

Dementia



Information for patients, relatives and carers

This leaflet aims to 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 numbers for helpful local and national services.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

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 at which 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 I know if I 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 yourself.

You or your carer/loved ones may 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- **Mood changes:** You may feel withdrawn, sad, frightened, or angry about what is happening to you.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:

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 the symptoms of 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?

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 'mild cognitive impairment' (MCI).

Recent research has shown that people with MCI are more likely to develop dementia, but having MCI does not always mean you will go on to develop dementia. Each year 10-15% of 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 men and women over the age of 65, and the risk increases with age. Younger people can have dementia as well. In 2013, there were more 42,000 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, but there is ongoing 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 three cholinesterase inhibitors:

- Donepezil
- Galantamine
- Rivastigmine

In addition, another drug called Memantine can be used. This is in another 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 and delirium).

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 may be a geriatrician (a doctor who specialises in caring for older people), a neurologist (a doctor who specialises in diseases that affect the nervous system), or a psychiatrist (a doctor who specialises in mental health).

Your doctor may 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 I be cared for if I 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 a planned (elective) 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 prefer, 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 King's College Hospital or another local memory clinic. Memory clinics are staffed by various health care professionals, including doctors, nurses, physiotherapists and occupational therapists.

One friend/relative/carer can be given a 'carers passport' (small card) to allow them to visit you outside designated visiting hours while you are in hospital.

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.

How can Carers, family relatives or friends help?

We encourage relatives, friends and carers to visit regularly because patients often feel very frightened and threatened by coming into hospital.

You can ask ward staff for a carer's passport (small card) to enable you to visit your loved one outside designated visiting hours while they are in hospital. King's College Hospital has signed up to John's Campaign, a nationwide initiative that promotes open access for carers to visit loved ones while they are in hospital. Originally this campaign focused on carers of patients with dementia but here at King's we believe all carers have the right to visit and support, rather than stay with their loved ones in hospital if they wish regardless of their diagnosis.

You can also help with their care by:

- letting us know if you think they are constipated
- bringing in daily newspapers to help them know what day it is
- bringing in photographs and any other mementos you think may help reassure them
- bringing in snacks and other food that they like to encourage them to eat.

Please ask ward staff for advice about how else you can help with their care.

Who can I contact with queries and concerns at King's College Hospital (Denmark Hill)?

If you would like to discuss any of these issues or would like more support, please contact the dementia and delirium team:

Tel: **020 3299 2478**



Who can I contact with queries and concerns at the Princess Royal University Hospital?

If you would like to discuss any of these issues or would like more support, please contact the Matron in Medicine:

Tel: **01689 863224**

Where can I get more information?

The Alzheimer's Society

The Alzheimer's Society provides help and information on living with dementia. Their website lists over a hundred publications on dementia, and their helpline is open seven days a week.

Helpline: **0300 222 11 22**

Southwark & Lambeth: **020 7735 5850**

Croydon: **020 8916 3587**

www.alzheimers.org.uk

Carers UK

Carers UK provides information, advice and support for carers of older, disabled or seriously ill family members or friends.

Advice line: **0808 808 7777**

www.carersuk.org

Admiral Nursing DIRECT is a national helpline and email service, provided by experienced Admiral Nurses and is for family and professional carers, people with dementia and those worried about their memory. It gives practical advice and emotional support to anyone affected by dementia.

Tel: **0845 257 9406** or email: **direct@dementiauk.org**

Pharmacy 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 3299 3347**



Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS:

Tel: **020 3299 3601**

Email: **kch-tr.pals@nhs.net**

You can also contact us by using our online form at

www.kch.nhs.uk/contact/pals

PALS at Princess Royal University Hospital,

Farnborough Common, Orpington, Kent BR6 8ND

Tel: **01689 863252**

Email: **kch-tr.palskent@nhs.net**



If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.



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King's College Hospital is part of King's Health Partners Academic Health Sciences Centre (ASHC), a pioneering collaboration between King's College London, and Guy's and St.Thomas', King's College Hospital and South London and Maudsley NHS Foundation Trusts.

For more information, visit www.kingshealthpartners.org 