

All about dementia



**Alzheimer's
Research
UK**

Make breakthroughs possible



This information is for anyone who wants to know more about dementia and the diseases that cause it. This includes people living with dementia, their carers, friends and family.

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Introduction

This booklet gives an introduction to the most common types of dementia - Alzheimer's disease, dementia with Lewy bodies, vascular dementia and frontotemporal dementia. It covers:

what they are

typical symptoms

causes

diagnosis.

There is also information about how you can help lower your risk of developing dementia.

The information here does not replace any advice that doctors, pharmacists or nurses may give you but provides some background information that we hope you will find helpful.

If you would like more detailed information about different forms of dementia, treatments or support for people affected by dementia, we have separate leaflets that could help. Please contact us for your free copies.

Sources

Please contact us using the details shown on the back cover if you would like a version of this booklet with references.

Review dates

This booklet was updated in November 2018 and is due to be reviewed in November 2020.

What is dementia?

Dementia is not a disease in itself. It is a word used to describe a group of symptoms that occur when brain cells stop working properly. This happens inside specific areas of the brain that can affect how you think, remember and communicate.

Common symptoms of dementia include the gradual loss of memory, decline in communication skills and difficulty with thinking and reasoning.

Alzheimer's is a disease that causes dementia. It is probably the best-known cause of dementia, accounting for about two-thirds of cases in older people. About 500,000 people in the UK have Alzheimer's.

Other brain diseases can cause dementia too. After Alzheimer's, the most common types of dementia are vascular dementia, dementia with Lewy bodies, Parkinson's dementia and frontotemporal dementia.

It is possible to have more than one of these diseases at the same time. Alzheimer's is sometimes seen with vascular dementia or dementia with Lewy bodies. You might hear this called 'mixed dementia'.

Rarer causes of dementia include Creutzfeldt-Jakob disease (CJD), HIV/AIDS and alcohol-related dementia.

Dementia affects over 850,000 people in the UK today. Most people with dementia are over 65, but it's estimated that over 40,000 under-65s have dementia. Dementia in people under 65 is often called early-onset or young-onset dementia and the most common causes are early-onset Alzheimer's disease and frontotemporal dementia. A range of other rare conditions may also be responsible for early-onset dementia.

Alzheimer's disease is the most common cause of dementia, affecting about

500,000
people in the UK

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 Alzheimer's or another form of dementia.

In dementia, memory loss is more serious than forgetting things occasionally.

There are many reasons why people become forgetful. Some medicines and drugs can affect memory, for example. Depression, anxiety, vitamin deficiency and thyroid problems can also cause forgetfulness, so it's important to get the right diagnosis.

Many people have a natural decline in memory and thinking as they get older. However, in some people this is a sign of a condition called mild cognitive impairment (MCI), where problems with memory are greater than expected for

their age. These problems still tend not to get in the way of a person's day-to-day life.

MCI can be caused by a range of underlying conditions and may or may not get worse. It does not necessarily lead to dementia but could indicate the early stages of a disease like Alzheimer's. For more information, you can request our booklet '**What is mild cognitive impairment?**'.

If you are worried about your memory, if it's getting worse, or interfering with everyday life, you should talk to your doctor.



Dementia often develops slowly and is not always obvious in the early stages. Symptoms similar to dementia can be seen in other illnesses. Sometimes it can be difficult to tell apart dementia from the usual mild forgetfulness seen in normal ageing.

Symptoms

You should see your doctor if you or your family and friends are worried about any changes in:

memory

general mental functioning

ability to carry out daily tasks

personality

behaviour.

Your doctor will be able to either reassure you or, if necessary, refer you to a specialist. Diagnosing dementia early is important to allow you to get the right help and treatments and to plan for the future.

Everyone with dementia will experience symptoms in their own way. Different diseases that cause dementia can have different early symptoms but many overlap.

Alzheimer's disease

Typical symptoms of early Alzheimer's include:

Regularly forgetting recent events, names and faces.

Becoming increasingly repetitive, e.g. repeating questions after a very short interval.

Regularly misplacing items or putting them in odd places.

Getting confused about the date or time of day.

Being unsure of where you are or getting lost, especially in unfamiliar places.

Having problems finding the right words.

Changes in mood or behaviour such as loss of interest in daily activity, becoming easily upset or annoyed or losing confidence.

