

Care and cure

The Alzheimer's Society research magazine

Globally united

Across the world and close to home, Alzheimer's Society supports research to improve the lives of people with dementia and find a cure.



Cancer and dementia

Peer support helps researchers to learn from people's experiences.

News

From artificial intelligence and stem cells to new starts and exciting discoveries, we update you on the latest research news.

Namaste Care

Find out how Alzheimer's Society research is changing care for people with advanced dementia.

40 years
2019





Dr Aoife Kiely
Editor

Welcome to Care and cure magazine

In this issue of Care and cure, we find out how Alzheimer's Society is connecting with research all around the world. In our feature on page 6 we introduce two new researchers Dr Elizabeth Dzung and Corrina Grimes. They are part of our international partnership with the Global Brain Health Institute. Our knowledge exchange fellowships are a joint effort with Alzheimer Nederland. We hear from previous recipients and learn about the next round of research on page 9.

We hear from researcher Mollie Price who is working with Talking Point, our online peer support community. They have created an online area for people affected by both dementia and cancer (page 10). This will allow researchers to learn from people's experiences.

Rosemary Phillips tells us her story on page 11. Caring for her parents, who lived with dementia, led her to work with the Society's Research Network.

We also update you on the latest dementia research news from Society-funded researchers and from around the world.

Thank you for picking up this issue of our research magazine – I hope you enjoy it!

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About us

Since 1990, Alzheimer's Society has funded £50 million of cutting-edge dementia research. Over the next decade we plan to invest £10 million per year in research and raise £50 million to support the UK Dementia Research Institute. This research helps to improve the quality of life of people with dementia by investigating prevention, improving practice in care and pursuing a cure.

alzheimers.org.uk/research



Stem cell research

Sian Gregory, in our Will to Remember team, helps people to access Alzheimer's Society's discounted will-writing scheme. Her background includes years of research into stem cells, and here she reports on some of the latest dementia research involving them.



What are stem cells?

Human stem cells present an exciting opportunity for future treatments. Some stem cells are described as 'pluripotent' because they can become any type of cell in the human body. In contrast, 'multipotent' stem cells can only go on to become one of a more restricted number of types of cell. Multipotent cells include human cortical neural stem cells – these can only grow into brain cells.

Although stem cells are mainly involved in our development while we're still in the womb, they also allow us to grow and repair damage throughout our lives. Some types of stem cell exist in certain parts of our body, such as the muscle, during our entire lifetime.

Stem cells and Alzheimer's

It has long been hoped that stem cell therapies could be used to repair the damage caused by diseases such as Alzheimer's. Although stem cell biology is a relatively new field, promising animal studies are beginning to show how stem cells might be able to treat diseases of the brain.

New research from Professor Eva Feldman at the University of Michigan has been testing this idea. Her research group placed human neural stem cells into the brains of mice that were showing the symptoms of Alzheimer's. The transplanted cells were put into the hippocampus, an area of the brain responsible for memory. The mice were then monitored to look for any changes in their thinking and memory skills.

The results

The mice had their memory tested for 16 weeks after the new cells were put inside their brains. The mice that had received the neural stem

cells showed an improvement in short and long-term memory. They also had better spatial awareness compared to animals without the stem cell treatment.

Another feature of Alzheimer's is the build-up of 'plaques' of a protein called amyloid within the brain. In the brains of the mice that had received the stem cell transplant, the number of amyloid plaques decreased. This study also showed that microglia – cells that 'mop up' amyloid plaques in healthy brains – had been activated in response to the stem cell transplant, helping to protect the brains of the treated mice.

The future

Although still in its early days, this research shows that stem cell therapy has the potential to become a treatment for diseases like Alzheimer's. It represents an exciting opportunity for further study, which someday might lead to human trials and therapies.

To learn more about Will to Remember and how leaving a gift in your will can support services as well as care and biomedical research, visit alzheimers.org.uk/willtoremember or call 0370 011 0290 to speak to Sian and her colleagues.



Welcome Fiona Carragher

Alzheimer's Society is delighted to welcome our new Chief Policy and Research Officer Dr Fiona Carragher.

Fiona Carragher joined the Society as Chief Policy and Research Officer in January, and she'll play a pivotal role in our vision to create a world without dementia. Fiona leads our growing and ambitious world-class research programme and portfolio, as well as our work to strengthen our position as the national charity leader on dementia health, social care policy and societal change.

