

Care and cure

The Alzheimer's Society research magazine

Taking part in research

We hear what it's like to take part in research



News roundup

The latest dementia in dementia related news

Missed connections

repurposed drug could fix lost connections in frontotemporal dementia

Cognitive behavioural therapy (CBT) for dementia

Dr Joshua Stott tells us about his research



Dr Aoife Kiely
Editor

Welcome to Care and cure magazine

Many of you very kindly completed the survey we sent out with the spring issue of Care and cure. I would like to take you through a whirlwind tour of some of the feedback.

You asked for more articles on what it's like to live with dementia. We agree that it is important to tell the stories of people with dementia. Our magazine, Dementia Together, is a great resource for this. Call 0330 333 0804 or see alzheimers.org.uk/subscribe to sign up.

You said you'd like to more articles on care research and research about being a carer. We agree that it is important to balance biomedical with care research. We will also be dedicating our autumn issue to carer research, so keep an eye out for that!

I was glad that the huge majority of you said the language we use in our articles is understandable. That said, I will also start including jargon-busting boxes to help explain new or complex terms.

You asked to hear more about a diverse range of research topics and for us to better highlight which involved Alzheimer's Society support or funding. You also asked for more images and diagrams to help illustrate articles. All of this input is enormously useful and we will work hard to satisfy as many of these requests as we can.

If you'd like to order additional copies of this magazine or write a letter to the editor for publication, please contact me at aoife.kiely@alzheimers.org.uk

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



Exercise and risk

We already know that regular exercise benefits our mental and physical health, but can it reduce dementia risk and delay its onset?

Recent research has highlighted the benefits of regular exercise for keeping our hearts and brains healthy. The last few months have seen the findings of several studies come out on this topic.

In February, a research paper studied the effects of exercise on people diagnosed with mild cognitive impairment. They found that a routine of aerobic exercise and resistance training improved memory and thinking skills. Aerobic exercise can be anything that gets your heart pumping, such as a brisk walk, gardening or a dance class. Resistance training includes exercises involving weights or resistance bands.

In March, a study reported that people who were fit in midlife have either a reduced risk or later age of onset of dementia than someone who is less fit. Looking at a group of women who completed a strenuous exercise bike session in the 1960s, when their average age was 50, the researchers followed their medical history until 44 years later. They said that the fitter the women were for the bike test, the later or less likely they were to develop dementia.

The study had some shortcomings. As Dr Tim Shakespeare, our Research Information Manager, said, 'While the results are promising and provide much needed motivation to get on the exercise bike, it's important to bear in mind the number of people in this study was small. It also only involved women, so it's not clear if we'd see the same results in men.'

'It's important to bear in mind the number of people in this study was small. It also only involved women, so it's not clear if we'd see the same results in men.'

Taking regular exercise is an important part of a healthy lifestyle. We know that what is good for your heart is good for your head. Exercise reduces the risk of heart disease, diabetes and depression, which are major risk factors for dementia. It can also help people with dementia to maintain confidence and improve their thinking skills and sleep. Exercise can also be an opportunity to engage and socialise with other people.

Alzheimer's Society's annual Memory Walk takes place this autumn.

Memory Walk is a sponsored walk for all ages and abilities to unite together to raise money to defeat dementia.

This year over 110,000 people plan to walk to help raise money for dementia research.

Visit memorywalk.org.uk to find Memory Walks in your area or organise your own!

What better way to enjoy the positive effects of exercise while also raising awareness of dementia and much needed funds for research.

Care home neglect and staff burnout

Study shows that neglect is common in England's care homes.

Researchers based at University College London carried out the largest ever survey of care home staff in England. Alzheimer's Society was involved in the partnership that supported this study. Care home staff anonymously reported both their positive and negative behaviours and those of other staff in the last three months. The survey also measured how busy the care home was and how 'burnt out' members of staff were. Burnout is a psychological measure of emotional, physical and mental exhaustion.

Care staff reported a small number of incidents of verbal or physical abuse. Reports of neglect were more common. These included making a person wait for care, avoiding people with behaviour that they found challenging, not giving enough time for eating and showing lack of care when moving a person. Neglect was most common in homes where staff had the highest levels of burnout. This suggests that care staff who are under the greatest pressure are unable to provide the level of care that they would like.

