

Register your interest in dementia research today

# Registration Form



StepUp for Dementia Research is a research participation and engagement service that connects individuals with researchers conducting studies relating to dementia.

**Help people living with dementia and their loved ones by registering to participate in research.**

To register today, complete the form below, call us at **1800-7837-123** or visit **www.stepupfordementiaresearch.org.au**

## Please read through the instructions carefully.

- On this registration form, you will find the basic information needed to register **either yourself OR someone else** for the StepUp for Dementia Research.
- You can only complete this form for one person.
- After completing and sending in this form, a letter of acknowledgement will be sent to you. This letter will include guidance on how to manage your account, including how to update your or the volunteer's information.
- For more information about the service, please consult the brochure enclosed with this form.
- **Please fill out the following details using BLOCK LETTERS in either BLUE or BLACK pen.**
- Please complete both Section A and Section B if you are registering someone else for StepUp for Dementia Research.
- Please return this form to **StepUp for Dementia Research, Level 1, R.C. Mills Building (A26), University of Sydney, Camperdown, NSW 2006**
- If you are signing up yourself as a volunteer, you **DO NOT** need to complete section B.

## Section A: Information about the person who should be matched to studies

In this section, please enter either:

- Your details (if you are signing yourself up as a volunteer) OR
- The details of the person (volunteer) for whom you are signing up

Title:	<input type="text"/>	First Name:	<input type="text"/>
Surname:	<input type="text"/>	Date of Birth (DD/MM/YYYY):	<input type="text"/> / <input type="text"/> / <input type="text"/>
Gender:	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other	Email: (if you have one)	<input type="text"/>

Who should researchers contact as the primary contact for StepUp for Dementia Research?

- Volunteer  Proxy who represents the volunteer

Please provide the primary contact detail.

Home Address:	<input type="text"/>				
Suburb/Town:	<input type="text"/>	State/Territory:	<input type="text"/>	Postcode:	<input type="text"/>
Telephone Number:	<input type="text"/>	Mobile Number:	<input type="text"/>		

How did you hear about StepUp for Dementia Research?

- |   |  |  |  |
|---|--|--|--|
| <input type="checkbox"/> Memory Clinic          | <input type="checkbox"/> Search Engine                 | <input type="checkbox"/> News Item           | <input type="checkbox"/> Family Doctor               |
| <input type="checkbox"/> Hospital               | <input type="checkbox"/> Dementia Australia            | <input type="checkbox"/> Exhibition or Event | <input type="checkbox"/> Care Home                   |
| <input type="checkbox"/> Referral from a friend | <input type="checkbox"/> Alzheimer's Western Australia | <input type="checkbox"/> Social Media        | <input type="checkbox"/> Other: <input type="text"/> |

Has the volunteer been diagnosed by a healthcare professional as having a form of dementia or cognitive impairment?  Yes  No

How would the volunteer describe their symptoms?  Mild  Moderate  Severe  Unknown

Does the volunteer have a first-degree relative (e.g., mother, father, sibling) with Alzheimer's disease or other types of dementia?  Yes  No  Don't know

**What is the diagnosis (if known)?**

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Alzheimer's Disease             | <input type="checkbox"/> Dementia with Lewy Bodies  | <input type="checkbox"/> Dementia in Huntington's Disease |
| <input type="checkbox"/> Vascular Dementia               | <input type="checkbox"/> Frontotemporal Dementia  | <input type="checkbox"/> Other types of Dementia          |
| <input type="checkbox"/> Mild Cognitive Impairment       | <input type="checkbox"/> Alcohol-Related Dementia   | <input type="checkbox"/> Not aware of specific diagnosis  |
| <input type="checkbox"/> Dementia in Parkinson's Disease | <input type="checkbox"/> Young (Early) Onset Dementia (Diagnosis made before the age of 65) |   |

**Has the volunteer experienced any of these health issues within the last 12 months? (If no, go to next question)**

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> Sleep disorders              | <input type="checkbox"/> Stroke              | <input type="checkbox"/> Depression                         |
| <input type="checkbox"/> Cancer                       | <input type="checkbox"/> High blood pressure | <input type="checkbox"/> Other mental/medical health issues |
| <input type="checkbox"/> Significant cardiac problems | <input type="checkbox"/> Diabetes            |   |

