

# DEMENTIA: YOUR QUESTIONS ANSWERED



# INTRODUCTION

This booklet answers some common questions about dementia and the diseases that cause it, such as Alzheimer's disease. It's for anyone who wants to know more about dementia. This includes people living with the condition, their carers, friends, and families as well as anyone interested in their own health.

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 GP as soon as possible.

This booklet was updated in July 2024 and is due to be reviewed in July 2026. 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.

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## ANY QUESTIONS

If you have questions about dementia or dementia research, or any feedback on this booklet, you can contact the Dementia Research Infoline on **0300 111 5111**. You can also email [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org) or write to us using the address on the back page.



# WHAT IS DEMENTIA?

**Dementia is not a disease itself, but a word used to describe a set of symptoms that are caused by different diseases that affect the brain. The symptoms of dementia can vary a great deal. They can include**

- problems with memory, decision-making, communication and/or movement
- confusion
- changes in mood and behaviour
- hallucinations.

## **I keep forgetting things, have I got dementia?**

Most of us forget things every day, like people's names or where we put our keys. But this is not necessarily a sign of dementia. In dementia, memory loss is more serious than forgetting things every now and then. It is memory loss that starts to interfere with everyday life, for example getting lost when going to the local shop.

There are many reasons why people can experience memory problems. Some medicines and drugs can affect memory. Depression, anxiety, stress, vitamin deficiency, infections and thyroid problems can also make people forgetful. If you are worried about your memory and it's getting worse, or getting in the way of everyday life, then you should talk to your GP as soon as possible.



## What is the difference between Alzheimer's and dementia?

Dementia can be caused by a number of different diseases, with Alzheimer's disease being the most common. Other causes of dementia include:

- vascular dementia
- dementia with Lewy bodies
- frontotemporal dementia.

In some cases a person's dementia is caused by more than one disease, such as Alzheimer's disease and vascular dementia. This is often called mixed dementia. You can contact us or speak with your GP for more information about the different causes of dementia.

## Is dementia becoming more common?

Many people are worried that dementia is becoming more common, or that it's a "new" illness. But this isn't entirely true. The word 'dementia' has been around for hundreds of years. However, the symptoms of dementia weren't linked to physical brain diseases until the early 1900s.

In the past many people who developed dementia didn't receive a diagnosis, which made overall rates seem low. This has started to change and for a few reasons, like less stigma being associated with the condition. Also, the number of people who seek a diagnosis each year is increasing. This makes dementia seem more common.

Some other factors are contributing to this rise, making dementia seem more common now than it used to be:

- The UK population is getting older on average, as people are living longer. Age is the biggest risk factor for dementia – as we get older, we're more likely to develop dementia. So an older population will have more people affected by dementia.
- More people are talking about dementia, with one in two people knowing someone who has had a diagnosis. This increased awareness will encourage people to seek help about their symptoms.

More than 200,000 people are diagnosed with dementia each year in the UK, and with advances in diagnosis and less stigma attached to receiving a diagnosis, this figure will continue to rise.

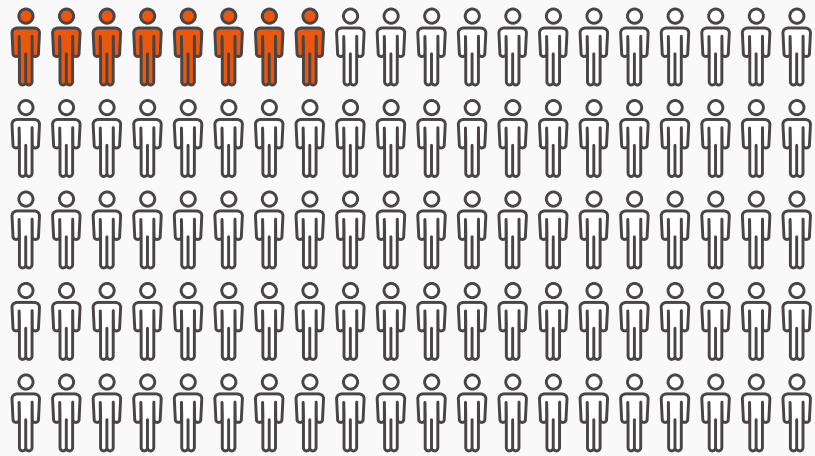
The good news is that the overall number of people who develop dementia (not just the number diagnosed) every year is falling in some communities. This is because people are now more aware of how to look after their health and manage medical conditions that can contribute to the development of dementia, such as high blood pressure and diabetes.

