

Registration form

Let researchers know you want to take part in vital dementia research



Register your details



Match to UK studies you may be able to take part in



Talk to researchers about their study



Decide whether or not you want to take part

Register today. Complete the form inside, call one of our helplines or visit:

www.joindementiaresearch.nihr.ac.uk

Delivered in partnership by

NIHR | National Institute
for Health Research



Join Dementia Research is funded by the Department of Health and Social Care

Why sign up?

Everybody should have the chance to find and take part in dementia research.

Join Dementia Research provides that chance, and can connect you to suitable studies taking place across the country.

By registering, you can play an important role in finding new ways to diagnose, treat, manage and care for people affected by dementia.

Helping future generations

Accessing new treatments

Why people like taking part in research

Doing something positive

Feeling part of something valuable

Follow us:



@beatdementia



/joindementiaresearch

Please read the following information carefully.

On this registration form, you will be asked to provide the basic information needed to register either yourself **or** someone else for the service.

You can only register one volunteer per form. Please complete an additional form for each volunteer you wish to register.

Completing this form creates an account for you with Join Dementia Research.

Once your account has been set up, you can improve your chances of matching to the most suitable studies by keeping your details up to date at all times. If you have provided us with an email address you will be able to do this online yourself. Alternatively you can call one of the charity helplines (see page 4).

You should hear from us within 21 days to confirm we have received this form and created an account. We will send you a welcome email or pack which will include guidance on how you can update the information you have provided.

The welcome pack and the website both contain more information about what happens once you have registered with Join Dementia Research. You can also find out more about how we look after and use your data.

Once registered, we hope you will enjoy being part of Join Dementia Research, but if you wish to be removed from the service, please email **manager.jdr@nihr.ac.uk** or contact one of the helplines.

If you do not wish to register by post, you can sign up over the phone by calling one of our charity helplines (details on page 4) or register online at: www.joindementiaresearch.nihr.ac.uk



If you do not wish to register by post, or need help registering, you can sign up over the phone by calling one of our charity helplines below:

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
0300 222 1122
Mon - Wed: 9am - 8pm
Thurs - Fri: 9am - 5pm
Sat - Sun: 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.

You can also register online at:

www.joindementiaresearch.nihr.ac.uk

**Important note for anyone completing this form on
behalf of someone else (a representative):**

We can only register a volunteer with their consent, or the consent of someone who holds Lasting Power of Attorney for the volunteer on health and welfare grounds (England and Wales) or Welfare Power of Attorney in Scotland.

If you do not hold this, we will only complete the volunteer's registration if the volunteer has signed the form themselves on page 13 or if one of our charity helpdesks is able to confirm over the phone that the volunteer agrees to be registered.

Information about the volunteer

On these pages, please write either:

- Your details (if you are signing yourself up as a volunteer) OR
- The volunteer's details (if you are signing up someone else).

**You must complete a separate form for
each person who wishes to volunteer.**

Before completing this section, **please read the relevant declaration text** on pages 13 or 14 and 15 carefully. You **MUST** answer **ALL** the questions on pages 5, 6, 7, 8 and 9.

The volunteer's details

Title (Dr, Mr, Mrs etc.)

Volunteer's first name

Volunteer's surname

Date of birth (DD/MM/YYYY)

Gender

Male ☐ Female ☐ Not Specified ☐

Home address

Town / city

County

Postcode

Phone

Email (please leave blank if you do not have one)



Is the volunteer registering as someone who has a diagnosis or concerns about symptoms of a dementia or memory-related disorder?

Yes ☐ No ☐

If yes, what is the volunteer's diagnosis?

- ☐ Alzheimer's disease
- ☐ Vascular dementia
- ☐ Mild cognitive impairment (MCI)
- ☐ Mixed dementia
- ☐ Dementia with Lewy bodies
- ☐ Frontotemporal dementia (FTD)
- ☐ Alcohol-related dementia
(including Wernicke-Korsakoff syndrome (WKS))
- ☐ Dementia in Parkinson's disease
- ☐ Dementia in Huntington's disease
- ☐ Other dementias
- ☐ Not aware of specific diagnosis

If no, does the volunteer currently help, support or care for a person with dementia or memory problems?

