

Care and cure

The Alzheimer's Society research magazine

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Dr Tim Shakespeare
Magazine Editor

Welcome to Care and cure magazine

While we work to find a cure, our mission at Alzheimer's Society is to create a society where people affected by dementia are supported and accepted.

Recent research has confirmed that the number of people living with dementia is expected to grow as the population ages, but many people don't receive the right support. Unlike for other conditions, people affected by dementia are burdened with huge costs for care. Too often, the care provided is inadequate.

Alongside our campaigns to improve care, we are investing £5.6 million into three new centres of excellence in dementia care research (page 7). These will focus on how to improve quality of life, access to support after a diagnosis and training for homecare workers. The interventions developed by each of these programmes could change the lives of people affected by dementia in significant ways.

Although it rarely attracts the same attention as clinical trials for new drugs, research into care can be just as rigorous, and its benefits can be striking. Highly skilled, knowledgeable and experienced researchers can demonstrate what does and doesn't work, which is essential to making the case for better care. But researchers alone can't ensure that good practice is implemented across the country. To make that difference, we all need to get behind them and campaign for our right to affordable, appropriate and evidence-based care.

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About us

Since 1990, Alzheimer's Society has funded £40 million of cutting-edge dementia research. We aim to increase investment in our research programme to at least £150 million over the next decade. This money funds important research that 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



Disrupted sleep

Researchers are investigating a possible link between sleep disruption and markers of Alzheimer's disease.

Not getting enough sleep has been linked to slower recovery after a stroke and a higher risk of heart disease. Could it also have an effect on Alzheimer's disease? The link between sleep disruption and an increased risk of developing Alzheimer's has been the subject of several recent studies.

Research in mice has shown that amyloid, a protein involved in Alzheimer's, builds up when the animals are awake and is cleared during sleep. Now researchers are investigating whether disrupted sleep might influence this process in people as well.

Two recent studies, looking at the cerebrospinal fluid (CSF) of people who have disrupted sleep, have shown an increase in biological markers that can indicate the disease's development. The researchers, from Washington University and the University of Wisconsin, measured levels of amyloid and tau, another important protein in Alzheimer's disease.

The first study, published in the journal *Brain*, found that a single night of disrupted sleep resulted in more amyloid, and a week of sleep disruption increased levels of tau.

The second study, reported in *Neurology*, expanded on this by looking at levels of other markers of

Alzheimer's, including signals of inflammation and brain cell activity. People who reported worse sleep quality tended to have markers in their CSF that were closer to those seen when someone has Alzheimer's. However, not everyone who reported poor sleep had these kinds of changes.

'While it appears that good quality sleep can help to keep the brain healthy, the exact relationship between sleep and Alzheimer's is still unclear.'
Dr Doug Brown

These studies show a link between sleep and some of the proteins involved in Alzheimer's, but an increase in amyloid doesn't necessarily mean a person will go on to develop the disease.

Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said, 'While it appears that good quality sleep can help to keep the brain healthy, the exact relationship between sleep and Alzheimer's is still unclear.'

'We need to see further studies that measure sleep in the clinic, and that follow people over a long period of time, to understand whether problems with sleep do actually increase the risk of Alzheimer's disease.'

Spotlight on prevention

More could be done to prevent dementia, according to a new report.

Research published by The Lancet's commission on dementia suggests that 35% of all cases of dementia could be prevented if nine risk factors were eliminated. These factors are poor education, hearing loss, hypertension, obesity, smoking, depression, physical inactivity, social isolation and diabetes. While eradicating these completely would be unlikely, it is promising that there are things we can do to reduce our risk.

For any individual, a range of factors may affect their risk of developing dementia. These include aspects of their lifestyle, genetics and environment. Many people with a healthy lifestyle will still get dementia, while others will have an unhealthy lifestyle but not get dementia. However, if we take the population as a whole and reduce all our risk factors, this research suggests that fewer people will develop dementia overall.

Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said, 'Not all of the nine risk factors are easily modifiable – factors like poor education and social isolation are incredibly challenging to address.

