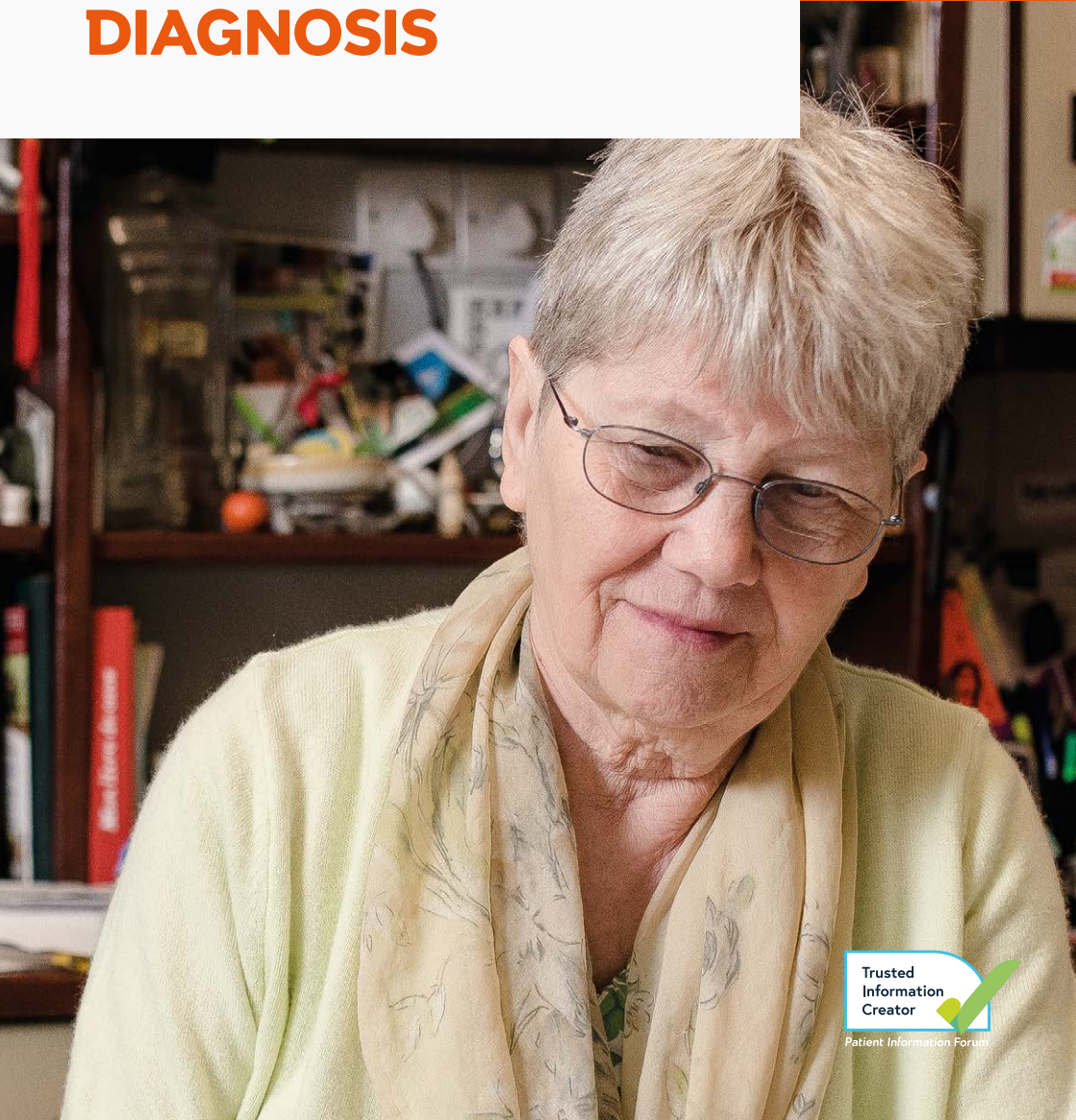


GETTING A DEMENTIA DIAGNOSIS





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INTRODUCTION

This booklet provides information about diagnosing dementia. It's for anyone who is worried about their own memory, thinking or other similar symptoms, or for people who want to know more about dementia and how it's diagnosed.