Yes ☐ No ☐

Does the volunteer have any disabilities?

- ☐ Hearing impairment
- ☐ Visual impairment
- ☐ Mobility problems
- ☐ Learning difficulties
- ☐ Communications
- ☐ None
- ☐ Other (please specify)

Does the volunteer have any other medical conditions?

- ☐ Down's Syndrome
- ☐ Diagnosed sleep disorders
- ☐ Cancer (in the last 5 years)
- ☐ Significant cardiac problems
- ☐ Pacemaker fitted
- ☐ Stroke
- ☐ High blood pressure
- ☐ Diabetes
- ☐ Depression / anxiety
- ☐ Other mental health issues
- ☐ Traumatic brain injury
- ☐ Epilepsy
- ☐ None
- ☐ Other medical condition (please specify)

If the volunteer has dementia, how would you describe the symptoms?

Everyone experiences dementia in their own way, but please select the option below that best describes the volunteer's symptoms. This will help match the volunteer to the right studies.

Mild ☐ Moderate ☐ Severe ☐ Unknown ☐

Is the volunteer currently taking any of these memory medications?

- ☐ Donepezil hydrochloride (Aricept)
- ☐ Rivastigmine (Exelon)
- ☐ Memantine hydrochloride (Ebixa)
- ☐ Galantamine (Reminyl)
- ☐ None of the above

Is there a history of dementia within the volunteer's family?

Yes ☐ No ☐ Don't know ☐

Does the volunteer have a carer / someone who knows them well, who supports them with dementia or memory difficulties?

Yes ☐ No ☐

When researchers contact the volunteer about study opportunities, what is the preferred contact method?

Email ☐ Phone ☐

How should we send updates and information from Join Dementia Research? (e.g. newsletters and surveys)

- ☐ Email
☐ Post
☐ I do not want to receive updates

How would the volunteer like to receive the Join Dementia Research welcome pack?

Email ☐ Post ☐

Volunteers may be eligible to take part in ethically approved studies into conditions other than dementia. Can we contact the volunteer about other approved research studies which are not dementia related?

Yes ☐ No ☐

How did you find out about Join Dementia Research?

- ☐ Memory service
☐ Exhibition/event
☐ Charity
☐ Other (please specify)

Please provide the name of the hospital / trust / memory service / event where you received this form:

Please choose one option that best describes the volunteer's ethnic group.

This question is used to match volunteers to certain studies. It also allows staff working on Join Dementia Research to understand how well we are reaching different communities.

- ☐ British (white)
☐ Irish (white)
☐ Any other white background
☐ White and black Caribbean (mixed)
☐ White and black African (mixed)
☐ White and Asian (mixed)
☐ Any other mixed background
☐ Indian (Asian or Asian British)
☐ Pakistani (Asian or Asian British)
☐ Bangladeshi (Asian or Asian British)
☐ Any other Asian or Asian British background
☐ Caribbean (black or black British)
☐ African (black or black British)
☐ Any other black or black British background
☐ Chinese or South East Asian
☐ Any other ethnic group
☐ Prefer not to say

How did you find out about Join Dementia Research?

- ☐ English
☐ Any other language (please specify below)

If you are registering someone else as a volunteer, please also complete your own details in the form on pages 10 and 11.

Please only complete pages 10 and 11 if you are registering somebody else for the service.

If you are signing up yourself as a volunteer, you **do not** need to complete these pages.

Although you are registering someone else, we also need some information about you. You can write the details of the person you are registering on pages 5, 6, 7, 8 and 9. You **MUST** answer ALL questions.

Before completing this section, please read Declaration B on pages 14 and 15 carefully.

Your relationship to the volunteer

What is your relationship to the volunteer?