'Though it's not inevitable, dementia is currently set to be the 21st century's biggest killer. We all need to be aware of the risks and start making positive lifestyle changes.

'The NHS Health Check pilot that we're supporting, where GP practices are raising awareness of dementia risk reduction among people in midlife, is an important first step in raising public awareness and shifting behaviour.'

Learn more about reducing your risk of dementia at alzheimers.org.uk/reducemyrisk

Dementia risk is down

A study published in the British Medical Journal has found that the risk of developing dementia has fallen steadily since 2002.

The study is based on data from a long-term research project following 18,000 men and women over the age of 50.

Between 2002 and 2013, researchers carried out interviews with people about their lifestyle and health. This included whether they were diagnosed with dementia, as well as testing their thinking abilities.

The researchers suggested that an increase in the amount of exercise was the biggest reason for the lower likelihood of developing dementia. Improved cardiovascular health may also play a part.

Although a healthy lifestyle won't protect everyone from dementia, the results show that changing trends could affect how many people develop dementia in total.

Importantly, the researchers predicted that by 2040, the number of people with dementia in England and Wales will increase to 1.2 million.

The reason the number is set to increase, even though risk is lower, is that more people are living longer.





Computer-designed drugs

Dr Francesco Aprile, winner of the Alzheimer's Society Outstanding Contribution to Dementia Research award, has published new work to speed up drug design.

Removing deposits of abnormal proteins from the brain is an important target for new drugs to combat Alzheimer's disease. One way of doing this is to develop antibodies – molecules that attach to abnormal proteins to bring them to the attention of the body's immune system so that they can be removed.

Recently it has become possible to use large computer databases of biological structures to design new antibodies. This can allow greater precision as well as reducing time and development costs.

Dr Aprile, an Alzheimer's Society research fellow at the University of Cambridge, has published new results in the journal *Science Advances* showing that antibodies designed using this technique can target specific regions of amyloid, a protein that is associated with the development of Alzheimer's.

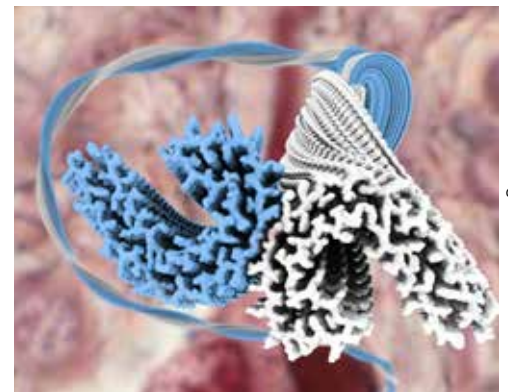
This precision means that the antibodies have potential to disrupt harmful forms of the protein without triggering a damaging immune response. However, there's a lot of work to do to develop these drugs further before they could be tested in people.

James Pickett, Head of Research at Alzheimer's Society, said, 'Over the last 50 years, advances in antibody technology have delivered radical new treatments for a wide range of common diseases, including rheumatoid arthritis, multiple sclerosis and some forms of cancer. While the research is still in the early stages, we are excited by the potential of this work and hope it can do the same for Alzheimer's disease.'

News in brief

Atomic precision

Researchers at the MRC Laboratory of Molecular Biology have revealed the atomic structure of tau for the first time. Tau is one of the characteristic proteins that build up in the brains of people with Alzheimer's disease. The incredibly detailed new picture of this protein could help scientists to design more precise drugs to act on it and stop damage to the brain.



Tau structures. Image credit: MRC LMB

Effects of stress

Stress in early life could influence thinking abilities later on, according to research presented at a conference in London. However, whether these stressful life events lead to an increased risk of dementia remains to be established. Research carried out over a longer timescale is needed to unravel these links.

Crossword clues

People who do more crosswords or other word puzzles tend to have slightly better memory and thinking skills, according to research from the University of Exeter. We don't know whether regular 'puzzling' improves these skills, or whether other differences between people who do the puzzles and people who don't might explain the link.



Making the case for care

Professor Gill Livingston makes a strong case for better dementia care backed by high quality research.

