



**HELP
BEAT
DEMENTIA**

**REGISTER YOUR
INTEREST IN
DEMENTIA
RESEARCH
TODAY**

REGISTRATION FORM

Join Dementia Research is a national service which enables you to be told about research studies that you may be able to take part in.

Signing up could take us a step closer to beating dementia.

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

www.joindementiaresearch.nihr.ac.uk

Delivered in partnership by



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 part in finding new ways to diagnose, treat, manage and care for people affected by dementia.

HELPING FUTURE GENERATIONS

"FIGHTING BACK" AGAINST THE DISEASE

ASSESSING NEW TREATMENTS

WHY PEOPLE LIKE TAKING PART IN RESEARCH

FEELING PART OF SOMETHING VALUABLE

Follow us:



@beatdementia



/joindementiaresearch

Please read the following information carefully.

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

You can only complete one form for one volunteer.

Completing this form creates an account for you on Join Dementia Research. Once your account has been set up, you can improve your chances of matching to a suitable study by answering more questions and by keeping your details up to date.

If you have provided us with an email address you will be able to do this online yourself, or alternatively you can call one of the charity helplines below.

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 booklet which will include guidance on how you can update your or the volunteer's information.

The welcome booklet 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@nih.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 below or register online at: **www.joindementiaresearch.nih.ac.uk**

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.

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 form for each person who wishes to volunteer.

Before completing this section, please read the relevant declaration text on pages 12 or 13 carefully. You **MUST** answer **ALL** the questions on pages 4, 5, 6, 7 and 8.

THE VOLUNTEER'S DETAILS

TITLE (Dr, Mr, Mrs etc.)

VOLUNTEER'S FIRST NAME

VOLUNTEER'S SURNAME

DOB (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

Does the volunteer have any disabilities?

- DEAFNESS
- BLINDNESS
- MOBILITY
- LEARNING OR INTELLECTUAL DISABILITY
- COMMUNICATION DIFFICULTIES
- NONE OF THE ABOVE
- ANY OTHER DISABILITIES (please specify)

Does the volunteer have any other medical conditions?

- DOWN'S SYNDROME
- SLEEP DISORDERS
- CANCER
- SIGNIFICANT CARDIAC
PROBLEMS
- STROKE
- HIGH BLOOD PRESSURE
- DIABETES
- DEPRESSION
- OTHER MENTAL HEALTH ISSUES
- NONE OF THE ABOVE
- OTHER MEDICAL CONDITION
(please specify)

Is the volunteer currently taking any of these memory medications?

- DONEPEZIL HYDROCHLORIDE (ARICEPT)
- RIVASTIGMINE (EXELON)
- MEMANTINE HYDROCHLORIDE (EBIXA)
- GALANTAMINE (REMINYL)
- NONE OF THE ABOVE

Does the volunteer have a carer / someone that knows them well, and who helps support them with their dementia or memory difficulties?

YES NO

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

MILD MODERATE SEVERE UNKNOWN

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

YES NO DON'T KNOW

How would the volunteer like to be kept up-to-date with research opportunities?

Please tick all that apply

EMAIL PHONE POST TEXT

Would the volunteer like to receive regular updates and information from Join Dementia Research by email (e.g. newsletters)?

YES NO

If the volunteer has not provided us with an email address but would still like to receive updates, please still answer 'YES'. As a minimum, the volunteer will be sent newsletters by post.

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

YES NO

How far would the volunteer be willing to travel to take part in a research study?

- LOCALLY (WITHIN 5 MILES)
- REGIONALLY (WITHIN MY COUNTY)
- NATIONWIDE (ANYWHERE)

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:

The questions below are used to match volunteers to certain studies and for staff working on Join Dementia Research to understand how well we are reaching different communities.

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

- 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

Is English the volunteer's preferred language?

YES NO

If no, what is the volunteer's preferred language?

IF YOU ARE REGISTERING SOMEONE ELSE AS A VOLUNTEER, PLEASE ALSO COMPLETE THE FORM OVERLEAF WITH YOUR OWN DETAILS.

IMPORTANT INFORMATION

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

- Declaration A (page 12) is for volunteers registering themselves;
- Declaration B (page 13) 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.

Once signed and completed, please put this 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

If you are registering someone else as a volunteer, we also need some information about **you**. You can write the details of the person you are registering on pages 4, 5, 6, 7 and 8. You **MUST** answer ALL questions.

Before completing this section, please read Declaration B on page 13 carefully.

Important note: We can only register a volunteer with their consent, or the consent of someone who holds lasting power of attorney (LPA) for the volunteer on health and welfare grounds.

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

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 this page.

YOUR RELATIONSHIP TO THE VOLUNTEER

What is your relationship to the volunteer?

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Do you hold lasting power of attorney (LPA) for the volunteer on health and welfare grounds?

YES NO

Should communications to the volunteer be sent through you?

YES NO

Should communications be sent directly to the volunteer?

YES NO

If you tick 'yes' to both of the above, both you and the volunteer will receive a welcome booklet.

YOUR INFORMATION AS A REPRESENTATIVE

TITLE (Dr, Mr, Mrs etc.)

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FIRST NAME

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SURNAME

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DOB(DD/MM/YYYY)

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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 Information Sheet 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. Only approved researchers, NHS staff, staff working at partner organisations or agencies working on behalf of Join Dementia Research can look at my information on Join Dementia Research. I give permission to these individuals to view my information and use this information for the purposes of delivering Join Dementia Research.
4. I understand that only approved researchers and NHS research staff will be allowed to access my medical records held by my hospital consultant and/or GP. I give my permission for these individuals to look at my medical records to help check my suitability for research studies.
5. I understand that I am free to withdraw at any time without giving a reason. If I withdraw, my medical care will not be affected.
6. I understand that if I withdraw, or in the event of my death, all my personal identifiable information will be removed from Join Dementia Research.

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 have lasting power of attorney formally in place for the registered person on health and welfare grounds, and it is my opinion that registration is in their best interests. (If I do not have this, I understand the registered person needs to sign the form themselves or provide contact details so that helpline staff can speak to them to confirm their wish to be registered.)
2. I confirm that I have read and understand the information within this form and can access a copy of the Volunteer Information Sheet on the Join Dementia Research website or 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. Only approved researchers, NHS staff, staff working at partner organisations or agencies working on behalf of Join Dementia Research can look at the registered person's information on Join Dementia Research. I give permission to these individuals to view the registered person's information and use this information for the purposes of delivering Join Dementia Research.
5. I understand that only approved researchers and NHS staff will be allowed to access the registered person's medical records held by their hospital consultant and/or GP. I give permission for these individuals to look at the registered person's medical records to help check their suitability for research studies.

Continued on page 14

6. 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.

7. I understand that if the registered person withdraws, or after their death, then all their personal identifiable information, and mine as their representative, will be removed from Join Dementia Research.

**I, THE REPRESENTATIVE, UNDERSTAND AND AGREE TO
DECLARATION B**

Signature

Today's Date

DD / MM / YYYY