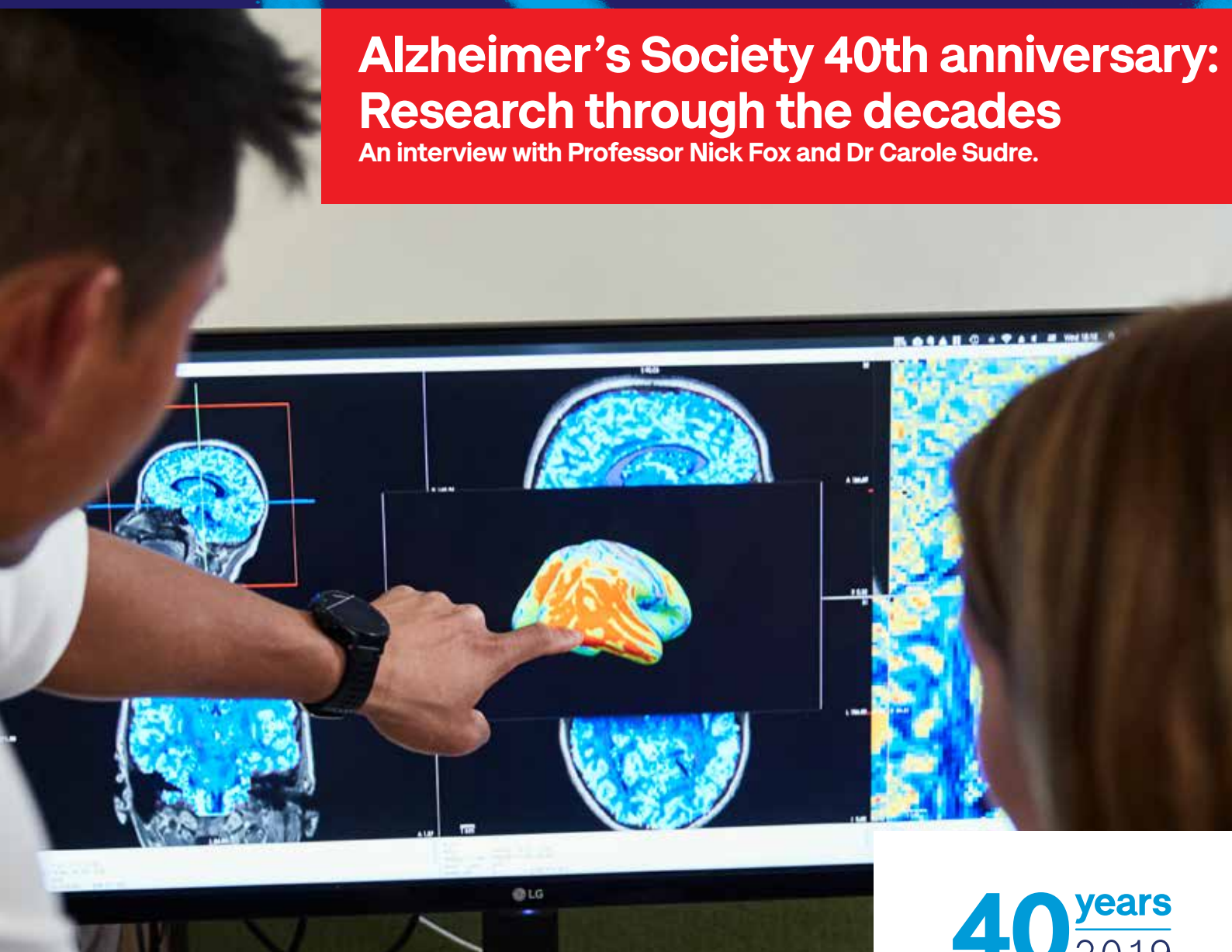


# Care and cure

The Alzheimer's Society research magazine

## Alzheimer's Society 40th anniversary: Research through the decades

An interview with Professor Nick Fox and Dr Carole Sudre.



### Caregiving HOPE

Research Network Volunteer Sandra Barker reports on the Caregiving HOPE study.

### Research news update

We catch up on global research and the latest discoveries.

