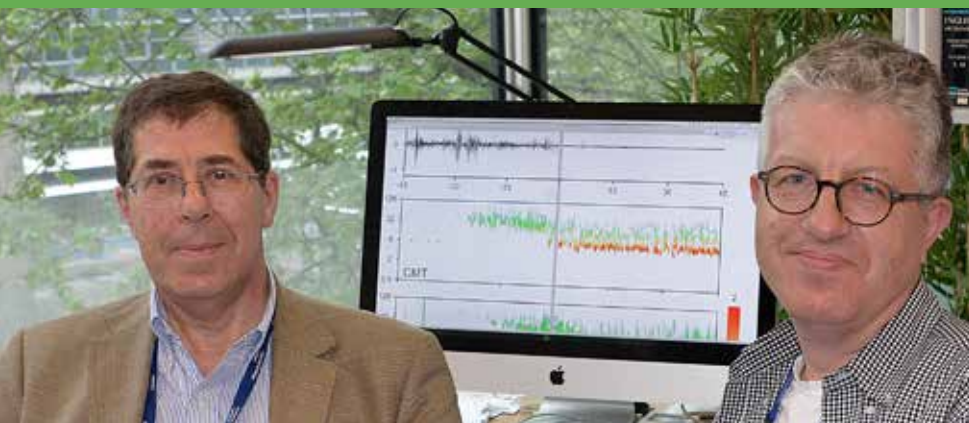


Care and cure

The Alzheimer's Society research magazine

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Sleep experts turn their attention to dementia.
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Dr Tim Shakespeare
Magazine Editor

Welcome to Care and cure magazine

It's been an exciting year to be involved in dementia research at Alzheimer's Society. We've seen the start of the UK Dementia Research Institute, we've established three centres of excellence in care research and we've seen results from our researchers presented at international conferences. This all brings us closer to improved treatments and care.

This is my last issue as editor of Care and cure, though I'm pleased to say I'll still be working at the Society, helping to share the benefits of research to support fundraising. We have ambitious plans to expand our research programme and we need a fundraising boost to make them happen.

In this issue we explore how research gives us hope for the future, even in the face of disappointing results from trials of new drugs. We hear how the UK Dementia Research Institute is starting to take shape, focusing on a project that brings new expertise to understand emerging links with sleep. We also show how Alzheimer's Society extends its impact, working in partnership to give people with dementia a strong voice in research.

The research we fund is only possible because of the generous charitable support we receive, so whatever your involvement in the dementia movement – whether you read and share this magazine, volunteer in our Research Network, donate to Alzheimer's Society or take part in research yourself – thank you.

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About us

Since 1990, Alzheimer's Society has funded £50 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



Disappointment and hope

In September, the pharmaceutical company Axovant announced the disappointing news that their experimental drug intepirdine has failed the final stages of testing.

Intepirdine was being tested as something to take alongside the existing Alzheimer's drug donepezil (Aricept). It wasn't expected to slow down the brain damage caused by Alzheimer's disease, but was designed to go further than existing drugs to help people cope with the symptoms. A previous smaller study of the drug had shown some promising results.

This most recent study involved over 1,000 people with mild to moderate Alzheimer's disease. However, people taking the drug in this larger trial did not see any substantial benefits in memory and thinking when compared to people taking an inactive pill (a placebo). There were also no improvements in how well people were able to complete daily activities such as dressing, cooking or using public transport.

Intepirdine is still being investigated as a treatment for dementia with Lewy bodies. Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said, 'After 15 years of waiting for a breakthrough, it's hugely disappointing that yet another drug for Alzheimer's disease has failed.'

This will come as a painful blow to the millions of people and their families desperate for new treatments.

'But this isn't cause to lose hope. Although dementia is currently incurable, our recent investment in the UK Dementia Research Institute will enable us to broaden our focus and increase the chance of finding new drugs.'

For too long research has focused on just a handful of pathways in the brain, but with the chance now to interrogate many more mechanisms involved in the progression of dementia, we're hopeful we can unearth new treatments.'