**THE NUMBER OF PEOPLE WHO DEVELOP DEMENTIA IS FALLING IN SOME COMMUNITIES.**



## Is it true that diseases like Alzheimer's only affect older people?

No, but most people with dementia are over the age of 65. In the UK around 70,800 people with dementia are under 65. Many of these people are likely to be in their 50s or early 60s but some rare types of dementia can affect people even younger. This is called early or young onset dementia.



**AROUND EIGHT IN EVERY 100 PEOPLE WITH DEMENTIA ARE UNDER THE AGE OF 65.**



# QUESTIONS ABOUT RISK

## What is a risk factor?

A risk factor is something that increases your likelihood of getting a disease. Some risk factors are things you can't control, such as your age or the genes you inherit. However, other risk factors are things you can influence, such as how active you are, or whether you smoke or drink alcohol.

The biggest risk factor for developing dementia is age, the older you are the more likely you are to develop it. For example, over half of the people in the UK who develop dementia are over the age of 90. However it is important to know that dementia is not a normal part of ageing.

## Does dementia run in the family?

Dementia becomes more common as people get older. Many of us will have a relative living with the condition – but this does not mean we will develop it too. Most of the genes passed down from our parents only have a small effect on our risk of developing dementia. So for most people, their likelihood of developing dementia is influenced as much by their age and lifestyle, as their genes.

In rare cases however, someone may inherit a faulty gene that directly causes a specific type of dementia. Some rare types of young onset Alzheimer's and frontotemporal dementia are caused by faulty genes which run in families

These 'directly inherited' dementias account for just one in every 100 (1%) cases of dementia, and symptoms often start in a person's 40s or 50s. For more information, ask us for our booklet '**Genes and dementia**'.

**ALMOST HALF OF DEMENTIA CASES ARE LINKED TO FACTORS WE CAN CONTROL.**



## Do other diseases or medical conditions affect my risk?

There is evidence that the following conditions can increase the risk of dementia:

- Parkinson's disease
- Down's syndrome
- stroke
- type 2 diabetes
- high blood pressure
- long term depression
- midlife hearing loss
- early memory and thinking problems known as mild cognitive impairment or MCI.

For advice on these conditions, you can talk to your GP or contact us for a list of organisations and support groups that can help.

## How can I reduce my risk of developing dementia?

While we cannot prevent dementia, there are things you can do to lower your risk of developing it. These risk factors are the same as for conditions like heart disease and stroke. By leading a healthy lifestyle and doing regular physical activity you can keep your heart healthy and lower your risk of developing dementia too.

For more information, visit [alzres.uk/risk](http://alzres.uk/risk) or ask for our booklet **'Reducing your risk of dementia'** using the contact details on the back page.

## For good brain health, and to help lower your risk of developing dementia:



If you have diabetes, ensure your condition is managed well



Keep physically and socially active



Don't smoke



Maintain a healthy weight



Eat a healthy balanced diet



Drink fewer than 14 units of alcohol per week



Manage high blood pressure and high cholesterol



Stay socially connected and challenge your brain



Have your hearing and eyesight checked regularly

# GETTING A DIAGNOSIS

## What should I do if I have memory and thinking concerns?

Memory and thinking problems aren't always a sign of dementia. Other illnesses, like thyroid problems and vitamin deficiencies can cause similar problems. These are easily detected via a blood test and can often be treated. It is important to see a doctor about your concerns as soon as possible.

If you are diagnosed with dementia, you may be prescribed medicines that can make day-to-day life a little easier. You can also access support, plan ahead and take part in research if you want to.

## How do I get a diagnosis?

Diagnosing dementia early, when symptoms are still mild is important. Your GP is the first person you should contact if you have concerns regarding your memory.

If your GP thinks you might have dementia, they may ask you to go to a memory clinic for more tests, to find out what's causing your symptoms. You can also ask someone you know well to go with you to help speak to the doctor about your symptoms. You can decide at any point to not be told your diagnosis.

## The GP will:



Ask about how your symptoms are affecting you



Do a blood test to rule out other illnesses



Check your blood pressure and balance



Ask you do to a short memory and thinking test

## At a memory clinic they may:



Do some in depth tests of your memory, thinking and communication



Do a brain scan to look for physical changes to the brain structure



Take a detailed look at symptoms and medical history

If you like, you can ask a loved one to find out instead. For more information, ask for our booklet '**Getting a dementia diagnosis**'.