Under the Care Act 2014, local authorities and care providers have a responsibility to protect and support people's needs. However due to numerous cuts to

budgets over the years, the reality of care provided can be far from adequate.

Dr Doug Brown, Chief Policy and Research Officer at Alzheimer's Society, said, '70% of people living in care homes have dementia, and it's clear from these findings that they're bearing the brunt of a chronically underfunded social care system.'

'By 2021, a million people in the UK will have dementia. The government must act now, with meaningful investment and reform, or we risk the system collapsing completely and people with dementia continuing to suffer needlessly.'

On the brighter side, this study also highlighted that the majority of staff care deeply about the people they support. They reported that they took time to get to know people in their care and enjoyed spending time with them. However, under so much pressure, even the best care home staff can be unable to provide the right support for everyone. This study provides strong evidence of the need for better training, support and wages for care home staff.

A road block for RAGE no success for Alzheimer's treatment

Lack of any positive effect on people with Alzheimer's disease brought a phase 3 clinical trial to a halt.

The study was testing whether after 18 months of treatment with a drug called azeliragon, people with Alzheimer's would do better on thinking and memory tests than people taking a placebo.

Azeliragon was designed to stop the immune system of the brain becoming overactive. The researchers knew that this over activation turned on a chemical called RAGE.

Amyloid beta is a protein that builds up in the brains of people with Alzheimer's, and RAGE might be the trigger that turns amyloid beta toxic, causing brain cells to die. Early testing of the drug had looked encouraging. Results had suggested that using the drug to block RAGE could stop amyloid beta from damaging the brain.

In early clinical trials, it looked like azeliragon might have needed more time to show an effect. Unfortunately, this longer phase 3 study confirmed that the drug had no benefit for people with Alzheimer's.

A phase 3 trial is a trial has made it through the first two phases of safety testing and is now being tested on a large group of people.

A **placebo** drug is made from a chemical that is known to have no effect on a person.

The **'placebo effect'** occurs when a person takes a pill and starts feeling and acting better, not knowing that the pill was a placebo.

If the drug works then its effect will be far greater and last longer than the 'placebo effect'. By having some people take a placebo researchers can cancel out this effect and be sure that it truly is the effects of the drug that is helping the person, not the placebo effect.



Repurposing a rheumatoid arthritis drug for dementia

New research suggests that drugs used to treat rheumatoid arthritis could reduce risk of developing dementia.

Research has suggested that inflammation plays a role in dementia. 'Inflammation' in this case means activation of the immune system of the brain rather than swelling. Yet clinical drug trials using anti-inflammatory drugs haven't shown any benefit for people with dementia. Some researchers suspect that it might be a matter of using different drugs, much earlier, before symptoms begin.

In February, Professor Christopher Edwards and colleagues in Southampton and Oxford published their findings. They suggested that anti-rheumatic drugs might reduce the risk of dementia. This research is currently in its very earliest stages. More in-depth research is needed before we can be confident of this finding.

This study wasn't a clinical trial. Instead it was an observational study, which means that the researchers looked back over the medical records of people with rheumatoid arthritis. They observed that people who had taken anti-rheumatic drugs appeared less likely to develop dementia than those who had not. We must bear in mind that their reduced risk of dementia could also have been due to other lifestyle factors. A clinical trial could rule out these other factors, as drug testing will be done in carefully controlled conditions.

Dr James Pickett, Head of Research at Alzheimer's Society, said, 'It is vital to explore whether drugs developed for other conditions also have benefits for dementia, as it could make it much quicker to get new drugs to the people who desperately need them. Alzheimer's Society is prioritising this approach to research.'

Based on this early evidence, Alzheimer's Society is now funding Dr Bernadette McGuinness at Queen's University Belfast, who is working with Professor Chris Edwards to take this research further. If this research is successful it will pave the way for a clinical trial to test whether these drugs can stop or slow the onset of dementia.

News in brief

Danger in the dark

A recent study suggested that head injuries experienced by actors and theatre staff in the frenzied darkness back stage might lead to dementia. This study didn't show that anyone affected would actually develop dementia, but it does highlight the need to take steps to avoid head injuries.



Menopause and memory

The female hormone oestrogen might be linked to memory health. Some studies propose that women who experience menopause later have a lower risk of dementia. New research suggests that a woman's lifelong fluctuations in oestrogen are more important in influencing memory than the age at which menopause occurs.

