



National Institute for
Health Research

WELCOME PACK

Thank you for
registering



Find us on:



Twitter
@beatdementia



Facebook at
/joindementiaresearch

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





WHY IS DEMENTIA RESEARCH IMPORTANT?

Dementia is one of the biggest challenges we face today. The number of people with Alzheimer's disease, vascular dementia, and other types of dementia, is set to double over the next 30 years.

Thank you for registering with Join Dementia Research. It is through research that we will find ways of developing effective treatments, improving dementia care and hopefully one day beating dementia.

But for research to progress we need more people to take part in dementia studies.

Dementia research is particularly important because our knowledge of the different dementias currently lags behind that of other major conditions, such as cancer or heart disease. We have to close this gap.



WHAT IS JOIN DEMENTIA RESEARCH?

Join Dementia Research allows you to register your interest in taking part in dementia research studies. If you match to a study, the researchers can then contact you to see whether you are eligible and if you'd like to take part.

WHAT ARE THE BENEFITS OF REGISTERING?

By registering with Join Dementia Research you increase your chances of being asked to consider taking part in an ethically approved dementia research study. Many people find taking part in research a rewarding experience and they enjoy the contact with research teams. All studies using Join Dementia Research will have been approved by a Research Ethics Committee. This means that they have been checked to make sure they protect the rights, safety and wellbeing of people involved in research.

Although taking part in a research study may not be of immediate benefit to you, it might help people in the future.

It is also possible that there will not be any suitable studies for some volunteers, but new research studies are starting all the time which may be suitable.

**25 MILLION
PEOPLE IN THE UK
HAVE A FRIEND OR
FAMILY MEMBER
WITH DEMENTIA**





WHO WILL BE ABLE TO SEE MY INFORMATION ON JOIN DEMENTIA RESEARCH?

Your information is managed by a team of staff based at the National Institute for Health Research Clinical Research Network Coordinating Centre (NIHR CRNCC). Only the Join Dementia Research management staff at NIHR CRNCC, approved researchers, NHS staff and the charity helpdesks registered to use Join Dementia Research will be able to see your information.

Approved researchers may be employed by the NHS, commercial organisations or universities. All researchers are assessed and approved on the basis that their employers are signed up to our terms and conditions, and data processing agreements; and that they are working on ethically approved studies. Researchers only access your information on Join Dementia Research in relation to studies that you match to.

A list of organisations approved to use Join Dementia Research is available on our website www.joindementiaresearch.nihr.ac.uk. Visit the site and click on 'Any questions?'. The information can be found under the section entitled 'Signing up'.

WHAT HAPPENS IF I MATCH TO A STUDY?

If you are matched to a study, this does not necessarily mean you are eligible to take part. Researchers and NHS staff may check your medical records to make sure you are suitable. If you are eligible, you may be contacted by the research team, and then can decide whether you want to take part or not.

WE WILL NOT RELEASE ANY OF YOUR PERSONAL INFORMATION TO EXTERNAL PARTIES. IF WE CONTACT YOU BY POST, WE WILL ONLY FORWARD YOUR ADDRESS TO OUR PRINTERS.





WHO WILL BE ABLE TO SEE MY MEDICAL RECORDS?

The information on Join Dementia Research is held separately from the medical records kept by your GP and/or your hospital consultant.

In some cases, a researcher may also wish to view your medical records. The extra details in your medical records will help them to assess whether they should approach you about a particular study.

When registering to use Join Dementia Research you are asked for your permission for your medical records to be looked at. Only approved researchers and NHS staff, who have been assessed in accordance with *Research in the NHS: Human Resource (HR) Good Practice* will be allowed to access your medical records. Anyone accessing your medical records must follow the *NHS Confidentiality Code of Practice* and the *Data Protection Act 1998*. **This means that they will only view the information from your medical records that is relevant to assess whether you may be suitable to be contacted about a research project, and must keep your information secure.** They will not disclose any information from your records to any unauthorised person. Unauthorised disclosure by any researcher of any information from your records is a criminal offence and may lead to their prosecution.

