

Care and cure

The Alzheimer's Society research magazine

Making history for 20 years

Research Network volunteers have been making Alzheimer's Society research meaningful for 20 years.



Accelerate to success

How Alzheimer's Society is fast-tracking great ideas.

Life in a brain bank

What it's like to work at a brain bank.

40 years
2019





Dr Aoife Kiely
Editor

Welcome to Care and cure magazine

We've had an exciting lead-up to summer at Alzheimer's Society. In Dementia Action Week at the end of May, researchers and volunteers across the UK united to make people with dementia feel more included in our communities. At our annual conference, held during the same week in London, researchers and policy experts updated us about what we all still need to do to improve the lives of people affected by dementia and to drive progress to a cure.

In this issue of Care and cure, we mark an incredible 20-year milestone for our Research Network. Barbara Woodward-Carlton takes us through the network's history and what it has supported the Society in achieving over the last two decades.

We also spotlight our researchers' latest achievements and round up the latest UK and global dementia research news.

Thank you for picking up this copy of Care and cure, we 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

Could air pollution cause dementia?

We've brought together neurologists, epidemiologists and experts on the effects of toxins in the brain to help us make sense of the research so far and what we still need to find out.

Research to date has linked air pollution to a wide range of health conditions, in particular respiratory and cardiovascular disease but also to certain forms of cancer and developmental disorders. Polluted air has also been implicated in impaired brain function and potentially dementia.

While there's a lot of hot air out there, we at Alzheimer's Society wanted to get a clear view of the facts. We brought together a panel of experts in neurology, epidemiology, environmental risk and how metals behave in the brain to advise us.

What is air pollution?

Air pollution refers to substances that are present in the air, or have entered the air, which have harmful effects. Air pollution can come from many sources and travel across distances, and it can interact with other molecules with various consequences.

Most research into whether air pollution is linked to dementia has been through studies of large populations, and there are limitations to them. Many base their findings on where a person is currently living, without taking into account the level of pollution at any previous addresses or at their workplace. These studies are often also retrospective—they look back on what has happened in a person's life, rather than recruiting

them and seeing how their health then changes over time. The latter gives researchers a better chance to observe cause and effect, and the ability to rule out coincidences.

An indirect link?

Though research to date has not shown how air pollution could directly cause dementia, evidence does point towards an indirect cause. It is likely that the effect of air pollution on our respiratory and cardiac health has a knock-on effect on brain health, increasing our risk of developing dementia.

More research is required

There is some evidence that particles from air pollution might be able to enter a person's brain. If these triggered a toxic response in the brain, this might cause damage that in turn increases the risk of dementia. However, we need more research to find out if this is really the case.

We do know that air pollution has a negative effect on our health, and it is encouraging to see more political engagement with this topic. On an individual level, the infographic suggests how we can limit our exposure to air pollution.

Does air pollution increase the risk of dementia?

We don't know yet.



Until we know more, you can still benefit your health



Reduce how much you use your car



Use the CityAir app to plan walking or cycling routes on quieter roads



Limit use of wood burning stoves or gas cookers



Check for alerts of high pollution days and avoid exercising outdoors on those days





Investigating mushrooms

Josie Clarkson, a dementia support worker and science writer in South London, looks at research into mushrooms and brain function.

Love them or hate them, mushrooms can divide the crowd – their texture and earthy flavour put some people off, while others enjoy them for precisely the same reasons. Tastes aside, mushrooms can be a valuable part of our diet, providing fibre and a range of vitamins and minerals.

Mushrooms also contain an antioxidant called ergothioneine. Reduced levels of ergothioneine have been observed in people with mild cognitive impairment (MCI), who also have an increased risk of developing dementia. This doesn't mean there's a link between eating mushrooms and dementia, of course, but these kinds of associations can be worth exploring.

A study in Singapore, of 663 people aged over 60, aimed to investigate any link between mushrooms and brain function. Over six years, Lei Feng and his team of researchers measured how many mushrooms the people taking part in the study ate. They also tested everything from participants' IQ, blood pressure and walking speed to their mental health. This included scoring them using a dementia symptom scale that is used to help diagnose MCI and dementia.