**40** years  
2019





**Dr Aoife Kiely**  
Editor

## Welcome to Care and cure magazine

The progress of dementia research doesn't slow down over the summer months and we have a jam-packed autumn issue to prove it. This – the 20th issue of Care and cure – coincides with the 40th anniversary of Alzheimer's Society. On this milestone, we highlight the progress of dementia research and look to the future. We sat down with Professor Nick Fox, a leading name in dementia research, and Dr Carole Sudre, an early career researcher, to hear their insights.

Looking to the future, we share the latest on the brand new £2 million UK Dementia Research Institute gene therapy centre led by Professor Chris Shaw. In care research news, we hear from Research Network volunteer Sandra Barker about the trailblazing work of the Caregiving HOPE project. We catch up on the START programme too, which has shown the positive impact of providing psychological support for carers.

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!

### 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](http://alzheimers.org.uk/research)

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# Have you heard?

Recent UK-based research suggests that middle-aged people with hearing loss who used a hearing aid had less age-related cognitive decline than those who didn't.



In good news for people with a hearing aid, research suggests that using one when needed may benefit your cognitive health in the long term. Using a hearing aid when you experience hearing loss in midlife could reduce the risk of your memory and thinking skills gradually fading, or it might slow this process down.

The research was carried out at the University of Exeter as part of PROTECT, an online study of healthy volunteers aged over 50. PROTECT aims to learn more about what happens to our brains as we age. In this study, the cognitive skills of over 50s who had hearing loss and either used a hearing aid or did not, were measured and followed up for two years.

The people who wore hearing aids performed better in tasks that required good working memory – the type of memory that we use during tasks or while holding a conversation. They also had faster

reaction times. This suggests that they are better able to perform daily tasks and stay engaged in conversation.

What is unclear is exactly why using a hearing aid has this impact. It seems unlikely that hearing loss directly triggers cognitive decline, otherwise younger people with hearing loss would also experience it. As this is not the case, the researchers suggest that hearing loss probably affects the person's ability to engage with their families and social groups. After all, isolation and loneliness have been suggested as factors that increase the risk of developing dementia.

At Alzheimer's Society, we're currently funding a project to improve hearing problems in care homes. The aim is to help make sure that anyone with a hearing problem receives the support they need.



## Blood test for Alzheimer's

Researchers in the US report a 94% accuracy rate in a blood test for Alzheimer's even before symptoms begin.

Exciting new research has shown that a recently developed blood test is 94% successful in detecting Alzheimer's disease.

The research, from Washington University School of Medicine, examined the blood of 158 people. Only 10 people in the study had cognitive decline. Each participant gave a blood sample, was screened for genetics and underwent a brain scan. Using the blood samples, the researchers measured the levels of amyloid beta protein, which builds up in the brains of people with Alzheimer's.

The greatest risk factor for Alzheimer's is age. In addition, the number of copies that you have of the gene APOE4 can increase your risk of developing the condition. The blood test was most accurate when researchers combined the measurement with an age of over 65 and APOE4 status.

At first the researcher thought they'd mismatched some of the results, as the blood test was positive

for amyloid beta but the brain scan looked normal and the person didn't have cognitive symptoms. However, when they followed up, an average of four years later, brain scans began to show the first signs of disease. This meant that the blood test was indicating the disease before the scan could detect it.

This blood test needs more testing to confirm its accuracy before it can be used confidently in practice, but it is a significant breakthrough. A key reason many trials for Alzheimer's drugs have failed is that researchers haven't been able to treat people before the condition takes hold. This test offers hope because it can detect signs of the disease before symptoms have begun.

Dr James Pickett, the Society's Head of Research, said, 'This test will speed up dementia research by identifying those at risk of Alzheimer's who might be suitable for clinical trials aimed at preventing or delaying the development of dementia.'



## Women and dementia – new insights

**Worldwide, women with dementia outnumber men two to one, but biomedical research is only now beginning to investigate why this is the case.**

At this year's Alzheimer's Association International Conference, held in Los Angeles, researchers reported that women are more likely to be affected by specific genetic mutations that can cause dementia. The fact that women and men may experience different kinds of genetic risk adds weight to the idea that medicine needs to account for these differences.

At the same conference, the largest focusing on dementia, we also learned that tau – a protein that builds up in the brains of people with some forms of dementia – spreads more rapidly through women's brains than men's.

outnumber men two to one across the world. Dementia also affects women differently, with symptoms like delusions, depression and reclusiveness experienced more widely in women than men.

