

TERMS AND CONDITIONS

DECLARATION A

I am registering myself as a volunteer

I confirm that I have read and understand the information within this form and can access a full version of the Volunteer Information Sheet on the Join Dementia Research website or via the helplines.

I understand that registration of my details on Join Dementia Research is voluntary.

I understand that my personal details will be stored securely and that I am free to withdraw at any time without giving a reason. If I withdraw, my medical care will not be affected.

Only approved researchers, NHS staff and the charity helpdesks can look at my information on Join Dementia Research. I give permission to these researchers and NHS staff to view my information to see if I am suitable for a research study. I also understand that a limited number of staff working for the National Institute for Health Research associated with the administration and management of the Join Dementia Research service may also see my information.

I understand that only approved researchers and NHS research staff that have been assessed in accordance with the *Research in the NHS: Human Resource (HR) Good Practice* procedures 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.

I understand that if I withdraw, or in the event of my death, all identifiable information will be removed from Join Dementia Research.

I understand that the information held and maintained by the Health and Social Care Information Centre will be used to inform Join Dementia Research in the case of my death.

We will not release any of your personal information to external parties. We will only forward your address to our printers so they can post out your welcome pack. If you provide an email address, we will send you an electronic version of the welcome pack.

DECLARATION B

I am registering someone else as a volunteer

I confirm that I have read and understand the information within this form and can access a full version of the Volunteer Information Sheet on the Join Dementia Research website or via the helplines.

I understand that registration is voluntary, and that personal details of the registered person will be stored securely.

I understand that registration can be withdrawn at any time without giving a reason. If the registered person withdraws from Join Dementia Research then their medical care will not be affected.

Only approved researchers, NHS staff and the charity helpdesks will be able to view the registered person's information on Join Dementia Research. Only these researchers and NHS staff will be able to view the registered person's information to assess their suitability for research studies. I also understand that a limited number of staff working for the National Institute for Health Research associated with the administration and management of the Join Dementia Research service may also see the registered person's information.

I understand that only approved researchers and NHS research staff that have been assessed in accordance with the *Research in the NHS: Human Resource (HR) Good Practice* procedures will be allowed to access the registered person's medical records held by their hospital consultant and/or GP. I understand that these individuals will have access to the registered person's medical records to obtain further information to assess their suitability for research studies.

I understand that the information held and maintained by the Health and Social Care Information Centre will be used to inform Join Dementia Research in the event of my death or that of the registered person.

I understand that if the registered person is withdrawn, or after their death, then all identifiable information will be removed from Join Dementia Research.

To the best of my knowledge, the registered person has not expressed any reluctance to participate in Join Dementia Research and it is my opinion that registration is in their best interest.

WHY SIGN UP?



Everybody should have the chance to discover and participate in dementia research.

Join Dementia Research provides that chance, and can connect you to dementia research studies taking place across the nation.

Here are four reasons to sign up:

Find research studies that match either to you, or the person you are registering.

Connect with researchers to show an interest in their studies.

Find us on:

 **Twitter**
[@beatdementia](https://twitter.com/beatdementia)

 **Facebook at**
[/joindementiaresearch](https://www.facebook.com/joindementiaresearch)

Freepost RTCX-BRAG-YSUH
Alzheimer's Research UK
Unit 3
3 Riverside
Granta Park
Great Abington
CAMBRIDGE
CB21 6AD



Join
dementia
research

HELP
BEAT
DEMENTIA

REGISTER
YOUR INTEREST
IN DEMENTIA
RESEARCH
TODAY


National Institute for
Health Research

REGISTRATION FORM

Join Dementia Research is a national service which makes it easy for anyone to register their interest in taking part in dementia research.

Signing up could make a real difference to you and others.

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

www.joindementiaresearch.nihr.ac.uk



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.





REGISTER YOUR INTEREST IN DEMENTIA RESEARCH TODAY

Please read the following instructions 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 this form for one person.

After completing and sending in this form, a welcome letter or email (and welcome booklet) should arrive within 21 days.

Your welcome booklet will include guidance on how to manage your account, where you can update your or the volunteer's information. If you do not wish

to update your information online, please call one of the helpline numbers below.

The welcome booklet and the website both contain more information about giving your consent to be part of Join Dementia Research.

If you wish to be removed from the service, please email: manager.jdr@nhr.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 helplines or register online at: www.joindementiaresearch.nhr.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.

Once your account has been set up, you can improve the likelihood of matching with a suitable study by answering a more detailed set of questions. If you have provided us with an email address you will be able to do this online, or alternatively you can call one of the helplines to update your account.

MOISTEN HERE AND STICK PAGE 6 TO THIS PAGE

PLEASE ONLY COMPLETE THIS PAGE 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. Please go to pages 4 and 5.

YOUR INFORMATION AS A REPRESENTATIVE

Although you are signing up someone else, we still need **your** information on this page. You can enter the details of the person you are registering on the next two pages.

You **MUST** answer **ALL** questions to complete a registration. Before completing this section, please read the declaration text B carefully on page 6.

TITLE (Dr, Mr, Mrs etc.)

FIRST NAME

SURNAME

DOB (DD/MM/YY)

GENDER Male Female
Not Specified

EMAIL (Please leave blank if you do not have one)

Do you have the same address as the volunteer?
YES NO

If you ticked no - please add **your** address below

HOME ADDRESS

TOWN / CITY

COUNTY

POSTCODE

PHONE

Your relationship to the volunteer

What is your relationship to the volunteer?

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.

TEAR ALONG PERFORATION AND KEEP PAGES 1 AND 2

3

MOISTEN HERE AND STICK PAGE 6 TO THIS PAGE

INFORMATION ABOUT THE VOLUNTEER

On the next two pages, please enter either:

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

Before completing this section, please read the declaration text carefully (either A or B) on page 6. You **MUST** answer **ALL** the questions on pages 4 and 5.

TITLE (Dr, Mr, Mrs etc.)

VOLUNTEER'S FIRST NAME

VOLUNTEER'S SURNAME

DOB (DD/MM/YY)

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 is being investigated for a dementia 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?

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

4

← MOISTEN HERE, FOLD IN HALF AND SEAL TO PAGE 4

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 your / their symptoms?
MILD MODERATE SEVERE UNKNOWN

How would the volunteer like to be kept up-to-date with research opportunities?
Please tick all that apply
EMAIL PHONE POST TEXT

Would you / they like to receive a regular newsletter?
YES NO

5

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Volunteers may be eligible to participate in ethically approved studies into conditions other than dementia, for example as a control participant. 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 MAKE SURE YOU READ THIS SECTION CAREFULLY

Please read the declaration text that applies to you (A or B) on page 6 carefully. If you do not sign in the box below to confirm your agreement to the terms and conditions, you will not be able to complete registration and you will not be considered for studies.

I HAVE READ, UNDERSTAND AND AGREE TO THE TERMS & CONDITIONS ON PAGE 6.

Signature

Today's Date

DD / MM / YYYY

MOISTEN HERE, FOLD IN HALF AND SEAL TO PAGE 4