Prevent the preventable, treat the treatable and care for people living with dementia. These are the principles at the heart of a comprehensive piece of work commissioned by prestigious medical journal The Lancet.

The report of The Lancet's commission on dementia, published in July, lays out the state of dementia prevention, diagnosis, treatment and care. Professor Gill Livingston at UCL (University College London) led 24 researchers from around the world in contributing to the report, part-funded by Alzheimer's Society.

The recommendations on prevention were widely reported in the media, but much less attention has been given to the comprehensive review of how to improve care for people affected by dementia.

'We were asked to come up with guidelines as to what we can do now to improve life for people with

dementia,' says Professor Livingston. 'They wanted us to think not only about the things that are definite, but also what would be a good idea to do now, based on the balance of evidence.'

When it comes to dementia care, the report covers a wide range of topics including the use of technology, the importance of tailoring care to individuals, and what can be done to protect vulnerable older people from abuse.

What we can do now

The report highlights particularly strong evidence on how to support people who care for a relative who has dementia. We know that better support is needed – for example, 40% of family carers have depression or anxiety. How to provide this support effectively is less certain.

'A lot of people are completely sure about what to do to support families, but disappointingly most things that are tried make little difference. Just giving information about dementia isn't enough,' says Professor Livingston. Here, the commission shows the way forward by summarising two effective programmes.

In the US, the Resources for Enhancing Alzheimer's Caregiver Health (REACH) programme has been shown to help people with Alzheimer's live in their own homes for longer by giving information about the disease, skills to manage care and strategies for dealing with stress.

In the UK, Professor Livingston leads the Strategies for Relatives (START) programme, which was adapted from REACH to be delivered by psychology graduates. START promotes coping strategies for carers of people with dementia, and the research shows that it is working.

'We need high quality evidence if we're to expect scarce health resources to be spent on these programmes,' says Professor Livingston, who is leading by example. The START programme has been tested in a randomised clinical trial. This means that people who took part were allocated randomly to receive either their usual treatment or the training and support from START.

'We've got the latest results from START, and the people who received the intervention had a fifth of the depression as those who didn't, even five years later. We've changed strategies in the long term and it makes a real difference,' says Professor Livingston.

The Lancet's commission identified a number of other areas where there is good evidence for interventions that improve care and quality of life for people with dementia. These include cognitive stimulation therapy carried out in groups to maintain thinking skills, and better training for nursing home staff to improve end-of-life care.

Room for improvement

At the same time, there are areas where the evidence is not yet strong enough, and research is needed to find out what works well. One such area is technology, which could be used to improve diagnosis, help people with their everyday lives and even support carers. However, we don't yet know what is really effective, and it's clear that technology is not a replacement for human contact.

Another pressing need is to understand how to make lasting change in care homes. 'Often, when researchers run a new intervention in a care home, the intervention stops once they leave. If you're going to make a real difference you have to think about how you'll change the culture, so when the researchers aren't there it keeps going. It's clear that we need strategies that are designed to be sustainable in the long term,' says Professor Livingston.

The field is starting to change and take account of these issues, and interventions are now being designed so that they can be scaled up and delivered in a cost-effective way.

'We have to think about how we're going to put the intervention into practice from the beginning. That's something we've realised over the last five to 10 years,' says Professor Livingston. 'We need to be able to replicate what we do, so we put it in a manual, and it needs to be scalable. That means thinking carefully about how many sessions are needed and who delivers them. If you need someone very highly skilled and it's going to take 30 sessions, it's not going to happen.'

Making a difference

Once researchers have an effective, practical and scalable intervention, they need support to get it used widely.

'I don't think researchers can do it by themselves,' says Professor Livingston. 'Other key stakeholders such as Alzheimer's Society, the National Institute for Health and Care Excellence and local clinical

commissioning groups play a part in making a case for these interventions and making them available.'

The commission's report has described changes that could have a big impact on dementia care, but it is also a call to action for us all to demand and deliver effective, evidence-based care for people affected by dementia.