MARIO the care robot

A care robot named MARIO is being tested by people with dementia at a care home in Galway, Ireland. MARIO is 1.37m tall and responds to voice and touchscreen activation. MARIO plays favourite songs, discusses photos and newspapers, and connects people with family and friends. Researchers hope that MARIO could be a helpful addition to essential human interaction.

Taking part in research

We hear from researchers running trials and people who have signed up to take part in them.

What are research trials?

Research trials are studies involving people. They test whether a treatment, therapy or activity is safe and how well it works. Researchers need both carers and people with dementia to sign up to test new care techniques and healthy volunteers and people with dementia to try new drug treatments, and some trials are looking for volunteers to study the effects of creative or sporting activities.

What is it like to take part in research?

PREVENT Dementia

Georgina Shomroni had seen the effects of dementia first-hand. Her grandfather, mother and aunt had all received diagnoses of dementia. Georgina was inspired to get involved in research by her mother and aunt, who had both joined research studies. She registered with Join Dementia Research and took part in a study playing online 'brain training' games, but she wanted to do more. When she received an offer to join PREVENT Dementia, she jumped at the chance.

PREVENT Dementia is a large-scale study that receives funding from Alzheimer's Society. Its aim is to discover the earliest signs of dementia. Scientists believe that it might be possible to detect these decades before symptoms begin. Researchers are examining a large number of healthy volunteers aged 40–59. They want to find out whether physical or mental signs point to an increased risk of developing dementia in later life.

Volunteers in the study take a range of tests, including brain scans and blood, urine and saliva tests, as well as memory and thinking tests to examine their brain health over time.

Professor Craig Ritchie from the University of Edinburgh is leading the PREVENT trial. He said, 'In the next 10 years we're going to get more and more evidence about the things people can do to prevent Alzheimer's dementia. Our aim is to be able to take any given individual and say, "Well your risk is X per cent and here are the things you can personally do to help prevent it.'

Georgina said, 'The PREVENT Dementia study seems to measure every aspect of the brain. One of the things I had to do was draw a clock face showing a particular time. I remember that when my mother had dementia, she once did this test, and all the numbers were bunched on one side of the circle.'

'They explain everything. They want to make sure that you know exactly what is going to happen and are still happy to proceed. All your personal information is handled well and becomes anonymous.'

Georgina also agreed to have an MRI scan and an optional lumbar puncture. When asked about what it is like to work with the research team Georgina said, 'They explain everything. They want to make sure that you know exactly what is going to happen and are still happy to proceed. All your personal information is handled well and becomes anonymous.'

Caregiving HOPE study

The Caregiving HOPE study focuses on carers living in Bradford, West Yorkshire. The aim is to understand feelings of obligation to provide care, willingness to provide care and how prepared carers feel to provide care. The study will also take into account how confident people feel in their caring role and how it affects their wellbeing.

The first part of the project involved finding both white British carers and carers from South Asian communities to take part. By interviewing these people, the researchers learned about the needs of carers from different cultural backgrounds. In





Dr Sahdia Parveen
Principal investigator
of the Caregiving
HOPE study

Based on this study, the researchers are putting together a resource called the good tips booklet. This aims to help prepare people for different stages of their caring role. In addition, this work will help to inform new ways to support carers, with services that are tailor-made to recognise cultural differences.

Impact of research trials

Dementia research is vital. Stories such as these highlight the rewarding experience of being involved in research. By taking part, researchers and participants alike can feel that they are improving the lives of people affected by dementia – and hope that one day their contribution might lead to the breakthrough of a cure.

the next stage, they posted out questionnaires and held discussion groups. From these they were able to better understand attitudes to dementia and care, and willingness and preparedness to be a carer.

Dr Sahdia Parveen is the principal investigator on this Alzheimer's Society-funded project.

Dr Parveen said, 'In this study, I hope to deepen our understanding of the challenges faced by people with different cultural backgrounds and how we can best draw attention to them. Identifying areas of support will help inform future development of support services and awareness campaigns, as well as recommending coping mechanisms for carers or people with dementia.'

One carer said, 'It was really nice to be asked about how willing I am to provide care, because that is not something carers are often asked by other people.'