Before joining us, Fiona was the Deputy Chief Scientific Officer for NHS England, supporting the 50,000-strong healthcare science workforce in the NHS. She worked on programmes ranging from antimicrobial resistance to hearing loss. A consultant clinical biochemist by background, Fiona has worked for two decades at Guy's and St Thomas' hospitals and King's College Hospital in London, and at Edinburgh's Royal Hospital

Fiona is committed to ensuring that we reach every person who has a dementia diagnosis and who wants our help. She wants to change the conversation on dementia so that it centres on the rights of people affected by the condition, and to drive research towards improving care and finding a cure.

Fiona says: 'I believe it will be through research, evidence building and innovation that we will be able to make a step change in care, prevention and one day a cure for dementia. There is so much for us to do, both in terms of driving policy and shining a spotlight on government to increase focus in this area, but also to catalyse a shift in our understanding of dementia through our continued investment in research.'



AI detects Alzheimer's early signs

Josie Clarkson, a dementia advisor and science writer in South London, reports on how artificial intelligence (AI) could help diagnose Alzheimer's disease earlier.

If a person is concerned about Alzheimer's, they might be sent to have a brain scan. A specialist memory consultant will carefully examine the scan to look for signs of Alzheimer's disease. They look for black spaces in scans of the brain where there shouldn't be any, showing places where brain cells have died. However, these gaps can only be seen when a person has had Alzheimer's for some time, so normal brain scans aren't very useful for detecting the condition's earliest stages.

Affected brain cells work more slowly before they die, which means they don't use as much energy. Measuring how much energy an area of the brain is using can show how healthy the brain cells within it are. In Alzheimer's, areas of the brain that are important for memory are usually affected early on. If these areas of the brain are using less energy, it could suggest that brain cells are being damaged by Alzheimer's disease.

The problem is that these changes in energy use are very subtle and difficult to see. This is where artificial intelligence (AI) – specially developed computer programmes that can rapidly analyse, learn and self-correct when performing a task – could help.

University of California researchers have used over 2,000 brain scans to train an AI to detect changes in energy usage. Over the course of the training, the AI learnt similar patterns it had seen in scans to help it spot signs of Alzheimer's disease.

The AI was tested using 40 patients' brain scans and assessed them all correctly. Most impressively, the AI detected Alzheimer's from scans taken of the participant's brains an average of six years before the person received a diagnosis confirming the condition.

The ability of this AI to diagnose Alzheimer's so early is ground-breaking. Treatment with anti-dementia medications is believed to be less effective because it often only starts after many brain cells have already died.

If an AI can help to diagnose people earlier, treatments may be more effective for them and they also have an opportunity to get involved in research sooner. This is also helpful to researchers who are especially interested in learning about the very earliest stages of the condition. Before this AI can be used more widely these results need to be double-checked in a larger and more diverse group of people.

Jog your memory

Recent research suggests that exercise causes the muscles of the body to release a hormone called irisin. We look at a study that suggests this hormone may help to improve memory in mice.

Irisin is one of the newest hormones to be discovered in the human body. Hormones are chemicals produced in one part of the body that travel through the bloodstream to affect another part. Recent research has shown that our muscles release irisin after exercise.

Researchers in Rio de Janeiro investigated how the irisin released after exercise affects the brains of mice that were bred to have Alzheimer's symptoms. The idea that physical activity could have a positive effect on memory comes up quite often, and these researchers suspected that irisin might be one reason. Their evidence suggests that irisin might help these mice to think more clearly.

The researchers also suggest that irisin might have less of an effect on the brains of people with Alzheimer's. They showed that there were lower levels of the protein that irisin is made from in the brains of people with Alzheimer's compared to people without the condition. Yet, based on this evidence, there are still major questions. For one, we can't be sure whether the irisin from our muscles can get into our brains to affect thinking and memory in the same way it does with mice. The brains of people are very different from those of mice, so we can't assume that what is true in mice will be true in humans.

The researchers say that irisin might one day represent a new way to reduce cognitive decline in people with dementia. Others have suggested that irisin could be a potential treatment for stroke, type 2 diabetes, obesity, cardiovascular disease and even polycystic ovary syndrome. However, all of these claims are based on a handful of small studies, and there is still so much that we don't know about irisin. Only more good quality research will show whether this hormone could one day offer a new way to limit the effects of Alzheimer's and other dementias.



Our research news

Recent research funded by Alzheimer's Society has advanced diagnosis, improved care methods and furthered our understanding of the causes of dementia.