Centres of excellence in care research

Alzheimer's Society recently announced our biggest-ever single investment in dementia care research – £5.6 million to establish three centres of excellence.

The centres, at Newcastle and Exeter universities and at UCL (University College London), are part of a groundbreaking initiative to address the urgent need for research into dementia care.



University of Exeter

Professor Linda Clare will lead efforts to measure and improve quality of life for people living with dementia, including understanding the impact of changes in the social care system.



Newcastle University

Professor Louise Robinson will tackle the 'postcode lottery' that exists for post-diagnostic support, developing and testing new guidelines to provide high-quality support after a dementia diagnosis.



UCL

Dr Claudia Cooper will address the absence of dementia training among care workers, improving people's independence by providing training for family carers and professional care workers.

Getting involved

Dr Anne Davidson Lund explains why she signed up as an Alzheimer's Society Research Network volunteer and what the role involves.

My father had Alzheimer's and we received such magnificent support from the Society that I wanted to give something back. Chatting with the volunteer co-ordinator at Alzheimer's Society, we agreed that my professional research background sat best with the Research Network. Now my godmother has dementia, so the personal link continues.

I started by reviewing applications for research funding online (posted forms are also available). The initial training and induction sessions were a good way to discover more about the Society and meet people from head office. Periodically, I offer comments to help researchers improve their applications before they apply for grants, or join discussions with academics preparing an application.

As with all other network members, I bring my personal experience of dementia to the role – in my case as a carer for my father, and now my godmother. I have a good understanding of the challenges faced by the research community and an acute sympathy for people living with dementia and their carers.

Being part of the Research Network means I'm well informed about research relating to dementia. It gives me access to accurate facts and figures to use in discussion, and to inject balance into conversations about media stories, which are so often inaccurate. I'm about to train as a Dementia Friends Champion too.

In the spring, I was invited to join the Society's care, services and public health grant advisory panel. We meet twice a year to review funding applications together. The time commitment is modest and quite flexible. An occasional face-to-face meeting, wherever it may be, is easy to accommodate and offers a chance to fit in social and cultural activities alongside.

In March 2015, Lancaster University approached Alzheimer's Society to find people with experience of dementia to help apply for funding. Two of us from the Research Network offered to help and lead the project's public patient involvement (PPI) element. Funding was secured from the National Institute for Health Research's Health Technology Assessment programme.

The project is a feasibility study to see whether it's possible to collect evidence on the effectiveness of Namaste Care, a method to improve end-of-life care for people with advanced dementia.

Our PPI brief is to comment on the research as it progresses and ask for any clarification we feel is needed, advise on communications with people who have dementia and their carers, and assist with dissemination and evaluation.

We have current knowledge of practice in care settings and can ground the academic theory of care research in the reality of care practice. We are well placed to suggest what is likely to be possible, which can save time, effort and money. And as we're not intimately engaged in the research, we can stand back and call attention to the more general but equally important aspects of the work, such as making sure the findings are shared widely.

We are looking for new Research Network volunteers – find out more at alzheimers.org.uk/researchnetwork



Public and patient involvement
Dr Anne Davidson Lund (left) with other members of the Namaste Care public patient involvement panel (David Scott, Dr Gladys Archer and Ted Thorley).



New Alzheimer's risk genes

A study funded in part by the Society has identified two new genes that influence the risk of getting Alzheimer's disease.

The research was led by Alzheimer's Society research fellow Dr Rebecca Sims from Cardiff University and published in the leading scientific journal Nature Genetics.

Dr Sims and her colleagues compared the DNA of tens of thousands of people with Alzheimer's to people of the same age who do not have the disease. This was to understand whether there were any genetic differences between the two groups that could pinpoint why some people are more at risk of developing the disease.

They discovered two genes with rare changes that were associated with risk of Alzheimer's. A change in a gene called PLGC2 was found to be protective. Changes in another gene, ABI3, were found to increase the risk of developing Alzheimer's.