The people who ate at least two 'standard portions' – that's over 300g – of mushrooms per week were 50% less likely to have MCI. This doesn't prove that eating mushrooms improved anyone's brain function, since there could be other reasons behind this finding. For example, people who generally eat healthier diets and are more physically active might also tend to eat more mushrooms. If that were true, then their lifestyle could explain their lower risk of developing MCI, with or without the mushrooms.

Despite this, it certainly could be worth investigating ergothioneine and other chemicals in mushrooms to see if they have any effect on their own.

These studies take time, but in the meantime we'd recommend enjoying a healthy, balanced diet with a variety of fruit and vegetables—and that could include mushrooms!

See www.nhs.uk/livewell for information and advice to maintain health and wellbeing.



Further impact of carer stress

New research shows that stress and lack of confidence in carers can also affect the quality of life and wellbeing of the person with dementia who they support.

We know that unpaid carers shoulder 75% of the costs of supporting a person with dementia. As people in the early and moderate stages of dementia rarely use services, family and friends collectively spend an average of five hours a day carrying out caring responsibilities.

University of Bradford researchers, working as part of the IDEAL study of living well with dementia, wanted to investigate how the experiences of the carer might influence ability of the person with dementia to live well.

They asked over 1,200 people living with dementia to tell them how they rated their own quality of life and sense of wellbeing and satisfaction with life.

They then ask their carers about their experiences of care-related stress, how competent they felt as a carer, whether they could identify positive aspects of providing care, if they felt that they faced any social restrictions, and how well they felt they were coping as a carer.

What did the researchers find?

Comparing the answers of people with dementia with that of their carers, the researchers saw a pattern emerging. When a carer reported feeling highly stressed, lacking competence and facing social restrictions, the person they cared for was more likely to rate their own quality of life, wellbeing and satisfaction as being low.

This research shines a light on how important the experience of the carer is, not only for their own wellbeing, but also for the person with dementia. This further underlines how crucial it is that carers are supported, both emotionally and practically.

Grow your own neurons

New evidence suggests that we might still be able to make new neurons as we age, and Sian Gregory, science writer and executive on our Will to Remember team, finds out what this means for Alzheimer's.

Memory and the hippocampus

Understanding how we think, learn and feel is a fast-paced and complex area of research. Different parts of the brain are responsible for different functions, from communication to our five senses. The hippocampus is essential for making memories, and neurons are cells in our brains that allow us to think, feel and act. In Alzheimer's, neurons in the hippocampus begin to die off early and it is the most severely affected brain area in the disease.

Making new neurons

The brain is different from other body parts, as it mostly does not regenerate as we age. Brain cells that you have as a toddler will more or less be the same ones that you live with throughout your life. Yet it has been suggested that the hippocampus might have a special ability to create new neurons as we learn. Evidence of the creation of new neurons in the human hippocampus was first shown in 1998 and has been hotly debated ever since. If true, it could represent a potential way to replenish the neurons that die off as a result of diseases like Alzheimer's. However, although the evidence of new neurons is strong in mice, research so far has struggled to confirm it in people.

New evidence

In April 2019, research from Dr Maria Llorens-Martin's group in Spain looked as though it could be the first clear evidence of the human adult hippocampus making new neurons. Dr Llorens-Martin's group showed not only this, but that this ability stays with us even into our 90s. They showed that the creation of new neurons is a slow process, with the cells gradually maturing into proper functioning cells over time.

Does Alzheimer's change this?

The researchers also examined the brains of people with Alzheimer's disease. They found notably fewer new neurons being made. As the disease progressed, fewer and fewer new neurons were made. Alzheimer's disease is characterised by the build-up of protein 'plaques' and tangles in the brain. The researchers noticed that the decline in new neuron production began before the plaques and tangles had formed. This finding could prove to be a key early diagnostic tool for the future.