'We'll continue to tackle dementia from every angle until we make the breakthroughs we're hoping for'

While we improve our understanding of the brain to develop new treatments, we're also looking at ways to speed up the drug development process.

Our Drug Discovery programme tests whether drugs already in use for other conditions – such as diabetes, rheumatoid arthritis or high blood pressure – can work for people with dementia too, potentially reducing development time in half. We'll continue to tackle dementia from every angle until we make the breakthroughs we're hoping for.

Novel solution

A daily nutritional drink produces mixed results.

Results from a clinical trial of a nutritional drink called Souvenaid were recently published in The Lancet Neurology. Souvenaid is a medical drink containing Fortasyn Connect – a combination of fatty acids, vitamins and other nutrients.

Dr Doug Brown, Director of Research and Development at Alzheimer’s Society, said, ‘This medical drink has been shown to slow the decline of thinking skills in people with mild memory problems who also have early signs of Alzheimer’s disease on a brain scan or a lumbar puncture test.’

‘This group of people don’t benefit from Alzheimer’s drugs, so this drink is one option to consider alongside regular exercise, avoiding smoking and eating a healthy, balanced diet to keep their memory sharp.’

‘This trial of Souvenaid did not meet the success criteria that would be needed for developing new drugs, so we cannot be confident of the drink’s benefits.’

‘Although there was less cognitive decline in people taking the daily drink over two years, the same number of people still went on to develop dementia as those who had a fake drink every day. We certainly can’t conclude that the drink slows progression of Alzheimer’s disease.’

‘People who are worried about their memory should not rush out and buy this drink without first talking to their doctor to find out if it could be suitable for them. There are many causes of memory decline, including normal ageing, so it’s important people are investigated for underlying Alzheimer’s disease before taking this medical drink, or any kind of treatment.’

Football and risk

There have been a number of news stories recently about the role of head injuries in football and whether this is linked to an increased risk of dementia.

This includes an announcement by the Football Association and Professional Footballers’ Association that they are commissioning a study to understand more about this issue.

In response to the increased interest, Alzheimer’s Society held a discussion with a group of experts on what needs to be done to understand more about head injuries in football and risk of dementia.

We know that a severe or traumatic brain injury can increase dementia risk. Research in the US has also looked into the effects of concussion and head injury in sport, particularly American Football.

This research has suggested a link between playing these sports and a dementia-like condition called chronic traumatic encephalopathy. However, evidence about smaller repeated injuries – such as from heading a football – and dementia risk is less clear.

There is a lack of high quality studies that examine the effects of mild head injury and dementia. In general exercise is thought to reduce dementia risk, and our expert discussion concluded that we need to understand more to make sure that everyone can enjoy playing sport safely.

We are calling for researchers to consider adding information about head injuries to existing long-term lifestyle studies, and for professional sporting bodies to monitor and record head injuries in their players.





Sense of smell

A large study has linked sense of smell and dementia, but this isn't a reason to worry that it is caused by dementia

A study of nearly 3,000 people in the US found that older adults with a poor sense of smell were more likely to develop dementia later in life. Although the link between smell and dementia risk is an important finding, there are some key questions we need to answer.

First, if someone fails the test, how likely are they to develop dementia? Despite the fact that risk of dementia was greater in people with poor sense of smell, only nine in 100 people who failed the test would be expected to get a dementia diagnosis within five years. This reflects the fact that it's common for people to experience changes to their senses, and people shouldn't worry that this is an early sign of dementia.

Second, if someone passes the test, how likely are they to develop dementia? The test has a clearer answer to this question, as 97 out of 100 people who pass the test won't develop dementia. So it seems that this test is more useful for telling us who won't develop dementia than who will.

In practice, no single test can diagnose dementia. Doctors use a range of different examinations – the strengths and weaknesses of new tests need to be compared to existing methods to understand where improvements can be made.

News in brief

Blood magnesium

Levels of magnesium in blood tests that are either higher or lower than normal have been linked to increased risk of dementia. However, when researchers looked specifically at Alzheimer's disease rather than all causes of dementia, the differences were not significant. A number of previous studies have looked into possible links between magnesium levels in the blood and the chance of developing dementia, but we are still without a clear conclusion.