Both of these genes are part of the brain's immune system and are found in specialised immune cells called microglia. There is emerging evidence that the immune system plays a key role in the development of Alzheimer's and researchers are particularly interested in the microglia, as one of their functions is to 'mop up' damaging deposits in the brain.

This study also complements several others that have found genes related to the microglia that might affect a person's Alzheimer's risk – these immune cells could be making a direct contribution to the disease's development.

Working out how different genes and proteins interact in the brain when someone has Alzheimer's is important. This information helps researchers to understand more about the underlying causes of the disease and can point us towards potential areas to target when developing treatments.

Dr Sims said, 'In addition to identifying two genes that affect the risk of developing Alzheimer's disease, our new research reveals a number of other genes and proteins that form a network likely to be important in its development.'

Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said, 'Over 60% of people with dementia have Alzheimer's disease, yet despite its prevalence we still don't fully understand the complex causes.'

'The discovery of two new risk genes for Alzheimer's is an exciting advance that could help to deepen our understanding of what happens in the brains of people with the disease.'

'Insights like this are vital to help unravel the complexities of Alzheimer's disease and show researchers where to focus their efforts in the search for new, effective treatments.'

Cardiff University is the site of one of the six centres of the UK Dementia Research Institute. This centre will use discoveries in genetics and the immune system, such as the ones made by Dr Sims, as a starting point for understanding the disease and producing new therapies.

Microglia under the microscope

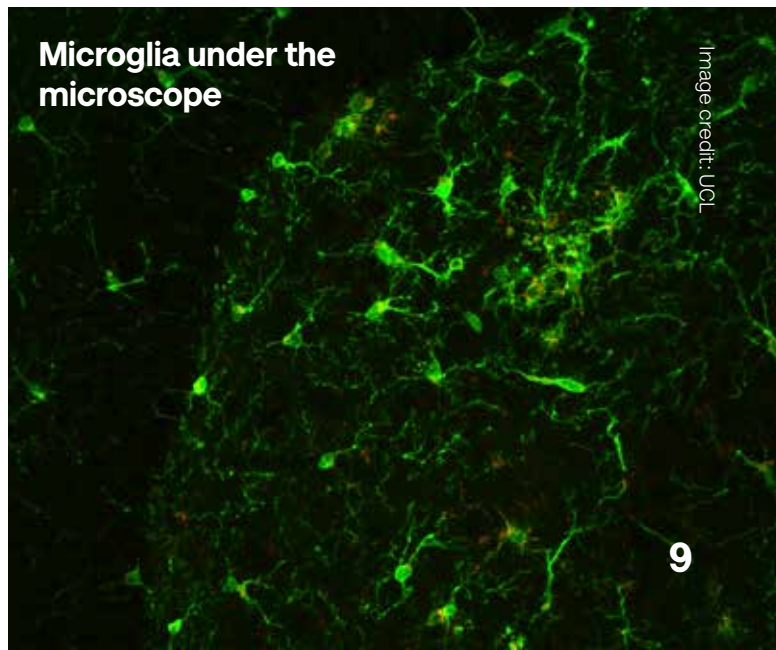


Image credit: UCL

A meeting of minds

The world's largest dementia research conference came to London in July, allowing researchers to share their findings widely.

Every year the US-based Alzheimer's Association brings dementia researchers and experts from around the world together to discuss the latest progress in the field.

We were thrilled that the 2017 conference brought over 5,600 researchers to the ExCeL Centre in London. Our research team was in the thick of it, learning more about many aspects of dementia research and discussing the latest news and views with experts. Here are just a few of our highlights.

Detecting the earliest signs

A key theme of this year's conference was how to identify who is most likely to develop dementia in the future. This is important because the people affected could then take part in clinical trials aimed at preventing the condition or treating it in its early stages.

Many discussions focused on biological signals called biomarkers that can offer up clues to someone's risk of dementia. Several researchers are looking for signals related to the two hallmark proteins of Alzheimer's, amyloid and tau.

Both of these proteins can be found in the cerebrospinal fluid using a lumbar puncture, also known as a spinal tap. However, lumbar punctures can be uncomfortable, so researchers want to find better procedures that can spot amyloid or tau.