Many participants in the Caregiving HOPE study were signed up to the study through Join Dementia Research. Join Dementia Research helped Dr Parveen to get in touch with people who are often harder for researchers to reach, such as younger carers. Many of the carers who took part welcomed having the opportunity to express themselves. One carer said, 'It was really nice to be asked about how willing I am to provide care, because that is not something carers are often asked by other people.'

Another said, 'I found completing the survey therapeutic, as the many varied questions covered my personal situation and encouraged me to think about my family relationships.'



Getting involved in research trials

Join Dementia Research has been making it easier than ever for people to get involved with research since it was launched in 2014.

Join Dementia Research is a collaboration between Alzheimer's Society, Alzheimer's Research UK, Alzheimer Scotland and the National Institute for Health Research.

If you are interested in getting involved in research you can sign up online at joindementiaresearch.org.uk or call 0300 222 1122.

You will be asked to complete a profile with some details about yourself. Researchers can then get in touch if your details match what a research trial needs.

Cognitive behavioural therapy (CBT) for dementia

Dr Joshua Stott tells us about his research.



Dr Joshua Stott

What is cognitive behavioural therapy?

Imagine that you are sitting on a bench in a park, you can hear ducks quacking and water lapping in a nearby lake. You might be thinking 'what a lovely day' and you might feel happy. Alternatively, you might be thinking 'I wish my partner was here' and feel sad as a consequence. The feelings you have might then cause you to act differently. If you are feeling happy you might take a stroll around the lake with a friend and treat yourself to an ice-cream. If you are feeling sad and low you might leave the park and go home feeling upset with yourself.

The above is an example of how the way in which we think affects our feelings, which, in turn, affect how we then behave. Cognitive behavioural therapy or CBT aims to help people understand these links between their thoughts, feelings and behaviours and use this understanding to make positive changes. CBT doesn't work for everyone but it has become a popular way of helping people to cope with anxiety, depression and other mental health problems.

Dr Josh Stott is an Alzheimer's Society-funded researcher based at University College London. He is investigating whether CBT could be altered to help people in the early stages of dementia, who also have anxiety and depression. We sat down with Dr Stott to learn more about his research.

How could CBT help people with dementia?

Depression and anxiety are more common in people living with dementia than in people who don't have dementia. We know that having depression and anxiety in addition to dementia can worsen dementia symptoms. Depression and anxiety are not an inevitable result of dementia.

Is CBT more difficult for people with dementia?

Every individual living with dementia is unique. Like the rest of the population, CBT is likely to work for some people with dementia and not for others.

While we don't yet know exactly who with dementia might benefit most from CBT, a few things may make it more difficult. CBT is a language based therapy, and for people with dementia who struggle with language, CBT may be more challenging.

In general, greater levels of cognitive impairment may make it more difficult to engage with CBT, however, it may be possible to tailor CBT according to an individual's level of functioning. One of the things that I have been working on is developing questionnaires that will help us to understand which type of CBT a particular individual living with dementia might be most able to engage with.

What would be the ideal stage to start CBT?

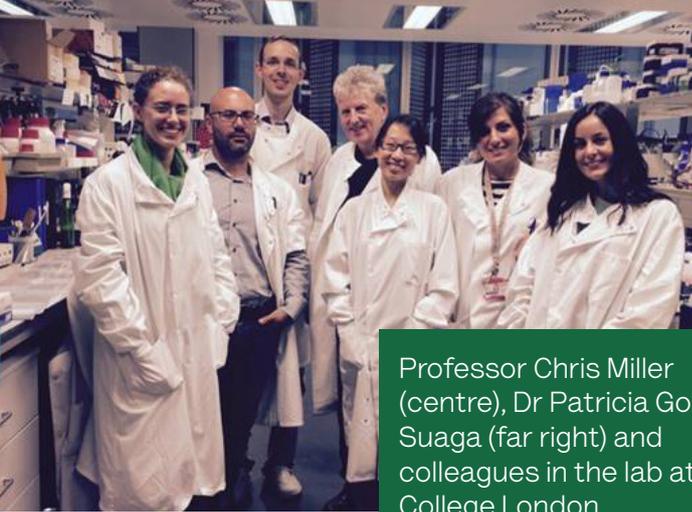
CBT is only relevant if you have both dementia and anxiety or depression. If you do have this combination of difficulties, it is good to start as early as you can. In an ideal situation, people would be assessed at the time of diagnosis with dementia and introduced to CBT then, if it seems like it might be appropriate.