AI brain scans

Researchers are using artificial intelligence (AI) to detect signs of dementia in brain scans. Specialised computer software is 'trained' to detect the difference between scans of healthy people and those of people with Alzheimer's disease. At this stage the software is not accurate enough to be relied upon, but with further research it may be able to provide doctors with an additional perspective.

New genetic test

Researchers working on the genetics of Alzheimer's disease have developed a test that combines information from more than 30 genes. By combining information from multiple genes, we can make a more accurate estimate of how likely someone is to develop dementia. This could prove useful for clinical trials that need to identify people who are likely to develop dementia, who don't yet have any symptoms.



Could you sleep your way to a healthier brain?

Experts researching the science of sleep turn their attention to dementia for the first time.

Poor sleep and dementia are common bedfellows. People with dementia often experience disrupted sleep, which can affect their and their carers' quality of life. In recent years, it has also been suggested that people with regular sleeping problems are at a greater risk of developing dementia. The nature of these studies makes it difficult to know what comes first – does poor sleep contribute to the development of dementia, or is it an early indication that disease is developing in the brain?

The UK Dementia Research Institute (UK DRI) has been established with funding from the Medical Research Council, Alzheimer's Society and Alzheimer's Research UK to get to grips with the fundamental causes of dementia, and sleep is one of the topics under investigation.

Fresh perspectives

Professors Bill Wisden and Nick Franks (pictured) have been studying the science of sleep at Imperial College London for almost a decade. Now for the first time, within the UK DRI, they're turning their attention to dementia.

'We're definitely bringing a left-field approach; most of us at the UK DRI Imperial centre don't have a background in dementia. The institute provides the right framework for unique collaboration, allowing us to learn from dementia experts while we bring new perspectives and techniques to the table,' explains Professor Wisden.

Their research into the role of sleep in dementia is only just beginning, but being part of the UK DRI is already changing their thinking about the brain. Professor Wisden says it's important to understand dementia in terms of how different parts of the brain work together.

'Even though I'm a professional neuroscientist, I've never had to think so deeply before about the brain as an organ,' he says. 'It's packed full of blood vessels and multiple cell types all working together. Dementia needs to be thought of as a problem of organ physiology, not just a problem of proteins and molecules.'

Why do we sleep?

We all know the effects of a bad night's sleep. Along with physical tiredness, you feel groggy and can experience changes in mood, memory and how quickly you're able to think. You can usually catch up on sleep the next night, but research in mice suggests long-term sleep deprivation can cause lasting damage to the brain that isn't recovered.

‘There is evidence to suggest this clearing process happens more when we are sleeping.’

Sleep is clearly a vital behaviour but, despite decades of research, scientists still can't agree its purpose. Some argue that it is necessary to reset connections between brain cells and suggest that while we sleep we process information from the previous day, allowing us to form new memories.

Another theory states that sleep exists to repair damage in the body and brain that has accumulated while awake.

This last theory is gaining more traction following a discovery in 2013 that the brain flushes out waste toxins during sleep.

‘Our brains don't have the same lymphatic draining system as other organs of the body,’ says Professor Wisden. ‘Toxins and waste are cleared out along the outside of walls of blood vessels, in the space made between the vessels themselves and other types of cell, called glial cells. There is evidence to suggest this clearing process happens more when we are sleeping.’

Clearing out faulty proteins

Many forms of dementia including Alzheimer's disease, frontotemporal dementia and dementia with Lewy bodies, involve the accumulation of faulty proteins in or around brain cells. If sleep is essential for clearing our damaged proteins from the brain, then it makes sense that long-term sleep disruption could increase or worsen the conditions that cause dementia.

Professor Wisden and Professor Franks want to confirm that the brain's waste disposal system is indeed more active during sleep and then find a clear mechanism for how this process works. ‘Once we know the mechanism, we can start thinking about how to enhance protein clearance as a potential way to treat neurodegenerative diseases,’ says Professor Wisden.

