

Care and cure

The Alzheimer's Society research magazine Issue 10 Spring 2017

Breaking the knowledge barrier

Professor Bart de Strooper lays out his ambitious vision for the £250 million Dementia Research Institute.

Page 6

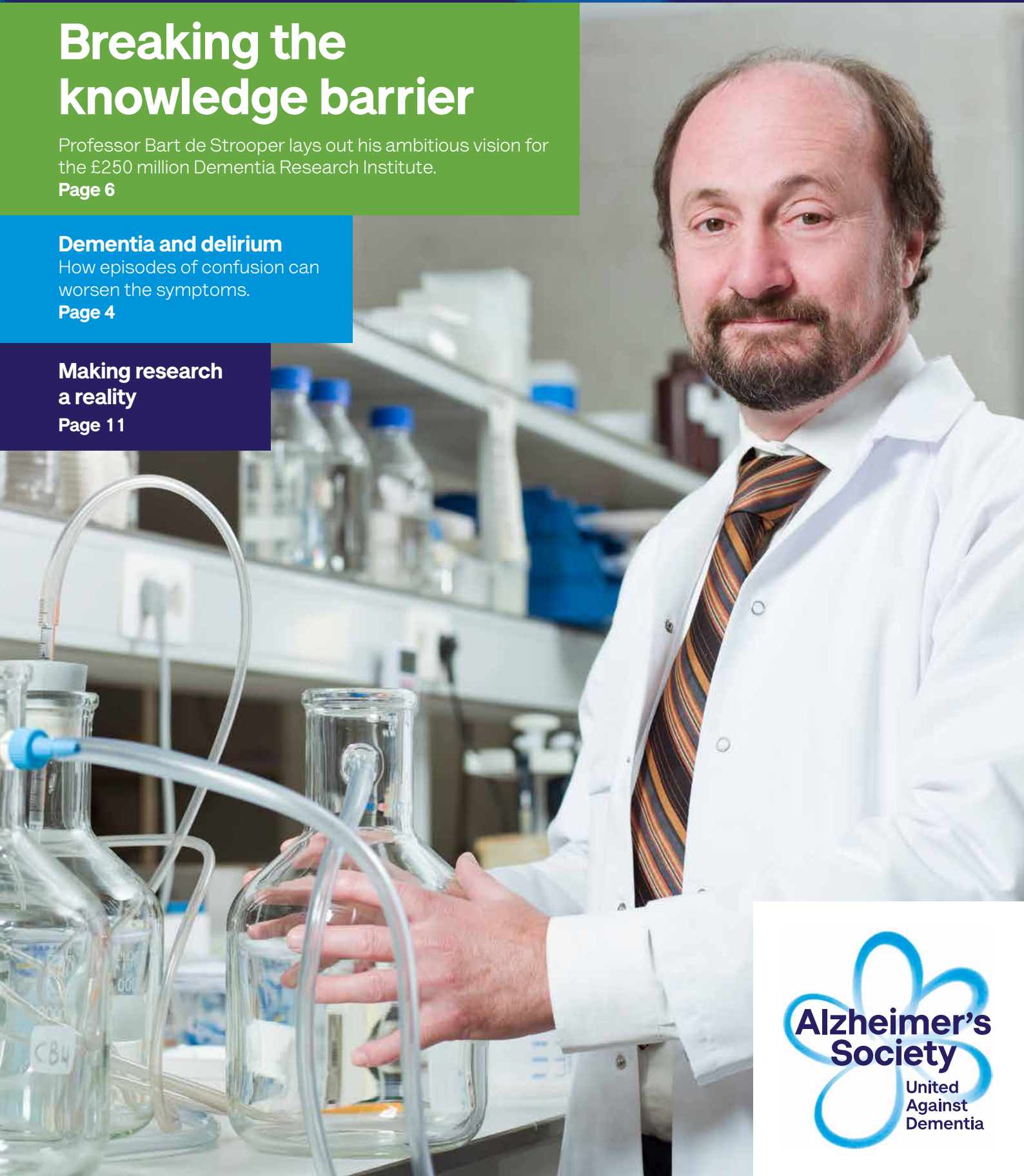
Dementia and delirium

How episodes of confusion can worsen the symptoms.

