



Dear Colleague,

We are delighted to welcome you along to the Winter edition of your ASI Research Newsletter. Below you will find information relating to our research activities in 2022 as well as updates on the work of our Dementia Research Advisory Team and a number of currently recruiting research opportunities through our TeamUp for Dementia Research service.

Dementia Research Advisory Team Updates



The [Dementia Research Advisory Team](#) is a group of people living with dementia and carers/supporters who are involved in dementia research as co-researchers. The members are supported by The Alzheimer Society of Ireland to contribute to dementia research in a Person Public Involvement (PPI) capacity. This means working alongside the research community throughout the research process - from devising research questions all the way to presenting findings at conferences.

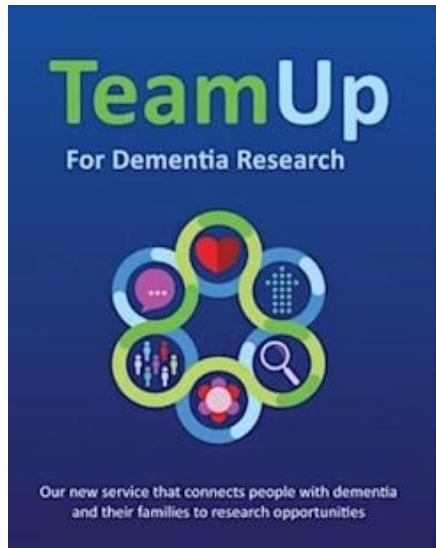
Throughout 2022 the members used their insights and expertise to collaborate on **13 ongoing projects** across a variety of universities. They **spoke at workshops and conferences** (both nationally and internationally!), **reviewed tender documents and funding applications** and excitingly, started to carry out their own research!

From selecting their research question, to designing their recruitment poster, hosting focus groups and devising survey questions, the members have been investigating **"The impact a diagnosis of dementia has on the person who becomes the caregiver / supporter."**

If people living with dementia and caregivers would like to contribute to this innovative research opportunity, there is a link to their brief survey below. (Please note, this survey closes on Wednesday 21st December at 5pm.) Important to note is that members of the Dementia Research Advisory Team come to us with no previous research experience. Lived experience of dementia is the only requirement to join the team.

Congratulations to the Dementia Research Advisory Team for all of their fantastic trail-blazing work in 2022!

TeamUp for Dementia Research



THE Alzheimer
SOCIETY OF IRELAND



**DEMENTIA RESEARCH
NETWORK IRELAND**
Prevention, Cure & Care for
Neurodegenerative Diseases

On Wednesday 7th December 2022, TeamUp for Dementia Research was featured in the final instalment of the DRNI's Hot Topics webinar series.

With a host of expert speakers (including Dr. Louise Hopper and Prof. Sean Kennelly), the webinar highlights the importance of and benefits to participating in dementia research. Dr Laura O'Philbin, Research and Policy Manager at The ASI closed off the panel by summarising the exciting developments' in the dementia research landscape in Ireland.

To watch back this important webinar, please click here: <https://www.youtube.com/watch?v=uT5Q5t7e2zY>

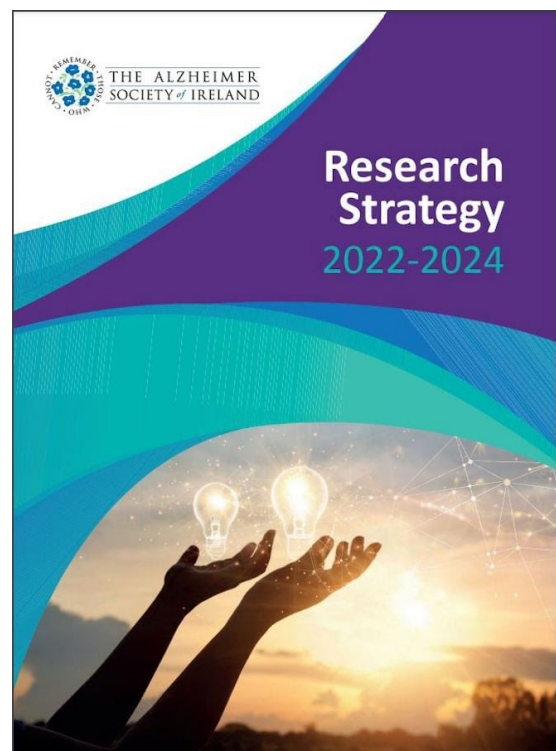
Research Strategy 2022-2024 officially launched

In June of this year, The Alzheimer Society of Ireland launched its 2022 - 2024 Research Strategy. This sets out the priorities, objectives and actions that will guide the work of the research team over the next two years.

