

Registration Form



StepUp for Research is a research participation and engagement service that connects individuals with researchers conducting studies relating to dementia and ageing (including aged care).

Help people living with dementia, older people 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** or **www.stepupforagingresearch.org.au**

Please read through the instructions carefully.

- On this registration form, you will find the basic information needed to register **either yourself OR on behalf of someone** for the StepUp for Research.
- You can only complete this form for one person.
- After completing and returning this form, a letter of acknowledgement will be sent to you. This letter will include guidance on how to manage 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 on behalf of someone for StepUp for Research.
- Please return this form to **StepUp for 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 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"/>		

Q1. How did you hear about StepUp for Research?

<input type="checkbox"/> Memory Clinic	<input type="checkbox"/> Dementia Australia	<input type="checkbox"/> Family Doctor/GP	<input type="checkbox"/> Ageing and Aged Care Engagement Hub
<input type="checkbox"/> Hospital	<input type="checkbox"/> Media (TV/Newspaper)	<input type="checkbox"/> Care Home	
<input type="checkbox"/> Referral from a friend	<input type="checkbox"/> Exhibition or Event	<input type="checkbox"/> Australia Dementia Network Clinical Quality Registry	<input type="checkbox"/> Other: <input type="text"/>
<input type="checkbox"/> Internet Search	<input type="checkbox"/> Social Media		

Q2. StepUp for Research supports two streams of research - dementia and ageing. Which of those fields of research would the volunteer be interested in participating in?

Dementia Research Ageing Research Both

Q3. Does the volunteer live alone?

Yes No

Q4. What type of accommodation does the volunteer live in?

- Private Residence Public or Community Housing Residential Care Home
 Hospice Retirement Village or Independent Living Unit Other

Q5. Does the volunteer have a carer / someone who knows them well, and who helps support them with their health issues?

Yes No

Q6. Has the volunteer been diagnosed by a healthcare professional as having a form of dementia or cognitive impairment? (If yes, go to Q7. Otherwise, go to Q10)

Yes No

Q7. What is the diagnosis (if known)?

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

Q8. How would the volunteer describe their symptoms?

Mild Moderate Severe Unknown

Q9. Is the volunteer currently taking any of these memory medications? (please tick as many as required) (Go to Q15)

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

Q10. Does the volunteer have any form of memory problem / possible dementia-related problem?

Yes No

Q11. Is the volunteer's memory worse than it was 3 years ago?

Yes No

Q12. Have other people expressed concern about the volunteer's memory?

Yes No

Q13. 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?

Yes No

Q14. Is the volunteer currently being investigated for a memory / possible dementia-related problem?

Yes No

Q15. 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

Q16. Has the volunteer experienced any of these health issues within the last 12 months? (If no, go to Q17)

- Sleep disorders High blood pressure Down's Syndrome
 Cancer Diabetes Asthma
 Significant cardiac problems Depression Arthritis/Musculoskeletal conditions
 Stroke Other mental/medical health issues

Q17. Is the volunteer currently taking any form of medication to help with mood/agitation?

Yes No Don't know

Q18. Does the volunteer have any of these difficulties? (If no, go to Q19)

- Deafness Mobility Communication difficulties
 Blindness Learning or intellectual disability Other

Q19. Which of the following describe the volunteer's ancestry?

- Australian Aboriginal or Torres Strait Islander Prefer not to answer
- Other (please specify):

Q20. Does the volunteer currently support, assist or care for a person living with dementia or memory problems? (please tick as many as required)

- No Yes - currently supporting/caring for a relative/friend who has dementia Yes - working as a support/care staff member
- No - previously supported/cared for a relative/friend who had dementia Yes - working as a health care professional Yes - working as an aged care provider/manager
- 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 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 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 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 Research (being staff from the University of Sydney, and others as notified from time to time); and
 - the Commonwealth Department of Health.

I consent to StepUp for 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 Research to contact me (tick boxes that apply):

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

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

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

Signature: Date: / /

Thank you for completing the registration form. If you are signing up on behalf of someone, please go to the next page.

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 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:	<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"/>

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?

- | | | |
|--|---|---|
| <input type="checkbox"/> Enduring power of attorney | <input type="checkbox"/> Agent | <input type="checkbox"/> Others equivalent to the above |
| <input type="checkbox"/> Guardian (including enduring guardian) | <input type="checkbox"/> A person empowered under law to act as agent or in the best interests of the volunteer | <input type="checkbox"/> None of the above |
| <input type="checkbox"/> Public Guardian (and his/her delegate) or interstate guardian | <input type="checkbox"/> 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?

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

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 Research?

Yes No

IMPORTANT FOR THOSE AUTHORIZED TO REPRESENT THE VOLUNTEER

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 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 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 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 Research (being staff from the University of Sydney, and others as notified from time to time); and
 - the Commonwealth Department of Health

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

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

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

Signature:

Date:

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