Vascular dementia

The early symptoms of vascular dementia may be similar to those of Alzheimer's. But vascular dementia can have many different symptoms, depending on the area of the brain affected.

The first symptoms of vascular dementia usually appear gradually but can develop suddenly depending on the cause.

Symptoms of vascular dementia can include:

Memory problems.

Disorientation.

Communication problems.

Becoming slower in thinking.

Personality changes including depression and losing interest in daily life.

Difficulty with walking, and falls.



Dementia with Lewy bodies

Dementia with Lewy bodies (also known as DLB or Lewy body disease) is thought to affect about 125,000 people in the UK.

Symptoms of DLB can include:

Variation in attention, alertness and confusion. These fluctuations can be very noticeable from day to day or even hour to hour.

Parkinson's-type symptoms, like slowing or difficulty walking, stiffness in the arms and legs and sometimes shaking or trembling.

Visual hallucinations. These can often involve seeing people or animals that aren't really there.

Fainting and falls.

Movements during sleep and vivid dreams.

Problems detecting smells.

Symptoms similar to Alzheimer's, including memory loss and disorientation.

The diseases that cause dementia can have different early symptoms, but many overlap.

Frontotemporal dementia

The term frontotemporal dementia (FTD) describes a number of different conditions. These include behavioural variant FTD and primary progressive aphasia, a term that covers several conditions affecting speech and language. FTD is quite rare and most commonly affects people aged 45-64.

Symptoms of FTD can include:

Changes in emotions. This may include a change in how people express their feelings towards others or a lack of understanding of other people's feelings.

Lack of interest. People may become withdrawn or lose interest in looking after themselves, perhaps not maintaining their normal level of personal hygiene.

Inappropriate behaviour. This might include making inappropriate jokes or being tactless. Humour or sexual behaviour may change. Some people become impulsive or easily distracted.

Overeating or changes in what people choose to eat.

People may develop unusual beliefs, interests or obsessions.

Difficulty with simple plans and decisions.

Lack of awareness of any personality or behaviour changes.

Decline in language abilities, for example problems forming or understanding words, repeating common words and phrases or forgetting the meaning of words.

Difficulty recognising people or knowing what objects are for.

Movement problems, including stiff or twitching muscles, muscle weakness and difficulty swallowing.

Diagnosing dementia, and which form of dementia someone has, is important. It will ensure that people can get the right support and treatments and can plan for the future.

Diagnosing dementia



Your doctor is the first person to contact if you have any worries about your health. If the doctor suspects dementia, you are likely to be referred to a memory clinic or specialist. These specialists may include old age psychiatrists, geriatricians, neurologists, clinical psychologists and memory nurses.



When you see a doctor or nurse they will ask you about your symptoms and medical history. They may also speak with your partner or someone close to you about your symptoms. You may be asked some questions relating to your memory and have a physical check-up.



There is a range of memory tests available, and you might have one or more of these during your assessment. Because dementia gets worse over time, the tests may be repeated, perhaps after six to 12 months, to see if there have been any changes.



Other tests, including blood tests and brain scans, may be arranged. Occasionally, your doctor may arrange an EEG (brain wave test) or a lumbar puncture (spinal tap). In a lumbar puncture, a needle is used to take a sample of fluid from the bottom of someone's spine. Together all of these things will help a doctor find out about any problems in memory or thinking and the likely cause.

If you are assessed for the possibility of having Alzheimer's or another form of dementia, you can choose not to know the diagnosis. You can also decide who else can be told about your diagnosis.

If you, or someone close to you, are given a diagnosis of dementia, you may have many questions about what to do next. You can ask your doctor about local services that can help you and your family. You may be entitled to benefits and other types of support.

How dementia progresses

Alzheimer's disease, dementia with Lewy bodies and frontotemporal dementia are all neurodegenerative diseases. This means that the symptoms get worse over time.

This is usually the case with vascular dementia too. The speed of change varies from one person to another and also between different diseases, but in most dementias, symptoms progress slowly over several years.

Everybody is unique and is affected in their own way. As dementia progresses:



Memory and thinking skills

People may find that their ability to remember, think and make decisions worsens.



Communication

Communication and language often become more difficult.



Behaviour and personality

A person's behaviour may change and some people can become withdrawn or depressed. Anxieties are also common.



