

Getting involved in dementia research



**Alzheimer's
Research
UK**

Make breakthroughs possible



Introduction

This booklet aims to tell you more about what's involved in volunteering for dementia research and how you can take part. Please contact us if you would like a version in a different format.

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The importance of volunteers for research

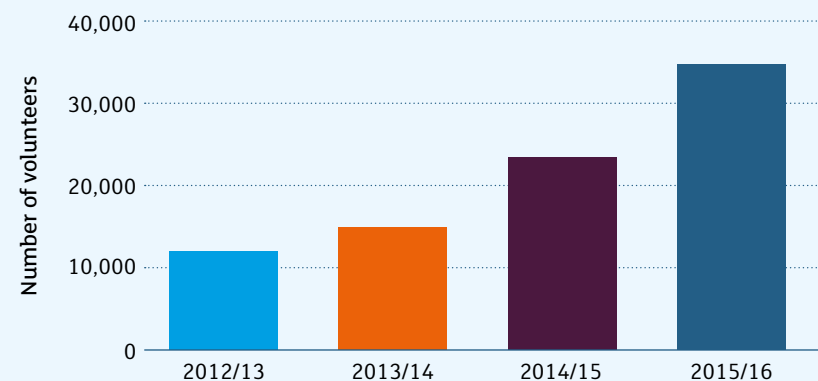
Dementia affects 850,000 people in the UK. It is the only condition in the top 10 causes of death without a treatment to prevent or cure it, or slow its progression.

Research offers hope.

Thanks to scientific research we understand more about the brain, and the diseases that affect it, than ever before. Scientists have only been able to make this progress because of the thousands of people who have volunteered to take part in dementia research studies.

We'll continue to make faster progress if more people agree to take part.

More than 34,000 people took part in dementia research in 2015/16, an increase of 156% over the previous two years.



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.



Carers of people with dementia are also needed to give their opinions, such as on accessing care or support.



Some dementia studies may focus on those over 65, but we'd encourage anyone over 18 to consider taking part.



“The number of scientists working on dementia in the UK has almost doubled since 2008. The next decade will see a new era for this research, but we need more volunteers taking part in studies if we are to find the first life-changing dementia treatments.”

Dr Carol Routledge
Director of Research, 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.

People often feel research is something positive they can do in the face of a progressive condition.

Volunteers may feel part of a community with other people taking part.

Some studies involving people with dementia include regular monitoring by doctors.

Research will lead to outcomes that could benefit those taking part or future generations.



What types of research can I take part in?

There are lots of different kinds of studies looking for volunteers.



“I’m incredibly enthusiastic about taking part in research. It’s easy to get involved in, easy to do and can take as little or as much time as you want. It makes me feel like I’m doing something positive in a situation that is anything but positive.”

Hayley Smith
Research volunteer



Laboratory research

Some studies benefit from donated blood or skin samples, helping scientists to understand the biological processes driving diseases like Alzheimer’s. These studies are key to developing new diagnostic methods and targets for future treatments.



Observational studies

These track people over time to see how lifestyle may affect a person’s risk of dementia. Researchers can monitor factors such as exercise, diet and smoking, to see how these might influence memory and thinking.

Monitoring brain scans and blood tests over time helps to search for early biological ‘markers’ of the diseases that cause dementia. This research could lead to faster and more accurate diagnosis in the future.



Care research

Some studies develop and evaluate care approaches, using questionnaires or interviews, to provide people with dementia with the best possible support. This kind of research could involve people with dementia, their families, friends or carers.