'Women's brain health is an under-studied topic, and, historically, the lion's share of dementia research has focused on men. Our researchers are hard at work to rectify this imbalance, with new information and greater focus on this area, potentially leading to the development of sex-specific drugs and risk-reduction strategies.'

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**'The facts speak for themselves – women living with dementia outnumber men two to one across the world. Dementia also affects women differently, with symptoms like delusions, depression and reclusiveness experienced more widely in women than men.'**  
**Fiona Carragher**

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Fiona Carragher, Chief Policy and Research Officer at the Society, says, 'The facts speak for themselves – women living with dementia



# Steps to prevent memory loss

## Could walking up to 9,000 steps per day reduce the brain damage caused by dementia years before symptoms begin?

We know that exercise is good for our general health, particularly for our hearts. Research suggests that regular exercise could also reduce the toxic effect of proteins that build up in the brain as dementia develops.

Research at Harvard Medical School showed that healthy people who exercised often had less cognitive decline as they aged than those who didn't. Using brain scans, they observed less build-up of the amyloid protein that is a characteristic of Alzheimer's disease. They also found less evidence of brain shrinkage linked to cognitive decline, and the same people performed better in memory tests.

It is important to remember that this was a short trial and none of the participants developed dementia within that time. For this reason, we cannot be sure that they would have a reduced risk of dementia.

Also, the researchers didn't test for the build-up of tau protein, which matches up with cognitive decline and brain cell death more closely than amyloid.

Dr James Pickett, Head of Research at Alzheimer's Society, said, 'This study adds to previous research showing that people who are more active have a slower reduction in their memory and thinking skills as they get older, lose fewer brain cells and have less amyloid – a hallmark of Alzheimer's disease – in their brain.

'However, this can only show us that levels of physical activity are linked to brain measures. It doesn't tell us that increasing activity would reduce your risk of getting dementia. There are ongoing trials to see if increasing activity can prevent cognitive decline and dementia, and we eagerly await these results. Prevention is key, which is why we're funding a variety of studies to better understand the different risk factors for dementia.

'What this research does suggest to us is that staying active is no bad thing in keeping your mind sharp and your brain healthy.'



## Our research news

Recent research funded by Alzheimer's Society has called out care cost injustice, identified risk and made the case for art intervention in dementia care.

### Unfair care costs

Our researchers have shown that unpaid carers are shouldering 42% of the annual cost of dementia care. Caring for a person with advanced dementia can incur expenses of £46,000 and more per year. We are using this evidence to help call for better support for people affected by dementia.

### Falls and blood sugar

We know that having low blood sugar can harm people with diabetes, but we're now also learning how people with dementia might be affected. Our researchers at University of East Anglia have shown that severe low blood sugar increases the likelihood of a person with dementia falling and getting injured. The researchers call for personalised monitoring strategies to reduce the risk of low blood sugar in people with dementia.

### Letting art in

In Nottingham, our researchers have been studying how to overcome barriers that get in the way of arts therapy in care homes. Their research highlights how artists can integrate arts programmes into the care of people living with dementia.

# Alzheimer's Society 40th anniversary: Research through the decades

Professor Nick Fox and Dr Carole Sudre share their insights on how far dementia research has come in the last few decades.

**Dr Carole Sudre**

Carole was awarded a junior fellowship by Alzheimer's Society in 2017.



Her research focuses on the relationship between damage to the brain's blood vessels and thinking and memory skills.

She is using specially designed artificial intelligence software to predict how blood vessel damage is likely to progress – vital information for a neurologist.

**Professor Nick Fox**

Nick was awarded one of our first research fellowships in 1993. Since then,

he has become a professor of clinical neurology, Consultant Neurologist at the National Hospital for Neurology and Neurosurgery and Director of the Dementia Research Centre at UCL in London.

A leading light in dementia research, Nick's work into brain imaging has had a global impact. He has received prestigious awards in recognition of his research into early detection, diagnosis and progression of the diseases that cause dementia.



## Looking back

**A fellowship is a researcher's first major step in becoming the leader of their own research group. Nick, can you tell us how significant receiving fellowship funding from the Society was to your career and research?**

Nick: The fellowship completely set the course of the rest of my life. The Alzheimer's Society fellowship put me onto familial Alzheimer's disease, and that has been my passion ever since. I honestly wasn't sure about what I was going to do, and the fellowship totally captured me for dementia research.