Do you hold power of attorney for the volunteer as described on page 4?

Yes ☐ No ☐

Who shall receive the communications about Join Dementia Research and study matches?

- ☐ Representative
☐ Volunteer
☐ Both

You can edit the rest of your communications preferences on **page 8**.

Your information as a representative

Title (Dr, Mr, Mrs etc.)

First name

Surname

Date of birth (DD/MM/YYYY)

Gender

Male ☐ Female ☐ Not Specified ☐

Email (please leave blank if you do not have one)

Do you have the same postal address as the volunteer?

Yes ☐ No ☐

If no, please add **your** address below.

Home address

Town / city

County

Postcode

Phone

Important information

Please read and sign the declaration text that applies to you.

- **Declaration A** (page 13) is for volunteers registering themselves;
- **Declaration B** (pages 14 and 15) is for people acting as a representative for someone else.

If you do not sign the relevant declaration to confirm you agree to the statements, you/the volunteer will not be registered and will not be considered for studies.

Please send your completed form in a stamped envelope addressed to:

Join Dementia Research (CONFIDENTIAL)
c/o Alzheimer's Research UK (INFOLINE)
3 Riverside
Granta Park
CAMBRIDGE
CB21 6AD

Office use only:

Declaration A

I am registering myself as a volunteer

1. I confirm that I have read and understand the information within this form and can access a copy of the Volunteer Guide on the Join Dementia Research website or via the charity helplines.
2. I understand that registration of my details on Join Dementia Research is voluntary, and that my personal details will be stored securely.
3. I give my permission for approved researchers, NHS staff, staff working at partner organisations or agencies working on behalf of Join Dementia Research to view and use my information stored on the system, for the purposes of delivering Join Dementia Research.
4. I give my permission for approved researchers and NHS staff to access the relevant sections of my healthcare records, for the purposes of matching me to research studies.
5. I agree to my information being held on Join Dementia Research, until I, or my representative, request withdrawal. Basic details of volunteers will be shared with other NHS organisations to identify if they have died, and I agree to this. If I withdraw, or if Join Dementia Research is notified of my death, then all my personal identifiable information will be removed from Join Dementia Research.
6. I understand that I am free to withdraw at any time without giving a reason and without impact on my medical care.

I, the volunteer, understand and agree to Declaration A

Signature

Today's Date

DD / MM / YYYY



Declaration B

I am registering someone else as a volunteer

1. I hold Lasting Power of Attorney for the volunteer on health and welfare grounds (England and Wales) or Welfare Power of Attorney (in Scotland). It is my opinion that registration reflects their wishes and best interests.
2. I confirm that I have read and understand the Volunteer Guide on the Join Dementia Research website or available via the charity helplines.
3. I understand that registration is voluntary, and that my details and the personal details of the registered person will be stored securely.
4. I give permission for approved researchers, NHS staff, staff working at partner organisations or agencies working on behalf of Join Dementia Research to view and use the registered person's information stored on the system, for the purposes of delivering Join Dementia Research.
5. I give permission for approved researchers and NHS staff to access the relevant sections of the registered person's healthcare records, for the purposes of matching them to research studies.
6. I agree to the registered person's information being held on Join Dementia Research, until withdrawal is requested by themselves, by me or by another person representing their interests. Basic details of volunteers will be shared with other NHS organisations to identify if they have died, and I agree to this. After withdrawal or notification of the registered person's death, all personal identifiable information about the registered person and me as their representative will be removed from Join Dementia Research.

Declaration continues on page 15

Continued from page 14

7. I understand that the volunteer can withdraw at any time, or I can do so on their behalf, without giving any reason. If the registered person withdraws from Join Dementia Research then their medical care will not be affected.

I, the representative, understand and agree to Declaration B

Signature

Today's Date

DD / MM / YYYY



Any questions?

@ manager.jdr@nihr.ac.uk

 @beatdementia

 joindementiaresearch

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