Recognition

People may have difficulty recognising household objects or familiar faces.



Restlessness

Problems with sleeping and restlessness at night may occur.



Anger

Anger or agitation can be common in the later stages of dementia.



Unsteadiness

It is common for people to be unsteady on their feet and fall more often.



Extra help

Gradually people require more help with daily activities like dressing, going to the toilet and eating.

Across the UK there are local services and support groups for people living with dementia and their carers. You can contact the organisations on page 14 to find out about support in your area.

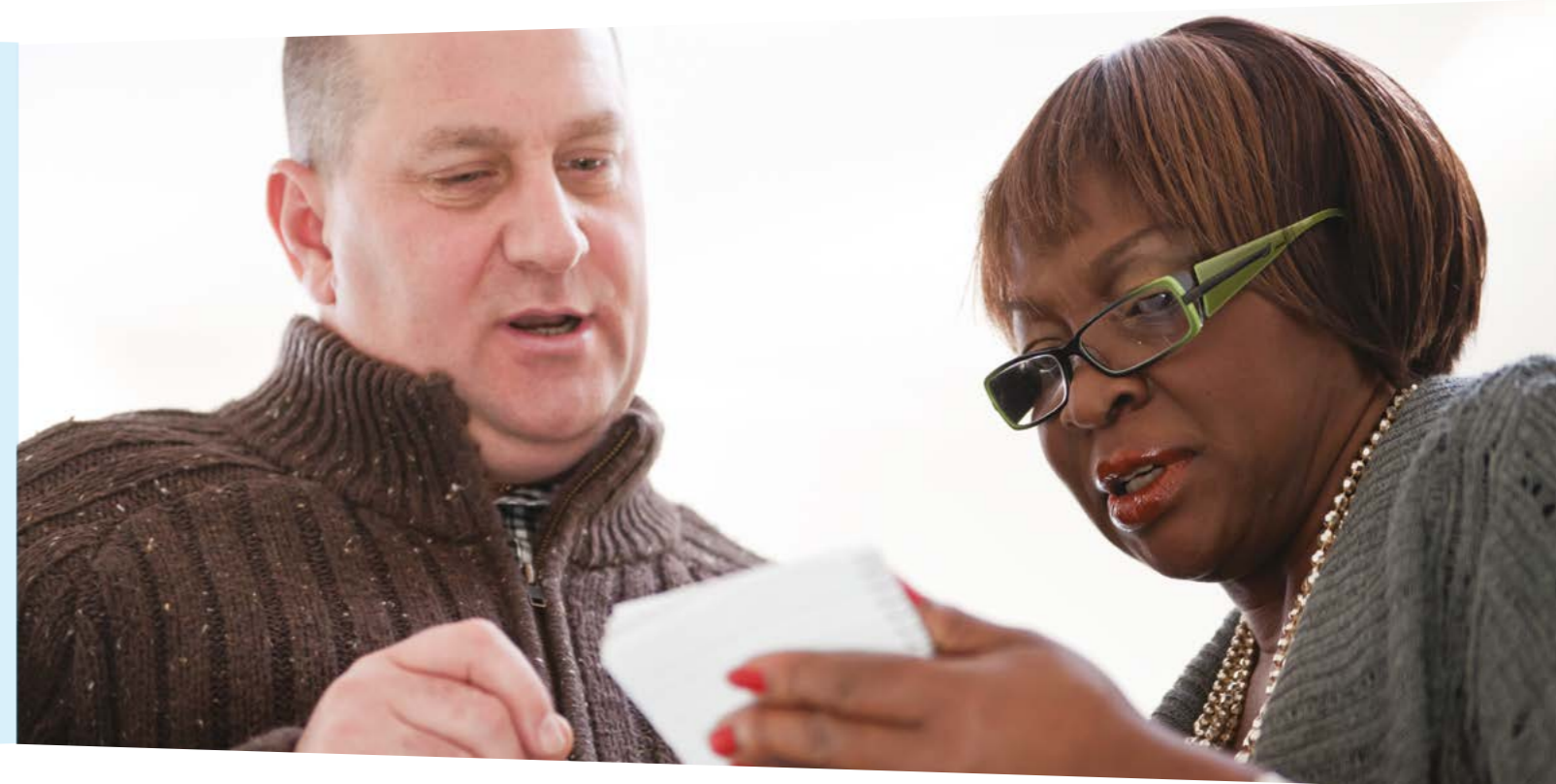
What treatments and drugs are available?