**Have you noticed a shift in public attitudes or understanding of dementia while you have been associated with the Society?**

Nick: Dementia is now part of our common experience in a way that it never was before. It's in books, films and sitcoms, and sadly affects many families. I think there are very few things that truly change the fabric of society. Yet we have seen a notable shift in attitudes to dementia, from people's conversations to our literature and culture.

**Both of you specialise in brain imaging – how far have brain scans come, in particular MRI?**

Nick: MRI (magnetic resonance imaging) has come a very long way in the last few years. We can use MRI to see structural change and now also changes in inflammation. Thanks to advances in molecular techniques, such as analysis of cerebrospinal fluid and blood, we also get a far richer understanding of disease.

## Looking to the future

**Carole, your research is an excellent example of advances in brain imaging. Could you describe it?**

Carole: We know that even the tiniest damage to small blood vessels in the white matter of the brain can lead to major damage and have a massive impact on cognition – thinking and memory skills. I am using artificial intelligence, specifically deep learning, to detect these areas of damage and to link their location with the cognitive impact.

**How has our understanding of the significance of small blood vessel damage improved?**

Carole: This has really changed in the last few years. Slowly, people have realised that you have a link between damage to small blood vessels in the brain and the acceleration of cognitive decline and onset of dementia.

We now know that the variety of symptoms is related to the location of the damage to blood vessels, though there is still a lot of research to do.

## Better diagnosis

### Why is early and accurate diagnosis important?

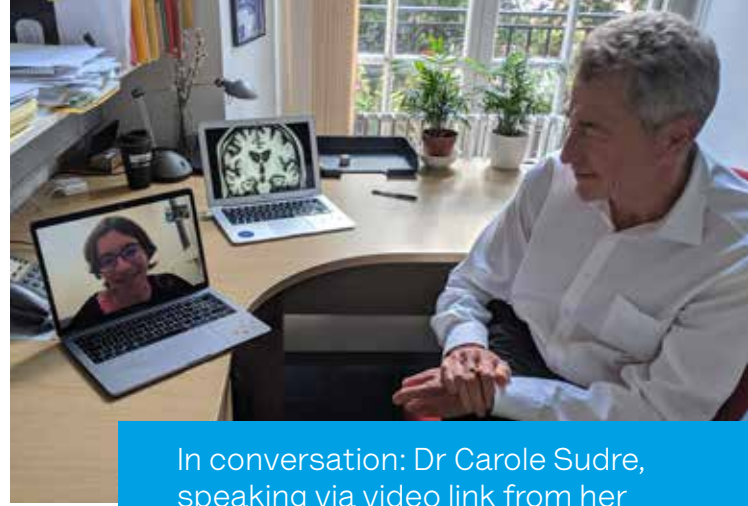
Nick: I believe that improving early diagnosis and giving greater precision is truly important. As it has been described to me, there's a 'great agony' of not knowing. Without accurate diagnosis, people may feel like it's themselves to blame or another condition, and they might seek inappropriate and ineffective treatment. All the time that they're being denied access to accurate diagnosis, they're being denied access to support and to appropriate treatments. Giving them an accurate diagnosis is a basic right – why should we not give them that?

Carole: I completely agree. It is important to make sure that people are taken care of as early as possible. It is at this point that future treatments are also likely to be most effective, before symptoms have progressed.

### What potential do blood tests hold?

Nick: I think these are real advances. I was sceptical when these blood tests focused on testing 30 different things at once. Instead, the tests have now been improved to detect single 'markers'. These can help to tell you about what is happening in the brain. This matches what we have already learned from spinal fluid and complements what brain imaging is showing us.

Carole: I think that taking these blood test measures together with spinal fluid and brain scans will help us to understand the early stages of dementia. A blood or spinal fluid test without imaging isn't enough to give us the full picture.



