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### Introduction

This booklet provides information about diagnosing memory problems. It's for anyone who is worried about their own memory and thinking problems, 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.

The booklet was updated in August 2021 and is due to be reviewed in August 2023. 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.

If you have questions about dementia or dementia research you can contact the **Dementia Research Infoline** call **0300 111 5111** 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

While it can be normal to experience difficulties every now and then, 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.



### What is dementia?

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

When someone develops dementia these changes can be very subtle, but over time they get worse. 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 various 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 the diseases that cause dementia damage the brain slowly over time. As this damage spreads and gets worse this causes problems with the way our brains work, giving rise to the symptoms of dementia.

The exact symptoms someone experiences will depend on the underlying disease and the areas of the brain affected. 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 over 40,000 people aged 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 www.alzheimersresearchuk.org/dementia-information/types-of-dementia/ or contact us on 0300 111 5 111 or infoline@alzheimersresearchuk.org

## **Symptoms**

Dementia symptoms gradually get 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.

The symptoms we list here may not apply to everyone. Dementia symptoms can be 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 doctor as soon as possible, who can



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, becoming repetitive, forgetting recent events



Changes in ability to think things through and solve problems



Losing track of the date or time



Changes in vision, balance, and walking



Struggling to find the right words when talking



Difficulty understanding instructions



Other changes to behaviour, personality, and mood



Making mistakes in everyday tasks



Becoming withdrawn and unmotivated

## 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)?

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

or twice a week.	the time, once or twice a day, once
	d or has anyone told you that you've elf during a conversation recently?
Are your sympto you enjoy doing	oms stopping you from doing the things ?
Which symptom	ns 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 9 it's best to make an appointment with a doctor, so that an accurate diagnosis can be made.

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



# When you go to the doctor 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. If your doctor suspects you may have dementia, they should refer you to a memory clinic or specialist for further tests.



### 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.
- Arrange for a lumbar puncture. This can help doctors identify which disease someone is likely to have based on "warning signs" 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 doctors and nurses will advise on longer term help, support, and treatments.

It's important that someone diagnosed with dementia sees their doctor regularly for a general check-up, this can be every 6 to 12 months.

# What to do if someone is reluctant to see their doctor

Some people may be reluctant to see their doctor, 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.
- Speak with the person's doctor'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.
- 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 to Admiral Nurses for more information and support on 0800 888 6678 or email helpline@dementiauk.org



# Why is early diagnosis important?

We understand that it can be overwhelming and scary for someone to see their doctor about memory and thinking problems, and that this can prevent some 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 and knowing which disease is causing dementia means that someone can:

- Access the right type of treatments and support for their condition.
- Ask their doctor 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.

Where possible during diagnosis, someone should be told which type of dementia they have. 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 doctor or **Alzheimer's Society** on **0333 150 3456** or **dementia.connect@alzheimers.org.uk** 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

Through the research we fund, our scientists are building a detailed picture 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 www.alzheimersresearchuk.org/research/researchprojects/

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 **www.joindementiaresearch.nihr.ac.uk** or scan the QR code



Alzheimer's Research UK is the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

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 details below.

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