# WHAT HAPPENS AFTER A DIAGNOSIS?

If a specialist makes a diagnosis of dementia, you will then be discharged back to your GP for ongoing treatment and support. People with dementia should see their GP for a check-up every six to 12 months.

## Is there a cure for dementia?

Unfortunately there is currently no cure for any of the diseases that cause dementia. When someone is diagnosed with dementia, they will have it for the rest of their life. If you've been diagnosed with Alzheimer's or dementia with Lewy bodies, you might be offered some medications that can make your symptoms easier for a time.

If you've been diagnosed with vascular dementia, you will be given advice about how you can limit further damage to your brain, such as managing a normal blood pressure and doing regular physical activity, avoiding smoking and keeping alcohol consumption within safe limits.

People with dementia may also benefit from cognitive and physical therapies. You can find out more about these in our booklet '**Treatments for dementia**'.

## Treatments available for people with dementia include:



Medication to help reduce memory and thinking problems in Alzheimer's and dementia with Lewy bodies



Complementary treatments to promote wellbeing – like music therapy and aromatherapy



Medication for anxiety, agitation, and aggression when necessary



Cognitive therapy



Speech therapy

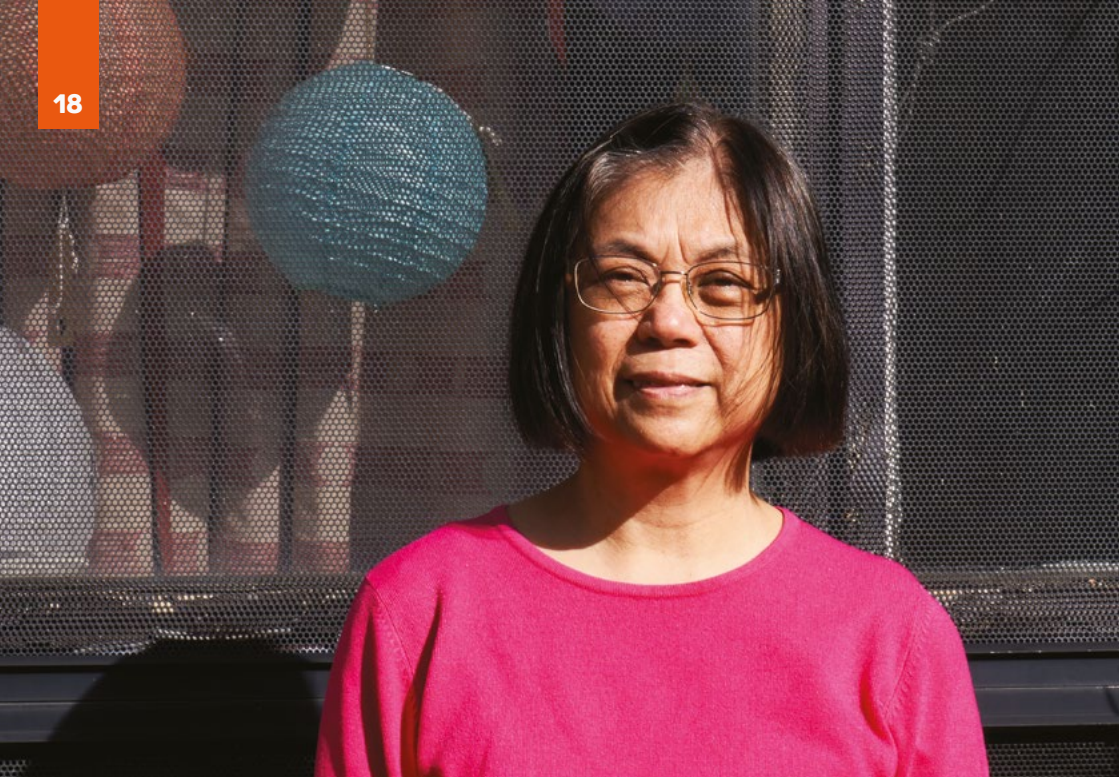


**FIND OUT MORE ABOUT NEW ALZHEIMER'S TREATMENTS:**

**ALZRES.UK/TREATMENT**

**0300 111 5111**

**OR SCAN THE QR CODE**



## What can I expect?

In the early stages of dementia different diseases can cause a range of different symptoms. For example, Alzheimer's disease usually causes problems with short-term memory, and frontotemporal dementia can cause issues with behaviour, speech and language.

For more information about the different diseases, ask for our booklet '**All about dementia**'. We also have detailed booklets about each type of dementia.