WHO WILL CONTACT ME ABOUT RELEVANT RESEARCH STUDIES?

You will be contacted by a member of your healthcare team or by a member of the study team carrying out the research, who will explain the study to you.

You can choose whether or not to take part in any research study and your choice will not affect you being registered with Join Dementia Research. You will always be in control. Join Dementia Research will record which studies you take part in.





WHAT IF I DO NOT MATCH TO A STUDY?

The more information you provide, the more accurately you can be matched to new studies.

You can increase your chances of being matched to suitable studies by logging into your account at www.joindementiaresearch.nihr.ac.uk and completing the information from the additional questions on your 'Volunteer Summary' page. You can also call the helpline numbers to provide the additional information.

Unfortunately, you may not always match to a suitable research study. But you can increase your chances of being matched by:

- expressing an interest in studies you initially match to on your account
- indicating your willingness to travel. Some areas of the nation may have more dementia research taking place than others. If you are willing to travel, you may be considered to take part in studies in those areas.

**WHO HAS
ORGANISED
AND FUNDED
JOIN DEMENTIA
RESEARCH?**

**The service is funded by the
Department of Health and
delivered in partnership with
the National Institute for Health
Research, Alzheimer Scotland,
Alzheimer's Research UK and
Alzheimer's Society.**





HOW DO I MANAGE MY ACCOUNT AND UPDATE MY INFORMATION?

If you have an online account you can access and update your information by visiting www.joindementiaresearch.nihr.ac.uk and logging in with your unique username and password. If you have forgotten your username, please contact one of the helplines.

When you are logged in, you will see your 'Volunteer Summary' page. Here, you can update or edit your own volunteer information as well as register someone else and maintain their information for them. If you don't have an online account, you can update your information by calling one of the helplines.

To get the most out of your Join Dementia Research account, please log in regularly to ensure your details are up to date. This will allow us to match you with studies more effectively. Alternatively, you can call one of our helplines on the phone numbers listed on the last page of this booklet.

WHAT IF THERE IS A PROBLEM?

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

If you have any problems relating to your participation in a particular research study, please contact the research team of that study.

Any problems relating to Join Dementia Research can be addressed by calling one of the helplines, or by contacting the Research Manager through the website. Visit www.joindementiaresearch.nihr.ac.uk and click on 'Contact us'.

Our complaints procedure can be found at:
www.joindementiaresearch.nihr.ac.uk/policiesandprocedures





WHAT WILL HAPPEN IF I WANT TO WITHDRAW FROM JOIN DEMENTIA RESEARCH?

You are free to withdraw your information at any time without giving a reason. Your information will be deleted. You will then not be contacted about any further studies. Withdrawing from Join Dementia Research will not affect any existing research studies you have chosen to join or the standard of healthcare you receive.

If you decide that you no longer wish to remain on Join Dementia Research please either contact the Manager or contact one of the charity helpline numbers:

Alzheimer
Scotland

0808 808 3000

Open 24 hours a day,
7 days a week.

(Scotland)

Alzheimer's
Research UK

0300 111 5 111

Monday – Friday
9am – 5pm

(UK wide)

Alzheimer's
Society

0300 222 1122

Monday – Wednesday 9am - 8pm
Thursday & Friday 9am - 5pm
Saturday & Sunday 10am - 4pm

(England, Wales & Northern Ireland)

Calls to Alzheimer Scotland are free. Calls to Alzheimer's Research UK and Alzheimer's Society 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.

Rheolwr Join Dementia Research Manager:
c/o NIHR Clinical Research Network Coordinating Centre
Minerva House, 5 Montague Close, London, SE1 9BB
email: manager.jdr@nihr.ac.uk



**SOME RESEARCH
STUDIES NEED
HEALTHY
VOLUNTEERS AS
WELL AS CARERS OR
FAMILIES OF PEOPLE
WITH DEMENTIA**





WHAT IS THE PROCESS FOR IDENTIFYING AND REMOVING THE DETAILS OF PEOPLE WHO HAVE DECEASED?