One intriguing idea is that CBT may be helpful before someone even develops dementia. This has yet to be researched, but we know that people who have anxiety or depression are more likely than the general population to develop dementia in future and it would be very interesting to investigate whether CBT or other interventions to treat anxiety and depression might have dementia preventative effects.

What is next in the research?

We are hopeful that CBT will prove to have positive outcomes for people with dementia, we are also very interested in investigating the potential preventative effects of CBT and other psychological therapies as mentioned above.





Professor Chris Miller (centre), Dr Patricia Gomez-Suaga (far right) and colleagues in the lab at King's College London

Professor Miller, Dr Patricia Gomez-Suaga and PhD student Naomi Hartopp are studying the relationship between mitochondria and the endoplasmic reticulum. They have found that normally these two parts of the cell stay in close contact with each other, tied to each other by chemical connections. However, they noticed that in conditions such as FTD these connections are often broken.

Professor Miller and colleagues became interested in a drug that is already approved for use in liver conditions. Their work is now testing whether this drug can repair broken connections between the mitochondria and endoplasmic reticulum within brain cells. They believe that repairing these connections could allow them to work together once more. In the case of FTD, brain cells may then be able to recover and function properly. The researchers are optimistic that this treatment could be used in other dementias.

This research is still in its very earliest stages. At the moment the chemical is being tested on brain cells grown in a dish in the lab, so it is still years from being tested in humans. That said, by focusing on an existing drug that we already know to be safe, this research is on a faster track to a potential treatment. Repurposing drugs in this way is a key aspect of our Drug Discovery programme.

Dr Gomez-Suaga said of the work 'This is now a very hot topic in scientific research. It has implications for dementia treatment and pharmaceutical companies are displaying interest in this field. We have made a major discovery by identifying some of the connecting proteins involved and our findings are enhancing drug discovery in this field.'

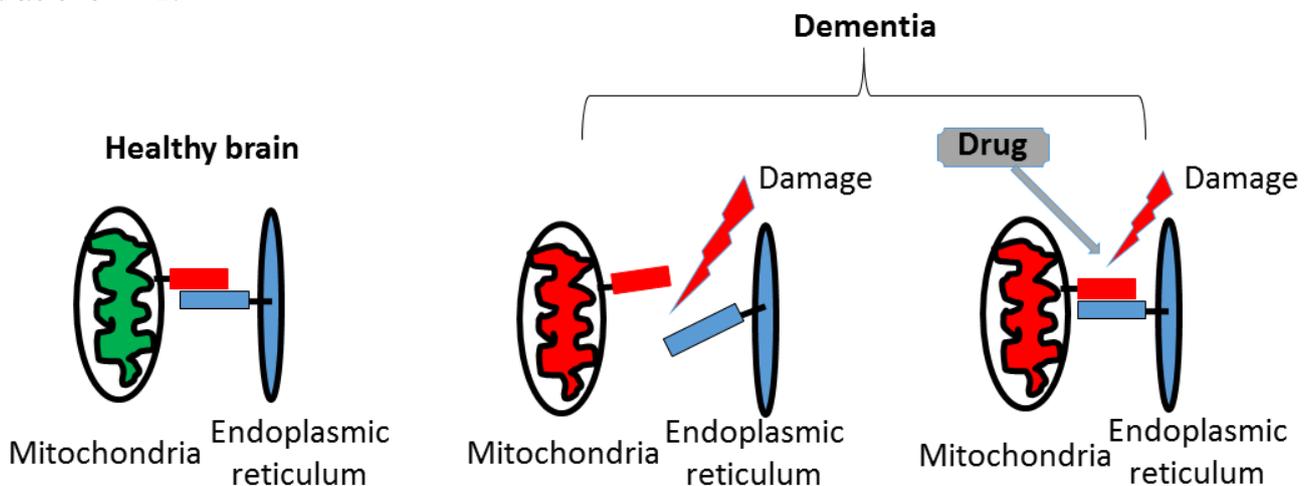
Missed connections

Repurposed drug could fix lost connections in frontotemporal dementia.