Recent advances in a brain scanning technique called positron emission tomography (PET) mean that researchers can now see who has deposits of amyloid in the brain.

Evidence presented at the conference shows that these scans can help to make a more accurate diagnosis in some cases. PET scans that can detect the tau protein are also now used in research.

Some researchers at the conference suggested that we'll eventually be able to make a diagnosis of Alzheimer's from the results of brain scans, even before symptoms develop. While these scans hold promise for the future, they are not yet ready for use in routine clinical practice and they are very expensive.

Working towards GREATness

One of the most exciting findings in dementia care presented at the conference came from the GREAT trial. Run by researchers at the University of Exeter, this trial focused on discovering whether 'goal-orientated therapy' could help people with dementia to live better.

People with dementia worked with an occupational therapist to set goals and work out the best ways to reach these. At the end of the study, the researchers found that the people who had received the therapy were better able to achieve their goals than a group of people who had not had the opportunity to work with an occupational therapist in this way.

This is just a tiny snapshot of the huge body of work discussed during the five-day conference. It is always great to hear the results of collaborations and dialogue, and we left feeling positive that so many researchers are uniting to share thoughts, data and expertise, and will continue to work together to make dementia a thing of the past.



Turning up the volume

Dominic Carter, Senior Policy Officer at Alzheimer's Society, describes work to turn up the volume on the voices of people with dementia.

Society often fails to listen to the voices of people affected by dementia. Alzheimer's Society has responded by carrying out our largest ever conversation with people who have dementia.

Our recent report – Turning up the volume: Unheard voices of dementia – is a unique look at what it is like to live with dementia today, based on what we were told by the people who know best.

It shares the stories of people affected by the condition, dispelling myths and presenting a realistic picture of their day-to-day lives.

We gathered evidence over several months in partnership with Ipsos MORI, the market researchers. We did this through a large-scale survey of people with dementia, in-depth interviews with people affected by dementia, and further surveys of carers and the wider public.

Of the in-depth interviews, 32 were conducted face to face with people who have dementia in locations across England, Wales and Northern Ireland, and five were over the phone with carers. This meant that nearly 4,000 people shared their experiences and views to help us build an overall picture.

'I won't answer the phone and I don't answer the door unless there is somebody coming who I know.'

Person with dementia

Worryingly, the evidence told us that some people with dementia do not get the support and understanding they need to live well on a day-to-day basis.

It revealed how ingrained views and misconceptions, among both the general public and people affected by dementia, can make life more difficult for people who are diagnosed with the condition.

'A lot of people don't want to know about it because they don't want to think that they may get it.'

Person with dementia

The impact of symptoms and a lack of appropriate support can lead to people feeling that they can no longer do the things they love. This can affect their sense of worth, self-identity and contribute to feelings of isolation.

Others described how they or their carers often find professional care hard to come by — and they then have to shoulder the considerable cost of this as well.

However, some people with dementia said that when they were supported well, in part by Alzheimer's Society services, then they can live well – continuing to do the things they enjoy, remaining connected to their community and seeing the people they wish to.

We need change so that more people can experience these benefits. That is why the findings from this work will inform our strategy over the next five years. By uniting against dementia, we can all make a difference.

We can be clear about what is needed from government and from society, but we also need your continued involvement. By uniting against dementia, our movement will help to find a cure, improve care, and offer support and understanding to everyone affected.

'Remember yesterday, look forward to tomorrow, live for today.'

Person with dementia

See alzheimers.org.uk/turningupthevolume for more about the findings and the research that informed them.



We're looking for people with dementia, carers or anyone interested in research to participate in studies.

Sign up today. Phone: 0300 222 1122 (local rates apply)

Online: www.joindementiaresearch.nihr.ac.uk

Join Dementia Research is funded by the Department of Health and delivered in partnership with the National Institute for Health Research, Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society.



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Take part in research

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Call 0300 222 1122 and ask about Join Dementia Research.

Join our Research Network

Involving people with dementia, carers and former carers to influence our research.

alzheimers.org.uk/researchnetwork

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