

Is it dementia?

What is dementia?

Dementia is not a disease but is a group of signs and symptoms.

Dementia rates are increasing

Around 850,000 people in the UK have dementia. By 2025 this number is expected to rise to over one million, with a projected rise to 2 million in 2050, so if you or someone you know is diagnosed with it, you are not alone. It mainly affects older people, both men and women, but it can be found in younger people. In the UK over 40,000 people under 65 years of age have dementia. Around two-thirds of people with dementia are women, although the reason for this is unclear.

Typical early signs of dementia

There are several types of dementia, the most common of which is Alzheimer's disease. The typical early signs of dementia are:

- Struggling to remember things – difficulty in recalling recent events
- Difficulty in working things out – finding it hard to follow conversations, remembering how to get dressed or make a cup of tea
- Difficulty picking up new skills – struggling to learn how to use a new appliance
- Struggling to adapt to physical or sensory changes – loss of confidence and difficulty with hearing aids, new glasses or walking aids
- Difficulties with orientation – problems wayfinding in familiar surroundings and coping with changes within the home environment

These symptoms occur when the brain is damaged, for example, following a stroke or the onset of Alzheimer's disease.

Everyone is different

The symptoms of dementia increase over time. It is gradual, and everyone experiences the changes at different speeds. There is no cure but there are treatments that help slow it down or help people cope with certain symptoms. And there are lots of ways of helping people live a full and happy life. These range from simple adaptations in the home to support from health and social care professionals, to financial help.

Having dementia does not automatically mean you have to go into a care home or hospital. Two thirds of people with dementia live in the community. Being old doesn't automatically mean you will get dementia. It is just more common in the elderly. Around 80 percent of people aged over 80 are bright and alert, if occasionally forgetful.

Why does it happen?

The brain is made up of millions of brain cells which send messages to each other. These messages tell us everything we need to know to cope with everyday life: such as how to

move, what we are seeing, how to speak. They also store our memories and control our emotions - such as laughing and crying.

In someone with dementia, some of these brain cells become damaged and die (in most cases, it is not yet known exactly why). As a result, their brain doesn't work as well as it used to; simple messages do not get through. Hence they become forgetful and can become confused by their surroundings. They may not remember something that happened yesterday, or how to get dressed. They may not recognise their husband or their friends. Sometimes finding the right word might be difficult.

If any of these things happen it can be frightening and frustrating. It can make someone anxious, unhappy and even angry. The world can seem a confusing and unfriendly place. But it doesn't have to be like this!



REMEMBER

Lots of people have dementia and live fulfilled lives
Because it is a common condition, there's a lot of help available
There are lots of simple ways of helping people adapt to their new circumstances

It isn't necessarily dementia

Memory loss and confusion are not always a sign of dementia. These symptoms can be due to other causes such as other physical health conditions. Just a few examples are:

- heart or kidney failure
- chest or urinary tract infections
- anxiety and depression
- side-effects of medication
- underactive or overactive thyroid
- dehydration
- low blood sugar

These conditions can all be treated, so it's very important to get a proper diagnosis from your GP.

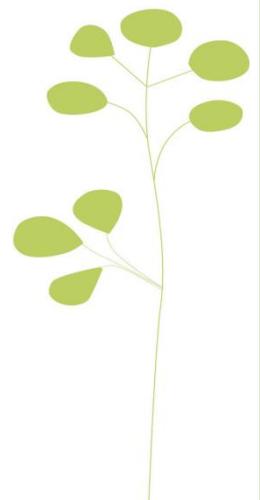
Types of dementia

There are several types of dementia. No two people developing the condition are the same, with its progression varying in every case.

Common misunderstandings

There is much popular misunderstanding and confusion about dementia. Perhaps not surprising since there is still much to learn about the condition. In general we still don't know exactly what causes it and although there are treatments, there is no known cure. However, there are certain things we can say for definite and which should help you if you are concerned that you or someone close to you may have it.

- Dementia is not inherited (except in a very few rare cases). If someone in your family has dementia, you are at no higher risk of developing it yourself.
- You cannot catch dementia – it is not contagious.
- Most people with dementia don't die of dementia. They die of illnesses and infections that everyone else gets.



