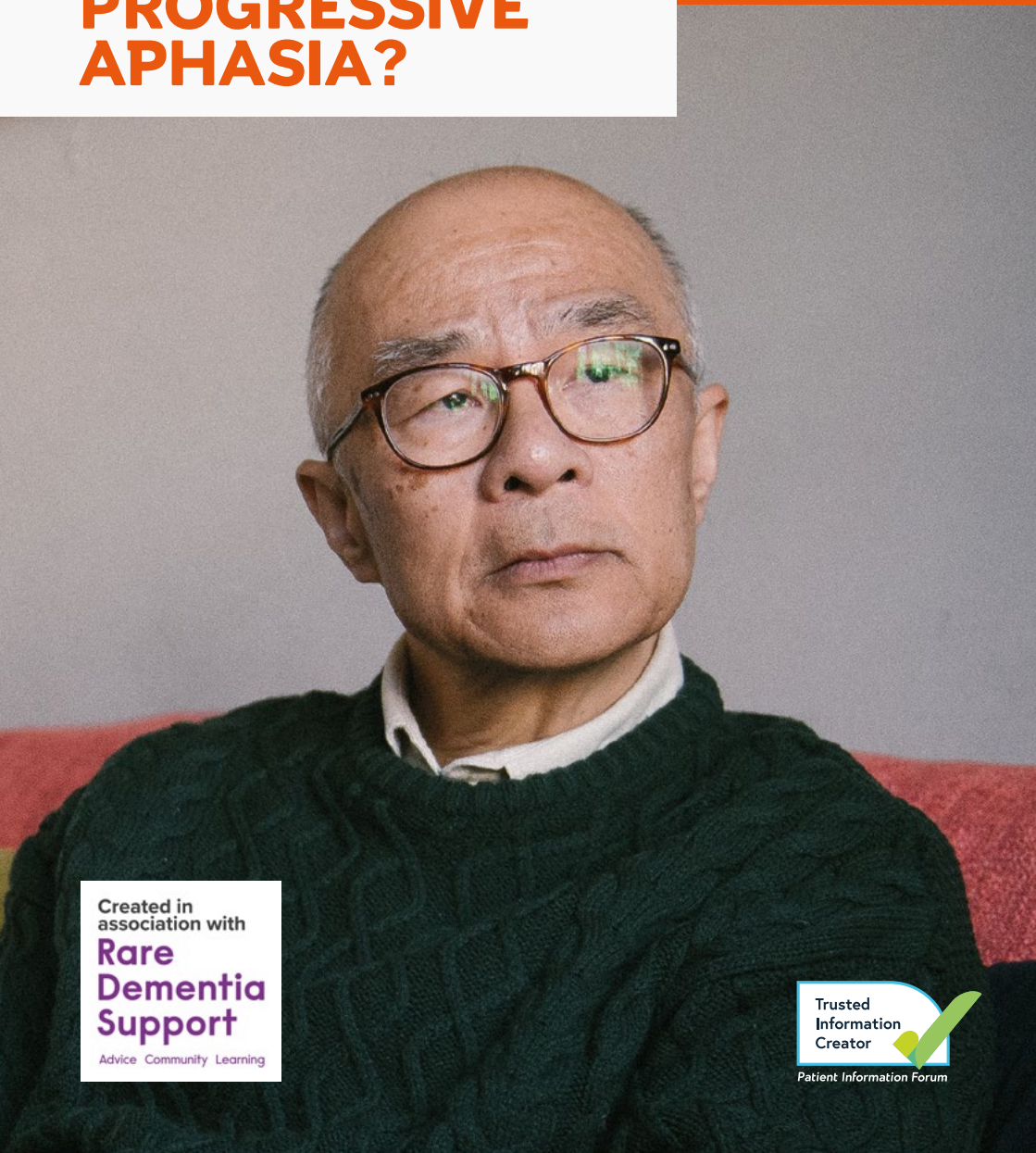
ALZHEIMER'S RESEARCH UK FOR A CURE

WHAT IS PRIMARY PROGRESSIVE APHASIA?