All of the diseases that cause dementia do get worse over time, affecting more and more of the brain.

Dementia affects each person differently. There is no set amount of time that someone will be able to function independently after a diagnosis. However there will come a point when someone with dementia won't be able to carry out day-to-day tasks by themselves anymore. Tasks like washing, eating, and taking medicines can become a lot harder as time goes on.

Eventually someone with dementia may forget the names and faces of their loved ones. This can be very hard for their families and friends. Because every person's experience of dementia is different, there is no way of knowing exactly when this will happen. However, it's important to remember that this is nobody's fault. It is also not a reflection of the person's true feelings towards their loved ones.

Many people with dementia need to move into a care home when symptoms become harder to manage, or it is unsafe for the person to live at home. Again, there is no set timeframe for when this will happen, as it depends on many factors.

Having a care assessment is important following a diagnosis. This can help to create a plan that's right for you. Find out more about care assessments on page 22.

**EVERY PERSON WITH DEMENTIA  
WILL EXPERIENCE SYMPTOMS  
DIFFERENTLY.**

# LIVING WITH DEMENTIA

## Can dementia be slowed down?

There is currently no known way to slow down the course of most types of dementia once it has started. But there are lots of things we can do to improve our general brain health and wellbeing. Some studies have suggested that these could also possibly slow extra damage that may happen to our brains over time but this hasn't been proven.

See page 13 for more information about steps we can all take to improve our brain health.

Someone with dementia may also be prescribed medication or therapy to help manage symptoms day-to-day. Whilst these won't slow down the underlying cause of their symptoms, they can make life a little easier for a time.

For information about new treatments available privately in the UK which can slow down Alzheimer's, visit [alzres.uk/treatment](https://alzres.uk/treatment)



## Do supplements help?

There is currently no reliable evidence that taking supplements can slow down the diseases that cause dementia or prevent them from developing in the first place.

There are lots of pills that are claimed to be able to reverse symptoms. Unfortunately there is no robust evidence behind any of these claims. If you're considering taking one of these supplements, you can talk to your GP, pharmacist or contact the Dementia Research Infoline to find out whether there is evidence behind any specific claims.



## Where can I go for help and support?

Local councils in Great Britain and Health and Social Care trusts in Northern Ireland have a duty under the Care Act (2014) to carry out, when requested, a care needs assessment for anyone with care and support needs.

Carers can also request an assessment to look at their own needs too. These are usually done at the person's home, face to face. You can request an assessment from your local council's Adult Social Services Team for yourself or for someone else by phone, in writing or online.

People living with dementia are more likely to experience emergencies. They may wander out of the house and find themselves in danger or fall over. This should be discussed during your care needs assessment. If you have security concerns, you can talk to a member of your local social support team. **In an emergency, call 999.**

For more information about dementia, including symptoms, diagnosis, treatments, and causes, visit our website [alzheimersresearchuk.org/dementia-information](https://alzheimersresearchuk.org/dementia-information)

Our information also includes a list of organisations that can help you with practical and emotional support if you or someone you know is affected by dementia. You can also contact us to request a physical copy of our booklet '**Support for people affected by dementia**'. There are organisations listed in this booklet that provide support with finances, housing, emotional wellbeing and legal advice.

Our website also includes resources for children and young people to learn about dementia and the diseases that cause it.

## What if I live alone?

Some people with dementia live alone. Having a good support network becomes very important when someone has dementia.

Staying in touch with people regularly can help to improve mental wellbeing. If there's a problem, someone will be more likely to notice and help out. Support networks can include family, friends, neighbours, local groups, and health and social care workers.

Organisations like **Age UK** can provide help, advice and befriending services. You can contact them on **0800 055 6112** or visit [ageuk.org.uk](https://ageuk.org.uk)



# PLANNING AHEAD

## Can I still drive with dementia?

Driving is an important source of independence. It can give us a sense of control over our day-to-day routine and ability to stay socially connected to others. One of the most common questions people ask after a diagnosis of dementia is whether they can still drive.

Getting a diagnosis does not mean your license will be automatically taken away from you. However, you are **legally** obliged to tell the **DVLA** and your car insurer as soon as possible. You can get in touch with the DVLA (Great Britain) at **0300 790 6806**, or the **DVA** (Northern Ireland) at **0300 200 7861**. Your doctor will also let the DVLA know of your diagnosis.