The information here does not replace advice that doctors, pharmacists, or nurses may give you. If you are worried about your health, including memory and thinking problems, speak with your doctor as soon as possible.

This booklet was updated in October 2023 and is due to be reviewed in August 2025. It was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers. Please get in touch using the contact details below if you'd like a version with references or in a different format.

ANY QUESTIONS

If you have questions about dementia or dementia research you can contact the Dementia Research Infoline on **0300 111 5111** or email infoline@alzheimersresearchuk.org or write to us using the address on the back page.

MEMORY AND THINKING PROBLEMS

Most of us forget things every day. We might forget the name of someone we just met, where we put our keys or why we walked into a room.

People of all ages experience these things, although many people find they get more common with age, or they may worry more about them as they get older. However, this type of forgetfulness is not necessarily a sign of dementia.

We can also experience problems with our thinking from time to time. We might find it hard to concentrate on something we are trying to do, or struggle to follow a conversation we are having. We may also have difficulties finding the right words, or speaking properly.

While it can be normal to experience difficulties from time to time, memory and thinking problems that start to have an effect on our everyday life may be a sign of something more serious.

Ongoing memory and thinking problems can have many causes, including:

- infections
- vitamin deficiencies
- an underactive thyroid
- stress, anxiety, and depression
- some medications you might be taking for other health conditions.

In some cases however, ongoing memory and thinking problems can be a sign of dementia. The best thing to do if you are experiencing any memory and thinking problems is to make an appointment with your GP who can do some tests to see what might be causing them.

THINKING PROBLEMS THAT START TO HAVE AN EFFECT ON OUR EVERYDAY LIFE MAY BE A SIGN OF SOMETHING MORE SERIOUS.

WHAT IS DEMENTIA?

The word dementia is used to describe a group of symptoms. These include changes in memory, thinking, judgement, emotions, movement and language.

When someone starts to develop dementia these changes can be very subtle, but over time they get worse and more noticeable. Symptoms of dementia will start to have an impact on a person's everyday life, making daily activities more difficult to do.

Dementia is not a disease itself, it is caused by different underlying diseases that affect the brain. Alzheimer's disease is the most common cause of dementia. Other types of dementia include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

Most of these diseases damage the brain slowly over time. As this damage spreads and gets worse, it causes problems with the way our brains work, leading to the symptoms of dementia. The exact symptoms someone experiences will depend on the underlying disease, and the areas of the brain it affects.

However, memory loss, changes in mood, and thinking problems can be some of the first noticeable symptoms in many types of dementia. It is also possible for dementia to develop suddenly, for example after a serious stroke.

Most people who develop dementia are over 65, but it can affect younger people too. It is estimated that nearly 71,000 people under 65 in the UK have dementia. When dementia is diagnosed in people under the age of 65 it is called young onset or early-onset dementia.

For more information about different types of dementia visit alzheimersresearchuk.org/dementia-information/types-of-dementia/ or contact us on **0300 111 5111** or infoline@alzheimersresearchuk.org

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SYMPTOMS

Dementia gradually gets worse over time. People can often find ways to cope with early symptoms, such as using lists, diaries or setting reminders.

This means that problems are not always obvious to others straight away. However, as symptoms get worse and become more noticeable, family and friends may start to recognise that someone is struggling.

Dementia affects people in different ways. The symptoms below could be signs of dementia, particularly if they are new and appear to be getting worse.

- Short-term memory loss, which might lead to someone becoming repetitive, forgetting recent events, or finding it difficult to learn anything new.
- Changes in ability to think things through and solve problems.
- Losing track of the date or time.
- Struggling to find the right words when talking.
- Difficulty understanding instructions.
- Making mistakes in everyday tasks.
- Becoming withdrawn and unmotivated.
- Other changes to behaviour, personality, and mood.
- Changes in vision, balance, and walking.

The symptoms we list here may not apply to everyone. Dementia symptoms are unique and individual to a person. What is important to remember is that if you notice symptoms are getting worse or are not normal behaviour, then it could be a sign that something is wrong.

If you are worried about any of these symptoms, it's a good idea to talk to your GP as soon as possible, who can investigate what is causing them.



