

Care and cure

The Alzheimer's Society research magazine

Caring for carers

Learn more about research that is focused on carers



News roundup

The latest in dementia related news

Stars of the show

Dr Claire Garwood is finding out whether star-shaped cells in the brain can help to fight dementia



Dr Aoife Kiely
Editor

Welcome to Care and cure magazine

In this issue of Care and cure, we pay special attention to carers – people who support a relative, friend or significant other who has dementia.

Alzheimer's Society funds a broad range of biomedical and care research. We're dedicated to finding a cure or treatment for dementia and improving life for people affected by the condition in the meantime. This includes carers and this issue shines a spotlight on three carer research projects that we currently fund.

Dr Kirsten Moore is working to improve awareness and understanding of the feelings of grief that carers can experience while the person they care for is alive (Page 7). At Brighton and Sussex Medical School, Professor Sube Banerjee and Dr Stephanie Daley lead a team in working to improve the quality of life of carers of people with dementia (Page 9). In our researcher profile, we hear about what drew Dr Nathan Davies to design a decision aid for end of life care (Page 10).

We also catch up on the latest global dementia news and hear about the biomedical work of Dr Claire Garwood, who is investigating whether star-shaped cells in the brain could be encouraged to keep supporting the neurons around them in dementia (Page 11).

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



GPS insoles for safer walking

The NHS in Dorset is testing GPS tracking insoles for people with dementia.

As a person's dementia progresses, they might feel the urge to walk about and even leave their home. Although walking can be a positive form of exercise, relieving stress and boredom, there can also be risks. In order to help keep people with dementia safe when walking, the NHS in Dorset is testing a new global positioning system (GPS) device.

People with dementia who consented to take part in the trial were given GPS-fitted insoles, known as SmartSoles, to test out. The insoles can be discreetly tucked into shoes and easily swapped between different pairs.

The aim of the insoles is to enable the person to be independent as well as safe. If the person walks away alone they can be easily located using a smart phone or computer that is connected to the insoles via an app. A notification is sent to the carer's mobile phone from the GPS tracker as soon as the person with dementia walks outside of a defined area, such as a garden or care home.

Sally Copley, Director of Policy, Campaigns and Partnerships at Alzheimer's Society, said 'Becoming lost and disorientated is a serious concern for people living with dementia and their loved ones – not only can it put them at risk of harm and stop them from being able to live independently, but also can cause great stress to families and carers.

'The use of GPS tracking for people with dementia is a contentious issue. Our research has shown that, when used appropriately, it can provide reassurance and even save lives. People with dementia told us that they want the technology to be easy to use and

putting it in slippers could achieve that, but it's also important that it's only used when it's wanted.

'The use of GPS tracking is a contentious issue. Our research has shown that, when used appropriately, it can provide reassurance and even save lives.'

'Ultimately it's a personal decision but it's crucial we find ways to help the 850,000 people living with dementia in the UK keep their independence. That is why we recommend that these technologies are discussed as early as possible after a diagnosis, so that the person living with dementia is able to give informed consent and, if they want to, begin benefiting from these potentially lifesaving devices, that will give them the confidence to go out and about without fear of getting lost.'

Alzheimer's Society has funded research in this area. Dr Ruth Bartlett at the University of Southampton worked with people with dementia, carers and the local police to find out whether GPS devices are appropriate and if they help people to remain independent for longer.

The study is now completed. Results suggest that GPS devices can be a useful tool when introduced at a stage when the person with dementia can consent and maximise the benefits to their independence.

This will help to inform dementia care policy and provide people with dementia, carers and police with practical guidance for the use of this technology.

Sleep apnoea and dementia risk

A closer look at the research behind the headlines.

Sleep apnoea is a condition where people either stop breathing for a time or their airway becomes temporarily blocked while they are asleep. People with sleep apnoea experience excessive snoring and tiredness during their waking hours.

The potential link between sleep apnoea and dementia risk has hit the headlines in recent months. Researchers in Australia have been investigating whether sleep apnoea has a connection to some of the early signs that someone may have a higher risk of developing dementia – thinning of certain brain areas and poor memory test scores. The researchers measured the amount of oxygen in a person's blood while they slept. Low blood oxygen would show that they weren't breathing properly and had sleep apnoea.

The results showed that people with low blood oxygen levels were more likely to have thinning in some areas of their brain than people who had high blood oxygen.