**Does the volunteer have any of these difficulties? (If no, go to next question)**

- |                                    |  |   |
|------------------------------------|--|---|
| <input type="checkbox"/> Deafness  | <input type="checkbox"/> Mobility                            | <input type="checkbox"/> Communication difficulties |
| <input type="checkbox"/> Blindness | <input type="checkbox"/> Learning or intellectual disability | <input type="checkbox"/> Other                      |

**Which of the following describe the volunteer's ancestry?**

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Australian              | <input type="checkbox"/> Aboriginal or Torres Strait Islander | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Other (please specify): | <input type="text"/>  |   |

**Is the volunteer currently taking any of these memory medications? (please tick as many as required)**

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Donepezil Hydrochloride (Aricept) | <input type="checkbox"/> Memantine Hydrochloride (Ebixa) | <input type="checkbox"/> None of the above |
| <input type="checkbox"/> Rivastigmine (Exelon)             | <input type="checkbox"/> Galantamine (Reminyl)           |  |

<p>Is the volunteer currently taking any form of medication to help with mood/agitation?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p>	<p>Does the volunteer have any form of memory problem / possible dementia-related problem?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>Is the volunteer's memory worse than it was 3 years ago?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>Have other people expressed concern about the volunteer's memory?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>Does the volunteer have difficulty with their job or usual day to day activities (e.g., shopping, driving, tax return) due to poor memory or thinking problems?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>Is the volunteer currently being investigated for a memory / possible dementia-related problem?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>

**Does the volunteer currently support, assist or care for a person living with dementia or memory problems? (please tick as many as required)**

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> No   | <input type="checkbox"/> Yes - currently supporting/caring for a relative/friend who has dementia | <input type="checkbox"/> Yes - working as a support/care staff member   |
| <input type="checkbox"/> No - previously supported/cared for a relative/friend who had dementia | <input type="checkbox"/> Yes - working as a health care professional                              | <input type="checkbox"/> Yes - working as an aged care provider/manager |
|   |   | <input type="checkbox"/> Yes - working as a volunteer                   |

**Make sure you read the following section carefully:**

**Declaration A: I am registering myself as a volunteer**

*I confirm the following:*

- I have read and understood the StepUp for Dementia Research Volunteer Information Sheet and Privacy Statement;
- I am 18 years of age or older;
- I am a resident of Australia;
- I understand that by participating in StepUp for Dementia Research, I am not committing myself to participate in any of the approved research studies that I am matched with; and
- I can withdraw from StepUp for Dementia Research at any time without giving a reason.

*I consent to:*

- the collection of my personal and health information for the purposes outlined in the Privacy Statement; and

- my personal and health information being used by/disclosed to:
  - personnel from approved research studies that I am matched with;
  - personnel from StepUp for Dementia Research (being staff from the University of Sydney, Alzheimer's WA and others as notified from time to time); and
  - the Commonwealth Department of Health.

I consent to StepUp for Dementia Research contacting me in relation to my account or to verify the information that has been collected from me during the registration process.

I consent to personnel from approved research studies contacting me in relation to studies that I am matched with.

**I would like StepUp for Dementia Research to contact me (tick boxes that apply):**

- to ask my opinion about improving StepUp for Dementia Research through polls and surveys;
- to inform me from time to time about StepUp for Dementia Research activities, such as service updates, and public involvement in dementia research opportunities; and
- to send me StepUp for Dementia Research newsletters.

I understand I can opt out of this contact at any time by changing my account settings on the StepUp for Dementia Research website or by calling the helpline.

I have read, understand and agree to the terms and conditions below.

Signature:

Date:

 /  / 

## Section B: Information about you, if registering on behalf of someone else

Although you are signing up for someone else, we still need YOUR information on this page.

You MUST answer ALL questions to complete a registration. Before completing this section, please read the declaration text found at the bottom of this form.

Important note: We can only register a volunteer with their signed consent, or the signed consent of someone who has legal authority (e.g., a guardian, enduring power of attorney, close family member or non-paid carer). You will be required to provide proof of this capacity by enclosing documentation when you return this form.

