

GETTING INVOLVED IN DEMENTIA RESEARCH



THE IMPORTANCE OF VOLUNTEERS FOR RESEARCH

Dementia affects almost 1 million people in the UK. It is the only condition among the leading 10 causes of death without any treatment to prevent or cure the diseases that cause it. Research is the only way to find a cure for dementia.

Thanks to scientific research, today we understand more about the brain, and the diseases that affect it, than ever before. This knowledge means that new treatments for dementia are finally on the horizon. Scientists have only been able to make this progress because of the thousands of people who volunteer to take part in dementia research studies and clinical trials

We'll continue to make faster progress as more people get involved and take part.

This booklet gives information about what might be involved in taking part in a dementia research study and how you can volunteer. It was written by Alzheimer's Research UK's Information Services team with input from expert and lay reviewers. It was updated in August 2023 and is due to be reviewed in August 2025. Please contact us if you would like a version in a different format.

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WHO CAN GET INVOLVED IN RESEARCH?

- People **with a diagnosis** of dementia have an important role to play in research studies.
- People **without** a diagnosis of dementia can help to make up control or comparison groups in some studies, and help scientists look at what affects our risk of developing dementia over time.
- **Carers** of people with dementia are also needed for studies to give their opinions and insight. They can share their experience on accessing care or support, or looking after someone with dementia. This can help shape services and inform new policies.
- People with a **family history** of dementia or those concerned about their memory.
- Some dementia studies may focus on those over 55, but **anyone over 18** can register their interest in taking part in research and help in the search for a cure.

OVER 75,000 PARTICIPANTS HAVE TAKEN PART IN OVER 670 STUDIES THROUGH JOIN DEMENTIA RESEARCH.



“Research volunteers are essential in order to find new treatments, ways to diagnose dementia earlier and increase our understanding about the diseases that cause dementia. With your help, we will find a cure.”

Dr Susan Kohlhaas

Executive Director of Research and Partnerships,
Alzheimer's Research UK

WHY GET INVOLVED IN RESEARCH?

People choose to take part in research for a number of reasons:

- Studies can provide volunteers with an opportunity to learn more about their dementia diagnosis and health. Some studies involving people with dementia include regular monitoring by doctors and more accurate diagnostic tests like PET scans and lumbar punctures.
- People often feel research is something positive they can do in the face of living with a progressive condition.
- Volunteers may feel more supported as part of a research study community.
- Outcomes help advance scientific understanding, improving prevention, diagnosis and treatment options for future generations, bringing us closer to a cure.

TESTS YOU MIGHT HAVE IN A RESEARCH STUDY

COGNITIVE TESTS

In dementia research, cognitive tests are used to measure a person's memory and thinking skills. This can help to identify if they are suitable to take part in a study before it starts. Also, by repeating these tests over time, researchers can see whether a treatment is working to slow down memory loss and improve brain function. Some tests also look at how well people can manage activities like eating and getting dressed to see what benefit a treatment may have on their day-to-day life.

“I used to think only people with dementia could volunteer to take part in dementia research studies. I signed up for research as a healthy volunteer and now I feel like I’m doing my part to tackle this devastating condition.”

Susie Hewer
Research volunteer



BRAIN SCANS

Brain scans allow researchers to look at physical changes in the brain like Alzheimer's. An MRI or CT scan shows structural changes to the brain, and an EEG (brain wave test) is used to look at brain activity. Specialist scans called PET scans allow researchers to look at the build-up of proteins, like amyloid and tau, which happens in the brain in Alzheimer's disease.

Research using brain scans can help to improve the way that dementia is diagnosed. In clinical trials, volunteers have regular brain scans to see if the treatment is stopping or slowing down the disease processes causing damage to the brain.

BIOMARKERS

Blood tests, or a procedure called a lumbar puncture, allow researchers to study “markers” in our blood and spinal fluid. These special markers show signs of both normal and abnormal disease processes. By measuring them, researchers can see if someone may go on to develop dementia or in a clinical trials, if a treatment is effective or not.

Lumbar punctures are a standard medical procedure used for a wide range of medical purposes, and side-effects are rare. They involve having a thin needle inserted into the lower spine to take a sample of spinal fluid.

WHAT TYPES OF RESEARCH CAN I TAKE PART IN?

LABORATORY RESEARCH

These studies could involve:

- donating blood or skin samples.
- brain donation after someone has died.