It's not what you say

Our researchers at the University of the West of England Bristol have investigated whether changes in how a person uses language might indicate the development of dementia. This could also inform how best to communicate with people as their dementia progresses.

Common genetic cause

Society-funded researchers at UCL (University College London) have discovered a new rare genetic cause of Alzheimer's, also proposing that some forms of frontotemporal dementia and motor neurone disease have a common genetic cause. This adds weight to the idea that different brain diseases might involve similar things going wrong.



Stroke drugs for vascular dementia

New drug trials for vascular dementia treatments are on the horizon thanks to our researchers at the University of Edinburgh. Early stage testing suggests that already licensed drugs could be used after a stroke to prevent further strokes and halt the development of vascular dementia.





Globally united

We introduce two researchers who are working to improve end of life care. Their research is just one example of how Alzheimer’s Society is connecting researchers around the world to tackle dementia.

The final years, months and weeks of life of a person with dementia can be a confusing and isolating time. Dr Elizabeth Dzung and Corrina Grimes are researchers dedicated to improving end of life care for people affected by dementia.

Motivated to create change

Working as a junior doctor in New York, Elizabeth saw that people with dementia were often subjected to overly aggressive medical treatments without any chance to improve their condition. These treatments could also worsen their quality of life in their last days.

She told us, ‘I felt a great deal of moral distress providing intensive care unit level treatment for people with advanced dementia who had not previously expressed their wishes for the type of care they’d like to receive.

‘I felt that I was not acting in their best interest by providing burdensome treatments.’

‘I felt that I was not acting in their best interest by providing burdensome treatments such as mechanical ventilation and resuscitation, when it could not improve their condition and may negatively affect the quality of their remaining life.’

The majority of Corrina’s professional career has been devoted to improving palliative and end of life care. She is currently Palliative Care Clinical Lead at the Public Health Agency, where she co-leads the Northern Ireland Palliative Care in Partnership Programme – Palliative Care in Partnership (RPCP).

The aim of this partnership is to design and support the delivery of linked-up services that enable people to have improved quality at the end of their lives.

Working globally

Last year, both Elizabeth and Corrina were awarded a prestigious Atlantic Fellowship from the Global Brain Health Institute. This gives future leaders in brain health and dementia the skills they need to make a difference. Those on the fellowship spend a year between the University of California, San Francisco and Trinity College Dublin, learning about economics, epidemiology, law, ethics, leadership, neuroscience, public policy and statistics.

Following their studies, this select group needed pilot funding to take their ideas into the real world. In partnership with the US Alzheimer’s Association and Global Brain Health Institute, we funded 21 of their projects in 10 countries. These included research into how the experience of being a Syrian refugee affects thinking and memory, the impact of better gut health on dementia symptoms, and how music could improve quality of life for people with dementia.



Our Global Brain Health Institute researchers: Dr Elizabeth Dzung (left) and Corrina Grimes (right).

Our collaboration with the Global Brain Health Institute and Alzheimer's Association is just one example of our commitment to international solutions for the worldwide issue that is dementia. Although funding UK-based biomedical and care research is our priority, working with global partners takes our investment further, connecting us with many more great minds and ideas.

We've also built partnerships across the world through the EU Joint Programme on Neurodegenerative Disease Research. Through this, we've joined forces with organisations in 15 countries – including Australia and Canada – and funded 10 new international research projects, eight of which will take place in the UK. You can read about our partnership with Alzheimer Nederland on page 9 – a knowledge exchange programme that is creating new connections and opportunities for researchers to learn advanced techniques.

Identifying need

The final stages of dementia can be difficult for medical and care professionals and for carers to identify. Palliative and end of life care has tended to be more closely based on cancer, yet all those with an advanced and progressive condition, like dementia, can benefit from a palliative care approach.

'We hope that the AnticiPal tool will help to alert GPs to the palliative needs of people with dementia in their care and support discussions and care planning.'

Corrina recognised that it was important to help GPs and the primary care team to have a way to identify people with dementia who would benefit from a palliative care approach. She also knew that the person's clinical record often holds indicators of their likely future need, such as swallowing difficulties and recurring infections.

To determine whether reviewing medical notes could be done more efficiently, Corrina is using a tool called AnticiPal. It shows how clinical data that is routinely collected by the GP can be used to help identify people in need of planning and care co-ordination. Encouraging results have been reported from research testing this method in Edinburgh. Corrina has recruited 30 GP practices across Northern Ireland to take part.