These include:

- Supporting the development of essential research infrastructure in Ireland
- Developing and supporting quality dementia research that is in line with The ASI's mission and values and is important to the communities in which we work.
- Translating and sharing evidence-based research to promote public awareness of dementia research.

Click [HERE](#) to read our Research Strategy.



TeamUp

For Dementia Research



The below research opportunities are currently recruiting through the TeamUp for Dementia Research service.

If you would like to take part in any of these studies, please email teamup@alzheimer.ie

MEMORY RECALL STUDY



Trinity College Institute of Neuroscience is conducting a study to investigate if we can modify brain networks to improve memory.

To be included in this study are you:

- 50 years old or above
- A native English speaker
- Diagnosed with amnesic Mild Cognitive Impairment (aMCI)
 - With no history of severe head injuries, psychiatric illness, epileptic insult, or dementia unrelated to Alzheimer's

Benefits of participating:

- Contribute to cutting edge research investigating memory
- These methods are non-invasive, non-pharmacological, safe, with few adverse side effects

We are Looking for Focus Group Participants



Are you someone who has been diagnosed with dementia?

Are you currently or have been a care partner to someone living with dementia within the last 2 years?

Would you like to take part in a focus group (group discussion) about physical activity and physical activities you enjoy



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
01-856 2200

ST. JAMES'S
HOSPITAL

SENSE-Cog: Validation Study: adapting tools for the early recognition of cognitive and sensory health problems.

Are you over 60 and want to contribute to memory research?

We are looking for people who struggle with their vision

We are seeking volunteers to participate in a study called 'SENSE-Cog' aimed at finding ways to help with the early recognition of memory and vision problems (already wear/need glasses).

You will be asked to complete a series of tasks to evaluate your memory, vision and hearing. **We need participants who already have vision (you already wear/need glasses) problems.**



Recruiting in January 2023!

Beat the January blues by taking part in one of the newly recruiting social interventions!

If you are not already a TeamUp for Dementia Research member, please click [here](#) to register and avail of the opportunities below.

Telehealth Music Therapy for People Living with Dementia and their carers (Pairs), will be a wonderful mix of music listening, music reminiscence and movement to music for people affected by dementia who cannot avail of traditional community supports.

Online Music Therapy

for community dwelling people with dementia and their spouse/partner in Ireland



What is involved?

Six online music therapy sessions [once a week for 1 hour]
Music resources to access at your own time
15 minute interview about your experiences of taking part

When: January 2022 for 6 weeks
Where: Online via Zoom

The Buddy Programme is an exciting opportunity for people living with dementia to partner up with a Transition Year student "Buddy" for 6 weeks. The pairs meet for one hour per week on Zoom and engage in a shared activity / chats!

INTERGENERATIONAL DEMENTIA INTERVENTION

- The Buddy Programme



- ▶ Meet for one hour per week on Zoom with a Transition Year student "Buddy"
- ▶ Over a 6 week period
- ▶ Engage in Shared Activity (and chats!)
- ▶ Meet 1:1 or in pairs (to be decided and agreed between the Buddies)
- ▶ Complete brief journal entry after each session to inform write up and future development of the Buddy Programme



Telehealth Music Therapy for People Living with Dementia and their carers (Groups) will be a wonderful mix of music listening, music reminiscence and movement to music for groups affected by dementia who cannot avail of traditional community supports.



Online Music Therapy Group

for community dwelling people with dementia and their carers/companions living in Ireland



What is involved?

- Six online music therapy sessions [once a week for 1 hour]
- Music resources to access at your own time
- 15 minute interview about your experiences of taking part

When: January 2022 for 6 weeks

Where: Online via Zoom

Happy Holidays & Best Wishes for 2023

We would like to thank everyone for their continued support for Dementia Research and wish you all a safe and enjoyable holiday season.



THE Alzheimer
SOCIETY OF IRELAND



From everyone here at
The Alzheimer Society of Ireland,
THANK YOU for helping us make a difference
in the lives of people impacted by dementia
in 2022.

We couldn't do it without your support.