Title:

First Name:

Surname:

Date of Birth (DD/MM/YYYY):

 /  / 

Gender:

 Male  Female  Other

Email:

(if you have one)

Right now, is the volunteer able to understand the information sheet and complete this form with your support?

 Yes  No

Are you currently the person authorised to represent the volunteer? (e.g. a guardian, enduring power of attorney, close family member or non-paid carer)

 Yes  No  Don't know

Which of the following best describes your role?

- Enduring power of attorney
- Agent
- Others equivalent to the above
- Guardian (including enduring guardian)
- A person empowered under law to act as agent or in the best interests of the volunteer
- None of the above
- Public Guardian (and his/her delegate) or interstate guardian
- Substitute decision maker

Are you the sole guardian?

(Are you the only person that would be considered as a legal guardian of the volunteer, or are they under the care of more than one legal guardian?)

 Yes  No  Don't know

If you are not the sole guardian are you able to act independently of the other guardian(s)?

 Yes  No  Don't know

Which one of the following best describes your relationship to the volunteer?

- Spouse in a close and continuing relationship to the volunteer
- A person who is a close friend with frequent personal contact to volunteer and is not paid to care for the volunteer
- De facto partner in a close and continuing relationship
- A person who is a relative of the volunteer with frequent personal contact to volunteer and is not paid to care for the volunteer
- A person who freely provides domestic services and support to the volunteer
- A person who freely makes arrangements for domestic services and support to the volunteer
- None of the above

Are you under the care of a guardian?  Yes  No

Which of the following apply to you right now?

- I am helping a volunteer who is here with me now
- I am in direct contact with the volunteer right now by telephone, skype, or other
- I am not currently in contact with the volunteer

Does the volunteer understand the information provided in the Volunteer Information Sheet and have they agreed to register with StepUp for Dementia Research?  Yes  No

**Documents:**

We need to see evidence of your legal authority to represent the person volunteering. Please note, if you do not enclose the documents now, you will be required to do this later, and **the volunteer will not be matched to any studies until this is completed.**

If you do not have access to a scanner, a picture taken on a camera phone and printed is acceptable.

Please enclose:

1. A copy of YOUR photographic identification (your current passport, driver's license, employee card, other photo ID issued by a government agency) OR a copy of a recent bill you have received. Please note: we do not require a copy of the volunteer's identification.
2. If you are a sole guardian/enduring power of attorney or able to act independently of the other guardian(s), a copy of the signed document that appoints you the volunteer's guardian, enduring power of attorney, or other authorisation.

**Make sure you read the following section carefully:**

**Declaration B: I am registering someone else as a volunteer**

*I confirm the following:*

- I have read and understood the StepUp for Dementia Research Volunteer Information Sheet and Privacy Statement;
- Both the volunteer and I are 18 years of age or older;
- Both the volunteer and I are residents of Australia;
- I understand that by participating in StepUp for Dementia Research, I am not committing myself or the volunteer to participate in any of the approved research studies that the volunteer is matched with; and
- The volunteer and I can withdraw from StepUp for Dementia Research at any time without giving a reason.

*I consent to:*

- The collection of the volunteer's personal and health information for the purposes outlined in the Privacy Statement; and
- This personal and health information being used by/disclosed to:
  - personnel from approved research studies that the volunteer is matched with;
  - personnel from StepUp for Dementia Research (being staff from the University of Sydney, Alzheimer's WA and others as notified from time to time); and
  - the Commonwealth Department of Health

*I consent to StepUp for Dementia Research contacting me in relation to my account or to verify the information that has been collected from me during the registration process.*

*I consent to personnel from approved research studies contacting me in relation to studies that the volunteer is matched with.*

*I would like StepUp for Dementia Research to contact me (tick boxes that apply):*

- to ask my opinion about improving StepUp for Dementia Research through polls and surveys;
- to inform me from time to time about StepUp for Dementia Research activities, such as service updates, and public involvement in dementia research opportunities; and
- to send me StepUp for Dementia Research newsletters.

*I understand I can opt out of this contact at any time by changing my account setting on StepUp for Dementia Research website or by calling the helpline.*

I have read, understand and agree to the terms and conditions below.

Signature:

Date:

 /  /