There are several important limitations to this study. Firstly, the researchers only tested 83 people, which is too small a group to represent everyone affected. Secondly, all those who took part had memory

problems – normally a study would use a second group with no cognitive problems to compare against. Thirdly, we can't be sure that any of these people would go on to develop dementia, since their memory problems could have been caused by other conditions such as high blood pressure and depression.

This study does underline that sleep apnoea is a serious condition and, if left untreated, could significantly affect your quality of life, so it remains important to speak to your GP if you are concerned about sleep apnoea.

Sleep and its potential role in protecting the brain has become an important area of dementia research.

Read about Society-funded sleep research in our winter 2017 issue, visit: alzheimers.org.uk/careandcurearchive for this and all past Care and cure articles.



Something in the air?

Exposure to air pollution and risk of dementia.

In recent years we've seen greater attention given to whether exposure to air pollution can put us at greater risk of developing dementia. Large studies have taken place looking at whether living in an area of high air pollution might increase dementia risk.

The idea of air pollution raising risk of dementia has been around for some time. Recent research has suggested that some of the particles we inhale from pollution can make it into our brains. It isn't clear how these might affect the brain or whether they start or worsen dementia.

Research presented at the Alzheimer's Association International Conference in Chicago in July suggested that exposure to air pollution could cause some areas of the outer layer of the brain – the cortex – to become thin. Another study found the same effect on the cortex, but found that air pollution did not result in an increase in deposits of the toxic amyloid protein, which is a feature of Alzheimer's disease. We still do not know whether air pollution is actually connected to dementia.

Were air pollution to cause dementia, we would expect more people to be diagnosed with the condition and at a younger age in cities and large towns than in rural areas – this isn't the case. While more research is required to understand how pollution particles might affect the brain, there is currently no reason to be unduly worried about pollution as a cause of dementia.

What we can do is focus on reducing our risk of dementia by making positive lifestyle changes like being physically active, eating a healthy diet, avoiding smoking and cutting down on alcohol.

BAN2401: Hope or Hokum?

As a drug trial announces positive early findings, we look at whether the hype is justified and what the results mean.

In July, the first news emerged that a drug called BAN2401 was producing positive effects in people with dementia. BAN2401 is a molecule designed to specifically bind to toxic amyloid protein and allow it to be removed. The drug is given twice a month via an injection and has been shown to be safe with minimal side effects.

Biogen and Eisai – the companies involved – both saw their stock prices rise after a press release said the drug had improved cognition in people receiving the highest doses of the drug and reduced the amount of amyloid in their brains. We had to wait until the Alzheimer’s Association International Conference in Chicago to get our hands on the hard facts of the research. Although the results look good at this time, it is still too early to be anything but cautiously optimistic.

Doug Brown, our Chief Policy and Research Officer, says, ‘It’s been 15 years since the last dementia drug treatment was developed, so any breakthrough in finding a new way to tackle this devastating condition is extremely welcome. We’ve known for a long time that the amyloid protein is involved in dementia, and Alzheimer’s Society has been funding years of research to understand exactly how.

‘Recent failed drug trials have suggested that targeting amyloid may not be the right approach to slow or stop Alzheimer’s disease – but this study’s results could challenge that, demonstrating instead some reduction of cognitive decline with high doses of this drug. It is only the second such drug trial offering hope that this approach is worth pursuing.

‘However, it’s still early days. The drug has to go through more extensive clinical trials to make sure they can replicate these exciting findings. Meanwhile, our researchers will be working tirelessly to explore all avenues for potential new treatments for dementia.’

The next step for BAN2401 is the phase 3 trial, in which thousands of people at different biomedical research centres would be given the drug. With a larger number of people taking the drug and potentially seeing positive results, we could be more confident that the drug is safe and that it really works.

Even if all goes well, this drug won’t be available for several years. Yet it is encouraging to see pharmaceutical companies using their expertise to tackle dementia.

News in brief

Lost birdsong

A Society-funded study has provided evidence that memory of sounds is stored differently from visual or verbal memory. They showed that an avid bird watcher with dementia held on to memories of bird features, feathers and human faces and voice but misplaced memory of birdsong. This helps us to understand why some types of memories are lost before others.



Fizzy factors

A recent study of 2,888 people suggested that drinking artificially sweetened fizzy drinks increases the risk of stroke and dementia. People who drank sugar-sweetened drinks had less direct risk of stroke and dementia, but were more likely to have diabetes or be obese – which can also increase dementia risk.



Alzheimer’s Society annual research review

To find out about the research that we have funded in the past year visit:

**[alzheimers.org.uk/
research-achievements](https://alzheimers.org.uk/research-achievements)**

Caring for carers

Alzheimer's Society was founded nearly 40 years ago by a small group of passionate and determined carers. Since then the Society has grown, reaching more people affected by dementia than ever before and funding a wide variety of biomedical and care based research projects.