**We wish you and yours a joyous and
peaceful Christmas.**





Dear Colleague,

September is World Alzheimer's Month making it the perfect time to welcome you along to the Autumn edition of your Alzheimer Society of Ireland Research Newsletter. Below you will find updates about developments within The ASI's research team, information relating to the recent celebration of TeamUp for Dementia Research's first birthday and some exciting new projects for the members of the Dementia Research Advisory Team. Pop on the kettle and enjoy the catch-up!

The Dementia Research Advisory Team

The Dementia Research Advisory Team is a group of people living with dementia and carers/supporters who are involved in dementia research as co-researchers. Ensuring the lived experience of dementia is at the heart of dementia research the members influence, advise, and work with researchers across Ireland. This is known as Person Public Involvement or PPI.

The members are currently supporting 15 different research projects. They have worked with researchers to devise survey questions, develop research materials for potential participants and shared insights into the practicalities of moving a research project off the page and actually engaging with people affected by dementia.

Over the course of the coming months we look forward to the members sharing their PPI experience with audiences in UCD, Trinity and Maynooth.

To learn more about the Dementia Research Advisory Team visit <https://alzheimer.ie/creating-change/research/ppi/>.



PPI Song Writing Workshop

In the famous words of Hans Christian Anderson; "where words fail, music speaks". Dementia Research Advisory Team members Gerry, Helen & Kevin have been involved as PPI contributors in Lisa Kelly's PhD research since October 2020. This research, supervised by Prof Hilary Moss & Prof Ita Richardson, aims to explore how telehealth music therapy may support community dwelling people with dementia and their families, particularly those who live in rural or isolated areas.

Gerry, Helen & Kevin alongside their partners and supporters Nuala, Carmel & Helena recently attended a song-writing workshop at the Irish World Academy of Music & Dance at the University of Limerick. The workshop was facilitated by established songwriter, Carl Corcoran, and co-facilitated by the lead researcher on this project, Lisa Kelly.

Lisa says "Thanks to a PhD student bursary from PPI Ignite @UL, we were able to meet in person for the first time, after having Zoom meetings for the last two years. Safe to say plenty of craic was had!"

The songwriting workshop aimed to capture the importance of PPI in dementia research in a creative, non-traditional way. The song is entitled 'Who Will We Tell'. It is hoped that once further funding is secured, the song will be professionally recorded and disseminated to the public. We can't wait to hear it!



TeamUp for Dementia Research

On July 12th we celebrated **TeamUp for Dementia Research's** official 1st birthday!

The service has grown tremendously in the past year and we look forward to continuing to offer the members unique and exciting opportunities to engage in dementia research.

Many thanks to all of the members for their ongoing commitment to improving dementia research in Ireland.

Thank you to the many TeamUp for Dementia Research members who took the time to share their insights into the service and taking part in dementia research. We look forward to sharing further videos with you soon. You can watch some of these videos on The ASI's YouTube channel.

News and Upcoming Events

32nd Alzheimer Europe Conference

Building bridges #32AEC



The Alzheimer Society of Ireland is proud to have been awarded eight presentations at the upcoming Alzheimer Europe Conference.

Bringing together members of the dementia community (people living with dementia, family carers, health and social care professionals, researchers & policy makers) from all over Europe and beyond.

The ASI will proudly support members of the Dementia Research Advisory Team to share their experiences of Running their own Research Project with their international colleagues.

**RESEARCH STUDY
YOUNG ONSET
DEMENTIA**

Are you living with a diagnosis of young onset dementia?
We would love to hear from you.

We are conducting a study exploring the experiences of young onset dementia in Ireland. We aim to gather information on experiences of using community services, and suggestions for development of further community supports.

We are holding a series of focus groups with people living with younger onset dementia, and care partners.

Focus groups should last approx. one hour and will be held online. All information provided will be kept anonymous and confidential.

If you are interested, please contact Caroline to express your interest and to hear more about the study.

The Alzheimer Society of Ireland recently commissioned the development of specific guidance on how Dementia Service Providers and Community Groups can support people with Young Onset Dementia living in their communities through devising new services or adapting existing services.

With insights from an expert advisory panel and feedback from people affected by Young Onset Dementia we look forward to launching the results of this important work on Wednesday 21st September, World Alzheimer's Day.

To stay up to date with ongoing developments in the dementia research community please make sure to follow The Alzheimer Society of Ireland on their social media channels below or [click here to read our Research Blog](#).