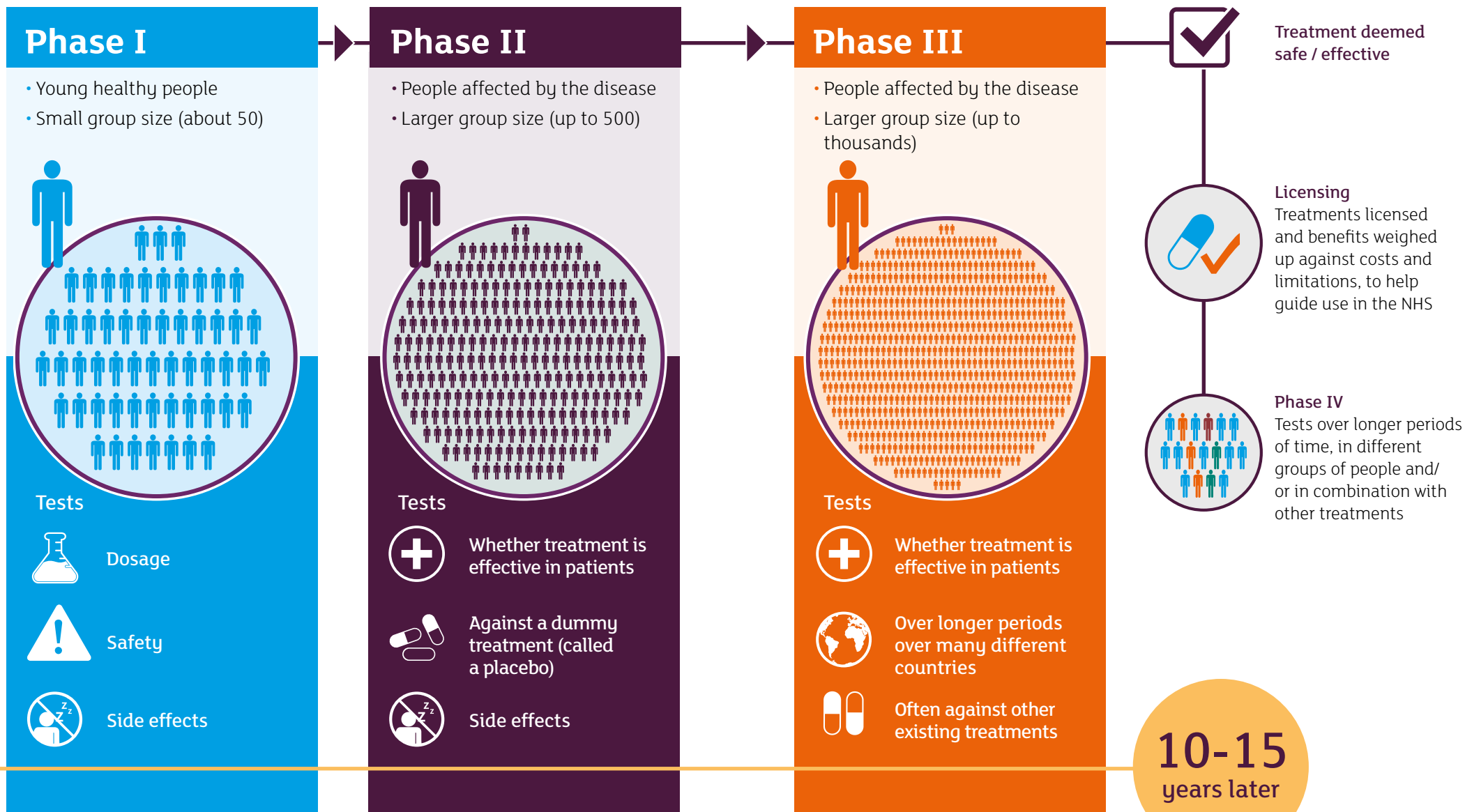
Clinical trials

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

A range of potential new dementia treatments are now in clinical trials. These trials will help to show which, if any, of these treatments will work.

Clinical trials

There are three main phases of clinical trials:



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 committee

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. Their job is to safeguard the rights, safety, dignity and wellbeing of research volunteers.



What is informed consent?

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

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.

What happens if someone lacks capacity?

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 can advise the researcher that taking part in the study is in the person's best interest. They must be sure that the person would not refuse. If a volunteer who can't provide informed consent shows signs of distress or resistance they will be withdrawn from the study.



Will I receive the new treatment being tested?

So that scientists can evaluate the effect of a treatment, volunteers are often split into 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 be made up of people who don't have dementia.

A placebo looks identical to the treatment being researched but has no therapeutic effect. This ensures that any benefit the treatment has is due to the action of the medicine, 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.

How are the groups decided?

In some studies, volunteers are randomly assigned to the control or experimental groups. Randomisation is important so that the groups are as similar as possible and any observed differences are due to the treatment, not the way volunteers were chosen.

