

Welcome Pack

By registering, you've already taken your first step towards taking part in vital dementia research studies.

Dementia is one of the biggest challenges we face today, but through research we can make real progress.

By registering, you will now be able to take part in studies you are suitable for. Through research, you will help us to understand more about dementia, and improve diagnosis, treatment and care.

This booklet will help you understand a bit more about how the service works.

Thank you so much for getting involved. Together we can make a difference to the lives of everyone affected by dementia.

Join Dementia Research team



Delivered in partnership by

NIHR | National Institute for
Health and Care Research

**Alzheimer
Scotland**

**ALZHEIMER'S
RESEARCH
UK** **FOR A
CURE**


**Alzheimer's
Society**

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What happens now?

You will be matched to studies you are suitable for. New studies are added all of the time, so if you don't get matched straight away, the chances are you will do before too long.

-  Ensure your details are accurate and up to date.
-  If you are matched to a study and express an interest in taking part, the research team will see if you are eligible. They will check your details and may consult your medical records. Many studies now take place online and for these you will receive a notification.
-  If you meet all the criteria for a study, you will be contacted by a member of the research team, who will explain the study to you.
-  You can then choose whether or not you would like to take part in any research you match to. There is no obligation to take part in a study.

What might a study involve?

All studies on Join Dementia Research have been approved by a Research Ethics Committee. This means your rights, safety and wellbeing will always be protected if you get involved in research.

Studies cover a variety of different areas, from prevention and diagnosis to new treatments and improving the quality of life for people with dementia and their carers/ those who support them.

Please don't be disheartened if you don't match with any research at first. New studies are being added to Join Dementia Research all the time. When a suitable study does come along, researchers will be able to see that you have already registered your interest.

Top tip

Improve your chances of matching to a study by keeping information such as your contact details and health information including diagnosis and medication up to date at all times.



Log in to your online account if you have one



Phone one of the charity helplines

How to manage your membership

You can change any of your settings or information at any time.



If you have an online account, log in and make changes yourself on your 'Volunteer Summary' page.



If you need any help making changes or don't have an online account, please contact one of the charity helplines who can make any updates on your behalf. All the phone numbers are listed on the back cover.





Change whether researchers contact you by phone or email.



Choose whether to receive email updates and newsletters.



Let us know about a change of address, contact details, health or medication.



Find out more about any studies you match to.



Set up alerts for future studies.



Express your interest in a study and/or take part in online studies right away.



Indicate how far you're willing to travel.

Keeping your data safe

All the personal information you have provided is managed in accordance with the Data Protection Act 2018. If you have any questions or concerns, or would like us to stop holding or using your data at any time, please let us know by phoning one of the charity helplines or emailing **manager.jdr@nihr.ac.uk**.

Your personal information can only ever be seen by the people working to deliver the Join Dementia Research service:

- ☒ Join Dementia Research staff
- ☒ Approved researchers
- ☒ Some NHS staff
- ☒ Agencies working on behalf of Join Dementia Research
- ☒ Charity helplines

We never share your data with anyone who hasn't been through the relevant approval and training processes.

Your medical records

The information you provide us is separate to your medical records, which are kept by your GP or hospital consultant. If researchers need information from your medical records to assess whether you are eligible for a study, they will only see information that is relevant to the study, and it is against the law for them to share this with anyone else.



For more detailed information about how we use your account information and keep it safe, please visit:
<https://www.joindementiaresearch.nihr.ac.uk/content/volunteersheet>

Any questions?

I have an online account and I've forgotten my password. What do I do?

If you have an online account and you forget your password, click the 'Forgotten password/username?' link in the top right-hand corner of the homepage. You can then reset your password using your username and email address.

Your username is your email address. If you are experiencing issues resetting your password and logging in, contact the charity helplines (see below for numbers).

How can I remove myself from Join Dementia Research?

We hope that you'll enjoy being part of Join Dementia Research. However, if at any point you no longer wish to be registered, you can delete your account yourself online or by contacting the charity helplines.

Once you do this, researchers will not be able to search for you anymore. Please note that your data will be anonymised rather than deleted, unless you specifically request for it to be deleted.



If you have problems relating to your clinical care, please contact your doctor.



For questions relating to taking part in a study, please contact the research team.



For anything else, please email manager.jdr@nihr.ac.uk or phone one of the charity helplines.

Contact us



You can call them or request a call back using the 'Register by phone' button on the website.

**Alzheimer
Scotland**
0808 808 3000

Open 24 hours a day,
7 days a week.

(Scotland)

**Alzheimer's
Research UK**
0300 111 5 111

Mon - Fri: 9am - 5pm

(UK wide)

**Alzheimer's
Society**
0333 150 3456

Mon - Wed: 9am - 8pm
Thurs & Fri: 9am - 5pm
Sat & Sun: 10am - 4pm

**(England, Wales &
Northern Ireland)**

Calls to Alzheimer Scotland are free, calls to other Helplines cost no more than a national call from any type of phone or provider and calls are included in any free call packages on landlines and mobiles.

joindementiaresearch.nihr.ac.uk



manager.jdr@nihr.ac.uk



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