There are several treatments available to help with the symptoms of Alzheimer's. There are also treatments that may help with the symptoms of other dementias. You can speak to your doctor for more information or request our booklet '**Treatments for dementia**'. Call us on **0300 111 5555**, or download a copy from our website, www.alzheimersresearchuk.org



What causes the diseases that lead to dementia?

The causes of dementia are not yet fully understood but research is making progress. Understanding the causes of dementia is essential for developing new treatments.



Alzheimer's disease

Scientists know that in Alzheimer's, two proteins build up abnormally in the brain. They are called amyloid and tau and form clumps called 'plaques' and 'tangles'. These interfere with the way brain cells work and communicate with each other. The plaques are usually first seen in the area of the brain that makes new memories. A lot of research is focused on finding ways to stop the build-up of these proteins and protect brain cells from harm.

Vascular dementia

Vascular dementia is caused by a reduction in blood flow to the brain. Blood carries essential oxygen and nutrients to the brain and without them brain cells die. The network of blood vessels that carries blood around the body is called the vascular system.

Stroke-related dementia is a type of vascular dementia that happens after a stroke. A stroke occurs when blood supply to a part of the brain is suddenly cut off. This may cause problems with movement, coordination, speech or sight. If a stroke causes memory loss and problems with attention, then a person may be diagnosed with post-stroke dementia. Multi-infarct dementia is vascular dementia caused by a series of small strokes in the brain, which a person might not notice when they happen.

Subcortical vascular dementia is caused by changes to very small blood vessels in the brain, often referred to as small vessel disease. The person usually does not notice these changes and their cause is not yet known. Over time, they gradually damage parts of the brain that are important for attention, memory and language.

Dementia with Lewy bodies

Dementia with Lewy bodies is caused by small, round clumps of protein that build up inside nerve cells in the brain. One of these proteins is called alpha-synuclein and the clumps it forms are called Lewy bodies. Similar changes occur in brain cells that control movement in people with Parkinson's disease, and some people with Parkinson's will go on to develop dementia.

The protein clumps damage the way nerve cells work and communicate with each other. The nerve cells affected by Lewy bodies control thinking, memory and movement. Researchers are working hard to understand what causes the protein to build up and discover ways to stop it happening.

Frontotemporal dementia

Frontotemporal dementia (FTD) is caused by a variety of abnormal proteins building up in the brain. The nerve cells affected are in areas of the brain called the frontal and temporal lobes. These areas control our personality, emotions and behaviour, as well as our speech and understanding of language. As the disease progresses, other parts of the brain become affected.

Does dementia run in the family?

Mostly, this is not the case. Our risk of developing dementia is determined by a complex mix of our age, lifestyle and whether we carry any risk genes. Researchers have found over twenty different versions of genes associated with an altered risk of Alzheimer's, but many only have a small effect on risk.

Some research has suggested that if you have a parent or grandparent who developed Alzheimer's disease over the age of 65 then your risk of developing the disease may be slightly higher than someone with no family history.

If you have several close relatives who have developed dementia under the age of 65, then it's possible the disease could be an inherited form of dementia. Certain forms of early-onset Alzheimer's and frontotemporal dementia can run in families and often start in the 30s, 40s or 50. These types of dementia are very rare.

Support for people affected by dementia

Dementia has a huge impact on someone's life, as well as on their family and carers. Accessing services and support can make a positive difference to those affected by dementia.

Some services will be provided by local authorities and others can be arranged through the doctor. For advice, contact your local authority social services department. The number will be in the phone book and on the council website. Everyone with dementia is entitled to an assessment that establishes their needs and suggests how those needs can be met.

The following organisations provide information, support and care services to people affected by dementia as well as their families and carers. For more information ask for our booklet, **'Support for people affected by dementia: organisations that can help'**.

The **Admiral Nurse Dementia Helpline** is supported by the charity Dementia UK. It offers practical advice and emotional support to people affected by dementia on **0800 888 6678**.

The **Age UK** advice line, **0800 169 2081**, can give you information about help available through social services, as well as advice about other issues faced by older people.