These samples help scientists to understand the processes that cause diseases like Alzheimer's. Taking part in these studies helps scientists to develop new ways to diagnose and treat dementia.



OBSERVATIONAL STUDIES

These studies track people over time, for example, to see how lifestyle factors may affect our risk of dementia, or how levels of certain molecules in our bodies change over time as we get older. **These studies can use:**

- questionnaires
- memory and thinking tests
- monitoring volunteer's health
- donating blood or other tissue samples.

Aspects of our daily lives that may affect our risk of dementia include inactivity, diet, alcohol consumption and smoking.

By asking volunteers to have brain scans and blood tests over time researchers can look for early 'markers' of the diseases that cause dementia. This research leads to faster and more accurate ways to diagnose dementia, and helps identify ways we can reduce our risk.

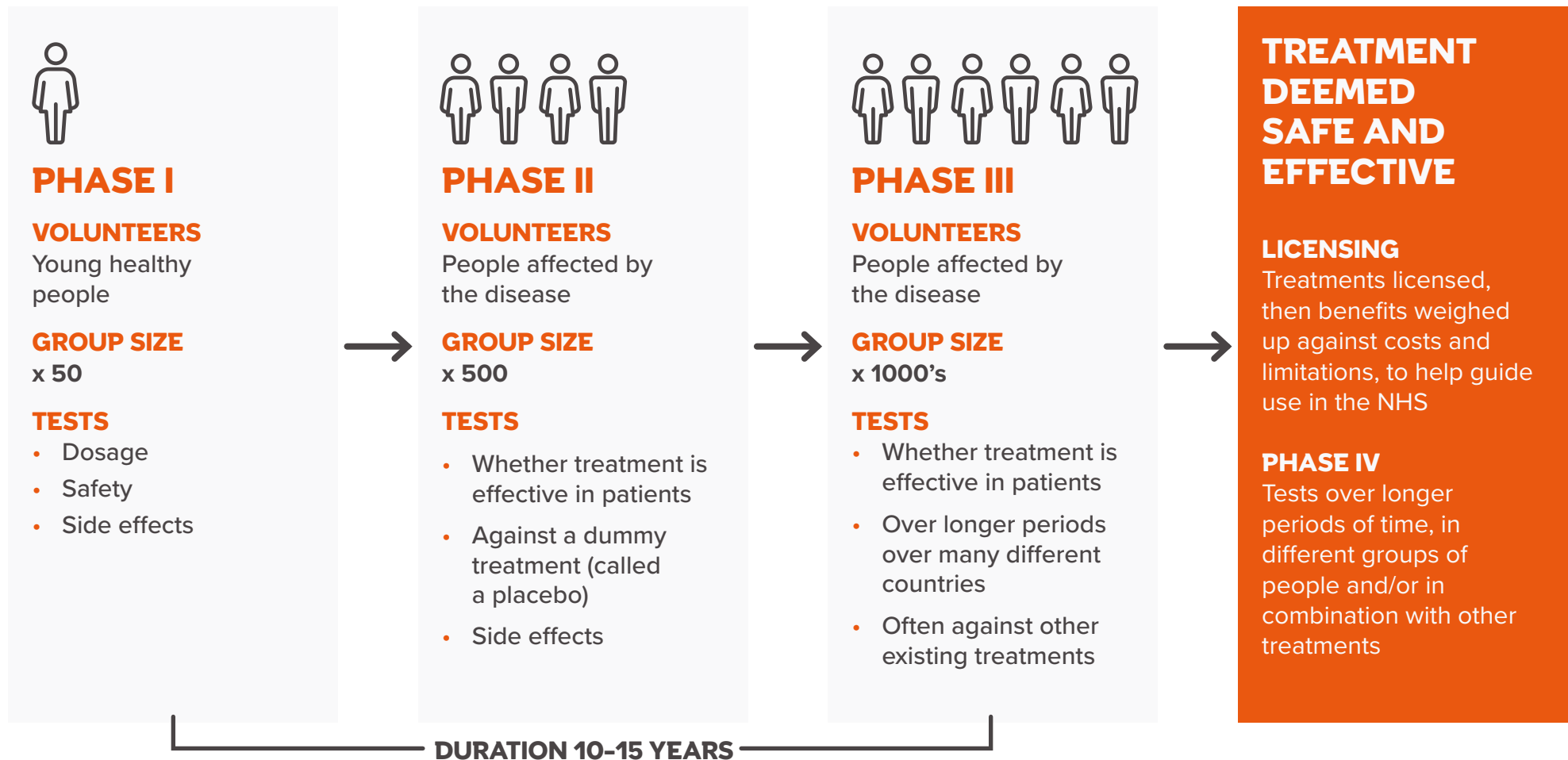
CARE RESEARCH

Some studies help to develop and evaluate dementia care, using questionnaires or interviews. This research aims to provide people with dementia with the best possible support and helps shape future care policies. This kind of study often involves people with dementia, their families, friends, or carers.

CLINICAL TRIALS

A clinical trial is designed to test the benefits and safety of a treatment or therapy. This could be a new medicine or a non-drug approach like a medical device, talking therapy or exercise programme.

THREE MAIN PHASES OF CLINICAL TRIALS



A range of potential new Alzheimer's disease treatments are now being tested in clinical trials. Volunteers taking part in these trials will help to show which new treatments will work and how they benefit people with dementia.

IF I TAKE PART IN A TRIAL WILL I RECEIVE THE NEW TREATMENT BEING TESTED?

So that scientists can test the effect of a new treatment, volunteers in clinical trials are often split into groups.

CLINICAL TRIALS GROUPS

- The **experimental group** will receive the treatment being tested and/or have the disease that is being studied.
- The **control group** will receive a placebo (dummy treatment) or receive normal care rather than take part in an intervention.

A placebo looks identical to the treatment being researched but does not contain the active drug. This ensures that any benefit the treatment has is due to the medicine itself, rather than the volunteers believing they are receiving an effective treatment (the so-called placebo effect).

Sometimes, the effect of a new treatment may be compared to that of an existing treatment. In most cases, you won't be required to stop any prescribed medications you're currently taking in order to trial a new drug. Some early phase trials – for example, those that are looking at a drug's safety and side effects - do not use placebos and instead test the drug in different doses in different groups.