When registering with Join Dementia Research all volunteers and representatives are asked to provide their consent for their health status information to be updated by Join Dementia Research if their individual status changes (i.e. when a person is deceased).

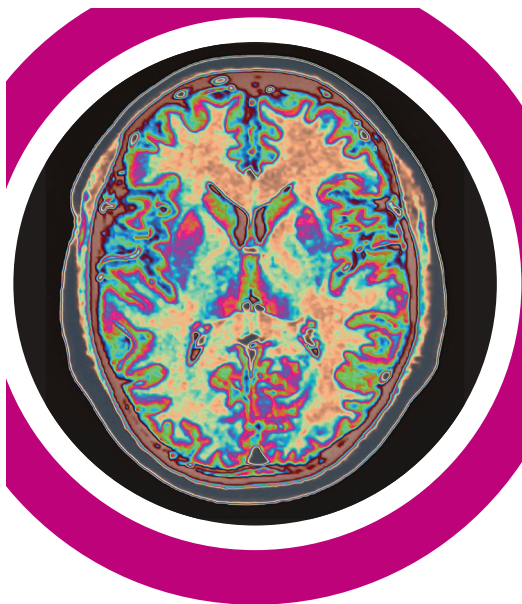
This involves the Health and Social Care Information Centre automatically notifying Join Dementia Research in the event of the death of a registered person. Their information would be cross-checked by the Join Dementia Research Manager, who will be responsible for updating the individual's status and deleting their information from the service. This procedure of updating and maintaining the service is in accordance with the Data Protection Act 1998.

WHAT CAN I DO ON MY ONLINE 'VOLUNTEER SUMMARY' PAGE?

- ✓ You can find the studies that match either to you, or the person you registered.
- ✓ You can read a description of each study you match to.
- ✓ You can express your interest in studies to let researchers know that you want to find out more.
- ✓ You can register a profile for someone else and manage their record for them.
- ✓ You can set up an alert to be informed of future studies.

www.joindementiaresearch.nihr.ac.uk





**VISIT THE WEBSITE
REGULARLY TO
SEE YOUR STUDY
MATCHES AND KEEP
YOUR INFORMATION
UP-TO-DATE**

WILL I DEFINITELY BE CONTACTED ABOUT PARTICIPATING IN A STUDY?

Unfortunately, there will not always be research studies that you are a suitable match for. This can be understandably disheartening for people keen to take part in research.

Having an account with Join Dementia Research does not necessarily mean that there will be a study available to you straight away. However, having a nationwide service means that studies can be started much more quickly, and new studies are starting all the time.

I FORGOT MY PASSWORD. WHAT DO I DO?

Please click the **'Forgotten password/username?'** link in the top right-hand corner of the homepage. You can then reset your password, by entering your username and email address. If you do not have a username or password, please call one of the charity helplines.

www.joindementiaresearch.nihr.ac.uk





CASE STUDY

Chantel & Nigel's story

Chantel and Nigel have been married for 32 years. Nigel was a bus driver for 30 years when he started to have problems with numbers and counting. This is when Chantel realised that there might be something wrong.

Nigel was diagnosed with Familial Early-Onset Alzheimer's Disease in 2009. It was on one of their visits to the hospital that their doctor asked if they would be interested in taking part in research, exploring the genetic causes of the condition.

"I can truly say that being involved in research changed our lives; we gained a better understanding of the disease and the research team were able to advise and support us all the way through. It's amazing what goes on behind the scenes. I was also able to cope better as the study researchers helped me understand the progression

of the disease and the medication options available.

It is important to be able to unite researchers with the general public, and this is what Join Dementia Research is doing. I am sure this will move the diagnosis forward for dementia and stop it. It is important we get to the bottom of why this is happening to so many younger people and to so many families."

Chantel





CONTACT DETAILS

For all general enquiries about Join Dementia Research
please visit our website at:

www.joindementiaresearch.nihr.ac.uk

or if you need help, please call:

Alzheimer
Scotland

0808 808 3000

Open 24 hours a day,
7 days a week.

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Research UK

0300 111 5 111

Monday – Friday
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