She says, 'We hope that the AnticiPal tool will help to alert GPs to the palliative needs of people with dementia in their care and support discussions and care planning.'

Corrina was inspired to work with us because we share her commitment to ensure that research findings are used quickly to make a difference in the real world.

The right care

Having seen how, even with the best intentions, end of life care can result in people with advanced dementia receiving unnecessary and even distressing treatments, Elizabeth wants to understand why this happens and what can be done to reduce it.

To do this, she'll be comparing care provided in four hospitals in the US, two in France and two in the UK. This type of study, called ethnography, involves observing hospital staff and people affected by dementia in their day-to-day activities and interviewing them. This should help her to understand why this kind of burdensome care gets put in place when neither doctors nor patients want it.

In the US, doctors might feel an incentive to promote expensive and unnecessary treatments. In any country, both doctors and carers might face a conflict between wanting to do what is best for the person and feeling they must do 'everything possible'. This could be made worse if doctors haven't clearly explained the risks and benefits of various treatments.

Elizabeth's previous research focused on the way clinicians approach end-of-life care in the US and UK. The culture of hospitals in the US tended to prioritise patient choice regardless of whether the treatments would be beneficial. UK doctors tended to make treatment decisions based on the patient's best interests. Her work highlights the benefits of learning from practices in other countries.

Including French hospitals in her current study will allow Elizabeth to compare a system that more closely resembles the UK's. She hopes that her work will highlight how the attitudes of medical professionals can be changed to empower people with dementia and their families to make the best-informed choices.

For our End of life care (531) factsheet, see [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications) or call 0300 303 5933 (local rate).



Namaste care

Malayka Rahman-Amin, Research Translation Manager at Alzheimer's Society, tells us about a therapy for people with advanced dementia, and how her role supports researchers to make a real-world impact.

Ensuring that people in the later stages of dementia receive excellent care is a priority for the Society, and I've been working closely with researchers involved in Namaste care.

Namaste care aims to enhance quality of life in the later stages of dementia, when people can feel isolated and unable to join in with activities around them. Developed in 2013 by Joyce Simard in the US, Namaste care helps the person to remain connected to others by focusing on their emotional as well as physical needs.

'Namaste' is a term from Hinduism meaning 'to honour the spirit within', and this is what Namaste carers aim to do by engaging a person's senses through sound, touch, smell, taste and sight. This can include hand massages or sharing familiar food or drink. The person's life history is used to tailor interventions – a former golfer could benefit from interacting with a golf ball, while for a knitter this could be a ball of wool.

The University of Worcester's Association for Dementia Studies has led research to see how Namaste care may be made more available in the UK, supported by one of our three-year implementation grants. These grants are designed to help researchers find ways to put evidence from their research into practice.

Isabelle Latham, managing the research project, says they have observed many benefits due to Namaste care, as well as insight into how care homes can introduce this approach effectively.

'We have seen weight gain, increased hydration, reduced agitation and restlessness, and increased communication and awareness,' she says.

'We have also learned a lot about the challenges of using Namaste care and what care homes need to do to make the change successful and long-lasting. Through our project findings, care homes all over the country will benefit from the experiences of our case study care homes.'

'We have seen weight gain, increased hydration, reduced agitation and restlessness, and increased communication and awareness.'

The project has been testing Namaste care in six care homes, through group sessions for people with advanced dementia. Four of the homes have committed to continuing to provide Namaste care after the testing finishes this summer – a good example of how this type of research can have a sustained impact. The researchers will present further news at the Society's annual conference in May.

To help spread the word about the benefits of Namaste care further, we have awarded the project team further funding to produce a film showing the approach in action.

For more about Alzheimer's Society Annual Conference on 21-22 May in London, visit alzheimers.org.uk/conference

An example of the calm and welcoming atmosphere created for Namaste care – soft, gentle moving lights, tactile items, gentle music and pleasing aromas.



Double Dutch

How researchers are benefitting from our knowledge exchange fellowships with Alzheimer Nederland



Alzheimer Nederland is the largest care and research charity in the Netherlands, as Alzheimer's Society is in the UK. Both organisations know that major advancements in dementia research and care wouldn't be possible without teamwork. With this in mind, we united to launch our first round of knowledge exchange fellowships in 2015.