People often describe mitochondria as being like the 'powerhouse of the cell'. They are the tiny jellybean-like organs that sit inside a cell that make energy from the nutrients your body takes in and sends this energy out for the rest of the cell to use.

The endoplasmic reticulum is another important part of a cell, as it makes the proteins and fats that the cell uses to work properly. To do this it must have energy, and this is where the mitochondria comes in, sending it packages of energy so that it can keep making proteins.

Frontotemporal dementia (FTD) is a form of dementia that causes symptoms including problems with language or changes in behaviour and personality. There are currently no treatments available for FTD.



The diagram above shows a healthy mitochondria and endoplasmic reticulum with a connection between them in a healthy brain on the left. On the right we can see how damage in dementia causes the connection to break and how the drug treatment repairs the connection

Working together to defeat dementia

On 14 March, 70 researchers and people affected by dementia came together to learn from one another at a very special event in York.

The day was organised by Research Network Volunteers Wendy Mitchell, Barbara Woodward-Carlton and Sandra Barker (pictured top right). Alzheimer's Society staff Matt Murray, Jamie Tullock and Aoife Kiely supported the preparations and came along to help out on the day.

Barbara Woodward-Carlton began the day by reminding us all why we were there. She told us about the history of Alzheimer's Society and the Research Network, and of the importance of research. Wendy Mitchell then introduced York's Minds and Voices (pictured right second from the top), a group of people living with dementia. They told us about their experiences with dementia and explained why research and raising awareness is important to them. They told us how they support people with a new diagnosis of dementia through the York Minds and Voices Dementia Course.

The researchers from the doctoral training centres of Bradford and Newcastle gave talks about their work and moved from table to table discussing their work with the group.

The day finished with time for questions and conversation about research and issues in dementia care. Alzheimer's Society, by bringing our researchers together with people affected by dementia, will work hard to keep this dialogue going.



Rising to the challenge

Professor John O'Brien and Dr Gary Nestor discuss the National Institute for Health Research's response to the Prime Minister's dementia challenge.

In 2012, Prime Minister David Cameron set a challenge that the UK should be a world leader in dementia by 2020. Research is a vital part of this. The National Institute for Health Research (NIHR) is focused on leading the way in making England a supportive and inspiring place for the finest minds in dementia research to thrive. We are also working closely with other organisations to strengthen dementia research in the UK as a whole. Through a number of initiatives, we have been starting to make a difference.

Supporting high quality research

Since the Prime Minister's challenge, NIHR has launched three dementia-focused funding calls. A funding call is an invitation to researchers from around the country to apply for the money they need to carry out their research. In doing this, the NIHR has also increased the number of people living with dementia who have been able to join clinical trials.

Improving researcher training

Despite dementia being one of the biggest global health challenges that we face, five times fewer researchers choose to work in dementia than in cancer. The NIHR felt it was important to encourage researchers who are new to the field to learn the skills they'd need to succeed in dementia research.

The NIHR introduced a training and skills programme to their Clinical Research Network in 2014, and this has achieved great results. Meanwhile this year the NIHR launched a new website called Dementia Researcher, which provides a place for researchers to network and share ideas and opportunities. This will enable early career dementia researchers to flourish.

Making it easier to get involved

In 2016, NIHR collaborated with Alzheimer's Society, Alzheimer's Research UK and Alzheimer's Scotland to launch Join Dementia Research (see page 6).



Expanding the scope of research support

NIHR's Clinical Research Network recently broadened its horizons to include health and social care research studies that take place outside NHS clinics. This means that the NIHR will now support studies run in residential care homes and by social care providers. We hope that this will give more people the chance to get involved in research studies – find out more at www.nihr.ac.uk/crn

Making a difference

The above initiatives are just a snapshot of NIHR's work around dementia research, which will continue over the years ahead.

We are delighted to report that our efforts are paying off. Each year we have seen an increase in the number of dementia research studies and a greater recruitment of people to taking part in research trials. Since last spring, we have been proud to support over 249 dementia studies and have helped to recruit over 32,000 people to take part as research participants.



Who will you walk for?

1 in 3 of us will be affected by dementia. Walk with us and raise funds for research.

Sign up at **memorywalk.org.uk**

Alzheimer's Society operates in England and Northern Ireland. Registered charity no. 296645 1809150



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.nihr.ac.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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