Dear Colleague,

We are delighted to welcome you along to the Summer edition of your ASI Research Newsletter. It has been a busy last few months with the launch of our new [Research Strategy](#), [Research Blog](#), a packed schedule of [Dementia Research Advisory Team](#) engagements and of course the ever-growing [TeamUp for Dementia Research](#) service.

Enjoy the catch-up below!

TeamUp for Dementia Research 1st Birthday!



On July 12th we celebrate the TeamUp for Dementia Research's official 1st birthday!

Thank you to everyone who has worked with us over the last year. **We have 170 members engaged with the service and more than 20 projects currently being offered to members.**

We have some exciting things planned for this 1st birthday so keep an eye on our social media channels!

Learn more or sign up for TeamUp For Dementia Research [HERE](#).

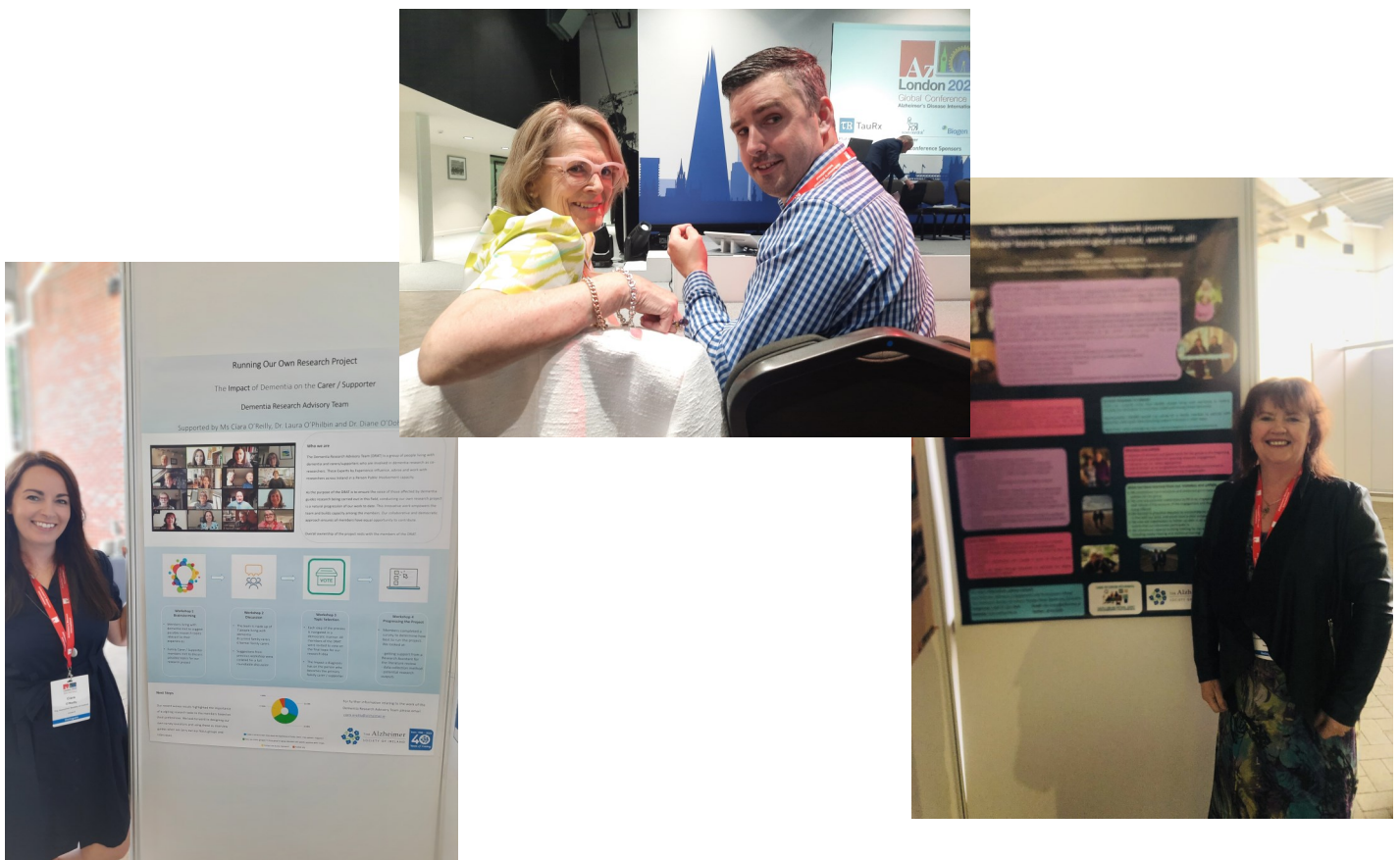
The Dementia Research Advisory Team at the Alzheimer's Disease International Conference



People with dementia and family carers/supporters from the Dementia Research Advisory Team were front and center at the Alzheimer's Disease International Conference that took place in London 9-11th June.