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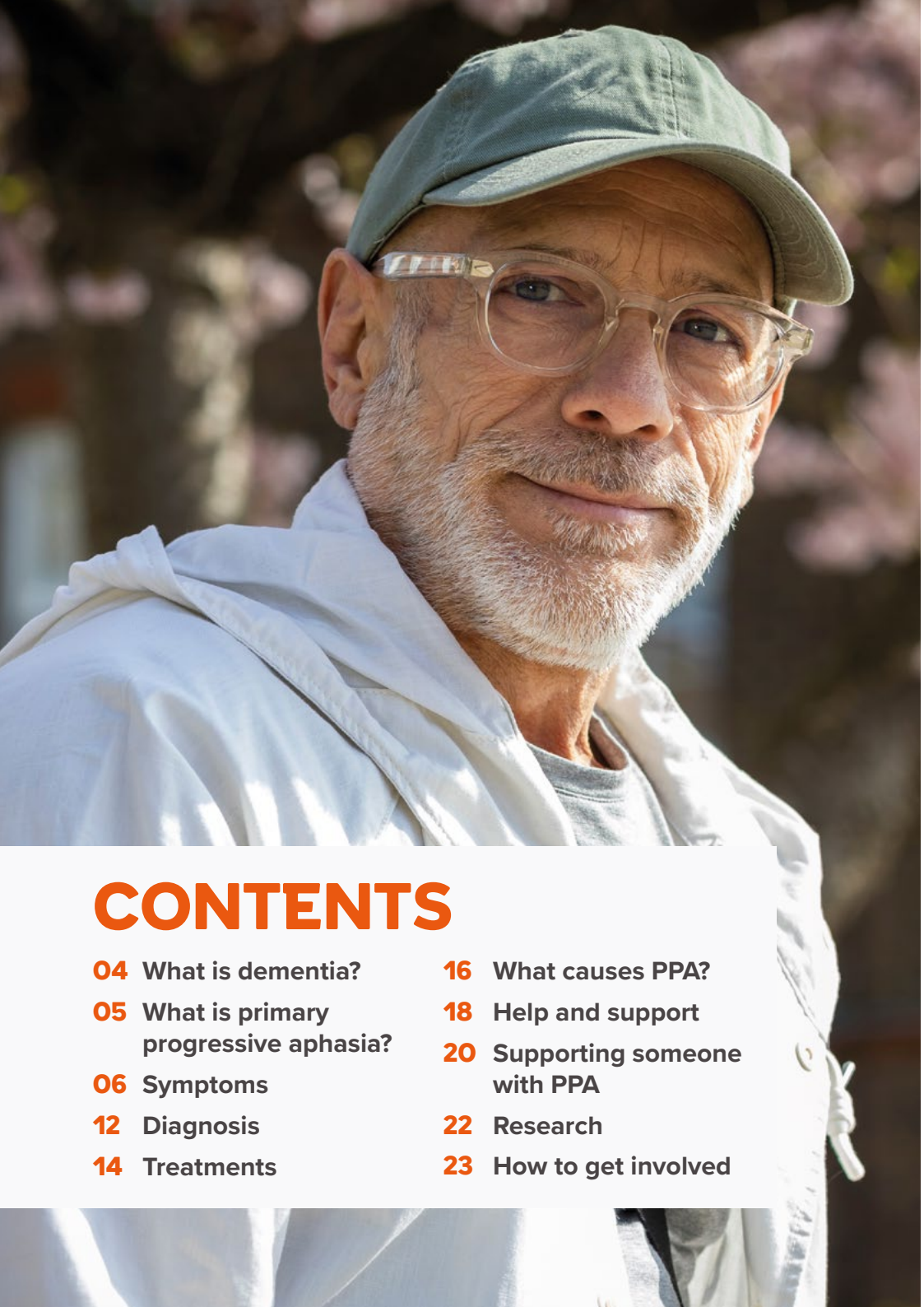