Caring for a person with dementia can be a rewarding but also a very challenging experience. Carers are faced with the often 24/7 challenge of supporting a person with dementia. This can lead to exhaustion, anxiety and stress. We provide information, advice and support through our website and publications, our online community Talking Point, the National Dementia Helpline and local services.

Over the next three pages, we take a look at some of the carer focused research that the Society is currently funding.



Feelings of grief

Dr Kirsten Moore is raising awareness and understanding of grief that carers may feel while caring for a person with dementia.

Dr Kirsten Moore has spent her career researching ways to support carers, including through the use of computers and exercise programmes. When she asked carers, they told her that while behavioural changes and incontinence are challenging aspects of supporting someone with dementia, feelings of grief are often the most difficult. Carers described this grief as feeling that they no longer had that person in their life to share their problems and discuss their life with.

In recent years, there's been greater awareness of what researchers call 'carer burden' – the stress and anxiety that carers may face. Yet, very little research has been published about the grief that people can experience while caring for someone with dementia. Dr Moore says, 'I felt that, while addressing issues such as depression and burden are important, if we fail to acknowledge grief and loss then carers may continue to struggle.'

Her research has driven Dr Moore to look at how we prepare for end of life in dementia. Based at the Marie Curie Palliative Care Research department at UCL in London, this Society-funded study will examine the impact of preparing for end of life on carers' feelings of grief while the person with dementia is alive.

Through a survey of memory services, Dr Moore found that while over two-thirds had a process to identify feelings of depression, burden and anxiety among carers, only 11% had a similar approach to grief. At present, Dr Moore and her team are creating a new resource for carers and seeing how this would best support them. The team will need to decide whether this resource will focus on carer grief or if it should address grief alongside preparing for the future and end of life.

To make the right decision, Dr Moore's team is interviewing carers and consulting with Experts by Experience – a group of current and former carers. They will also hold a workshop, bringing carers and professionals from all areas of dementia care together to decide what the resource should contain.



Dr Kirsten Moore (left) with project research assistant Sophie Crawley (right).

Carers will give them their thoughts on whether the resource should be online, written or in audio-visual form. The aim is to develop a resource that carers can use as and when needed, without being constrained by appointments.

'I felt that, while addressing issues such as depression and burden are important, if we fail to acknowledge grief and loss then carers may continue to struggle.'

Once the resource has been created, the next step will be to test it to make sure it works and is useful in the real world. Dr Moore's team will start by testing the resource with people who are currently carers. If carers agree that the resource is useful and worthwhile, Dr Moore will take it further, perhaps also making a version to raise awareness and understanding among healthcare professionals.

Get involved:

If you are a family member or friend who cares for someone living with dementia and are interested in taking part in this study, please contact :

Dr Kirsten Moore
kirsten.moore@ucl.ac.uk
or call 020 7679 9488

Carer quality of life

Alzheimer's Society-funded research provides a new way to understand the needs of carers and improve their quality of life.

There are around 700,000 carers supporting people living with dementia in the UK. Balancing their own needs alongside their caring role can be a challenge and carers may struggle to look after their own wellbeing. It may seem impossible to find the time, or selfish to try to. Yet, when a carer looks after their own mental, emotional and physical wellbeing, they are in a better position to continue to be there for the person with dementia. It is essential that we find effective ways to support carers and help them to have a good quality of life.

Although there are ways to measure depression, anxiety 'carer burden' and the rewards of caring, there are few specific tools available to assess the quality of life of people who care for someone with dementia.

'Without family carers the dementia care system in the UK would collapse.'

A team of researchers at Brighton and Sussex Medical School, led by Professor Sube Banerjee and Dr Stephanie Daley, set about developing a tool to measure quality of life in carers of people with dementia that could be used across a range of research trials and health and social care services. In developing the tool, they worked with researchers from the University of Kent, UCL, King's College London, University of Southampton and London School of Economics.

They developed a tool called C-DEMQOL by working out what we didn't know about carer quality of life. The team identified what factors are important for quality of life through interviews and focus groups with carers and a small selection of care professionals.

They found seven common themes that influenced carer's quality of life:

1. The physical and emotional health of the carer.
2. Feelings of responsibility and the physical and emotional demands put on the carer.
3. Personal needs, such as a carer's need for personal time and space.
4. The carer's relationship with the person with dementia.
5. How the carer feels about their role, do they accept it and feel effective?
6. The carer's feelings about the future.
7. Support for the carer from family community and health service.

