

Dementia – information for patients, relatives and carers

This leaflet will help you understand dementia better. It describes the main types of dementia, their causes and symptoms, and how it is diagnosed. It also explains how to make sure that you get the right care in hospital, and gives you contact numbers for helpful local and national services.

What is dementia?

Dementia is a general term used to describe a set of symptoms. These symptoms often include

- loss of memory
- mood changes
- problems with communicating
- difficulty completing day-to-day tasks
- problems with reasoning.

Dementia is progressive. This means that the symptoms will gradually get worse. The speed this happens usually depends on the person, and the type of dementia they have.

There are many different types of dementia and they are often called by the same name as the condition that caused the dementia in the first place.

How will you know if you have dementia?

You are unique and will experience dementia in your own way. It may be that your family and friends are more concerned about your symptoms than you are.

Below are some things that you, your carer or loved ones might notice:

Loss of memory

It is usually your short-term memory that is affected. For example, you may forget what happened earlier in the day, or you may not be able to recall what you have been talking about. You may repeat things or forget the way home from the shops. Your long-term memory usually remains intact.

Mood changes

You may feel withdrawn, sad, frightened, or angry about what is happening to you.

Communication problems

It may be hard to find the right words for things, and you may find yourself having to describe what an item does instead of being able to name it.

Daily living skills

People living with dementia sometimes find it difficult to maintain their daily routine and activities independently. Patience, prompting and support from carers and loved ones can encourage independence and can have a big impact on how capable and confident a person living with dementia feels.

What causes dementia?

There are several diseases and conditions that cause dementia, including the following.

Alzheimer's disease

This is the most common cause of dementia. It gradually changes the chemistry and structure of your brain and causes brain cells to die. Problems with short-term memory are usually the first obvious sign.

Vascular dementia

This is caused by your brain not getting enough blood and oxygen. Without enough oxygen, brain cells die and cause vascular dementia. This can happen after a stroke or because the arteries (blood vessels) supplying oxygen to your brain are damaged. You can experience the symptoms suddenly after a stroke, or over time (after a series of small strokes).

Dementia with Lewy bodies (DLB)

This type of dementia gets its name from tiny abnormal structures, called Lewy bodies, which build up inside the nerve cells in the brain. Lewy bodies cause brain tissue to break down and prevent the brain from functioning properly. Symptoms can include confusion and hallucinations (seeing or hearing things that are not really there), as well as finding it hard to plan, reason and solve problems. Your memory may be affected too. This form of dementia shares some characteristics with Parkinson's disease and may mean that you are not able to have certain types of medications.

Fronto-temporal dementia (including Pick's disease)

This type of dementia is usually caused by damage to the front part of your brain, and is more likely than other types of dementia to affect people at a younger age. The most obvious signs are changes in your personality and behaviour.

What is mild cognitive impairment (MCI)?

You may be having problems with your memory, but your doctor may not think the symptoms are severe enough to diagnose you with a type of dementia, particularly if you are still managing well. Some doctors call this condition MCI.

Recent research has shown that people with MCI are more likely to develop dementia, but having MCI does not **always** mean that you will go on to develop dementia. Each year, around 2 in every 10 people with MCI go on to develop Alzheimer's disease.

Who gets dementia?

There are about 850,000 people in the UK with dementia. It mainly affects people over the age of 65, and the risk increases with age. Younger people can have it as well – there are more than 40,000 people in the UK under the age of 65 who have dementia.

There is evidence that, in a few rare cases, the diseases that cause dementia can be inherited. Some people with a particular genetic make-up are more likely to develop dementia.

Can dementia be cured?

Most types of dementia cannot be cured, although there is continued research into developing drugs, vaccines and other treatments.

A number of drugs have been developed that can temporarily alleviate some of the symptoms of certain types of dementia. These drugs include the following 3 cholinesterase inhibitors:

- donepezil
- galantamine
- Rivastigmine

In addition, another drug, called memantine (a glutamate receptor antagonist), can be used. This is in a different class of drug to the cholinesterase inhibitors.

How is dementia diagnosed?