The researchers will use cutting edge microscopy techniques to follow the movement of proteins in the brains of live, active mice. They'll track how quickly proteins move into the blood vessels when mice are asleep and awake, and also after periods of disrupted sleep.

‘It's actually really easy to stop a mouse from sleeping. You just keep presenting it with novel objects and the mouse is so interested in exploring them that it doesn't go to sleep.’

Enhancing waste disposal

Professors Wisden and Franks have discovered a type of brain cell that is more active when the mice go to sleep, but that doesn't seem to play a role in controlling the sleep-wake cycle. They are going to artificially activate these cells and see what they do, hoping to reveal a critical role in the waste disposal process.

‘The ultimate goal of our research might be treatments that can mimic sleep processes in the brain’, says Professor Wisden.

They will also be working with Dr Nir Grossman, an engineer by background who has recently joined the UK DRI at Imperial College London as a UK DRI Fellow. Dr Grossman has developed a new technique to induce brain waves in small areas of the brain by passing electrical currents through the scalp.

Working together, the team will generate the brain waves of sleep (called delta waves) in awake mice to see if they can artificially stimulate the brain's waste disposal system. As the technique is non-invasive, it has the potential to be used in people if their results show promise.

The team will generate the brain waves of sleep (called delta waves) in awake mice to see if they can artificially stimulate the brain's waste disposal system.

Professor Wisden acknowledges that sleep will not be the whole story when it comes to dementia. After all, people who get a full night's sleep can still go on to develop the condition.

The UK DRI at Imperial College London is looking broadly at the environmental factors that might influence the development of dementia.

In the long term, the team hope that by understanding how factors such as sleep play a role in the disease process, they can develop ways to remove their effects and ultimately delay or prevent the onset of dementia.

Assistive technology

Dr Lisa Newton is a GP and Alzheimer's Society clinical research fellow. Here she explains more about what assistive technology is, what is available and how it can be obtained.

Assistive technology is the name given to devices that can support people to live more independently and to stay safe at home or outside. It does not have to be 'hi-tech' – for example, a walking stick can be described as an assistive technology.

Assistive technology can be tailored to the needs of the individual and can work alongside existing care practices. However, it should never replace personal contact and care.

My research focuses on how we can help people with dementia to get the right information at the right time about assistive technology that may help their independence, and to be able to access it.

What assistive technology is available?

There are lots of assistive technologies available for people with dementia. This includes clocks that can tell you whether it is day or night, automated pill dispensers and locator devices for things that get lost a lot, like keys. There is even a special plug that means you will never flood the bath.

Many technologies have been developed to help people with dementia to stay safe, including detectors for gas, high temperatures and smoke that can either sound an alarm or alter the supply.

There are also some ongoing studies to understand whether using GPS technology to track someone's location could reduce the risk of becoming lost.



Where can I obtain assistive technology?

You can obtain assistive technology by buying privately or through social services, the NHS (as part of continuing health care or intermediate care services) or some housing providers.

It can be purchased from a number of sources including the Alzheimer's Society shop – see shop.alzheimers.org.uk or call 0300 124 0900 (local rate) – and the AT Dementia website.

Social services can conduct an 'assessment of needs' that could recommend assistive technology. However, availability varies between different local authorities. Some fire services will come to your home to assess risk of fire and may suggest devices.

Research suggests that the earlier people affected by dementia start using assistive technology, the more likely it is to be helpful. My research project aims to find out what information is provided by memory services and how they support people to access assistive technology.

Many technologies have been developed to help people with dementia to stay safe, including detectors for gas, high temperatures and smoke.

The project involves a survey and interviews with professionals and people with dementia to identify 'best practice'. We hope the research will be used to design better information resources and ways to access assistive technology.

It is important to note that not everyone will find this technology suitable, and if something is turning out to not be helpful or is causing distress then it should not be used.

If you have dementia, make sure that you have conversations with your family, carers, healthcare professionals and local authority to ensure that you can access the technology that would be of most benefit to you.

