should record the support you are to receive from both health and social care staff, and should be agreed between them and you and your carers. The care plan should name the people who will make sure that the plan is followed.

You and your care team should discuss your care plan regularly and make changes to it as your needs change. How often this happens should be agreed with you and your carer.

You and your carer should be given up-to-date advice and written information about the services in your area, including how the NHS and social services (including voluntary services) work together, and how you and your carer can make contact with these services.

You have the right to receive financial support. Your care team should tell you about the types of financial support that are available, which may include:

- direct payments from social services to pay for help with care
- attendance allowance
- disability living allowance.

You should be offered additional help to manage payments and allowances. You and your carer should also be told about the difference between care provided by the NHS and care provided by social services so that you can find out whether you are entitled to **NHS Continuing Care**.

### Questions you might like to ask your health and social care team

- Please tell me more about dementia.
- How is dementia likely to affect the things I can and cannot do?
- Are there any support organisations in my local area?
- How can I make sure that I receive the right services?
- Can you provide any information for my family/carers?
- Where can I find out more about making written instructions about my care and recording my **preferred place of care**?

## Keeping independent

Your care plan should include details about how you can help yourself to stay independent. This might involve daily activities, taking up new skills and doing some light exercise. You should always be encouraged to do things at your own pace and to do things that you enjoy.

You should receive support to help you continue living in your own home. This may include making sure that you have equipment in your home to help you get around and look after yourself. Other things that can help include electronic memory aids and diaries.

## Treatments for different types of dementia

Although dementia is a lifelong illness that usually gets worse over time, there are treatments that can slow its development or help with some of the symptoms. There are two kinds of treatment.

- Some treatments may help with symptoms that affect your thinking and memory (**cognitive symptoms**).
- Other treatments may help with symptoms that affect your mood and how you behave (**non-cognitive symptoms**).

Some of the treatments are recommended for specific types of dementia and some are for all kinds of dementia.

If you have what is called mixed dementia (for example, Alzheimer's disease and vascular dementia, or Alzheimer's disease and dementia with Lewy bodies), you should usually be treated for the type that is thought to be the main cause of your dementia.

*Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your health and social care team.*

## Treatments for cognitive symptoms

If you have **mild** or **moderate dementia**, you should be offered the chance to join other people with dementia in a **cognitive stimulation programme**.

### *Drugs for Alzheimer's disease*

A NICE 'technology appraisal' has looked at when and how donepezil, galantamine and rivastigmine (drugs known as acetylcholinesterase inhibitors) and another drug called memantine should be used for Alzheimer's disease. This technology appraisal (number 217), published in March 2011, updates an earlier technology appraisal. Information about the technology appraisal is available from [www.nice.org.uk/TA217](http://www.nice.org.uk/TA217).

*NICE 'technology appraisal guidance' advises on when and how drugs and other treatments should be used in the NHS. For more information see [www.nice.org.uk/TA](http://www.nice.org.uk/TA)*

#### **What has the NICE technology appraisal said?**

NICE recommends donepezil, galantamine, rivastigmine and memantine as possible treatments for some people with Alzheimer's disease (see below).

You should be able to have donepezil, galantamine or rivastigmine if you have mild to moderate Alzheimer's disease.

You should be able to have memantine if you have:

- moderate Alzheimer's disease and cannot take donepezil, galantamine or rivastigmine **or**
- severe Alzheimer's disease.

When assessing how severe your Alzheimer's disease is, and your need for treatment, healthcare professionals should take into account any disabilities or difficulties in communicating you might have.

Only specialists should prescribe these drugs in the first instance, and you should only continue to take them while you, your doctors and your family or carers agree they are having a worthwhile effect on your symptoms. You should have regular check-ups while taking any of these drugs, and if you have a carer, they should be asked about how you are doing.

#### **Why has NICE said this?**

NICE looks at how well treatments work, and also at how well they work in relation to how much they cost the NHS. NICE recommended donepezil, galantamine, rivastigmine and memantine for the people described above because the benefits they provided justified their costs.