This programme enables researchers to learn new techniques from experts in their field, so they can take their research to the next level. It also builds and strengthens vital relationships between researchers that will spark new ideas and collaboration in the future.

In the first round, seven fellowships meant that care and biomedical researchers in the UK and Netherlands could spend up to a year in the other country. In December 2017, we brought these researchers together in Amsterdam to talk about the programme's impact on their work.

'I was able to bring this technique back to my home university and share it with my colleagues and in training new researchers.'

'At the Netherlands lab, I learned a new technique for looking at the behaviour of brain cells in the living brain,' said one researcher. 'I was able to bring this technique back to my home university and share it with my colleagues and in training new researchers.'

Another said, 'We took the opportunity to compare dementia services in the UK and Netherlands, which gave us the chance to share culture and good ideas with our fellow researchers.'

The researchers' feedback was overwhelmingly positive, and we decided to go ahead with another round of fellowships that have just been awarded.

Strathclyde and Amsterdam

Dr Kieren Egan from the University of Strathclyde will spend time with Professor Anne Margriet Pot at Vrije University Amsterdam to investigate ways to empower people with dementia who live alone. Maintaining a social life is an important element of living well with dementia, but this is a challenge when up to one-third of people with the condition live on their own.

Liverpool and Maastricht

Dr Clarissa Giebel from the University of Liverpool will join Dr Hilde Verbeek at Maastricht University to see what prevents people with dementia from using care services. Clarissa hopes to use this evidence to support people to live independently for longer.

Leiden and Edinburgh

From Leiden University Medical Centre, Dr Boyd Kenkhuis will visit the University of Edinburgh to work with Professor Josef Priller. Boyd will learn how to grow stem cells, taken from people with Alzheimer's, into immune cells. He'll also investigate whether iron might be involved in triggering inflammation within the brain.

Amsterdam and Worcester

Finally, Marleen Prins from the Netherlands Institute of Mental Health and Addiction will visit Professor Dawn Brooker at the University of Worcester. Their research will focus on ways to improve support for family carers of people with dementia.

We look forward to updating you on the outcomes of these research projects.



Talking about cancer and dementia

A researcher has joined forces with our online community to create a supportive area for people who care for someone who has both dementia and cancer.

The number of people living with dementia in the UK is set to rise to one million in the next three years, by which time almost half of the population can expect to be diagnosed with cancer during their lifetime. Clearly, a growing number of people with dementia will also have cancer at some point.

Not much is known about what life is like for people who have both dementia and cancer – very little research has explored their unique experiences and needs. The same goes for the experiences of family members and friends who care for them, and the specific challenges they face.

Mollie Price is a psychology PhD student at Leeds Beckett University. Interviewing the carers of people with dementia and cancer has allowed her to piece together a better understanding of their experiences, challenges and needs.

‘We hope that, by creating a designated area, these carers can access a social support network of others who understand the unique challenges they face.’

Mollie told us, ‘Many carers said that, although they were given information about cancer and about dementia, they received very little information about this specific combination of conditions and how they might interact, with poor co-ordination between specialists. They wanted tailored information and to speak to others caring for a person with dementia and cancer, and to read their experiences.’

Mollie has now teamed up with Serena Snoad, who manages Talking Point – our online community where 65,000 members have free, round-the-clock access to ask and answer questions, offload concerns and share experiences.



Mollie and Serena launched a specific area on Talking Point dedicated to people caring for someone living with both dementia and cancer.

‘One of the benefits of online support is that it is easily accessible 24/7 from home,’ said Mollie. ‘This addresses some of the barriers of face-to-face support groups, which can be difficult to attend due to caring responsibilities, particularly when caring for a person with multiple conditions.’

‘We hope that, by creating a designated area, these carers can access a social support network of others who understand the unique challenges they face.’

This project is part of a larger dementia and cancer research programme at Leeds Beckett University. Other projects are looking at effective hospital-based cancer treatment, and the care and support needs of people living independently or in a care home.

Our healthcare system typically assumes that people have one long-term condition, and there is a lack of support for people affected by more than one. The dedicated area on Talking Point is, to our knowledge, the first digital research project of its kind. It gives carers the chance to talk about their experiences and find practical and emotional support.

Mollie will find out what aspects of the area have been most useful and what support these carers would like to see in the future, drawing on the online conversations and through a survey.

During the project, people will get the chance to have their questions answered by cancer and dementia experts through the special area. The first of these Q&A events took place in January with Lorraine Burgess, a Macmillan dementia nurse consultant at the Christie Hospital in Manchester.