Future potential

This research is important because it highlights how Alzheimer's is not a natural part of growing older. Instead, this data suggests that far fewer new neurons are made in the brains of people living with Alzheimer's disease than in older people without the condition. This research is still in the very earliest stages and further study is needed. Yet, armed with this new knowledge, researchers can begin to consider using the creation of new neurons as a potential therapy for Alzheimer's disease.

Our research news

Recent research funded by Alzheimer's Society has improved early detection, enhanced care practice and deepened our understanding of how the brain functions.

Brain tune

Our researchers at UCL in London have been getting musical, using brain scans to find out which parts of the brain work together to understand melodies and how this is affected in dementia. This helps us to better understand how our brains appreciate music and how this could be used in future therapies.

Early detection

New evidence from our researchers suggests that a new biomarker in blood could predict the onset of genetically inherited Alzheimer's up to 15 years in advance. Further research will find out whether it could do the same for non-genetic forms of the condition.

Living well

Our researchers in Exeter have provided evidence that living with multiple conditions along with dementia negatively affects a person's ability to live well. They call for greater awareness of this issue among health and social care professionals, and a multidisciplinary approach to care provision.



Making history for 20 years

Barbara Woodward-Carlton, a founding member of the Research Network, shares some history and her experiences as a volunteer through the years.

By the late 1990s, Alzheimer's Society had been funding research for over 10 years and was receiving an increasing number of applications for funding. Harry Cayton, the Society's Chief Executive at the time, appointed its first Director of Research, Dr Richard Harvey. They shared a vision to fund not only high quality research, but research that was meaningful and relevant to people affected by dementia. To do this they set about establishing the Quality Research in Dementia programme, which would later become the Research Network.

Richard toured the Society's regional offices and carer groups to recruit volunteers to the Research Network. It was during this time that I joined as a volunteer, along with more than 100 people with dementia, carers and former carers. This groundswell was a strong indication of our enthusiasm to be active participants in the Society's research programme. At the time, I would never have expected to still be a member 20 years later!

Through its Research Network, Alzheimer's Society was now able to formally include people affected by dementia in selecting and monitoring research grants by 1999. The idea of inviting active public participation was still a revolutionary concept at that point, though 'public and patient involvement' is now routine in medical research. As pioneers, Alzheimer's Society has ensured that the voice of people affected by dementia has been instrumental in enriching the work done by researchers.

What does the Research Network do?

Anyone with personal experience of dementia can join the network. Members get involved in a variety of ways, such as:

- Helping to make decisions about what research to fund
- Monitoring the progress of research projects
- Supporting researchers in their work in many ways, from developing grant applications through to sharing the results of their work.

Shaping research and policy

I started monitoring my first research project in 2002 – the Focused Intervention Training and Support (FITS) project. I visited the researchers to keep an eye on the progress of the project. This was a landmark study that I was proud to be a part of, addressing the overuse of antipsychotic medications in care homes.

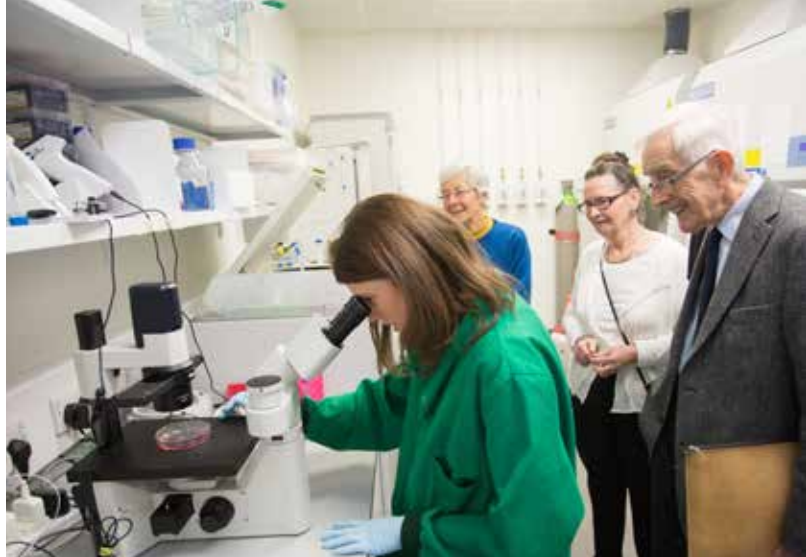
When the FITS researchers told us the results, we were so thrilled that the hair stood up on the backs of our necks.