It is very important to get a proper diagnosis. We need to be sure that the changes you are experiencing are symptoms of dementia rather than another illness with similar symptoms to dementia, for example, depression or delirium (if you would like to know more about delirium, please ask for a copy of our leaflet).

A diagnosis can help you, your carer and your loved ones to prepare and plan for the future. Once you have a diagnosis, it may also be possible to prescribe you drugs for Alzheimer's disease.

Dementia can be diagnosed by your GP or by a specialist doctor. The specialist might be a geriatrician (caring for older people), psychiatrist (mental health), or a neurologist (diseases of the nervous system).

Your doctor might ask you to do a number of tests to check your basic thinking processes and your ability to do daily tasks. They may book more tests for you, such as blood tests, a brain scan or a more in-depth check of your memory, ability to concentrate and thinking skills.

How will you be cared for if you need to come into hospital?

Hospital can be confusing and frightening when you have dementia, and it may make you more confused than usual. You might find the ward loud and unfamiliar, and you may not understand why you are there.

If you have dementia and need to stay in hospital, you may be admitted to a general or a specialist hospital ward. Your stay with us may be as part of an elective (planned) procedure, such as a cataract operation, or after an accident, such as a fall.

It is important that all staff are aware that you have dementia. We ask your carers to give us as much information about you and your condition as they can, so that we can carefully tailor the care that you receive.

Your named nurse should explain to other members of staff how your dementia can affect your

behaviour and how you communicate. They should also tell staff whether you prefer to be called by your first name, title or by a nickname.

The Alzheimer's Society produces a booklet called [This is Me](#), which can be used to write this information down. When it is filled in, it gives us a snapshot of who you are, with details about your needs, interests, and what you like and dislike.

If you have memory problems and need further memory checks, you might be referred to a memory clinic after you have gone home from hospital. This could be a clinic at Guy's or St Thomas' Hospitals or your local memory clinic. Memory clinics are staffed by various health care professionals, including doctors, nurses, physiotherapists (mobility specialists) and occupational therapists (specialists in helping you with every-day activities).

Carers: looking after yourself

When you are caring for someone with dementia, it can be easy to ignore your own needs and forget that you matter too.

If you are caring for someone with dementia, be prepared for the fact that you will need support at some point. You will probably need a lot of different types of help and support, ranging from practical care to give you time off from being a carer, to having someone to talk to about your feelings and concerns. Think about what help you might need, and where you can get it from, before you actually need it. That way, when the time comes, you will know where to turn.

Be clear about what support you need, especially when you ask for help in the form of services, and be assertive and persistent. Make it clear that you cannot continue with your caring role unless you receive the support that you need for yourself.

Useful sources of information

The Alzheimer's Society provides help, information and publications on living with dementia, and their helpline is open seven days a week. Helpline: 0300 222 11 22
Southwark & Lambeth: 020 7735 5850 Croydon: 020 8653 2818 **web:** www.alzheimers.org.uk

Carers UK provides information, advice and support for all carers of family members or friends.
Advice line: 0808 808 7777 **web:** www.carersuk.org

Dementia UK provide the specialist dementia support that families need. **tel:** 020 8036 5400 or **email:** info@dementiauk.org

Contact us

Always include contact details for relevant services with opening hours. Include useful helplines and websites – the KIC can help you with this. Provide details of who to contact if the patient is worried about anything, or if something goes wrong.

Ensure that the patient is given a location for the service if they are going to need to travel there themselves.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **web:** www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline, **tel:** 020 7188 8748, Monday to Friday, 9am-5pm, **email:** mymedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service, **tel:** 020 7188 8801, **email:** pals@gstt.nhs.uk. To make a complaint, contact the complaints department, **tel:** 020 7188 3514, **email:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch, **tel:** 020 7188 8815, **email:** languagesupport@gstt.nhs.uk

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, **tel:** 111, **web:** www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing, **web:** www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch, **tel:** 0800 731 0319, **email:** members@gstt.nhs.uk **web:** www.guysandstthomas.nhs.uk/membership

Leaflet number: 3778/VER2

Date published: April 2021

Review date: April 2024

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