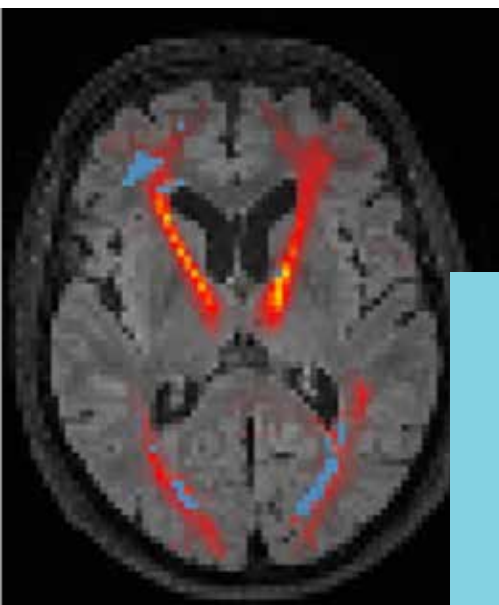
In conversation: Dr Carole Sudre, speaking via video link from her research visit to Boston in the US, with Professor Nick Fox in his office in London

## Working with the Society

### What's it like being funded by us?

Carole: What I find unique about Alzheimer's Society is that, every six months, I meet with my monitors from the Research Network. This is an extremely good experience, because each time I meet them I am with people who are very interested in what I am doing and want to know more. I always come out of this extremely energised and motivated. I feel like you are not just funded by the Society, when you interact with the staff and the Research Network you become more personally attached to and involved in your own project and in your relationship with the Society.

Nick: Alzheimer's Society is made up of really committed staff and volunteers, including on the Research Network. People working for the Society want to make a difference, it's more than simply a job. This makes one feel more of a wish to be part of the Society in a wider sense than just as 'somebody who is funded'. When I first joined the Society, I was explicitly told that I was to be an ambassador for them, so I went out and spoke at lots of local offices. I've had some really thought-provoking questions and great insights from meeting those people. I recall a volunteer who collected me from the station in Sheffield when I was just starting out. He told me how important he felt it was to improve diagnosis. He said, 'Let me tell you about the agony of not knowing,' and that has stuck with me.



This is an image from Carole's research, showing the brain taken horizontally through the head, with areas of damaged blood vessels (blue) along with bundles of brain cells (red and yellow).

# Gene genie

**We know that some types of dementia are caused by inherited gene mutations, but what if we could fix these genes to stop them causing disease? Alzheimer's Society is partner in the UK Dementia Research Institute, which is investing £2 million in an initiative to do just that.**



Professor Chris Shaw

Gene therapy is a cutting-edge technique that is still in the experimental stages. So far it has been used to treat genetic forms of blindness and sickle cell disease, and it's had encouraging results with haemophilia and some forms of cancer.

**'The gene therapy field is undergoing a renaissance. At UK DRI, we believe in taking big risks that could reap big rewards.'** Dr Adrian Ivinson

## How does it work?

Viruses have evolved to use clever ways to package and transport their genetic information into cells of our body. Once inside a cell, the virus is able to reproduce and spread. Scientists can use these abilities to deliver healthy human DNA into a cell instead. This can stop mutated DNA from causing disease, meaning that gene therapy may replace drug treatments and surgery to treat many types of genetic conditions.

## Where is this research being done?

The UK Dementia Research Institute (DRI) has awarded £2 million for Professor Chris Shaw to set up a hub of gene therapy research at King's College London. He said, 'We're looking forward to building a key resource for the institute – pushing us further and enabling innovative research in gene therapy.'

**'We're looking forward to building a key resource for the DRI – pushing us further and enabling innovative research in gene therapy.'**

**Professor Chris Shaw**

Alzheimer's Society is a founding partner in the UK DRI, alongside the Medical Research Council and Alzheimer's Research UK. The institute comprises seven top research centres and it is already attracting the best and brightest global and UK researchers in dementia, care and technology.

Dr Adrian Ivinson, UK DRI Director, Operations, says, 'The gene therapy field is undergoing a renaissance. At UK DRI, we believe in taking big risks that could reap big rewards.'







# Sharper diagnosis

**Gemma Roberts, a clinical fellow at Newcastle University, is looking at new ways to improve brain and heart scanning methods for better accuracy when diagnosing Lewy body disease.**

## Tell us about yourself

I am an Alzheimer's Society-funded clinical fellow. This means that I carry out my PhD research while continuing to work in my NHS clinical scientist role of nuclear medicine physicist, where I use radioactive chemicals to diagnose and treat diseases. For me, this mostly involves performing and reporting heart scans to look for coronary heart disease.