Page 4

Making research a reality

Page 11





Dr Tim Shakespeare
Magazine Editor

Welcome to Care and cure magazine

Alzheimer's Society is leading the movement to transform the landscape of dementia by providing support, changing communities and driving research. It's a formidable aim that can't be achieved overnight. To get there we need to be bigger, bolder and more ambitious. That's why we have a striking new brand and why this magazine has an eye-catching new design.

Our new brand will help us make dementia and Alzheimer's Society impossible to ignore, which is essential for us to deliver on our new five-year strategy – the New Deal on Dementia. This strategy will allow us to fund more research, create lasting change, and improve care and support for everyone whose life is touched by dementia. Our £50 million funding for the UK Dementia Research Institute is central to this ambition. In this issue, the institute's newly appointed Director, Professor Bart de Strooper, describes his vision to break down barriers in the search for new treatments (page 6).

Supporting researchers at the start of their careers is also crucial to developing the next generation of dementia experts. We launched our Dementia Research Leaders programme three years ago to support the best and brightest scientists to work on dementia. In this issue we look back at what it has achieved so far (page 10).

Thank you for being part of the growing movement towards our vision of a world without dementia.

In this issue

3 Risks of pollution

Could living close to a major road increase the risk of developing dementia?

4 Brain training

A comprehensive review of existing evidence suggests that brain training could help people with mild memory problems.

4 Dementia and delirium in hospital

Research suggests episodes of confusion and disorientation can worsen the symptoms of dementia.

5 Leading cause of death

Latest figures from the Office for National Statistics show that dementia is the most common cause of death in England and Wales.

5 News in brief

6 Breaking the knowledge barrier

How Professor Bart de Strooper will lead the new Dementia Research Institute to advance our understanding of dementia.

8 Interpreting our genes

PhD student Isabel Castanho is discovering how genes are turned on and off in Alzheimer's disease.

9 Learning from experience

Involving people affected by dementia to train the next generation of healthcare professionals.

10 Capacity for success

Looking back after three years of our Dementia Research Leaders programme.

11 Making research a reality

Working to put care innovations into practice.

About us

Since 1990, Alzheimer's Society has funded £40 million of cutting-edge dementia research. We aim to increase our investment in our research programme to around £100 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.



Risks of pollution

Living close to a major road is linked to a slight increase in dementia risk, according to a large Canadian study.

This study of approximately 6.6 million people living in Ontario, Canada raises important questions about how environmental factors could contribute to our risk of dementia.

The researchers used postcodes to measure how close people lived to a major road and analysed medical records to see if they developed dementia, Parkinson's disease or multiple sclerosis. The part of the study investigating dementia involved 2.2 million people aged between 55 and 85 over a period of 10 years.

Compared with people living 300m away from a major road, the risk was 7 per cent higher for people living within 50m, 4 per cent higher from 50–100m and 2 per cent higher from 100–200m from a major road. These are small differences in risk. Overall, 57 out of every 500 people in the study developed dementia. A 7 per cent increase in risk means that 61 out of every 500 people living within 50m of a major road developed dementia.

It is not clear from the study which element of living near a busy road was related to dementia risk. It could be air pollution, traffic noise or another factor.

Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said, 'Although

this was a thorough study in a large number of people, the research hasn't yet shown what causes this link, so we can't be sure that reducing pollution or noise from traffic would decrease the risk of dementia.'

'This study does not show that heavy traffic causes dementia.'

Dr Brown

We need more research to build on these findings and expand our understanding of the complex factors that cause dementia. However, this study does not show that heavy traffic causes dementia and people should not be thinking about moving house based on the research.

Professor Martin Rossor, NIHR National Director for Dementia Research at University College London Hospitals, said, 'While this study does not provide sufficient reason to drive individual choices if available, it is an important public health message on the dangers of air pollution and the contribution of the built environment in responding to the dementia challenge.'

The best evidence we currently have to reduce your risk is to avoid smoking, get regular exercise, eat a healthy, balanced diet and keep blood pressure in check.