They had proved that, with better training for care home staff, they could provide person-centred care and reduce the unnecessary use of antipsychotic drugs. This greatly increased the quality of life of people with dementia as well as staff, and gave their families piece of mind.

A developing network

Over the years, Research Network volunteers have expanded their roles, based on their skills and interests. We have helped the Society to set research priorities and strategies, interviewed research grant applicants and new staff members, and sat on research steering committees. We have been invited to speak about the importance and impact of dementia research at Society events, as well as to the media and at national and international conferences.

Alongside my fellow Research Network volunteers, I have campaigned to raise public and parliamentary awareness of dementia and the need to increase funding. Thanks to the dedication of the network over the past 20 years, we have seen a significant increase in dementia research funding and improvements in health and social care policy.



James Pickett, Head of Research at Alzheimer's Society, said, 'The research network was created to ensure that Alzheimer's Society funded research through its programme that was relevant to people with dementia. But the network and its members have done so much more; they have changed the national conversation on recognising the right of people being researched to be involved in decisions about research.'

'They have changed the national conversation on recognising the right of people being researched to be involved in decisions about research.'

James Pickett

The future of dementia research

Anna-Louise Smith, our Research Engagement Manager, supports the activities of Research Network volunteers.

'It's clear why the Research Network is valued so highly across the dementia research field. Many of the Society's achievements in research have come about due to the contributions of our dedicated volunteers.

Over the past 20 years, our network has been at the forefront of making improvements, including campaigning to widen access to treatments, highlighting the need to reduce unnecessary antipsychotic use, lobbying for more research into improving care, and implementing research into practice.

We are now focused on growing the network and providing more opportunities for people to get involved, share their lived experience and help to drive dementia research forward.'

As Research Network volunteers, we are still using our knowledge, experience and reflections 20 years on to help further good quality, evidence-based research. Now numbering over 300, our involvement helps to ensure that dementia research is of relevance to people affected by the condition.

Join us

No qualification, scientific knowledge or research experience is needed to be a Research Network volunteer. If you have a 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 or call 020 7423 3563 to find out more.

Accelerate to success

Alzheimer's Society's new ground-breaking crowdsourcing Accelerator programme aims to inspire and recruit innovations and inventions to help people with dementia to live better.

Alzheimer's Society's new Accelerator Programme allows us to partner with external 'innovators' – engineers, designers, developers, entrepreneurs, anyone with a good idea. Partners receive up to £100,000 investment and a 12 month partnership with our Innovation team to help develop their product or service and to bring their idea to life.

It could be an innovative idea about a simple product that makes an everyday task easier for a person living with dementia, or an idea for a new service or way of working for care home staff. Experts from Alzheimer's Society can advise partners on planning, budget, resource management and how to evaluate their product or service so that the impact of the idea on people affected by dementia can be measured.

The Society is delighted to announce its first two partners:

- How Do I? an app, which helps people affected by dementia to stay independent for as long as possible with smartphone videos.
- Jelly Drops – Sweet treats that help to ease dehydration.