WHAT ARE MY SYMPTOMS?

Use this space to record information about your symptoms. It's useful to say **how long** you've had a symptom for, **how often** you get them and whether they have **got worse** over time.

You can take this with you to your appointment, to help you explain your symptoms to your GP.

Are you forgetting things regularly?

What kind of things are you forgetting (names, where you've put things, recent events, conversations)?

Are you experiencing any significant changes from normal (e.g. sleep, mood, hearing, vision)?

Is it becoming difficult to follow instructions or carry out tasks around the house?

How often does this happen? For example, all the time, once or twice a day, once or twice a week.

Have you noticed or has anyone told you that you've repeated yourself during a conversation recently?

Are your symptoms stopping you from doing the things you enjoy doing?

Which symptoms are you most worried about?



DIAGNOSING DEMENTIA

Diagnosing dementia early, when symptoms are still mild, is important. If you notice any symptoms like those described on page 8 it's best to make an appointment with a GP, so that an accurate diagnosis can be made.

It's helpful if someone else who knows you well can go to the appointment too or speak with the doctor.

When you go to the GP with memory and thinking problems:

- They will ask about your symptoms and how they are affecting you. You can use the space on page 11 to record information about your symptoms. A relative or close friend may also be asked what changes they have noticed in you.
- You'll be asked about your medical history and the doctor may give you a physical check-up, checking your blood pressure and balance.
- You will have some blood tests, to rule out some possible causes like vitamin deficiencies and thyroid disorders. You may be asked for a urine sample.
- You will be asked to do a short test of memory and thinking. This usually involves being asked a series of questions and carrying out tasks with a pen and paper. You do not need to prepare for these tests.

AT THE MEMORY CLINIC

If your GP suspects you may have dementia, they are likely to refer you to a memory clinic or specialist for further tests. Some people may have to wait several months before their memory clinic appointment.

If you would like information and support in the meantime, please contact our **Dementia Research Infoline** on **0300 111 5111** or **infoline@alzheimersresearchuk.org**

A memory clinic or specialist can:

- Perform more in-depth memory and thinking tests to determine the severity of symptoms. These tests assess memory, language, visual and spatial awareness, levels of attention and ability to reason and solve problems.
- Send someone for a brain scan. Different types of brain scan are used to look for changes that occur in the brain when someone has a disease that causes dementia. If the doctors can see changes in certain areas of the brain this can help them to diagnose the type of dementia someone has.
- On rare occasions arrange for a lumbar puncture. This can help doctors identify which disease someone is likely to have based on certain substances in the spinal fluid.

When someone receives a dementia diagnosis it can come as a shock. Other people feel relieved to have an explanation for their symptoms and the change in their health. People can choose not to know their diagnosis if they prefer not to and can choose someone else who will be told.

Usually, a memory clinic concentrates on making the diagnosis and advising on first steps in support and treatment. After that, a person goes back into the care of their GP practice, where they will get advice on longer term help, support, and treatments.

**IT'S IMPORTANT THAT SOMEONE
DIAGNOSED WITH DEMENTIA SEES
THEIR GP REGULARLY FOR A GENERAL
CHECK-UP. THIS CAN BE EVERY
6 TO 12 MONTHS.**

WHAT TO DO IF SOMEONE IS RELUCTANT TO SEE THEIR GP

Some people may be reluctant to see their GP or may not realise they are experiencing memory and thinking problems. This can make it difficult to encourage them to get a diagnosis.

To support someone you are concerned about you can:

- Explain that it may not be dementia that is causing their symptoms, and that it is important to get any health concerns checked out.
- Keep a diary of any symptoms or behaviour changes you observe over the course of a couple of weeks. A person experiencing these symptoms may not be aware or forget when these things happen.
- Some people find it can be helpful to discuss these changes with their loved ones.
- Speak with the person's GP's surgery yourself, explain the symptoms you are concerned about and how they are affecting them. Sometimes writing a letter or email to the surgery can be helpful.
- Speak to specialist dementia nurses called **Admiral Nurses** for more information and support on **0800 888 6678** or email **helpline@dementiauk.org**



WHY IS GETTING A DIAGNOSIS IMPORTANT?