Day and Night clock, automated pill dispenser and many more assistive technologies are available from the Alzheimer's Society Shop alzheimers.org.uk/shop or call 0300 124 0900



People involved in the SHARED project including research nurses, co-investigators, members of the advisory group and co-researchers.

SHARED endeavour

A study making recommendations for hospital discharge involves people affected by dementia as researchers, not only participants.

People affected by dementia, whether they have dementia or are carers or former carers, are central to research. Research would not happen without their involvement as participants, and they can use their expertise to shape research programmes, including through our Research Network. But in some studies, people with personal experience can also be involved as members of the research team. People involved in this way are often called 'co-researchers', as they collect and analyse data in addition to providing guidance.

This approach has seen particular success in a study called 'Services after hospital: action to develop recommendations' or SHARED. In the SHARED study, funded by the National Institute for Health Research, people with personal experience of dementia were involved in conducting interviews and studying transcripts to develop themes and recommendations.

The researchers overcame a number of barriers to involve co-researchers in this way. Dr Carole Mockford, who led the study at the University of Warwick, said, 'We had some challenges getting the co-researchers involved, including arrangements for paying them and permission from NHS trusts to let them interview staff on hospital premises.'

Alzheimer's Society, a partner on the project, helped to remove some of these barriers by setting up a study group. We assisted co-researchers with paperwork for security checks and provided insurance cover for them.

Twelve co-researchers were involved in the study, half from the Research Network and half from other local volunteer networks. Sue Boex, a Research

Network volunteer, was one of them. This was a new experience for Sue, who said, 'I was very nervous obviously, it was quite a learning curve but we had plenty of training.'

All the volunteers received three days of training in topics such as research ethics, interviewing and data analysis. Sue carried out interviews with patients and carers about their experience of being discharged from hospital, and could see how her experience was valuable to the study. 'Because we'd been through what they were going through, that helped,' said Sue. 'They wanted someone to listen to them. It was a really worthwhile experience.'

Dr Mockford appreciated the fact that co-researchers could provide a different perspective. She said, 'Their friendly but professional approach put the study participants at ease. Discussions between the co-researchers and study participants at the focus groups were very lively and ultimately successful.'

Along with a number of researchers and co-researchers, Sue is a co-author of two published academic papers written about the SHARED study. One, published in the journal *Research Involvement and Engagement*, describes the process of starting the study and involving co-researchers. The other, published in *Health Expectations*, shares the findings from the interviews.

This paper puts forward three recommendations to support a smooth transition from acute hospital care to the community for people who have memory loss.

- The first is to have a written, mutually agreed and meaningful discharge plan.
- The second is to have a named co-ordinator who is a point of contact for services and support.
- The third is to improve the quality of care provided by agencies in people's homes.

The challenge now is to build on these user-led recommendations to make meaningful change. It's clear that involving people affected by dementia will be just as important when taking these next steps.

Out of the lab

They spend their working days striving to find better treatments for dementia or improve care, but many of our researchers are also giving up their precious free time to support us.

Pedalling to Paris

Five University of Exeter researchers cycled an astonishing 350 miles from London to Paris to raise money for Alzheimer's Society. The team comprised Andy Randall, lead of our Exeter Doctoral Training Centre, Society fellow Francesco Tamagnini, geneticists Jonathan Mill and Eilis Hannon, and stem cell researcher Talitha Kerrigan.

They had to deal with torrential rain, extreme pain and sheer exhaustion, but made it to the French capital in one piece. They raised an amazing £11,500 as a reward for their efforts.

Dr Tamagnini said, 'I have never done anything so hard. I have met new friends and I have consolidated the bond with the rest of the Exeter crew. I realised I love cycling. Now I know that I will probably have to ride for a lot of miles in the path of scientific research, with my colleagues and friends, to finally find a solution and defeat this dragon. And I know we can make it.'

Their dedication did not go unnoticed. Dr James Pickett, Head of Research at Alzheimer's Society, said, 'We are delighted that the team from the University of Exeter have succeeded in completing their gruelling challenge.'