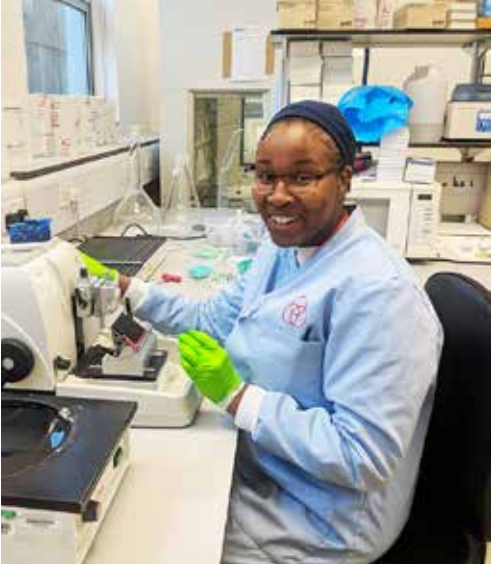
The smartphone app 'How do I?' helps people with dementia to carry out everyday tasks like boiling a kettle, by flashing up 'how to' videos when their phone scans an object. As well as providing helpful prompts the videos can help to remind people with dementia of fond memories. Loved ones are able to record an explanation of a photo, and the memories that it captures.

The innovative Jelly Drops were invented by Lewis Hornby after his grandmother, who has dementia, was hospitalised for dehydration – a widespread problem for people with the condition who can forget to drink or not wish to. Jelly Drops overcome this issue by providing efficient and appealing hydration. These bright, tasty treats are over 90% water, with added ingredients to make them even more hydrating. Eating one full box of drops is the same as drinking three full cups of water, which is more than many people with dementia currently consume a day.

Alzheimer's Society is the only charity to be using such innovation to find the best products, offering £100,000 and specialist guidance to the partners to bring their products to market. More information can be found at:

alzheimers.org.uk/accelerator





Life at a brain bank

Shalmal Jones is a research technician at the Brains for Dementia Research brain bank, King's College London

What led you to working in the brain bank?

I have always liked science, and while studying psychology in college my interest in neuroscience was sparked by the story of Phineas Gage. He was a railroad worker in the 1800s who survived a severe brain injury when an iron rod entered his head through his cheek and exited through the top of his skull. He recovered physically but his personality was drastically altered.

I wanted to learn more about the brain and how brain injury, stress and disease can influence its function and our behaviour. I qualified as a biomedical scientist and jumped at the opportunity to take the job at the brain bank, where I could contribute my skills for processing and examining donated brain tissue.

What is a typical day like for you at the brain bank?

When a brain is donated to the Brains for Dementia Research brain bank, it is divided in two from front to back. Both sides are divided into blocks of brain regions that are affected by different dementia-related diseases. One side is quickly frozen to -80°C . The other side is preserved in chemicals and embedded in wax.

One aspect of my work involves these wax blocks of brain samples. I use a specialised machine to cut very thin slices of the wax-embedded tissue and mount these onto microscope slides. After this, I use special dyes and markers to highlight structures, brain cells and toxic proteins that have built up in that person's brain.

The second aspect of my work involves preparing brain samples for researchers who have applied to Brains for Dementia Research to receive tissues from us. We can send them either frozen tissue samples or wax tissue on glass slides, depending on the type of research that they want to do.

Do you think people have misconceptions

about what brain banking is like?

Yes – a lot of people imagine it is very different from how we actually work. Brain donation and banking is a very careful and organised process. We always aim to work with the families of donors in the most compassionate way. There are clear protocols and procedures set in place from the time of death of the donor to when their tissue is used for research.

What is your favourite thing about working for Brains for Dementia Research in the brain bank?

My favourite thing is being part of the brain banking network that we are building across the UK, which is opening up conversations about brain donation for research.

At our recent public and patient involvement event, I had the chance to speak to some of our current donors and their study partners (person close to them who will support the brain donation). They were so interested in the science and techniques behind getting a diagnosis and about how their brains will help research after they die.



Five years of PREVENT

We take a look at past and potential achievements of PREVENT, a landmark study to discover new biomarkers for dementia.

PREVENT is a UK and Ireland research project that is testing healthy people aged 40–59 regularly to discover new biological and psychological factors that could affect their risk of developing dementia later on.

On 25 February, PREVENT celebrated five years since recruiting its first study participant. In that time, it has grown from a single research centre to five sites across the UK and Ireland, at the universities of Edinburgh, Oxford, Cambridge, Imperial College London and Trinity College Dublin. Over 550 people have signed up to take part in PREVENT, and the researchers plan to have recruited a total of 700 by the end of the summer.