- Eating fish, 'superfoods' or special supplements is not a prevention against dementia
- If you are overweight or have high blood pressure, you could be at risk of developing dementia because you are at higher risk of having a stroke or heart disease
- People with dementia are not children, and will respond to how you treat them
- Many people with dementia, with the right support and access to help and information can lead productive and happy lives for many years.

Types of dementia



Alzheimer's disease

Alzheimer's disease is the most common type of dementia. It's found in more than half of people diagnosed with dementia. It is a physical disease causing permanent damage to individual brain cells, due to the build-up of proteins causing Plaques and Tangles. The numbers of damaged cells gradually increase over time, so the brain starts to function less and less well. It may begin slowly, and the decline can happen over a number of years. It usually affects short-term memory first. Gradually, everyday tasks become more and more difficult. No two people are the same.

Vascular dementia

Vascular dementia is the second most common type of dementia. The blood supply to the brain is damaged or cut off. As a result, some brain cells die. This can happen either suddenly, following a stroke, or more gradually after a series of 'mini-strokes' or 'infarcts'. These mini-strokes can be so small that they go unnoticed to begin with. Then the person might have a sudden change but remain stable until the next 'mini-stroke'. With vascular dementia, people start to forget things and find day-to-day life harder to cope with.

Mixed dementia

Ten percent of people diagnosed with dementia will have mixed dementia, a combination of Alzheimer's disease and vascular dementia. The symptoms will include elements of both.

Lewy body dementia

Lewy body dementia affects around 10 percent of people with dementia. It's caused by tiny, round deposits (Lewy bodies) that damage the brain tissue. This causes the brain to function less well in sending and receiving messages. The effects can be patchy and sporadic, so someone with this type of dementia can vary quite a lot day to day. As well as affecting memory, people can have hallucinations, physical stiffness, weaknesses in their arms and legs, and tremors. It is also related to Parkinson's disease, so some people with Parkinson's disease may develop this type of dementia, but people with Lewy body dementia don't necessarily get symptoms of Parkinson's disease.



Fronto-temporal dementia

Fronto-temporal dementia (including Pick's disease) damages the front and side parts of the brain. This means people are likely to have behavioural and mood changes and may find it difficult to judge situations or plan ahead. They may do things at the wrong time or in the wrong place. Problems with memory are not as common, or occur later. Younger people, usually under 65, are more likely to be affected. Alcohol-related dementia (including Korsakoff's syndrome) is caused by a lack of vitamin B1. Heavy drinkers may not be able to absorb the vitamin well, and may also have a poor diet. This type of dementia particularly affects the short-term memory. Stopping drinking halts the condition and, with the right treatment, may even reverse it.

Other conditions

These are the main types of dementia. However, other illnesses or conditions can cause dementia. Mild cognitive Impairment (MCI) for example, is a term used to describe problems with cognitive function (mental abilities such as thinking, knowing and remembering). People with MCI may have difficulties with day-to-day memory, but not enough to be defined as dementia.

Further information on the different types of dementia can be found on the Alzheimer's Society website (www.alzheimers.org.uk).

Is it dementia?

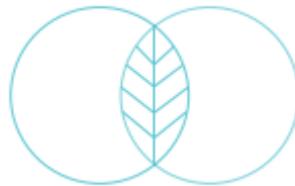
Who hasn't forgotten somebody's name or where they've put their shopping list?

Memory worries

If we forget things, it's usually because we were thinking about something else, or were distracted by other people. It could also be due to tiredness or anxiety about something.

As we get older, most of us find our memory is not as good as it used to be. However, it can be hard to tell if this is an early sign of dementia. Certainly becoming forgetful is a common symptom of dementia, but memory problems can be caused by other things too.

In this section you can find out what to do if you're concerned about your memory or the memory of someone you know.



Dementia is about more than just being a bit forgetful

Here are some common questions to ask yourself or the person you are concerned about.