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INTRODUCTION

This booklet provides an overview of a condition called primary progressive aphasia (PPA), a rare type of dementia. It's for anyone affected by the condition, or for people who want to know more about PPA and how it is 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 April 2025 and is due to be reviewed in April 2027. It was written by Alzheimer's Research UK's Information Services team with input from Rare Dementia Support, and expert and lay 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

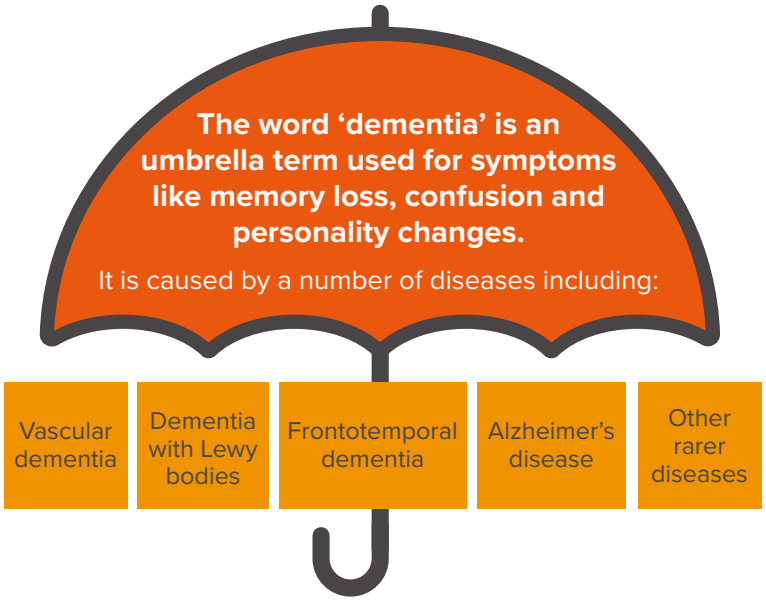
If you have questions about dementia or dementia research, you can contact our Dementia Research Infoline on **0300 111 5111** or email **infoline@alzheimersresearchuk.org** or write to us using the address on the back page.

WHAT IS DEMENTIA?

The term dementia describes a group of symptoms that may include:

- Memory loss, confusion, mood and personality changes.
- Difficulty with day to day tasks.
- Language and communication problems.

The symptoms of dementia get worse as time goes on, so over time a person will need more help with everyday life. Dementia is caused by different diseases that affect the brain. These include Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia.



WHAT IS PRIMARY PROGRESSIVE APHASIA?

Primary progressive aphasia (PPA) is caused by diseases that affect parts of the brain that control our language, personality, emotions and behaviour.

PPA affects the left frontal lobes of the brain, this is where our speech and language are processed. In most cases, PPA is caused by frontotemporal dementia. Symptoms of PPA usually start in someone in their late 60s. But it can affect people older or younger than this.

NON-FLUENT VARIANT PPA

Damage to parts of the left frontal lobe that control how we physically speak.

LOGOPENIC APHASIA

Damage to part of the left temporal and parietal lobes that process words and meaning.

SEMANTIC VARIANT PPA

Damage to parts of the left temporal lobe that support understanding of language and factual knowledge.

SYMPTOMS

Speech and language problems are the main symptoms of PPA. All types of PPA get worse over time. However, different types of PPA affect speech and language in different ways.

SEMANTIC DEMENTIA

People with semantic variant PPA, also called semantic dementia, often forget the meaning of words, and what objects and concepts are. This is what the word ‘semantic’ means.