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

Brain training

Researchers combined results from existing studies of computerised brain training, finding that it can help to improve thinking skills.

Online brain training is growing into a multimillion pound industry. In 2015, a study funded by Alzheimer's Society found that a brain training package can improve memory and reasoning skills, and help older people in their day-to-day lives. However, less is known about whether brain training can prevent dementia specifically.

In this recent study, researchers at the University of Sydney looked at results from 17 clinical trials carried out over the past 20 years. They measured changes in the thinking skills of people who have dementia and people diagnosed with mild cognitive impairment, who have minor problems in areas such as memory or language.

The researchers found that brain training could help people with mild cognitive impairment to improve their cognitive skills – memory, learning and attention – as well as their mood and perceived quality of life. However, the same effects were not seen for people living with dementia.

Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said, 'We've seen a lot of excitement recently about brain training to help protect against dementia. While there's not much evidence that it can delay or prevent the condition, this review shows that it could help people with mild cognitive impairment to improve their memory, thinking and learning.'

'We're seeing more and more evidence of the real-life benefits of brain training, helping us to find potential ways of holding on to our cognitive abilities. Now we need to work out how we could turn specially designed brain training into activities that are widely accessible and available.'

Dementia and delirium in hospital

Delirium is a temporary state of confusion and disorientation that is quite common among older people, especially people in hospital and people living with dementia. In this study, researchers examined the brains of 987 people from Finland and the UK. Each person's memory, thinking skills and experiences of delirium were recorded over 10 years towards the end of their life.

People who had experienced delirium or who had dementia-related changes in their brains showed a greater decline in memory and thinking skills than people without dementia or delirium. The key finding was that people who had experienced both dementia and delirium showed the most severe decline in their cognition over the 10 years prior to death.

Dr Clare Walton, Research Manager at the Society, said, 'This study suggests that delirium is not just a result of dementia-related changes in the brain but might independently cause problems with cognition. We don't understand why yet, but future research should look at the long-term impact of delirium on the brain.'

'We often hear of people who have developed memory and thinking problems or dementia after a stay in hospital. Understanding how delirium is involved and whether it can be prevented or treated is a pressing issue.'





Leading cause of death

Figures from the Office for National Statistics show that dementia is the most common cause of death in England and Wales.

The figures show that just over 60,000 people died due to dementia in 2015, which is slightly more than the number of deaths caused by coronary heart disease.

There are a number of reasons for the increase in deaths recorded as being caused by dementia. More people are now receiving a diagnosis of dementia than before. Doctors have a better understanding of what happens when a person with dementia approaches the end of life. Our ageing population means that more people are living longer, and so are more likely to develop dementia. There have also been changes in the way that the cause of death is recorded, which means that dementia is logged on death certificates more often.

The statistics combine the number of deaths due to Alzheimer's disease and other types of dementia, but numbers of deaths due to different types of cancer are reported separately. If all types of cancer were reported as a single group, cancer would be the most common cause of death overall.

Martina Kane, Senior Policy Officer at Alzheimer's Society, said, 'The news represents improvements in diagnosis rates, general awareness and the accuracy of reporting, but it also reflects rising numbers of people with dementia.'

'While there remains no cure for the condition, everyone who develops it will sadly still have the disease when they die. It is therefore essential that people have access to the right support and services to help them live well with dementia and that research into better care, treatments and eventually a cure remain high on the agenda.'

News in brief

Sauna benefits

Regular saunas could reduce the risk of dementia, according to a new study. Middle-aged men in Finland who take a sauna more than four times a week were two-thirds less likely to develop dementia over a 20-year period. However, this type of study alone cannot tell us whether starting a regular sauna habit is a worthwhile way to improve brain health.

Mediterranean diet

An increasing amount of evidence indicates that eating a healthy diet rich in oily fish, fresh vegetables and nuts is good for your brain and can help to maintain your memory as you get older. A recent study suggests that a Mediterranean-style diet could help to slow brain shrinkage due to ageing, though we can't yet say that it prevents dementia.



Link to kidney damage

Protein in urine – particularly a protein called albumin – may be linked to an increased risk of problems with thinking and memory skills or even of developing dementia in later life. This could be because kidney damage and dementia share risk factors or because kidney damage affects the brain. More detailed research with large numbers of people is needed to confirm the link.