'Not only have they already raised a huge amount of money but they are also doing fantastic research to help us understand, treat and ultimately cure dementia.'

Welcoming Memory Walkers

If you went to this year's Memory Walks in Nottingham, Exeter, Liverpool, Cheltenham or Brighton you may have been lucky enough to bump into some of our researchers. Equipped with special T-shirts, 'Ask me about my research' signs and even models of brains, the researchers braved the rain, cold and a large number of dogs to chat to walkers about the work they're doing.

Attending Memory Walks is always emotional for our researchers, who have the chance to connect with supporters and show people how the work they do is making a difference to people affected by dementia.

Professor Louise Serpell, lead of the Alzheimer's Society Doctoral Training Centre in Sussex, attended the Brighton walk with several other researchers. 'It was very moving to see people walking for their relatives,' she said.

Professor Jerry Turnbull, an Alzheimer's Society grant holder from the University of Liverpool, took part in the city's walk. He said, 'This funding is vital for the development of new treatments and it's fantastic to see the support from so many people at Memory Walk.'

Join thousands of people walking to defeat dementia at Memory Walk 2018. Sign up today at memorywalk.org.uk or call 0300 330 5452 and start fundraising today

'We are incredibly grateful to all our researchers for the amazing work they do. We are continually impressed by their amazing efforts to raise money for us and their dedication to help people affected by dementia' - the Research team



Memory walk participants Professor Dawn Brooker, Karen Gray PhD Student, Teresa Atkinson Senior Research Fellow plus canine companions Sophie and Oscar.



Dr James Pickett
Head of Research
at Alzheimer's
Society

Setting the care research agenda

James Pickett, Head of Research at Alzheimer's Society, explains how we've led an ambitious piece of work to advance research into quality of life for people living with dementia, as well as for their families and carers.

It has been widely publicised that the amount of investment going into dementia research has increased in recent years, but to date there has been much more work aiming to find a cure for dementia rather than to improve the lives of people living with dementia today. For example, a global database of dementia research projects finds only 3.4% of the 5,837 research projects added over the last three years address care, support and health economics of dementia. That's fewer than 200 projects worldwide.

One reason for the disparity may be the high political attention given to finding a cure. In 2013, G7 nations set out the ambition to identify a cure or a disease-modifying therapy for dementia by 2025. This has driven the allocation of funding and resources towards research strategies that maximise the chances of this becoming a reality.

Alzheimer's Society has long championed the importance of striking a balance between 'cure' and 'care' research. So, we set out to develop additional ambitions to describe what may be achieved in other areas – for instance in prevention research, but also diagnosis, intervention and care. We worked with a group of leading researchers, clinicians and people with dementia to set five additional goals:

- Prevent future cases of dementia through increasing knowledge of risk and protective factors.
- Maximise the benefits to people living with dementia and their families when seeking and receiving a diagnosis of dementia.
- Improve quality of life for people affected by dementia, by promoting functional capabilities and independence, while preventing and treating negative consequences of dementia.
- Enable the dementia workforce to improve practice and skills by increasing evidence to inform changes in practice and culture.
- Optimise the quality and inclusivity of health and social care systems that support people affected by dementia.

For each of these goals, we developed a specific set of recommendations about the type of research that was needed to deliver them. For instance, we came up with 10 recommendations for the third goal.

Some of these recommendations concentrate on gaps in our knowledge, such as developing effective ways to manage and treat symptoms like depression, anxiety and pain. Others focus on particular stages of dementia, including the need to focus on more advanced dementia.

Some of our recommendations look at ways to improve the research process or the ways studies are designed. For example, many studies that involve carers narrowly assume this means a spouse or partner. We need to develop new methods to study the more complex dynamics of carer relationships, which in turn will make it easier for more people to be involved in research.

We came up with 30 new recommendations in total and an action plan suggesting how to implement them. Together, these form a roadmap for the future of care research that will be published at the end of 2018.

Although it is a useful first step, a roadmap document won't transform dementia research on its own. Now the hard work starts. We will work with researchers, funders and partners to turn the recommendations into a reality.



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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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.

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