The C-DEMQOL tool - a list of questions based on these themes - was tested in three stages with a total of 446 carers. They were interviewed and asked for feedback so that the tool could be improved at each stage.

Throughout the study, the researchers worked closely with the Lived Experience Advisory Panel, all of whom have cared for people with dementia, stroke or long-term mental illness. They helped the research team make sure that the questionnaire truly reflected the concerns and experience of carers.

Dr Stephanie Daley says, 'Without family carers the dementia care system in the UK would collapse. However, the role of family carer can be challenging, which can affect wellbeing and quality of life.'

The C-DEMQOL tool was developed because it is vital that we sustain and improve quality of life of carers of people living with dementia and will allow health and social care sectors to do just that. Future researchers will be able to use this tool to better understand and measure the needs of carers and create a better quality of life for all those affected by dementia.

Photograph of the researchers with the Lived Experience group (Left to right: Yvonne Feeney, Thurstine Basset, Jay Kramer, Katherine Eastland, Ellen Jones, Dr Tom Page and Dr Stephanie Daley).



Decisions: End of life care



Dr Nathan Davies.

Dr Nathan Davies talks about his research

Who are you?

My name is Dr Nathan Davies. Born and raised in a small town in south Wales, I studied psychology at Exeter before moving to London where I completed my PhD at UCL and have been here ever since. When I'm not working you'll likely find me in the gym, cooking up a storm in the kitchen or watching Formula One or tennis (I'm in the queue for Wimbledon most years).

What drew you to end of life care?

After graduating, I worked as an assistant psychologist in memory services. It really struck me how we would see a person with dementia a few times and not see them again. I was interested to understand what happened later on, and my PhD focused on end of life care for people with dementia. Since then, my focus has been to understand the experiences of carers and how we can use this information to improve care and services. I'm working to find ways to support carers with the emotional and significant decisions that they have to make on behalf of the person they care for towards the end of life and in the later stages of dementia. This will produce a tool to help people with dementia take part in decision-making along with their carer.

Why is it important to support carers in making end of life decisions?

The end of life is hugely important – we all want to end our lives in a comfortable, respected and dignified manner. This topic has so often been neglected in dementia care research, but I believe that some of the best work on this subject is now coming out of the UK. We know that families find the later stages of dementia and the end of life very difficult, with feelings of anxiety, guilt, prolonged

grief and sadness. Healthcare professionals, even those with years of experience, also struggle with this topic. The research we are doing has the potential to have a huge impact on people with dementia, carers and professionals.

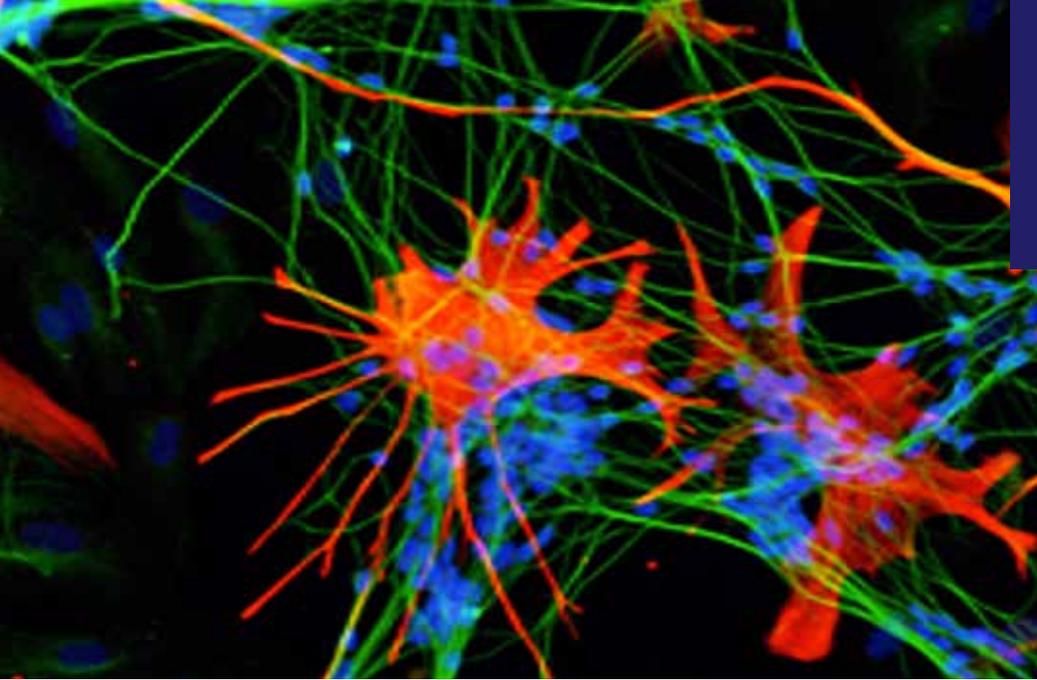
'The end of life is hugely important – we all want to end our lives in a comfortable, respected and dignified manner.'