Someone with semantic PPA may:

- Have trouble using the right word – often saying another word or using a vague term like ‘thing’. This may start with names and other object words they don’t use very often. As time passes, people will also struggle with more common words and often ask what words mean.
- Forget what items are used for, like every day or household items, tools and appliances. For example not knowing the TV remote operates the TV.
- Talk about things at great length and in a vague or repetitive manner.
- Find it harder to understand other people’s feelings.
- Find it difficult to understand less familiar topics.

In the later stages, they may:

- Tend to say less.
- Develop changes in behaviour and personality, like sudden obsessions or mood swings, strong preferences for sweet or other specific foods, and difficulty understanding social situations. These are more common and occur earlier in semantic variant PPA than the other types of PPA.
- Find it difficult to recognise people they know, objects around the house or familiar sounds.
- Need much more assistance to manage day-to-day life.

NON-FLUENT VARIANT PPA

You might also hear this type of PPA be called progressive non-fluent aphasia. People with this condition have trouble speaking and make mistakes in how they say words or construct sentences, this is what the term ‘non-fluent’ means.

People with non-fluent variant PPA may:

- Have trouble producing words, although they know what they want to say. Speaking may take a lot of effort and words may not come out right.
- They may speak more slowly, seem to stutter and be hard to understand.
- Often confuse opposite words such as using yes, when they mean no.
- Find that words come out in the wrong order or are missed out altogether.

Over time, they may develop other symptoms including:

- Problems with reading, writing and spelling.
- Have more difficulty understanding what people are saying
- Changes in behaviour and mood, for example becoming frustrated, or depressed.
- Find it harder to make decisions or plans.
- Have difficulties swallowing food and drink.
- May develop similar symptoms to Parkinson’s disease such as slowness, stiffness or clumsiness of movements.

LOGOPENIC APHASIA

Logopenic means ‘lack of speech’. People with logopenic aphasia have trouble finding the words they want to use.

For example, they may:

- Have trouble remembering the right word. The person may pause as they try to find the word they want.
- Speak more slowly and hesitantly and find it hard to say words correctly.
- Have trouble understanding and remembering more complex verbal information. This can make it hard to follow detailed conversations.
- Experience behavioural symptoms such as frustration, agitation and withdrawal from social situations.

Over time, someone with logopenic aphasia may develop other symptoms. For example, they may:

- Forget conversations or appointments.
- Become lost.
- Find it hard to work out how much change they need for a bus fare.
- Struggle to use household appliances, like washing machines.

These later symptoms are similar to those in Alzheimer’s disease. You can speak to your doctor if you are concerned about any of the symptoms mentioned.

IS IT ALWAYS CLEAR WHAT TYPE OF PPA SOMEONE HAS?

Someone with PPA may show symptoms of more than one type of PPA at the same time, or as their condition progresses. With all three types of PPA, problems get worse over time. It becomes harder for people to say what they need to, move about on their own and look after themselves.

Dementia is different for everyone who has it, and the speed at which it progresses can vary widely. Over time, someone with PPA will need more and more care and support until the end of their life. You can find some tips for supporting someone with PPA on page 20.

“My dad took early retirement at 58. His symptoms started with him not being able to find words every now and then. We realised that there was something not quite right, but because his memory was fine we thought it couldn’t be dementia. Following his diagnosis, he lost the ability to read and write and then his speech went. He used to make random noises. In the later stages he also wandered and got lost on more than one occasion.”

- Ben, whose dad was diagnosed with logopenic aphasia

DIAGNOSIS

It is important to get a diagnosis of dementia as soon as possible so that the right treatment and support can be given. If you are worried about symptoms of dementia, your health or someone else's, you should make an appointment with your doctor.

After some initial tests, if your doctor suspects PPA or another form of dementia, they may send you to a memory clinic. Here, a doctor or nurse will run through more detailed tests with you.

These may include:

- Questions about your symptoms and medical history.
- Speaking to your partner or someone close to you about the problems you are having.
- A physical check-up.
- Assessments of your thinking and language skills, memory, and other aspects such as behaviour, sometimes with a specialist speech and language therapist or psychologist.
- A brain scan, usually MRI.
- Possibly blood tests or other specialist tests such as a lumbar puncture.

