



TeamUp For Dementia Research

Frequently Asked Questions and Information

Contents

About TeamUp For Dementia Research	2
1. What is TeamUp For Dementia Research	2
2. Who can sign up?	2
3. What are the benefits of signing up to TeamUp For Dementia Research?	2
4. Are the research studies safe?	3
5. What kind of research could I take part in?	3
Signing Up For TeamUp For Dementia Research.....	3
1. Do I have to sign up?	3
2. How do I sign up?	4
Data protection and privacy	4
1. Will my information be safe?	4
2. How can I contact The Alzheimer Society of Ireland Data Protection Officer?	4
Matching to research studies.....	5
1. What happens after I have signed up?.....	5
2. Will I definitely be contacted about participating in a study?	5
Leaving TeamUp For Dementia Research	5
1. What will happen if I want to leave TeamUp For Dementia Research?	5
2. How do I withdraw from TeamUp For Dementia Research?	6
Troubleshooting.....	6
1. What if there is a problem?.....	6

About TeamUp For Dementia Research

1. What is TeamUp For Dementia Research

TeamUp For Dementia Research is a service where people living with dementia and their families can register their interest in participating in dementia research. It connects you with researchers who are conducting studies in the area of dementia (e.g. prevention, diagnosis, treatment, care, and cure). This service is managed by the Alzheimer Society of Ireland and was created in collaboration with Dementia Research Network Ireland.

2. Who can sign up?

- People living with dementia in the Republic of Ireland
- Current or former family members/supporters over the age of 18

We welcome people from diverse backgrounds including (but not limited to) the LGBTQI+ Community, The Traveller & Roma Community and Black, Asian & Minority Ethnic Groups.

3. What are the benefits of signing up to TeamUp For Dementia Research?

- By signing up to TeamUp For Dementia Research, you increase your chances of taking part in ethically approved dementia research.
- Many people find being involved in research a rewarding experience and they enjoy contact with research teams.
- Although taking part in a research study may not be of immediate benefit to you, it might help people in the future.



- Some people with dementia and their carers/supporters have told us that taking part in research gives them hope for future generations and makes them feel like they are doing something valuable.
- It is also possible that there will not be any suitable studies for some volunteers, but new research studies are starting all the time.

4. Are the research studies safe?

All studies using TeamUp For Dementia Research have been approved by a Research Ethics Committee. This means that they have been checked to make sure they protect the rights, safety and wellbeing of people involved in the research.

5. What kind of research could I take part in?

Being part of TeamUp for Dementia Research allows you to see which research studies match your information and preferences. You can then choose if you would like to take part in studies that you match with.

There are different types of research. Some might include once-off interviews or surveys, while others might involve taking part in an intervention (e.g. art class, music therapy, exercise programme) over a period of time.

Different research studies have different aims. Some might look at ways of preventing dementia or improving diagnosis. Others might look at ways to improve care homes, community supports or quality of life.

Signing Up For TeamUp For Dementia Research

1. Do I have to sign up?

No, it is your choice whether you sign up to TeamUp For Dementia Research. If you decide to sign up, you will be asked to provide your consent. This means confirming you are happy to be part of TeamUp For Dementia Research. You have lots of choices about how we store and share your information and you can talk this through with us before you sign up.

Whatever you decide, it will not affect the standard of healthcare you receive or are entitled to. You can withdraw from TeamUp For Dementia Research any time.

2. How do I sign up?

To register you must first arrange a call-back with a member of our team. We will then sign you up for TeamUp For Dementia Research over the phone.

To arrange a call-back, visit www.alzheimer.ie/TeamUp/Register and complete the contact form.

Alternatively, you can arrange a call-back through our National Helpline on 1800 341 341. The Helpline is open six days per week (Monday to Friday 10 am to 5 pm, Saturday 10 am to 4 pm).

Data protection and privacy

1. Will my information be safe?

We take the security of your information seriously. Before starting this project we did a full assessment to look at how we can minimise any potential risks to data protection. We will always abide by prevailing data laws and General Data Protection Regulation (GDPR). If a breach occurs, we will ensure that this is addressed appropriately and efficiently. For more information about data protection please read our [Privacy Statement](#).

2. How can I contact The Alzheimer Society of Ireland Data Protection Officer?

Address: DPO, The Alzheimer Society of Ireland, National Office, Temple Road, Blackrock, Co. Dublin. Email: dataprotection@alzheimer.ie

Matching to research studies

1. What happens after I have signed up?

- After you register, The ASI will store your details and use these to match you to research studies that you are eligible to take part in.
- If you match to a research study we will contact you to let you know.
- If you have chosen to receive updates and newsletters, we will also send you newsletters 4-6 times per year by email.
- We will contact you at least once per year to make sure you still want to be on the TeamUp For Dementia Research database.

2. Will I definitely be contacted about participating in a study?

- Registering with TeamUp For Dementia Research does not necessarily mean that there will be a study available to you straight away. However, when a suitable study does come along, we will be able to link you with the researchers.
- It might take a while before you match with a research study but new studies are starting all the time.

Leaving TeamUp For Dementia Research

1. What will happen if I want to leave TeamUp For Dementia Research?

- You are free to withdraw your information at any time without giving a reason.
- We will remove all of your personal information from TeamUp For Dementia Research.
- You will not be contacted about any further studies on TeamUp For Dementia Research.
- Withdrawing from TeamUp For Dementia Research will not affect any existing research studies you have chosen to join or the standard of healthcare you receive.

2. How do I withdraw from TeamUp For Dementia Research?

If you want to withdraw you can contact us by e-mail, post or phone and we will assist you

E-mail: teamup@alzheimer.ie

Post: FAO Cíara O'Reilly, The Alzheimer Society of Ireland, Temple Road, Blackrock, County Dublin

Phone: Cíara O'Reilly on 085 870 9671

Troubleshooting

1. What if there is a problem?

If there is a problem, get in touch with us and we will help you to take your next steps.

E-mail: teamup@alzheimer.ie

Phone: Cíara 085 870 9671

If you require further information or would like to discuss any aspect of TeamUp For Dementia Research you can contact us using the information above.

Thank you for taking the time to read this guide