

Volunteering for Research

Many dementia research studies rely on volunteers both with and without dementia to take part. For more information on types of dementia research, see the Alzheimer Scotland information sheet on [Dementia Research](#).

Consent to take part in research

Although people with dementia may want to take part in medical or other research, their consent must not be taken for granted.

People with dementia should decide for themselves whether they want to take part in research and the type of research they are interested in. They can then show their willingness to participate in research by making an advance statement to say so, or by granting someone a welfare power of attorney, giving the person the power to consent to research on their behalf.

Giving consent does not mean that you (or your relative) have given up any legal rights. Also it does not force you to continue with the research if you wish to stop for any reason. Anyone can drop out at any time, and there will be no implications for him or her.

Laws and Guidelines

The Adults with Incapacity (Scotland) Act 2000 sets out clear rules for what medical, surgical, psychological, nursing or dental research can be done with people who cannot consent. The full act can be viewed online at www.legislation.gov.uk/asp/2000/4/contents

The Scottish Dementia Working Group (SDWG) created a collection of core principles in order to ensure that people

with dementia are meaningfully involved in research. These principles can be viewed online at www.coreprinciplesdementia.wordpress.com

What to expect

When you volunteer for any research, you should be provided with an information sheet, which will vary in length and detail depending on the type and complexity of the research. You should take time to read it carefully as it will tell you about the research organisation, the reason for the research, and what will be involved. You should also have the opportunity to talk through your questions and concerns with the researcher.

Before taking part in research you must ensure you or your family member are fully aware of what it will entail. The questions below may help to deciding whether or not to take part in research:

1. What is the purpose of the research and intended benefit? Has the research been approved by a recognised and reputable institution (such as the NHS or Higher Education Institution) medical and social ethics committee?
2. What does the research involve for people who take part? (extra visits/ blood tests/injections, etc)
3. Will people taking part benefit from participation?
4. How long will it go on?
5. Where would I (or my relative) have to attend and how often?
6. Does the person taking part in the trial have to have a carer to take part?
7. Might people taking part be in a group

used for comparison (control group) and receive a placebo (dummy pill) or no treatment? If the research involves treatment, can participants continue with the treatment after the end of the trial if it has benefits for them?

8. What information will they send you once the research is completed?
9. Will expenses be paid?

Someone from the research team should be able to give a satisfactory answer to any of the questions above.

If you decide to take part in the research, you should take some time to think about the information and answers you have been given. You may want to speak to your partner or family, your GP or hospital consultant before making up your mind. An important question for relatives making the decision on behalf of someone with dementia is whether he or she would wish to participate if he or she could understand what was involved.

If you have any complaints about the research, take it up initially with the head of the research. If you are not able to get a satisfactory answer, bring the matter to your local NHS Board, or talk to someone on Alzheimer Scotland's Freephone Dementia Helpline (0808 808 3000) about the problem.

What happens after the research?

When the research is over, it is likely that you will want to know the results. However, there is no obligation for a researcher to share their findings with research participants or their relatives. Usually they are prepared to do so and may send you a copy of the report or paper. In some cases this may take years, especially if the research is being carried out in several centres, or in several countries.

If the research involved treatment, sometimes it will be obvious whether the treatment helped, made no difference or made matters worse. But the researchers will not normally be able to provide information on the response, effect or

outcome on an individual basis. In new treatment trials, it is not always possible to continue with the treatment after the trial is completed, as the treatment may not yet be licensed, but you should be made aware of this at the beginning.

Ethics in research

All trials conducted in the UK, must have been reviewed and approved by an Ethics Committee. Ethics are a set of principles that guide researchers who are carrying out research with people. Ethical principles are designed to protect the safety, dignity, rights and well-being of the people taking part. The job of an ethics committee is to make sure that the researchers abide by these principles. Who makes up the committee membership will be dependent on the type of research. They may consist of health care professionals, senior academics and members of the public, normal people who can offer their perspective. There is a specific ethics committee in Scotland that deals only with trials where participants may lack or lose capacity during the trial (including unconscious patients or patients with illnesses like dementia).

Research Organisations

Alzheimer Scotland Dementia Research Centre

The Alzheimer Scotland Dementia Research Centre, at the University of Edinburgh, was created to provide a high quality environment for dementia research and to house a brain tissue bank. The centre's ongoing research and more information about donating brain tissue can be found at www.alzscotdrc.ed.ac.uk

Join Dementia Research

Join Dementia Research is a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies. Anyone, with or without dementia, can register as a volunteer by visiting their

website at:

www.joindementiaresearch.nihr.ac.uk

Signing up is the first step in becoming involved in supporting vital research studies across the nation.

The Dementia and Neurodegenerative Research Network

The Dementia and Neurodegenerative Research Network is funded by the Chief Scientist Office to promote a culture of clinical research in dementia and neurodegenerative diseases across Scotland and improve recruitment to high quality studies from both urban and rural areas to advance understanding and develop new treatments.

The Network supports researchers from a range of disciplines across Scotland within the NHS and Care Home settings. People with dementia or neurodegenerative diseases, their carers and the public also have the opportunity to get directly involved in the network and help individual researchers develop their ideas.

For more information call 01738 562322 or go to www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease

Laws and regulations

There are many laws and regulations governing clinical trials, with the primary objective of these laws being to safeguard the public's safety and wellbeing.

All clinical trials conducted in the UK involving new medicines, treatments or existing medicines for a new purpose are covered by legislation. Anyone carrying out clinical research is subject to audits and statutory inspections by the government's regulatory authorities, to ensure that there are no breaches of these laws. In 2004, these laws became enshrined in the UK statute books.

It takes many years of research to get a new medicine/treatment to volunteers, the general population or clinical trials. All decisions about whether or not a drug or treatment can be prescribed are made by the government's licensing authority, the Medicines and Healthcare products Regulatory Agency (MHRA), on the strength of evidence from clinical trials. All drugs and treatments routinely prescribed today will have undergone these rigorous trials.



The logo for the Alzheimer Scotland Dementia Helpline is a purple rectangle with a pink border. In the top left corner, a pink rounded rectangle contains the text '24 HOUR' in white. Below this, the word 'Dementia' is written in white. In the center, there is a white icon of three stylized human figures. To the right of the icon, the text 'Alzheimer Scotland' is written in white, with 'Action on Dementia' in smaller white text below it. The word 'Helpline' is written in large, white, sans-serif font across the middle. At the bottom, a pink rounded rectangle contains the text 'Freephone 0808 808 3000' and 'Email helpline@alzscot.org' in white.

Alzheimer Scotland
160 Dundee Street
Edinburgh EH11 1DQ
Email: info@alzscot.org
Tel: 0131 243 1453
www.alzscot.org

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