Do you/they:

- find it hard to remember everyday words or the names of friends?
- find it difficult to remember recent events but easily recall things from the past?
- feel the forgetfulness is more than just the odd occasion?
- find it harder to carry out simple tasks?
- find it hard to follow conversations or programmes on TV?
- often lose a train of thought?
- have difficulty remembering what's just been heard, seen or read?
- notice people saying 'you've already told me that'?
- find it difficult to follow simple instructions?
- feel confused even when in familiar places?
- get anxious, depressed or angry about being forgetful?

Also, ask family and friends if they've noticed any behavioural changes. If the changes are more than just the 'odd memory lapse' it's likely that they will have done. They will probably be worried and anxious to help.

If any of this raises concerns, organise an appointment with your GP to discuss them.

Talk to your GP

When memory problems get worse and they affect daily life, it's important to visit a GP for a checkup. It may not be dementia, so a GP can check if it is something that is easily treatable. Conditions or illnesses that can cause memory problems include:

- Chest infections
- Urinary tract infections
- Depression and stress
- Side-effects of medication
- Heart or thyroid problems

It's a good idea to take a relative, friend or carer with you when you see your GP. Talk together about the things that are of concern before the appointment and jot down a list of questions to ask before going. This will help your GP and ensure that nothing is overlooked. Having someone else to make notes during the appointment will also be useful later. However, at some stage during the appointment the doctor may want to talk to their patient on their own.

Finding out if it is dementia?

When memory problems get worse and they affect daily life, it's important to visit a GP for a checkup.

The first step is to visit your GP

Your GP will ask about general health and will probably do some routine tests, such as taking blood and urine samples. These will be to check whether there are other conditions that could be causing the symptoms. Questions by the GP may include asking about sleep patterns, appetite and feelings of anxiety or being under pressure. This is to discover if stress or depression could be a cause.

The doctor will ask specific things about any particular concerns and about memory. That is why it's useful to have jotted down a few notes beforehand. The doctor will then do some simple tests to find out more about memory and understanding. One of these is called a mini-mental state examination (MMSE). The doctor may also ask a family member, friend or carer what changes they have noticed.

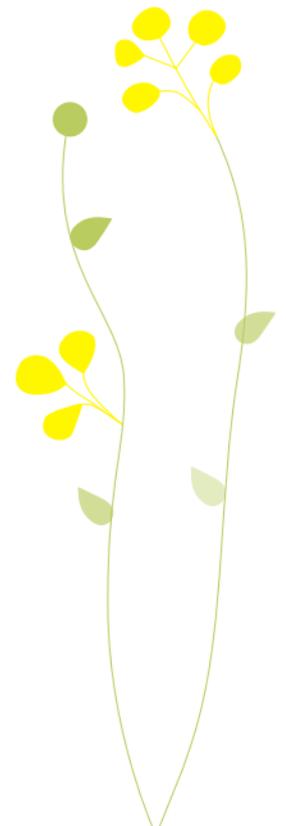
Don't be afraid to ask for explanations of anything. The doctor may then organise a referral to a specialist consultant or a memory clinic.

What does it mean to be 'referred'?

If your GP feels there is a need for further assessment or investigation, you will usually be 'referred' to a consultant psychiatrist who is a specialist in memory problems, sometimes based at a Memory Clinic. He or she is highly experienced in the diagnosis and, if required, treatment of dementia. The consultant may be supported by a dementia specialist nurse who will also be able to help to advise 18 19 you on any additional help you may need. Memory Clinics operate throughout the country at main community locations and offer assessment, support, information and advice to those with memory problems and their carers.

What happens when I'm referred?

This appointment involves a doctor or nurse talking with the individual and a relative (or close friend), who is able to explain the difficulties or problems being experienced and their effect on daily living. The team will carry out some tests to find out the strengths and weaknesses of memory, so it is important to take along reading glasses or hearing aids if these are used. It also involves gathering detailed information about the individual's



background, past medical history, any current medical problems and medications currently being taken. Sometimes, you will be asked to have an MRI scan or blood tests. The first appointment may take between 1 and 2 hours. It is difficult to be precise about timing as all cases and circumstances are different and may need varying amounts of time.