There are different tests and other methods that doctors can use to assess how severe someone's Alzheimer's disease is, including tests designed to be used for people with a learning disability.

### ***Drugs for other conditions***

If you have mild problems with your thinking and memory, but have not been diagnosed with dementia, you should not be offered an acetylcholinesterase inhibitor to treat **cognitive symptoms**, except if you are taking part in a clinical trial.

If you have vascular dementia, you should not be offered an acetylcholinesterase inhibitor or memantine to treat cognitive symptoms, except if you are taking part in a clinical trial.

*If it appears that the treatment described in this booklet is suitable for you, but it is not available, you should talk to your local Patient Advice and Liaison Service (PALS) in the first instance. If they are not able to help you, they should refer you to your local Independent Complaints Advocacy Service.*

## Treatments for non-cognitive symptoms

First, your care team should look at the situations that may affect your mood and the way you behave (for example, things that make you upset or agitated). They should look at things like your physical and mental health, whether you are in any pain and side effects of medicines you are taking. Your treatment and care should be planned to suit your needs (including taking account of your culture and beliefs), recorded in your notes, and reviewed regularly by your care team.

If you are agitated you should be offered therapies to help calm you. These may include:

- aromatherapy, which uses plant extracts and oils to help relaxation
- therapies that appeal to the senses, such as light displays and sounds
- music and dance
- contact with pets or other animals
- massage.

## Drugs for non-cognitive symptoms

You should be offered help and treatment without drugs before you are offered medication, unless you are severely distressed or are at risk of hurting yourself or someone else.

### Antipsychotic drugs for non-cognitive symptoms

If your **non-cognitive symptoms** are mild or moderate, you should not be offered an **antipsychotic** because they can have serious side effects.

If you have severe symptoms (such as **psychosis** or you are very agitated), you may be offered an antipsychotic for a period of time, but only after your doctor has talked to you in detail about the possible benefits and risks, which can include having a stroke or a heart attack. If you start taking an antipsychotic, it should be at a low dose at first, and your doctor should monitor you very carefully.

## Acetylcholinesterase inhibitors for non-cognitive symptoms

Type of dementia	Medication
Alzheimer's disease	You may be offered an acetylcholinesterase inhibitor if your non-cognitive symptoms are very distressing to you and other treatments have not worked or are not suitable.
Dementia with Lewy bodies	You may be offered an acetylcholinesterase inhibitor if your non-cognitive symptoms are very distressing to you.
Vascular dementia	You should not be offered an acetylcholinesterase inhibitor, except if you are taking part in a clinical trial.

### *Treatment for people whose behaviour is very disturbed*

People with dementia can sometimes become violent, aggressive or very agitated. Some things, such as lack of privacy, lack of things to do, or poor communication, make this more likely. The care team should try to put these problems right. If people with dementia do become very disturbed, and there is a risk to themselves or to others, the staff caring for them should keep things as calm and as safe for them as possible.

If all efforts to reduce the risk of harm have not worked, staff may sometimes need to sedate the person with a drug called a benzodiazepine or an **antipsychotic**. The drug should usually be one that is taken by mouth and in a low dose.

If an injection is needed, it should usually be into a muscle, not into a vein, and the healthcare professional should check the person's blood pressure, pulse, temperature and breathing. He or she should also check for any side effects of the drugs (such as unconsciousness, tremor or restlessness). Very rarely, more than one type of drug may need to be injected if sedation is needed urgently.

If a person has been sedated, staff should explain why this was needed. Because it can be a very upsetting experience, people who have been sedated and their carers should be given the chance to discuss what happened with the care team. This should be written in the person's notes.

Healthcare professionals who use medications to help with agitated behaviour should have been trained in using them and understand their risks.

## Treatments if you also have depression or anxiety

If you have **depression** or **anxiety** you may be offered a **psychological treatment** called **cognitive behavioural therapy**, which may involve your carer. You may also be offered other help, such as:

- therapy that encourages people to remember events in their life (called reminiscence therapy)
- therapies that appeal to the senses of touch, sight and hearing, such as hand massage, light displays and music
- contact with pets or other animals
- physical exercise.