HOW ARE THE GROUPS DECIDED?

In most studies, volunteers are **randomly assigned** to the control or experimental groups. This is important so that the groups are as similar as possible and any differences in the results are due to the treatment, not the way volunteers were chosen.



WILL I KNOW WHICH GROUP I AM IN?

In trials involving placebos, it is important – as far as possible – that volunteers don't know whether they are receiving the treatment or the placebo. This is known as 'blinding'. Researchers also shouldn't know which volunteers are in the treatment and placebo groups, so they don't treat them any differently. This is known as 'double blinding'.

Before a new treatment can be approved for use in people, researchers must show a beneficial effect in clinical trials. These are often run at the same time across lots of different countries.

“My dad got involved with research when he had mild Alzheimer's disease as he wanted to help future generations. We are glad we took part in research; it gave my dad a real sense of purpose at a time when he was coming to terms with his diagnosis at the relatively early age of 64.”

Hannah Wilson

Alzheimer's Research UK fundraiser who supported her father when he took part in research



IN MOST CASES, YOU WON'T BE REQUIRED TO STOP ANY PRESCRIBED MEDICATIONS.

HOW DO RESEARCHERS KNOW IF THE TREATMENT IS EFFECTIVE?

Volunteers in clinical trials are closely monitored before, during and after taking part in the study. Researchers keep a close eye on changes in volunteers' health, like how their brains work, whether any new symptoms appear, and the levels of markers for diseases (see section on biomarkers, **page 07**). This helps the researchers figure out if the treatment is working.

There are various ways researchers will monitor volunteers, and it is likely that they'll repeat a combination of tests during the trial. Both the people getting the new treatment and in the comparison group will do these tests. Researchers can then compare results to see if the treatment is effective.



IS TAKING PART IN RESEARCH SAFE?

There are some key features of medical research that ensure the safety of volunteers and the reliability of findings. Some apply to all kinds of studies; others only apply to clinical trials.

ETHICS APPROVAL

Before a study involving volunteers can start, researchers must submit a study plan to an ethics committee made up of independent scientific experts, as well as members of the public. The job of the ethics committee is to safeguard the rights, safety, dignity and wellbeing of research volunteers. A study cannot be conducted without ethical approval.

WHAT IS INFORMED CONSENT?