What is next for you and your research?

I am enjoying leading some really compelling research projects and working closely with people with dementia and their families. I hope that my end of life decision aid project can be rolled out as a larger trial, and so potentially become routine practice to improve the lives of people affected by dementia.

I enjoy the variety of my work – one day I am speaking to groups of people affected by dementia, the next I'm presenting at a research conference or teaching students. I aspire to build my career in dementia research to make a difference to people with dementia and their families.





An astrocyte (red) grown in a dish with brain cells (green and blue).

Stars of the show

Dr Claire Garwood explains how astrocytes – star-shaped cells in the brain – support neurons and how their support could be turned back on in dementia.

Tell us about yourself

My name is Claire Garwood, and I am a research fellow based at the Sheffield Institute for Translational Neuroscience. My research focuses on understanding the role that astrocytes play in the development of Alzheimer's disease. I'm also a mum to two little girls and a keen runner.

Looking to the stars

I've been investigating the role of astrocytes in Alzheimer's since my Society-funded PhD, which I completed late in 2010. We call astrocytes the 'stars of the brain' because they have a star-like shape, but also because they have many important roles, including providing essential nutrients and other chemicals to neurons to ensure their survival. As neurons are the brain cells that we need to make thoughts and send instructions to the body, this means that astrocytes are critical for brain health. You might also be surprised to learn that astrocytes actually outnumber neurons in the human brain.

We know that astrocytes change early on in Alzheimer's, but we don't yet have a good understanding of why these changes occur and how they contribute to the disease. One of these changes is that astrocytes no longer respond to insulin correctly. Insulin is a hormone found naturally in the body.

It works to help glucose enter our cells so that they can make energy. We know that when the cells of the body stop responding to insulin, this can result in diabetes. My current research project looks at what this change in insulin response means for astrocytes – how do they make energy and, critically, do they still provide support to neurons?

How astrocytes can help

I have developed a system where I grow astrocytes in a dish and give them chemicals to impair their ability to respond to insulin. These 'impaired' astrocytes are then grown with neurons. Early results indicate that these astrocytes can still support neurons. However, if we put the astrocytes under the type of stress they'd face in the brain of a person with Alzheimer's, they stop supporting neurons. This means that if we can help astrocytes to work properly in Alzheimer's disease, then they will continue to support neurons and hopefully prevent them from being lost.

Next steps

In addition to this work, I am also developing a system where neurons and astrocytes can be grown together on specialised 3D structures. It is hoped that by developing 3D culture systems, we can model the human brain more effectively in a dish. I hope to secure a senior fellowship to develop this work further.



Research notices

En-choir-ing minds

Vicky McClure, Alzheimer's Society ambassador, is working the Created Out of Mind research group to better understand the positive effects of music on people living with dementia.

The team formed a choir of people with dementia and carers (pictured right). Vicky and the researchers will find out if music has a positive impact on the lives of those involved and brain scans will show if the effect goes deeper.

The whole process is currently being filmed by Curve Media for a BBC documentary that will be broadcast later this year.



The choir will be performing live at Nottingham Concert Hall on the 5 September at 3pm. You are welcome to go along and show your support. Free tickets are available at: www.trch.co.uk/whats-on

100,000 genomes project is looking for participants

To investigate new potential genetic links to dementia researchers are analysing the genetic information of people with young onset dementia.

The researchers are in a race against time to recruit more people, and with only a matter of weeks left to go before they must close the project they need as many participants as possible.

Getting involved is easy.

People under the age of 60 who have a young onset form and a family history of dementia can sign up by contacting the researchers at:

Floey Urban: floey.urban@nhs.net 020 3448 4274

Ambreen Tariq: ambreen.tariq@nhs.net 020 3448 4276

The researchers will need you to complete a consent form and research questionnaire, and will need a small sample of blood for analysis.

The researchers won't be able to provide individual genetic results.

For more information visit www.genomicsengland.co.uk





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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