Visit alzheimers.org.uk/talkingpoint to join Talking Point and search ‘cancer and dementia’ to find the dedicated area.



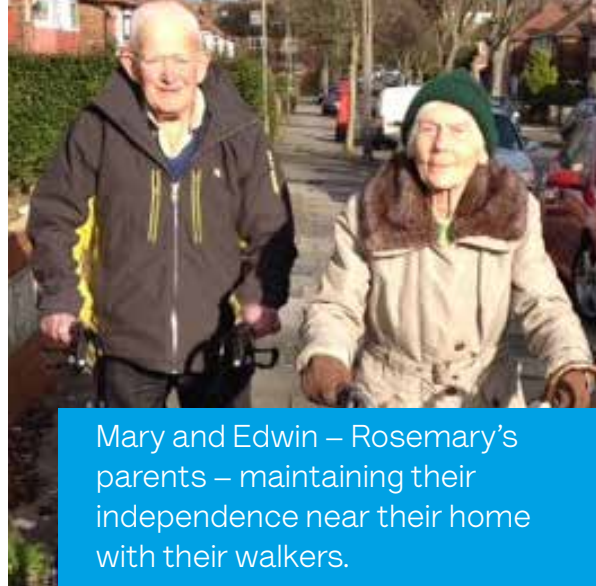
Guiding research

Rosemary Phillips shares her experiences as a Research Network volunteer.

I have been a member of Alzheimer’s Society Research Network since 2012. I first came across it on the Society’s website, where I saw something about reviewing scientific and care grant applications. I quite liked the idea of getting back into my research background, so I decided to apply and see what happened. I thought that I might have something to offer, it would do me some good and I might enjoy it.

I was a carer for both of my parents who were living with dementia up until they died, my mother four years ago and my father two years ago. My mother had been diagnosed with Alzheimer’s disease in her mid-nineties and my father with vascular dementia following a series of transient ischaemic attacks. I supported them with house and hospital things, helping them to get about when they couldn’t do it themselves. They had both been active and independent so I wanted to support them in keeping as much independence as possible.

To me, being involved in the Research Network and other Alzheimer’s Society activities is a luxury because I can do things that I really enjoy doing. I feel that I am useful, I feel that I am making a difference and I am grateful to be able to do it because I know not everyone else can. Learning the science can be challenging, as my background is in maths. I still find the biomedical side of dementia to be hard work but I am getting better. And I enjoy doing it.



Mary and Edwin – Rosemary’s parents – maintaining their independence near their home with their walkers.

A few years on and I am now very busy with the things that have come from Alzheimer’s Society. It has filled the gap that was left after my parents died. The Research Network led onto other things – I now sit on an advisory panel for lay people and we have a say on which grant applications should be funded. I have joined panels to help in interviewing new Society staff members. I have also monitored a couple of projects, which involves going to visit the researchers every six months. This gives the researchers a chance to explain where they’re at, what they’re doing and where it’s going next. I then report back to the Society to report on progress and say if we have any concerns. It’s really interesting.

One of the projects I monitored was that of Professor Claire Goodman’s PhD student at the University of Hertfordshire. The research involved investigating what makes a good dementia-friendly initiative in a healthcare setting. Three of us met up with her every six months and, by the end, we felt like we were part of it because we were so involved and so engaged.

Join the Research Network

At Alzheimer’s Society, we believe that people affected by dementia can make a unique and valuable contribution at every stage of research.

No qualifications, scientific knowledge or research experience is needed to be a Research Network volunteer. If you have personal experience of dementia as a carer, former carer or person with dementia, you can help and support our research.

Visit alzheimers.org.uk/researchnetwork to find out more and get involved.

Researchers say:

‘Working with Research Network volunteers was a valuable addition to the project. They acted as critical friends for the study. They contributed information and shared their personal experiences of accessing health care for relatives who have dementia. It has been useful to share the emerging findings with them to make sure that the findings have relevance for people with lived experience.’

Professor Claire Goodman



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is our
only hope
to beat
dementia**

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Call 0300 222 1122 and ask about Join Dementia Research

Join our Research Network

Involving people with dementia, carers and former carers to influence our research, alzheimers.org.uk/researchnetwork

General enquiries

enquiries@alzheimers.org.uk

Magazine enquires: Aoife Kiely

Research Communications Officer and Magazine editor
aofe.kiely@alzheimers.org.uk

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