We had a **'Meet the Experts by Experience'** panel discussion with four members Kevin Quaid, Helena Quaid, Helen Rochford-Brennan and Carmel Geoghegan sharing their stories and highlighting their roles as Person Public Involvement (PPI) Contributors and Experts by Experience. This session was facilitated by Research Project Officer Cíara O'Reilly.

The Dementia Research Advisory Team also had a poster presentation at the conference, supported by Cíara that looked our Run Our Own Research Project.



5 things older LGBT+ people need you to know

Dr. Sinéad Hynes & Megan Oglesby from NUI Galway recently gave staff at The Alzheimer Society of Ireland a wonderful presentation on their work "Developing consensus-based recommendations for the delivery of dementia services for the LGBTQIA+ community in the Republic of Ireland".

This research identifies the future needs that older LGTBQIA+ people and their care partners living in Ireland have in relation to dementia care service delivery, and 2) develops consensus-based recommendations for dementia service provision in Ireland.

This research has been highlighted as part of RTE's Brainstorm.

LGBT Ireland Conference June 2022

A number of staff at ASI attended LGBT Ireland's Pride 2022 Older Persons Healthcare Conference at the Royal College of Surgeons in Ireland, Dublin. Dementia Advisor Vanessa Bradbury took to the stage as part of a panel discussion on inclusion, sharing her experiences of completing the LGBT Ireland Champions Training.

(A special thank you to LGBT Ireland for the photo of the ASI team).



Communications Officer Niamh Burke, Social Media Officer Sradha Sudarsanan and Research Project Officer Cíara O'Reilly also had the opportunity to meet briefly with Minister for Mental Health and Older People, Mary Butler TD.

Check out our Research Blog!



Don't forget to check out our Research Blog!

We aim to get 2-3 blogs out a month, highlighting new research, events, early career researchers, people affected by dementia etc.

One of our latest blogs highlights the work of Prof David O'Connell from University College Dublin. This plain language summary showcases up and coming research by Prof David O'Connell & his team on the emergence of new research that could lead to new Alzheimer drug development.

You can read his blog [HERE](#).



 **1800 341 341**



We are delighted to welcome you along to the Spring edition of your ASI Research Newsletter. It has been a busy start to 2022 with the launch of our new [Research Blog](#), a packed schedule of [Dementia Research Advisory Team](#) engagements and of course the ever-growing [TeamUp for Dementia Research](#) service.

Enjoy the catch-up below with a cup of something hot.

TeamUp for Dementia Research

The [TeamUp for Dementia Research](#) service launched in July 2021. From the outset it has been an incredibly active and varied service.

Already in the first quarter of 2022, we have offered our members 7 different research projects - from surveys to focus groups to one-to-one interviews.

If you have not yet matched with a study please do not be concerned. Our recently launched [Research Blog](#) covered the very important topic of "Inclusion & Exclusion Criteria" (ie, [how you are matched with a study](#)). It will only be a matter of time before a study relevant to your interest area comes up.

TeamUp
For Dementia Research
Connecting People and Research

500,000 people are affected by Dementia in Ireland, with 30 people diagnosed every day.

Do you want to have your voice heard in Dementia Research in Ireland?

To learn more:
visit: www.teamupfordementia.ie
email: teamup@alzheimer.ie
phone: 1800 341 341

DEMENTIA RESEARCH NETWORK IRELAND
Prevention, Care & Care for Neurodegenerative Diseases

THE ALZHEIMER SOCIETY OF IRELAND

Other Research Opportunities

Though the TeamUp service is dynamic and fast paced, it is still in its infancy - we cannot say yes to every research project. The Alzheimer Society of Ireland has long recognised that research is improved by having more people involved. We would therefore like to highlight some research opportunities (outside the scope of the TeamUp service) below. The contact details for the relevant researchers are included.