If you have depression and the treatments above have not worked or are not suitable, you should be offered **antidepressant** medicine. Your doctor should explain the risks and benefits of the treatment. He or she should also explain that it is important to take the drug as prescribed, that it will not start working straight away and that you may have some withdrawal symptoms when you stop taking it.

### Questions you could ask about any treatment or therapy

- Please tell me why you have decided to offer me this particular type of treatment.
- What are the pros and cons of having this treatment?
- Please tell me what the treatment will involve.
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- What are my options for having other treatments instead?
- Is there some written material (like a leaflet) about the treatment that I can have?

### Questions you could ask about drug treatments

- Are there any long-term effects or side effects of taking this medicine?
- What should I do if I get any side effects? (For example, should I call my GP, or go to the emergency department at a hospital?)

## Care in a care home

Although every effort should be made to care for you in your own home for as long as possible, you may be offered a short stay in a care home as a break ('respite') for your carer or for you. As your condition worsens, you may need longer-term care in a care home.

In both your own home and in short- and longer-term care in a care home you should be encouraged to do activities that are suited to you and help with your condition.

## Care in hospital

As far as possible treatment and care should be available to people with dementia without having to stay in hospital. But there may be occasions when a stay in hospital may be helpful, such as for people who are behaving in a disturbed way and are a risk to themselves or others and for people with complex physical and mental health difficulties.

## Palliative care and care for people nearing the end of life

The care team should make sure that **palliative care** is available to people with dementia from the time that they are diagnosed until the end of life. The team should consider the person's needs so that they can maximise their quality of life.

For people nearing the end of life the care team should assess their needs, make them feel comfortable and enable them to die with dignity and in a place of their choosing. Any decisions about care and **resuscitation** should take account of the wishes of the person with dementia. Care should also include support for carers during their bereavement.

People nearing the end of life will be encouraged to eat and drink by mouth for as long as possible. Feeding by tube should not usually be used for people with **severe dementia**. If a person nearing the end of life has a fever, the care team should make sure he or she is assessed; simple methods to cool the person (such as medicines for fever) may be sufficient. Distress or changes in the person's behaviour may be caused by pain; this should be assessed and treated if necessary.

## Information for carers of people with dementia

Caring for a person with dementia can be difficult and upsetting. As a carer, you have a legal right to have your own needs assessed. Assessments (where you will be asked about any psychological distress you may have, and about the impact of caring for someone with dementia) should happen as often as needed, including (if appropriate) after the person you are caring for has entered residential care. You should be offered **psychological treatments** such as **cognitive behavioural therapy** if you are distressed or depressed.

To help you in your role as a carer, you should be offered:

- education about dementia and its treatments (in a group or on your own)
- support in groups with other carers that is suited to your needs
- support and information over the telephone or the internet
- training courses about dementia, the services available and problem-solving techniques to help with caring for someone with the condition
- the chance to involve other family members in family meetings.

The person you are caring for might also be involved in some of these activities.

You should be given support in attending any of the activities listed above, such as help with transport or someone to look after the person you are caring for while you are out.

The care team should make sure that you have the opportunity to take short breaks (or 'respite'), which should be suited to where you live, the demands on your time, and also the needs of the person you are caring for. These breaks might include day care for the person you care for, someone to look after him or her during the day or at night, or an overnight or short-term stay for the person in residential care. Transport should be provided if necessary.

You and the person you are caring for have the right to receive financial support where available. Some types of support that may be available are described on page 8. You may also be entitled to receive carer's allowance.

### **Questions you could ask about caring for a person with dementia**

- What can I/we do to help and support the person with dementia?
- Is there any additional help that carers might benefit from or are entitled to?
- How much respite care am I entitled to on a regular basis?
- What financial benefits may we be entitled to and where can we find information about them?

## Glossary

**Advocacy services** Advocacy services can make sure that a person's wishes are explained to those involved in care. They can speak on people's behalf if they are unable to communicate their needs and make sure they receive the information and care they should.

