

ASI Research Newsletter

Summer 2023



THE ALZHEIMER
SOCIETY of IRELAND

Dear Colleague,

We are delighted to welcome you to the Summer edition of your ASI Research Newsletter. Below you will find information relating to recent research activities, information relating to the work of the Dementia Research Advisory Team, updates from our TeamUp for Dementia Research service and an insightful report on the Cost of Living while caring.

The Experience of Dementia in Ireland 2023 - We need your help!

The Alzheimer Society of Ireland is running a **national survey** to capture a snapshot of the experiences of people affected by dementia – those living with the condition and their families, caregivers and supporters. **We want to understand more about your key challenges and what support is needed.**

The information gathered from this survey will be used to inform our political advocacy, service planning and awareness-raising about dementia.

Participants can be located anywhere in the Republic of Ireland.

As the experience of living with dementia is different to the experience of supporting / caring for a person with dementia, there are two versions of the survey.

To begin the survey, please check out our website www.alzheimer.ie. However, if you would prefer to complete this survey over the phone with the support of a member of the Research Team simply let us know by emailing research@alzheimer.ie. This survey will close 5pm on the 23rd June 2023.

TeamUp for Dementia Research turns 2!

TeamUp for Dementia Research will soon celebrate its 2nd birthday! Since its inception in 2021, the service has grown considerably. We are proud to now support over 300 people affected by dementia to take part in ethically approved dementia research in Ireland!

Members have undertaken a variety of research opportunities such as interviews, focus groups and surveys. They contribute to lab-based, online and in-person research, often reporting overwhelmingly positive experiences of taking part. The service is adaptive and responsive, continuously improving itself to honour its person-centred ethos.

If you have not yet matched with a research opportunity please do not worry. It is only a matter of time until the right research project comes along for you.

To register as a TeamUp member, please check out www.alzheimer.ie.



Dementia Research Advisory Team

Who, what, why, where and how?

Who are they?

The Dementia Research Advisory Team (DRAT) is a group of people living with dementia and family caregivers.

What do they do?

The DRAT members are supported to engage with the research community in a Person Public Involvement (PPI) capacity. This means they work alongside researchers as co-contributors.

Why?

For research to be relevant and of value, it is vital to keep the lived experience of dementia at the heart of the research process. There is no previous research experience needed to become a PPI Contributor, the DRAT members are Experts by Experience and use their unique insights to improve research.

Where?

The DRAT members meet every 6 weeks online and come together 3-4 times per year for workshops and training.

Outside of these team meetings, the members connect directly with the researchers whom they are supporting, either in person or online, as is practical.

How?

Members are typically invited to work with a researcher or research team from the outset of their project, this ensures the lived experience is contributed throughout all stages. Drawing on their expertise as people affected by dementia, they collaborate with researchers on everything from setting research priorities to designing information leaflets and sharing research findings.

To learn more about the work of the Dementia Research Advisory Team [click here](#).



Report Launch: The Cost of Living While Caring



The Cost of Living while Caring

A brief report on the financial situation of family carers of people with dementia in Ireland



This brief report focuses on the financial situation of family carers of people living with dementia in Ireland. It highlights the financial challenges experienced by family carers.

This publication results from a collaboration between The ASI and Family Carers Ireland (FCI). It follows an analysis of feedback provided by family carers of people with dementia surveyed as part of FCI's The State of Caring 2022 report.

You can read the report in full on our website, www.alzheimer.ie