Outside of work, I have two dogs and sing in a chamber choir. I'm also learning to play the accordion and I do folk singing, though everything is on hold at the moment while I write my PhD thesis!

## What is your research about?

Lewy body disease (LBD), referring to mild cognitive impairment with build-up of characteristic 'Lewy bodies' in the brain, can be difficult to diagnose. Its symptoms mean it can look like Alzheimer's and also like Parkinson's. Even using a brain scan, it's sometimes still hard to be certain of a diagnosis. Part of my work is to find out if a second scan – one that looks at nerves connected to the heart – could help diagnosis. We know these nerves become damaged and degraded in LBD and in Parkinson's, but not in Alzheimer's.

I'm testing new and advanced ways to take and process these images, so we can get a more accurate idea of what is going on in the brain and heart. I'm also using a combination of models called 'phantoms' and computer models to make scans clearer and cancel out the signal loss caused by other organs and body fat.

## What drew you to this area?

Newcastle is one of the world's leading centres for ageing and dementia research. It's a great place to work, with a lot of collaboration between leading names researching dementia with Lewy bodies, in areas from nuclear medicine and old-age psychiatry to biomedical research departments. I first got involved in dementia research through the SUPERB project. This showed some early results related to LBD that made me want to take the research further.

I also have a personal connection to dementia. Several of my family members have lived with the condition, and my aunt sadly passed away during the course of my research with Alzheimer's.

## How do you carry out your work?

My work involves using both brain and body scanning machines, healthy older volunteers, computer modelling systems and phantom models. Scans can look blurry if the signal from the radioactive tracer is blocked or deflected by other body parts or body fat. 'Phantoms' are detailed mannequins of the head and chest that I use to help make scans more accurate. For example, I used the chest phantom to show how a scan of a healthy person can look abnormal when I add panels to represent body fat. I was then able to use computer software to correct this, producing a clear and accurate scan.

## Why is this research important?

Getting an early diagnosis of dementia and identifying which disease has caused the condition is very important. With the advance of more accurate diagnostic techniques, we have learned that more people than we had initially thought have a mixture of Alzheimer's and LBD. I think it is really important that we move away from thinking about these conditions in binary terms, but instead think more about their combination, how this affects the person and how new treatments could target both.



# Caregiving HOPE

**Research Network volunteer Sandra Barker, who is also project monitor for Caregiving HOPE, describes how network volunteers have been supporting research into caring for a person with dementia.**



From left to right: Ripaljeet Kaur, Sandra Barker, U Hla Htay, Wendy Mitchell and Fin Kerry.

In 2015, Alzheimer's Society agreed to fund a project at the University of Bradford to look at how obliged, willing and prepared people from both white British and South Asian communities are when faced with caring for a person with dementia.

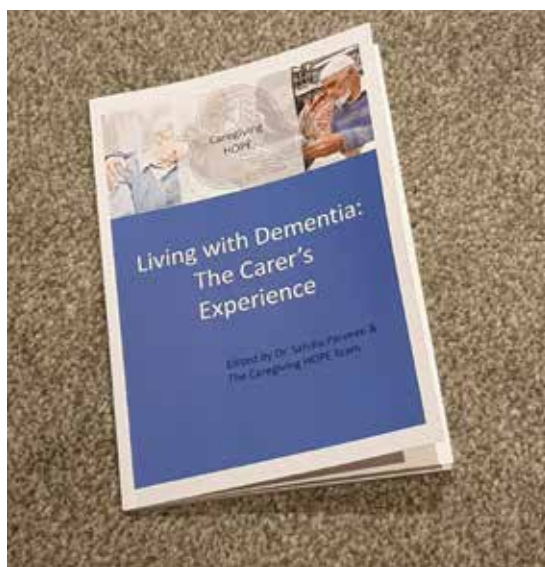
'Public and patient involvement' is key to research at Bradford, and the project's Principal Investigator, Dr Sahdia Parveen, brought a project panel together to guide and support the research. The panel comprised key professionals as well as carers. Along with Wendy Mitchell and U Hla Htay, I was one of the designated Research Network monitors for the project and we agreed to join the panel. It has been an enlightening and very rewarding experience.