Non-verbal Communication

Dr. Aviva Cohen and her team in UCD have developed an innovative new app called Empathic. This unique app aims to help people who are no longer able to communicate verbally to independently communicate their emotions.

It uses artificial intelligence to interpret short recordings of non-verbal vocalisations.

Aviva and her team are now looking for people who fall into the above category, as well as with their formal and informal care providers, to trial the app.

For further information visit seamlesscare.ie or email Aviva@seamlesscare.ie



Children of People with Young Onset Dementia

Cathal Blake is completing his PhD through the School of Psychology in Dublin City University. The focus of much of his research work to date has been people affected by Young Onset Dementia.

Now moving into the next phase of his research, Cathal is looking to meet with children or young people across the three educational stages; primary school (from 7 years of age), secondary school and university, who live with (or have lived with) a parent diagnosed with young onset dementia.

If you would like to be involved in this important piece of research please contact Cathal on cathal.blake25@mail.dcu.ie



Research Opportunity



School of Psychology, Dublin City University

Study Title:

Childrens perspectives of parental young onset dementia



Who are we looking for?

We are looking for young people living with (or who have lived with) a parent diagnosed with young onset dementia.

Would you like to talk about your experiences?

What's involved?

An interview (**either online or in person**) lasting between 30-60 minutes with Cathal Blake (PhD student, School of Psychology, DCU.





For online interviews, you will need access to a device (e.g., a laptop or iPad) which has a camera and a microphone.

If you would like to know more, please contact the researcher at cathal.blake25@mail.dcu.ie

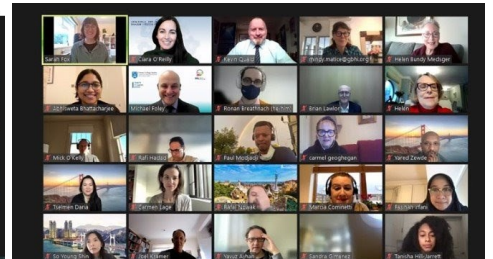
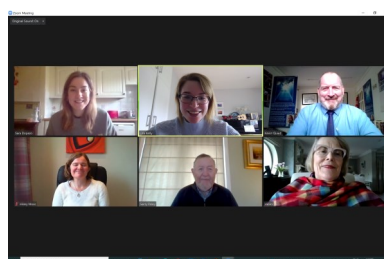
The Dementia Research Advisory Team

Members of the Dementia Research Advisory Team are internationally recognised for their contributions to research. They use their "lived experience" as people living with dementia and individuals with an experience of caring for someone affected by dementia to guide and advise the dementia research community.


The ASI's Research Team (Laura, Diane and Cíara) support the members to engage collectively in their own research, as well as to consult on no less than 13 other projects.

We are currently recruiting new members living with dementia to join the Dementia Research Advisory Team. You can take part from anywhere in the country and there is no experience necessary.

If you would like to learn more about the work of the Dementia Research Advisory Team please [click here](#) or email ciara.oreilly@alzheimer.ie



Important Upcoming Research



RESEARCH STUDY
YOUNG ONSET
DEMENTIA

Are you living with a diagnosis of young onset dementia?

We would love to hear from you.

We are conducting a study exploring the experiences of young onset dementia in Ireland. We aim to gather information on experiences of using community services, and suggestions for development of further community supports.

We are holding a series of focus groups with people living with younger onset dementia, and care partners.

Focus groups should last approx. one hour and will be held online. All information provided will be kept anonymous and confidential.

If you are interested, please contact Caroline to express your interest and to hear more about the study.

 **UCC**
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

caroline.kilty@ucc.ie / 085-764 1000
Centre for Gerontology and Rehabilitation
& School of Nursing and Midwifery, UCC.

Putting Research Into Practice

The Alzheimer Society of Ireland recognises the need to develop specific guidance on how Dementia Service Providers and Community Groups can support people with Young Onset Dementia living in their communities. This should be done either through the development of new services or the adaptation of current services.

This vital piece of work is being led by Dr. Siobhán Fox and Dr. Caroline Kilty from UCC, with the support and input of members of the Dementia Research Advisory Team and other expert panel members.

Opportunities to be a part of this work will soon be advertised through the [TeamUp for Dementia Research](#) service.

If you are not already a member of TeamUp but would like to be involved in this study please click on the link here: <https://alzheimer.ie/creating-change/research/teamup/register>