Alzheimer Scotland provides the National Dementia Helpline **0808 808 3000** in Scotland as well as local services all over Scotland for people with dementia and their families.

Alzheimer's Society runs the National Dementia Helpline in England, Wales and Northern Ireland on **0300 222 1122**. They can give you information, support, guidance and signposting to other appropriate organisations.

The **Carers Trust** works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member. Contact them on **0300 772 9600**.

Carers UK offers advice and information to carers through booklets, factsheets and its website. Their Adviceline can be contacted on **0808 808 7777**.

The **Lewy Body Society**, in partnership with Parkinson's UK, provides support and advice to people with dementia with Lewy bodies, their families and carers. You can contact a helpline advisor on **0808 800 0303**.

The **NHS** provides free, confidential information and advice for carers through Carers Direct on **0300 123 1053**.

Rare Dementia Support runs specialist support services for people living with, or affected by, five rare dementias:

- frontotemporal dementia (FTD)
07341 776 317
- posterior cortical atrophy (PCA)
07388 220 324
- primary progressive aphasia (PPA)
07388 220 355
- familial Alzheimer's disease (FAD)
07388 220 323
- familial frontotemporal dementia (fFTD)
07592 540 555.

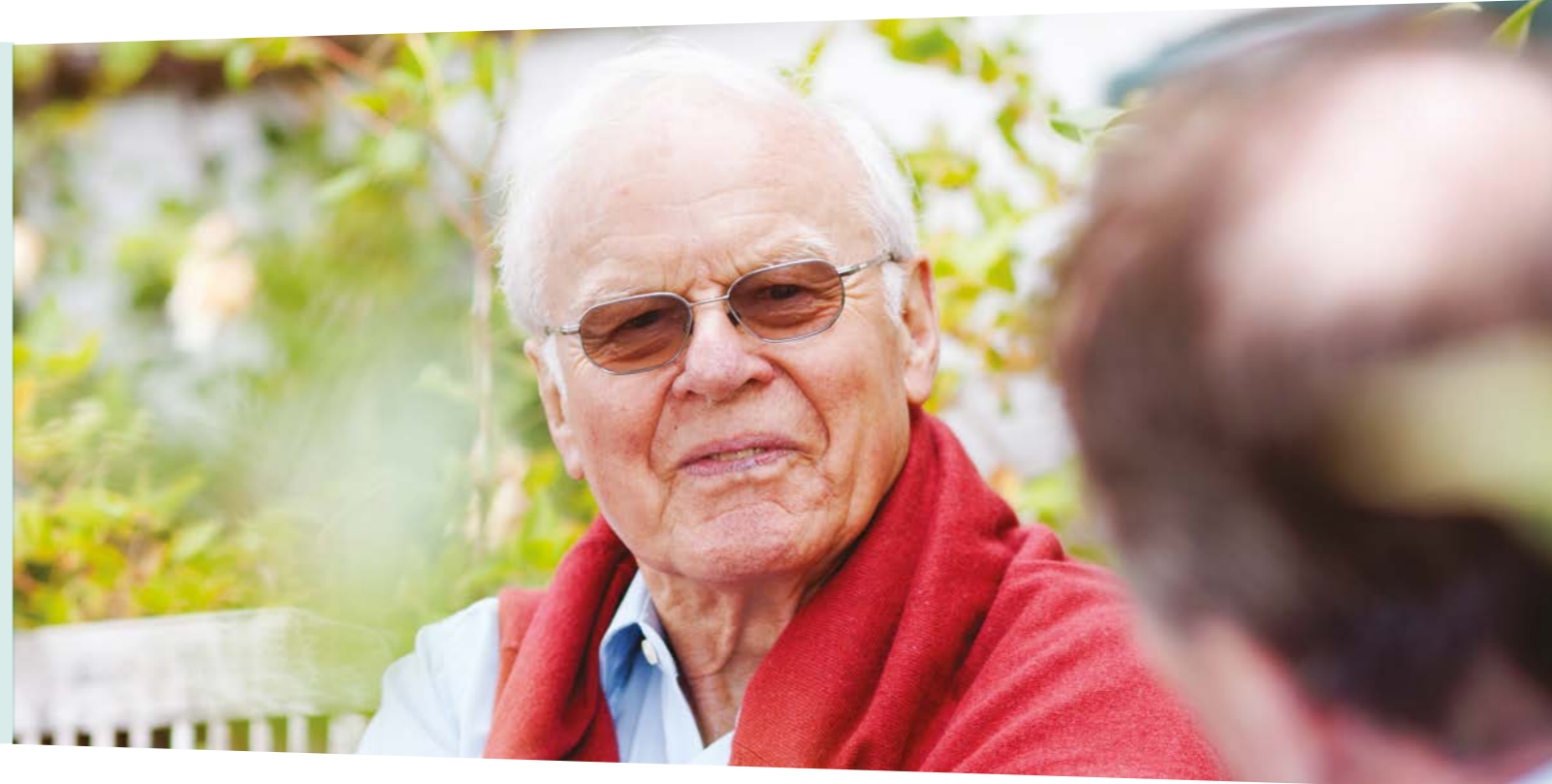
They run regular support group meetings and offer newsletters, telephone support and access to information and advice. Call one of the numbers above or email **contact@raredementiasupport.org**