By the end of the appointment the clinic team aim to have completed an assessment, discussed the results and helped plan any future treatment or care. Details of other services which may be helpful will also be made available.

A follow-up appointment will usually be made after three months to undertake a progress review. This appointment takes about half an hour and is an opportunity to discuss any concerns and assess the benefits of any advice or medication that has been given.

Planning ahead

Having dementia does not mean you no longer have a life.

Help and support

If the doctor or specialist diagnoses dementia, it is normal to feel shocked, frightened angry, upset or disbelieving. However, the types of help and support services available are increasing, to which the doctor will provide access. The doctor may also prescribe treatments that they feel are suitable. These can sometimes lessen the symptoms, so the earlier a diagnosis is made the better.

Dementia affects everyone in different ways and the symptoms are more complex than just forgetting things. There are many types of dementia (of which Alzheimer's disease is just one).

A diagnosis of dementia does not mean sudden illness or dependency on others, or the need to move into a care home. A diagnosis can help with planning for the future, staying in control and enable living independently at home.



Remember, having dementia does not mean you no longer have a life.

With the right help and support, a diagnosis will give you time to plan ahead and organise help where it's needed - practical, financial and professional - to allow a full, active and independent life.

Coping with a dementia diagnosis

This will be a worrying and stressful time for yourself and family, even if you have had concerns about your memory for a while. After receiving your diagnosis is a crucial time, when you will need support and reassurance from both your family and professionals.

Dementia is a progressive condition, which means that the symptoms gradually get worse. The progression follows a very individual process and each person will experience dementia in a different way. Some people will experience a lot of symptoms, others not as many.

It is important at this time to take stock and think about what is important to you and what you value. You need to think ahead and make plans now, to ensure that what you would wish to happen later on will be carried out. As the dementia progresses, there may come a

time when you are unable to advocate for yourself. You need to discuss things with people close to you. It is probably a good idea to write down all your concerns and future wishes, and also to consider end-of-life choices. It will be helpful to those closest to you if you have put in place a plan that incorporates your culture, values and ideas.

Other things to consider

It's a good idea for all of us to think about what might happen to us in later life.



Advance decisions

"An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT, or a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future." You can find out more about advance decisions from the NHS Choices website's section on End of Life Care.



Wills

If you want to make decisions about who you would like to benefit, you can include this in a will. You can also include your wishes regarding your funeral. A good source of information about writing your will can be found on the government website (www.gov.uk/make-will). There is also good advice about advance funeral wishes on the Bereavement Advice Centre's website (www.bereavementadvice.org).



Lasting Power of Attorney

For general information about a Lasting Power of Attorney (LPA) see our **Diagnosed with Dementia?** booklet and in particular the **Who You Must Tell** section. Please remember that there are two types of LPA and the Personal Welfare LPA is concerned with appointing an individual who would look after day-to-day matters such as health, care and your home. The best source of information is the Office of the Public Guardian (OPG) section of the government website (www.gov.uk).



Support organisations

For more information or advice, please call Dementia Care on 0191 217 1323 and ask to speak to one of our Dementia Guides. They offer free face-to-face support for people with dementia and their families in Newcastle upon Tyne, Hexham and the surrounding areas.

A variety of support groups will exist in your local area. To find out who they are and how to contact them, it may also be useful to contact some of the national organisations listed here:

Age UK

www.ageuk.org.uk
or call 0800 169 2081

Alzheimer's Society

www.alzheimers.org.uk
or call 0845 300 0336

The Lewy Body Society

www.lewybody.org
or call 0131 473 2385

Carers UK

www.carersuk.org
or call 0808 808 7777

The Princess Royal Trust

www.carers.org
or call 0844 800 4361

Concerns regarding financial or other abuse of a vulnerable person

If you have any concerns regarding financial or other abuse of a vulnerable person, you should contact the **Office of the Public Guardian**:

PO Box 16185
Birmingham
B2 2WH

Tel: 0300 456 0300 or
Email: customerservices@publicguardian.gsi.gov.uk

Opening hours:
Monday, Tuesday, Thursday and Friday - 9 am to 5 pm
Wednesday - 10 am to 5 pm