You can voluntarily give up your driving license. If you would like to keep your license, the DVLA will ask you to fill in a form. This allows them to get in touch with your doctor to ask how your symptoms are affecting you. You may have to take a supervised driving assessment.

Based on this medical report and assessment, the DVLA will decide whether it's safe for you to drive. They may revoke your license right away or ask for regular reviews based on updates from your doctor. They will confirm this decision in writing.

## How does a dementia diagnosis affect my insurance?

**Car insurance:** if you choose to continue driving after a diagnosis of dementia, your insurer may increase your premium. You can discuss this with your provider when you tell them about your diagnosis.

**Life insurance:** should remain valid after a diagnosis of dementia and will still be paid out. However, you can't get life insurance after a diagnosis. You can discuss more details with your insurance provider.

**Health insurance:** will not cover treatments for dementia. Your insurance might cover the cost of getting a private diagnosis, though. You can discuss this more with your provider.

**Travel insurance:** some agencies refuse to cover people living with dementia. You can get in touch with **Tourism For All** for details of insurance providers that are inclusive of people with dementia on **0845 124 9971**.

## Can I claim benefits for a dementia diagnosis?

People affected by dementia may be eligible for benefits. This is because having dementia may mean a person or their loved one has to stop working, or that there are added costs of living. This might include covering care costs.

A care needs assessment or carers assessment (page 22) can help to identify any benefits you may be entitled to. For more information about benefits and dementia, contact the **Alzheimer's Society's** Dementia Advisors on **0333 150 3456** or **Alzheimer Scotland** on **0808 808 3000**.

## What plans should I start making now?

If you or someone you love is diagnosed with dementia, it's important to talk about the future. People with dementia will eventually lose the ability to make decisions by themselves, so having these conversations early on can allow their wishes to be carried out.

You may also wish to put in place a Lasting Power of Attorney (LPA). There are two types: financial, and health and welfare. This document allows a designated person to make decisions on someone else's behalf, if they cannot make it themselves. If an LPA is not submitted, the person's wishes may not be carried out if they are deemed unfit to make decisions.

For more information on legal and financial plans, request our free **'Planning for the future'** pack or visit **alzres.uk/plan-for-the-future**



## Should I tell people that I have dementia?

Although you're legally required to tell the DVLA and insurance provider about your diagnosis, you don't need to tell other people in your life if you don't want to.

You might want to keep it to yourself until you've come to terms with the news, and that's okay. Alternatively, you might want to tell your friends and family so you can have the right assessments, support and put a care plan in place together as early as possible. It's recommended you tell someone close to you in case of an emergency.

If you're still working most people don't need to tell their employer if they're diagnosed with dementia. However some people do. It's worth checking your employee health policies if you're unsure. Some may prefer to keep their diagnosis to themselves for a while so that it doesn't affect their relationships. Others may want to tell their colleagues, so that they can get some extra support.

**MOST PEOPLE DON'T NEED TO TELL THEIR EMPLOYER IF THEY'RE DIAGNOSED WITH DEMENTIA.**



## CAN I TAKE PART IN RESEARCH?

**Yes. Anyone over the age of 18, with or without dementia, can take part in dementia research. Research is the only way to bring about lifechanging treatments and prevention methods, and we need more people to volunteer for studies.**

Join Dementia Research is a UK-wide service run by the NHS that allows volunteers to be matched with studies that they can take part in. Signing up is quick and easy and can be done over the phone, by post or online. There are lots of different types of studies on the service. Some can be done from home on your computer, and others involve visiting a nearby research hospital. Signing up is not a commitment to take part, but it is a good way to see what studies you can take part in and get involved.

People with and without dementia, and carers can take part in research studies. You can register to take part at [joindementiaresearch.nihr.ac.uk](http://joindementiaresearch.nihr.ac.uk) or to register over the phone call us on **0300 111 5 111**.

You can also request our booklet '**Getting involved in dementia research**' for information about why volunteering for research is so important and what you could be asked to do.



## RESEARCH

**Alzheimer's Research UK has funded over £214 million of pioneering research into the treatment, diagnosis and prevention of dementia.**

As the UK's leading dementia research charity we've invested in more than 1,000 projects since 1998. Your support has allowed us to fund thousands of dementia researchers based across the UK and the world.

We believe that medical research will deliver life changing preventions and treatments, and better ways to detect and diagnose the diseases that cause dementia.

With continued support, we will fund many more studies into dementia. We promise we will not stop until dementia can no longer destroy lives.

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

**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](http://alzres.uk/reviewer)

**CONTACT US**

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