Before you agree to take part in any study, research staff must describe it to you in detail. They will tell you about the possible benefits and risks and explain your rights as a research participant.

They must also answer any questions you have. If you are happy to go ahead, you will be asked to sign a consent form stating that you understand what is involved in the study and you agree to take part. You can change your mind even after signing the form. If you do change your mind, you are free to withdraw at any time without giving a reason, and without this affecting your medical care. Every study is different.

Choosing not to take part in one study doesn't prevent you from taking part in others. You decide which studies you are happy to take part in on a case-by-case basis.

“Taking part in research was very straight forward. Usually both my wife Trina and I were involved. Trina having had a posterior cortical atrophy (PCA) diagnosis and me taking part in the control group. It was always interesting to talk to the researchers and it certainly improves our overall understanding of PCA.”

Graeme & Trina Armstrong

Research volunteers & Alzheimer's Research UK Champions



“After signing up to Join Dementia Research, I was selected to take part in a study looking at brain connections. I had an MRI scan, so the researchers could take several short scans of my brain. It's satisfying to know that I am, in a small way, contributing to the progress of vital dementia research.”

Jude Clarke

Research volunteer

WHAT HAPPENS IF SOMEONE CANNOT CONSENT?

People with dementia may not always be able to provide informed consent. This is known as 'lacking capacity'. There are strict rules about the recruitment of people to research when they are unable to make informed decisions.

Researchers may only recruit people without capacity if it is not possible to carry out the research with those who are able to consent. In these cases, a close relative or someone holding Lasting Power of Attorney on health and welfare grounds can give consent on their behalf if they believe that taking part in the study is in the person's best interest. They must be sure that the person would not refuse if they did have capacity to decide for themselves. If a volunteer who can't provide informed consent shows signs of distress or reluctance, they will be withdrawn from a study.

JOIN DEMENTIA RESEARCH

Join Dementia Research is a UK-wide service that allows you to register your interest in taking part in dementia research, matching you to research studies looking for volunteers. It is not a research study itself.

Signing up is easy and is the best way to find out what studies you can take part in. You just need to provide some information about yourself and your health. It is also possible to sign up for someone else if that person has expressed a wish to take part in research and consents to signing up. Once registered, you can take part in **online research** into dementia risk and dementia care, by doing questionnaires and memory tests via the Join Dementia Research website.



If you match to a **face-to-face study**, a researcher may contact you to explain what is involved and ask if you'd be interested in taking part. You have time to think about whether you would like to take part in each study before you decide; you do not have to take part in every study you are matched to.

More studies are added to Join Dementia Research all the time so there are plenty of opportunities to take part across the UK. You can also withdraw from Join Dementia Research at any time.

There are other opportunities to take part in dementia research and research into other conditions though a service called **Be Part of Research**. You can explore the opportunities available on their website at bepartofresearch.nihr.ac.uk



FIND OUT MORE AND SIGN UP

Visit www.joindementiaresearch.nihr.ac.uk or call the **Dementia Research Infoline** on **0300 111 5111**.

Join Dementia Research is delivered by the National Institute for Health and Care Research in partnership with Alzheimer's Research UK, Alzheimer Scotland and Alzheimer's Society.

PATIENT AND PUBLIC INVOLVEMENT

Taking part in a research study is not the only way that people can contribute to dementia research. It is important that dementia researchers work with non-scientists when planning their study, particularly people who have been affected by dementia, so that their work is as relevant as possible.

Alzheimer's Research UK works with lay volunteers to review grant applications from scientists who apply for charity funding. The process involves reading a selection of application summaries and completing a short review form. We ask them to comment on whether studies are worthwhile and are addressing issues that are important for people affected and their families.

For more information about Alzheimer's Research UK's volunteer opportunities:

Email volunteer@alzheimersresearchuk.org

Visit alzres.uk/volunteer

STILL HAVE QUESTIONS?

If you have questions about dementia research or want to find out more about how you can get involved in studies, contact our **Dementia Research Infoline** on **0300 111 5111** or email infoline@alzheimersresearchuk.org

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.

RESEARCH

Alzheimer's Research UK is the UK's leading dementia research charity. We exist to change the way we treat, diagnose and prevent dementia. And then, we will find a way to cure it.

To do this, we've invested over **£176 million** in the best research, powering the most forward-thinking scientists and joining forces with world-class organisations. 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.**

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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