Sahdia wanted to look at how carers and future carers view caring for someone living with dementia, and what factors – in terms of obligation, willingness and feeling prepared to care – affect their caring role and their ongoing health and stress levels. She was also keen to explore the assumption that South Asian families 'will look after their own' – is that the case, and how do family members feel about that?

Key findings include that South Asian carers felt more culturally obligated to provide care, and also that white British carers were more willing to provide emotional and nursing care. Both groups were equally willing to provide practical support, such as cooking and cleaning. For all carers, being better prepared was associated with being more willing to provide care and with less 'carer burden' – the stress, depression and sometimes anxiety that carers may face.

As Research Network volunteers and panel members, we have been fully involved in developing research materials and in helping and advising on the recruitment of participants for the study. We also supported Sahdia in a successful application for an Alzheimer's Society dissemination grant. This will be to publish a book of carer experiences, and also to hold an event for carers and professionals to report on the study and to consult them on what we do next with the results.

It is very clear that, given the extent to which the country relies on family carers, better support for those carers is key.



**For more information about the Caregiving HOPE study, please see:**  
[www.bradford.ac.uk/dementia/research/caregiving-hope](http://www.bradford.ac.uk/dementia/research/caregiving-hope)

# A fresh START

**Carers can face stress, anxiety and depression while caring for a relative with dementia. A new research project shows the value of specially designed psychological support for helping them to cope.**

Families provide the majority of care for people with dementia living at home. Evidence shows that caring can have negative effects on the mental and physical health of the carer. Carers have been shown to need more days off work due to ill health, and they are more likely to experience anxiety and depression than non-carers.

A group of researchers led by Gill Livingston, Professor of Older People's Psychiatry at UCL in London, developed an intervention designed to reduce symptoms of depression and anxiety in carers of relatives with dementia. The intervention was named 'START' – STRAtegies for RelaTives – and the results of testing were published this year.

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**'I can see now that an intervention like START would have allayed some of my earlier anxieties by giving me appropriate practical information, advice about services, support, coping strategies, and helping me learn how to relax.'**  
**Shirley Nurock.**

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Shirley Nurock, a former carer who worked on the project as a liaison with the families, said, 'After my husband developed Alzheimer's disease in his 50s, I spent 15 years caring for him. I was stressed and anxious throughout, feeling powerless as I watched him deteriorate, torn between prioritising care for him, seeing my children through their teenage years and keeping an eye on my ageing parents.'

'I can see now that an intervention like START would have allayed some of my earlier anxieties by giving me appropriate practical information, advice about services, support, coping strategies, and helping me learn how to relax. Learning that it can have such long-term effects is extremely encouraging.'

The intervention takes the form of specially trained community therapists. They work with carers to identify individual challenges and to help them find the right solutions for their situation, rather than telling them what to do.

The sessions support carers to communicate well, manage and reframe negative thoughts, access support, plan for the future and increase pleasant activities. At their final session, the carer and therapist agree a plan for the future based on what the carer felt was working.

Shuhala Abbas, a dementia support worker based in Newham who was trained to deliver START, said, 'The work I got to do with START was really meaningful. Personally, I feel that START gave me the opportunity to work closely with carers, building a relationship that I normally wouldn't get to, helping them to deal with the everyday practical sides of caring.'

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**'Personally, I feel that START gave me the opportunity to work closely with carers, building a relationship that I normally wouldn't get to, helping them to deal with the everyday practical sides of caring.'**  
**Shuhala Abbas**

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The START trial was the first of its kind to show that carers of relatives with dementia benefit from psychological support sessions. It showed not only short-term benefit but that participants continued to use the skills and coping strategies they had learned for years afterwards.

High levels of carer stress and difficulty coping have been shown to precede the person with dementia moving into a care home. The researchers suggest that START may be able to reduce care home admission and help people with dementia to remain at home when appropriate.



**Attendees of the first START Training Day for Dementia Support Workers'. Left to right: Louise Winetroube, Elizabeth Martins, Shuhala Abbas and Dr Penny Rapaport Clinical Psychologist UCL.**



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to beat  
dementia**

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### **Take part in research**

Sign up online at [www.joindementiaresearch.org.uk](http://www.joindementiaresearch.org.uk)  
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### **Join our Research Network**

Involving people with dementia, carers and former carers to influence our research, [alzheimers.org.uk/researchnetwork](http://alzheimers.org.uk/researchnetwork)

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**40** years  
2019