It can understandably be overwhelming and scary for someone to see their GP about memory and thinking problems, and this can prevent people from seeking medical help. There are reasons why getting a diagnosis of dementia is important.

Getting a diagnosis can help someone and their loved ones understand what is causing symptoms, and this can be a relief. It means that people can make adjustments to ensure they can live independently and as well as possible, to help improve their quality of life.

An early diagnosis means that the person will be able to access the right help, treatments, and support services. It also means they have more time to plan for the future, to make important decisions about legal and financial matters, and future care options. An early diagnosis also means they may be more suitable for certain research studies, like clinical trials, should they wish to take part.

Diagnosing which type of dementia someone has is also important. Dementia is not a disease itself, but a word that describes the symptoms someone experiences when they have a disease like Alzheimer's or vascular dementia. Where possible, someone should be told which type of dementia they have.

Having an accurate diagnosis means that someone can:

- Access the right type of treatments and support for their condition.
- Ask their GP and nurse the right questions about their health and treatment.
- Find the right information about their condition and be better prepared for the next steps.
- Understand how symptoms affect them and how they might progress.
- Be matched with the right type of study if they wish to take part in research.

However, even after specialised tests, it can be difficult for a doctor to be sure of the type of dementia a person has. This is because there is still a lot to be learned about the diseases causing dementia.

RESEARCHERS AND SCIENTISTS ARE WORKING HARD TO DEVELOP NEW, AND MORE ACCURATE WAYS OF DIAGNOSING DISEASES LIKE ALZHEIMER'S.

WHERE TO GO FOR SUPPORT

There is lots of help and support available for people who are affected by memory problems and dementia.

If you have questions about symptoms, or about getting a diagnosis of dementia you can contact **Alzheimer's Research UK's Dementia Research Infoline** on **0300 111 5111** or infoline@alzheimersresearchuk.org

Following a diagnosis, it's important to think about planning for the future. Everyone with a diagnosis is entitled to an assessment of their needs by their local social services.

You can find out more about this by contacting your GP or **Alzheimer's Society** on **0333 150 3456** or dementia.connect@alzheimers.org

They also provide information on local support services in England, Wales, and Northern Ireland.

Alzheimer Scotland provides dementia support advice and information about local services in Scotland. Call **0808 808 3000** or email helpline@alzscot.org

The **Admiral Nurse Helpline** offers practical and medical advice to people affected by dementia and their carers, and also those with concerns about getting a diagnosis. Call **0800 888 6678** or email helpline@dementiauk.org



RESEARCH

Alzheimer's Research UK has funded over £210 million of dementia research, including over £25 million of research into diagnosis of dementia and the diseases that cause it.

Better and earlier diagnosis is vital in the search for a cure for dementia. The earlier people receive a correct diagnosis, the earlier they can access appropriate treatments and support.

Through the research we fund, our scientists are building a detailed understanding of what happens in the brain and how these changes can be detected. This is essential for improving diagnosis and developing new ways to detect the diseases that cause dementia earlier than we currently can.

To find out about the research we fund you can visit alzheimersresearchuk.org/research/researchprojects

Early diagnosis is part of the journey towards finding a cure. Without diagnosis, we can't intervene and prevent, or slow down the diseases that cause dementia. Without diagnosis a cure is ineffective. Without diagnosis there is no cure.

**We are Alzheimer's Research UK.
We exist for a cure.**

HOW TO GET INVOLVED

People with and without dementia play an important role in dementia research.

More people are needed to take part in vital studies to help scientists test new methods of diagnosis, treatment, and support.

If you're interested in taking part in research you can register to see which studies you can take part in via **Join Dementia Research** at joindementiaresearch.nihr.ac.uk or scan the QR code here



**YOU CAN FIND OUT MORE
AND REGISTER HERE**

joindementiaresearch.nihr.ac.uk You can also register over the telephone on **0300 111 5111**

Alzheimer's Research UK is the UK's leading dementia research charity. We provide free dementia health information, like this booklet and others.

If you would like to view, download or order any of our other booklets please use the details below. If you'd like to help us review and improve our booklets, visit alzres.uk/reviewer

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