Will I know which group I am in?

In clinical trials, it is often important 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 considered for use in people, researchers must show a beneficial effect in a number of independent 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 as he took part in research

How do researchers know if the treatments are effective?

Volunteers in clinical trials are closely monitored before, during and after the course of the study.

By monitoring changes in health outcomes, such as brain function and symptoms over time, researchers can tell if the treatment is having an effect. There are various ways researchers will monitor volunteers, and it is likely that they'll use a combination of tests. Volunteers in both the experimental and control groups will undergo these tests so that researchers can compare results to see if the treatment is effective.

Cognitive tests

These are tests designed to assess how well someone's brain is working. In dementia research they are used to measure a person's ability to remember and process information. By repeating these tests over time, researchers can see whether a treatment is helping to slow down memory loss and improve symptoms or not. 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 that are associated with dementia. 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, such as amyloid and tau, in the brain.

Biomarkers

Blood tests, or a procedure called a lumbar puncture, allow researchers to study molecules in our blood and spinal fluid. These may show signs of normal or abnormal biological processes. By measuring these molecules, researchers can see if a treatment is being effective or not. Lumbar punctures are a standard medical procedure used for a wide range of medical purposes, and side-effects after a well-conducted lumbar puncture are uncommon.

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.

Signing up is easy. You just need to provide some information about yourself and your health. It is also possible for a representative to register on someone's behalf if that person has expressed a wish to take part in research.

If you match to a study, the research team may contact you to explain what is involved and ask if you'd be interested in taking part. You can think about it before you decide; you do not have to take part in every study you are matched to. Whatever you decide, your details will stay on the register and you may be matched to new studies in the future.

You can withdraw from Join Dementia Research at any time.



Find out more and sign up:

Visit www.joindementiaresearch.nihr.ac.uk

Call the **Dementia Research Infoline** on **0300 111 5 111**.

Join Dementia Research is delivered by the National Institute for Health 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 members of the public can contribute to dementia research. It is important that dementia researchers work with the public, particularly people who have been affected by dementia, so that their work is as relevant as possible.

Alzheimer's Research UK would like to recruit Lay Review Volunteers to review grant applications from scientists planning studies involving people. The process involves reading a selection of application summaries and completing a short review form. We ask you to comment on whether studies are practical for people with dementia and are addressing issues that are important for people affected and their families.

For more information about how to become an Alzheimer's Research UK Lay Review Volunteer email LRV@alzheimersresearchuk.org



“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



Still have questions?

If you have questions about dementia research or want to find out more about how to get involved, contact our **Dementia Research Infoline** on **0300 111 5 111** 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.



“There are never enough people involved in dementia research: we desperately need more volunteers to help take on what is the greatest medical challenge of the 21st century.”

Prof Martin Rossor
NIHR National Director for Dementia Research



Research

Alzheimer’s Research UK has funded over **£119 million** of pioneering research into dementia and the diseases that cause it.

Through the research we fund, our scientists are building a detailed picture of what happens in the brain in these diseases.

This is essential for improving diagnosis and developing new treatments. Backed by our passionate supporters, and with the help of volunteers involved in research studies, we continue to support scientists who are taking us one step closer to a life-changing treatment.

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Send me more information

For free information, simply complete this slip and drop it straight in a post box. Alternatively, phone us on **0300 111 5555**.

I would like to know more about

Dementia: causes, symptoms and diagnosis (SCIHIAAD)

Treatments for dementia (SCIHITMT)

The latest dementia research (SMTTHINK)

Name

Address

Email

We'd like you to be the first to know about the latest research and how your support makes a difference, as well as ways you can get involved and help fund our life-changing work. We'll keep your information safe and never sell or swap it with anyone.

Let us know how we can contact you (tick below):

Post Email Telephone Text message

You can change how we talk to you at any time, by calling **0300 111 5555** or emailing enquiries@alzheimersresearchuk.org

Our Privacy Notice can be found at www.alzheimersresearchuk.org/privacy-policy and explains how we will use and store your information.

GIR19

We are the UK's leading charity powering life-changing breakthroughs in dementia research.

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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