Together, these will help a doctor to work out what is causing the speech and language difficulties and other symptoms.

PPA is a rare type of dementia, not often seen by doctors. This means it may take longer than usual to get the right diagnosis.

When someone gets a diagnosis of PPA, they may want to make plans for the future. This includes decisions about working, driving, care options, legal and money matters. Find out about help and support for families affected by dementia on page 18.

> "Dad had all these tests, and I remember going to see the specialist. It took around 18 months from before initial appointment to get his PPA diagnosis."
>
> **- Ben, whose dad was diagnosed with logopenic aphasia**

TREATMENTS

There are currently no medicines available to stop the progression of PPA, but there are treatments that may help with some of the symptoms.

A referral to a speech and language therapist can be useful at any time after a diagnosis. The therapist will assess your speech, language and communication difficulties and how they are affecting you or making everyday life difficult. They can also help with eating, drinking and swallowing difficulties.

People with PPA may also find it useful to see a physiotherapist, occupational therapist or dietitian for support with movement and swallowing symptoms. People with dementia may be offered antidepressants, or non-drug treatments like cognitive behavioural therapy (CBT) to help with mood and anxiety symptoms.

People with logopenic aphasia may be prescribed medicines commonly used to treat symptoms of Alzheimer's. This is because it can be caused by Alzheimer's rather than frontotemporal dementia (FTD) which causes other types of PPA. Unfortunately there are no medications available yet to treat FTD.

New Alzheimer's treatments lecanemab and donanemab are licensed for use in people with typical, early stage Alzheimer's. If you would like to find out if they are suitable for you, then you can speak with a private provider. Find out more at **alzres.uk/treatment**

For more information, ask for our booklet **'Treatments for dementia'**.

WHAT CAUSES PPA?

PPA is caused by diseases that affect brain cells in the front and sides of the brain, called the frontal and temporal lobes. Therefore, it is often referred to as a type of frontotemporal dementia. However logopenic aphasia can be caused by Alzheimer's disease too.

In PPA, as with all types of dementia, brain cells become damaged and die. Over time this leads to the symptoms.

Damage to brain cells in PPA is caused by an unusual build-up of certain proteins. This includes proteins called TDP-43 and tau, and researchers are working hard to find out why this happens and how it damages brain cells.

Most cases of dementia are caused by a mixture of factors including age, genetics, lifestyle and environment. We cannot change our age or genes. However we can influence some lifestyle factors that increase our risk of dementia.

It is common for people with these conditions to have symptoms of PPA in addition to other symptoms. Although motor neuron disease can be caused by the same proteins as PPA, it is rare for people with PPA to develop motor neuron disease.

Different types of PPA are often linked to different protein changes in the brain:

- **Semantic variant PPA** is mainly linked to changes in the protein TDP-43.
- **Non-fluent variant PPA** is most often linked to changes in the protein tau.
- Most cases of **logopenic aphasia** are linked to the same underlying processes involved in Alzheimer's disease. This includes the build-up of a protein called amyloid in the brain, which damages brain cells over time. This is why logopenic aphasia is often called an unusual or 'atypical' form of young onset Alzheimer's.

YOU CAN FIND OUT ABOUT DEMENTIA RISK FACTORS AND STEPS YOU CAN TAKE TO REDUCE YOUR RISK AT ALZRES.UK/RISK

HELP AND SUPPORT

A diagnosis of PPA will affect people in different ways and can come as a shock. People and their families may need time to come to terms with a diagnosis.

With the right information and support, people can carry on with their day to day lives for some time. Some people find that talking to others in the same situation can help.