YoungDementia UK provides information, advice and support for people under 65 diagnosed with dementia, their family and friends. Call **01865 794311** to find out about support available in your area.



All about risk

Alzheimer's and other causes of dementia are complex diseases and conditions. We are making progress in understanding how they develop and it's clear that they don't have one single cause.



It is likely that a mixture of our age, genes and lifestyle could contribute to our risk of developing dementia.

The risk of developing most types of dementia increases with age. That means as we get older, we are more likely to develop the condition. One or two people in every 100 of those aged 65 to 69 years have dementia, but this figure rises to one in five for those aged 85 to 89.

Developing dementia is not an inevitable part of getting older. It is caused by different diseases, most commonly Alzheimer's.

We can't change our age and there is currently no way we can completely prevent dementia but there are some simple things we can all do that might help lower our risk.

A risk factor is anything that can increase your likelihood of developing dementia. Risk factors for cardiovascular disease (like heart disease and stroke) are also risk factors for all types of dementia.

It's a good idea to keep healthy by:



not smoking



controlling high blood pressure



reducing your cholesterol level



controlling your blood glucose if you have diabetes



exercising regularly



achieving and maintaining a healthy weight



eating a healthy, balanced diet



only drinking alcohol within the recommended limits.

Some studies suggest that enjoying an active life, with lots of interests and hobbies, might be beneficial. Other researchers have found that spending more time in education is associated with a lower risk.

There is currently not enough evidence to suggest that omega-3 fish oil or vitamin supplements could reduce the risk of dementia. It is not advised to take NSAIDs (non-steroidal anti-inflammatory drugs like aspirin or ibuprofen), HRT (hormone replacement therapy) or statins to protect against dementia, as research is continuing in this area. You should talk to your doctor before taking any supplements or drugs that claim to prevent dementia, as most are unproven and they can have serious side-effects.

You might read or hear about other risk factors for dementia. Despite occasional publicity, research has shown that eating meat, exposure to aluminium and living close to power lines are not risk factors for dementia. There is also no firm evidence that turmeric, ginkgo biloba, ginseng or coffee can protect against dementia.

Some studies suggest that enjoying an active life, with lots of interests and hobbies, might be beneficial

Taking part in research

Volunteers, both with and without dementia, who take part in research studies or clinical trials play an essential role in helping scientists to understand dementia and test potential new treatments.

Join Dementia Research is a national service that allows you to register your interest in taking part in dementia research studies. It is operated by the National Institute for Health Research in partnership with Alzheimer's Research UK, Alzheimer's Society and Alzheimer Scotland.

Visit www.joindementiaresearch.nihr.ac.uk or call the **Dementia Research Infoline** on **0300 111 5 111**.



The research we fund

Alzheimer's Research UK has funded over **£100 million** of pioneering research into the causes, diagnosis, prevention and treatment of dementia.

Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make breakthroughs possible.

We believe that medical research can and will deliver life-changing preventions, treatments and one day, a cure for dementia.



Find out more

If you have questions about research or want to get involved, contact the **Dementia Research Infoline** on **0300 111 5 111** or email infoline@alzheimersresearchuk.org. You can also write to us at the address on the back of this booklet.

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages. Interpreter services are available.

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

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



Contact us

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Dementia Research Infoline

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