**Antidepressant** A medicine that can help symptoms of depression.

**Antipsychotic** A medicine that can treat **psychosis** (when a person has **hallucinations** or **delusions**).

**Anxiety** Feelings of worry or fear that can be difficult to control.

**Cognitive behavioural therapy** A **psychological treatment** in which people work with a therapist to look at how their problems, feelings and behaviour all fit together. It can help people to deal with negative thoughts and to change behaviour that may have developed since they became ill.

**Cognitive stimulation programme** A kind of treatment that involves doing activities that require some thought and solving problems, which can be enjoyable.

**Cognitive symptoms** Symptoms of dementia that affect memory, thought processes, concentration, and ability to read and write.

**Delusions** Believing things that are not real.

**Depression** A mental disorder that causes a loss of pleasure in things that were enjoyable before, withdrawal from family and friends, and negative and self-critical thoughts. Other symptoms may include feeling tearful, feeling irritable or tired, loss of appetite, and sleep problems.

**Hallucinations** Seeing or hearing things that are not really there.

**Lasting power of attorney** This allows a person to choose someone to make decisions about their healthcare, legal affairs and finances if they no longer have the ability to make decisions. It replaces a similar system known as 'enduring power of attorney'.

**Mild dementia** Symptoms that can give some difficulty to the person with dementia, including some loss of memory, feelings of disorientation and finding it hard to cope with complex problems.

**Moderate dementia** Symptoms that can give significant difficulty to people with dementia, including severe loss of memory and feelings of disorientation, and finding it very hard to cope with everyday problems.

**NHS Continuing Care** Fully funded care for people who do not need to stay in hospital but who do need long-term medical and nursing care.

**Non-cognitive symptoms** Symptoms of dementia that affect a person's behaviour and mood. Such symptoms might include those of **depression** and **anxiety**. Other symptoms include **hallucinations, delusions** and aggressive or very agitated behaviour.

**Palliative care** Care that helps to relieve the symptoms, such as pain or anxiety, of an illness that can't be cured.

**Preferred place of care** A plan that allows a person with an illness to make decisions about their care in the future, including where they would like to die.

**Psychological treatment** A broad term used to describe meeting with a therapist to talk about feelings and moods.

**Psychosis** A serious mental disorder in which a person has **hallucinations** and/or **delusions**.

**Resuscitation** Procedures that doctors use to revive a person who is not breathing.

**Severe dementia** Symptoms that can give great difficulty to people with dementia, including very severe loss of memory, feelings of disorientation and an inability to make judgements or undertake simple tasks.

## More information about dementia

The organisations below can provide more information and support for people with dementia and their carers. Please note that NICE and SCIE are not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Alzheimer's Society, 0845 300 0336, [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
- Carers UK, 0808 808 7777, [www.carersuk.org](http://www.carersuk.org)
- Parkinson's Disease Society, 0808 800 0303, [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

NHS Direct online ([www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support.

### About NICE

NICE produces advice (guidance) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider all the research on the condition and treatments, talk to people affected by it, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

*To find out more about NICE, its work and how it reaches decisions, see [www.nice.org.uk/aboutguidance](http://www.nice.org.uk/aboutguidance)*

### About SCIE

SCIE's aim is to improve the experience of people who use social care by developing and promoting knowledge about good practice in the sector. Using knowledge gathered from diverse sources and a broad range of people and organisations, it develops resources which it shares freely, supporting those working in social care and empowering service users.

*To find out more about SCIE and its work, see [www.scie.org.uk](http://www.scie.org.uk)*

*This booklet and other versions of this guideline aimed at health and social care professionals are available at [www.nice.org.uk/CG42](http://www.nice.org.uk/CG42) and at [www.scie.org.uk/publications/misc/dementiaguidelines.asp](http://www.scie.org.uk/publications/misc/dementiaguidelines.asp)*

*You can order printed copies of this booklet from the NHS Response Line (phone 0870 1555 455 and quote reference N1145).*

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ISBN 1-84629-313-8  
N1145 15k 1P Nov 06