PPA Support Group

The Rare Dementia Support national PPA Support Group holds several meetings a year in London, helping people living with PPA to meet and talk to others. Email PPA Support Group at **contact@raredementiasupport.org** or visit the website **raredementiasupport.org/primary-progressive-aphasia**

Young Dementia Network

The Young Dementia Network is a support group for people under 65 with any form of dementia, and their families. Their website **youngdementianetwork.org** has a range of resources, including information about local services. They also have a Facebook group: **facebook.com/YoungDementiaNetwork**

Admiral Nurse Dementia Helpline

The Admiral Nurse Dementia Helpline offers practical and emotional support to anyone affected by dementia, including advice on managing the symptoms. Call **0800 888 6678** or email **helpline@dementiauk.org**

Alzheimer's Society

The Alzheimer's Society provides information and help for people with all forms of dementia and can tell you about local support groups in your area. Call **0333 150 3456**.

You can also talk to your doctor or nurse for advice on caring for someone with PPA.

SUPPORTING SOMEONE WITH PPA

For people with any type of PPA, their speech and language is affected first. When talking to someone with PPA, there are things you can do to help them:

- Find a quiet place to talk.
- Ask one question at a time.
- Acknowledge their frustration when they show it, don't dismiss it.
- Ask the person how you can help them communicate.
- Speak clearly and so that the person can see you speaking.
- Check that you have understood what they mean.
- One-to-one conversations can work better than talking in groups.

If someone is finding eating and swallowing hard, ask your GP for a referral to a speech and language therapist to assess their swallowing. This is really important, as there may be things they can suggest to reduce the risk of food and drinks going down the wrong way.

If someone is finding eating and swallowing hard, these may help:

- Try not to have foods that require a lot of chewing like thick pieces of meat.
- Cut food up into small, manageable pieces.
- Add sauces to meals.
- If eating becomes slower, a plate-warmer will help to keep food warm and nicer to eat.

Over time, someone with PPA will need more help with day-to-day life, for example with washing and dressing. It is important to think about safety at home and any changes you may need to make.

For people still working, PPA may make doing a job more difficult. It is helpful to talk to close family early on, about options such as lasting power of attorney, and home care and care homes. Ask for our booklet **'Dementia: Your questions answered'** for more information about these topics.

FOR ORGANISATIONS OFFERING HELP AND SUPPORT

Ask for a copy of our booklet **'Support for people affected by dementia: organisations that can help'** or visit our website **alzheimersresearchuk.org**

RESEARCH

As the UK's leading dementia research charity, we are working to revolutionise the way we treat, diagnose and prevent dementia. And then, we will find a way to cure it.

With generous support and donations from people across the UK, we are able to fund the important research being led by scientists here and across the world. And we know this can get us closer to a cure.

So far, we've invested over **£176 million** in the best research powering the most forward-thinking scientists and joining forces with world-class organisations. This includes over **£5 million** of research into different types of frontotemporal dementia, including those linked to PPA. With your support, we promise we will not stop until dementia can no longer destroy lives.

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

STAY UP TO DATE WITH THE LATEST DEMENTIA RESEARCH

Call **0300 111 5555** or scan the QR code.

HOW TO GET INVOLVED

Research is the only way we'll find new ways to prevent, diagnose and treat dementia and scientists need your help. Without people volunteering to take part in research, finding a cure would be impossible.

People with dementia, their carers, and people without dementia are all needed to take part.

Anyone over the age of 18 can register to Join Dementia Research, which is run by the NHS. This will match you to research studies you are suitable for. Then you get to choose which ones to take part in.

People have many different reasons for wanting to volunteer for dementia research, and it's their support that will drive forward our progress and change the lives of everyone affected by dementia.

Join them today.

Find out more and register to take part by calling the Dementia Research Infoline on **0300 111 5111** or visiting **joindementiaresearch.nihr.ac.uk**

Join dementia research

Alzheimer's Research UK is the UK's leading dementia research charity.

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VISIT

alzheimersresearchuk.org/dementia-information

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