What does the study involve?

New PREVENT participants are invited to one of the five research centres to take part in a range of physical and mental tests. The tests measure heart and lung health and general fitness, and samples are taken of their blood, saliva and often spinal fluid. Participants are asked to complete memory and thinking tasks, while brain scans look at brain structure and function. Lifestyle questionnaires also cover diet, medical and psychological history, sleep and personality.

This first round of tests acts as a baseline, so that when the researchers run the same tests with people two years later and in years to come, they can compare them to identify any subtle changes that might predict the development of dementia.

PREVENT will follow participants for many years and collect an enormous amount of information about risk and the early detection of dementia. Treatments based on this knowledge may one day be used to delay or even stop the onset of dementia symptoms in people who are at risk of developing them.

What has PREVENT achieved so far?

PREVENT is already making an impact, with the researchers sharing their experiences and recommendations on effective ways to involve people in research. They have provided evidence that some early changes in small blood vessels in the brain might increase the risk of Alzheimer's disease in older people who carry a particular gene. They have also suggested that changes in how people use language during conversations could be an early indicator of the first cognitive changes that are associated with dementia.



If you are interested in taking part in PREVENT, call the researchers on 020 8483 1823 or use the contact form at www.preventdementia.co.uk

Care and technology

A ground-breaking £20 million research centre will develop new technologies to create dementia-friendly homes and provide insights into how dementia develops.



In April, the UK Dementia Research Institute launched a new centre as part of its Care Research and Technology programme. The centre, based at Imperial College London and the seventh opened as part of the institute, has received an investment of £20 million from the Society, Alzheimer's Research UK and the Medical Research Council.

Alzheimer's Society has been using its voice in the UK Dementia Research Institute to ensure that, as well as looking for treatments, we can also improve the lives of people living with dementia today through care, technology and public health research.

The Care Research and Technology centre brings engineers, doctors and researchers together with people affected by dementia. They will use technology such as artificial intelligence, robotics and wearable sensors to see how dementia-friendly homes could help people with the condition to live well at home for longer. We support the development of technology that won't further isolate people with dementia, but which supports social interaction and improves quality of life.

Artificial intelligence will be developed that is capable of getting to know the habits and routines of a particular person. This could then pick up on changes such as infections, sleep disturbance or altered behaviour, allowing the care and support they receive to be adjusted.

Robotic systems will be used to create smart homes that allow voice-controlled interaction to support or enhance human interaction. This could include switching on lights, playing music or displaying photos, but also helping to keep the person safe by switching off the oven.

Fiona Carragher, Chief Policy and Research Officer at the Society, said, 'Developing dementia shouldn't have to mean losing your independence and your choice over whether to live in your own home. But we know there can be problems and we want to find solutions.'

'Developing dementia shouldn't have to mean losing your independence and your choice over whether to live in your own home.'

Fiona Carragher

The Care Research and Technology centre aims to develop technology that can pick up early signs so that people get the help they need before problems hit a crisis. One fifth of hospital admissions for people with dementia are due to entirely preventable causes such as falls and infections.

Professor David Sharp, Neurologist at Imperial College London and Director of the new centre, said, 'The new technologies will allow us to intervene at an early stage. What's more we'll be able to improve our understanding of dementia onset and progression.'

We look forward to sharing new developments with you as we work with our team of incredible researchers to improve care for today and find a cure for tomorrow.



Rise to the challenge and bake to beat dementia



Sign up for your free fundraising kit at cupcakeday.org.uk

0300 222 5770
cupcakeday@alzheimers.org.uk



Alzheimer's Society is a registered charity in England and Wales (296645); the Isle of Man (1128) and operates in Northern Ireland.



Keep up to date

Care and cure is the research magazine of Alzheimer's Society. To receive a copy of this magazine quarterly, please sign up at alzheimers.org.uk/careandcure

Take part in research

Sign up online at www.joindementiaresearch.org.uk
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

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