Breaking the knowledge barrier

Alzheimer's Society is a founding partner in the UK's first dedicated Dementia Research Institute. This is our biggest ever single investment in research and will play a critical role in our mission to transform the landscape of dementia.

The award-winning scientist Professor Bart de Strooper was selected to lead the UK's landmark Dementia Research Institute after a competitive recruitment process last year. Professor de Strooper is a prominent Belgian dementia researcher at the University of Leuven. The location of the institute's hub will be UCL (University College London) and up to six regional centres are to be announced over the coming months.

The pledge of £250 million towards the Dementia Research Institute, in partnership with the Medical Research Council and Alzheimer's Research UK, marks one of the single biggest financial commitments to dementia research in the history of Alzheimer's Society.

Professor de Strooper has an ambitious vision for this investment. 'The aims of my directorship are to bring international talent to the UK and establish a unique research environment to deliver a step change in this important field,' he says.

Having driven scientific excellence as Director of the Vlaams Institute for Biotechnology in Belgium, Professor de Strooper is well respected for his work to understand the fundamental mechanisms that underlie Alzheimer's disease.

Time to grow

'It is time to accelerate the research agenda', says Professor de Strooper. 'For Alzheimer's disease we only have treatments that help to relieve the symptoms, and treatments for other types of dementia are even more limited. What is needed is curative therapy – treatments that can slow or stop the progression of these diseases.'

There have been no new treatments approved for any form of dementia since 2003, but biomedical research has yielded important insights and progress has been made in brain imaging and early diagnosis. 'These promising new developments call for us to intensify our research efforts towards real prospects for new treatments,' says Professor de Strooper.

‘Developing truly successful medication will require a much deeper understanding of the mechanisms underlying the loss of brain cells than we have today. The drugs that are currently being tested are based on our early understanding of how these diseases work. New efforts based on a more thorough biological understanding have much greater potential, but investment in research is needed to achieve that deeper knowledge.’

Professor de Strooper is clear about the research areas that could provide insights for future treatments. These include aspects of fundamental biological changes seen in many different forms of dementia, such as inflammation, dysfunction of the connections between brain cells and the abnormal processing of certain proteins in the brain. Translating better understanding of these into potential new treatments will be vital.

A strategy for success

How do you set up a research institute to bring about this change? Professor de Strooper says, ‘My aim is to set a dynamic pace and to establish a vibrant, ambitious and interactive neuroscience community.’

He recognises that creative thinking will be needed and that research is unpredictable, so the institute will provide an environment that allows scientists to carry out exploratory and innovative work. At the same time there will be clear priorities and leadership so that funding is given to the most promising lines of work.

‘There will be at least 400 people at the institute, including up to 25 professors and 25 fellows. The concentration of expertise in the institute should be attractive for talented and creative scientists from around the world.’

‘We are looking for the world’s best neuroscientists, and will be encouraging scientists who have excelled in other areas to shift their interest to dementia. These leaders will be supported to inspire younger scientists and care for their careers, making the Dementia Research Institute an important platform to train the next generation of scientists.’

‘Of course the Dementia Research Institute will not exist in isolation, and one of the attractions for me in this new role is the ability to tap into the UK’s world-class dementia research networks,’ says Professor de Strooper.



Quality of care

Research to improve care for people with dementia is further from Professor de Strooper’s specialist scientific expertise, but it is firmly on the agenda.

‘The Dementia Research Institute must address the needs of people already living with dementia,’ says Professor de Strooper. Part of the funding will go towards care-related and public health aspects of dementia. This will be established in a second phase of development, led by an associate director who will connect with wider research activity in this area already taking place in the UK.

‘I think we can improve the quality of care research, and Alzheimer’s Society will be a good partner in this,’ says Professor de Strooper. ‘There are many things that are already known to help people living with dementia, such as personalised care and avoiding inappropriate prescriptions of certain drugs. We need to look at the evidence closely to see exactly what is known to work, and establish how we are going to implement these measures across the board.’

The vision for the Dementia Research Institute is bold and ambitious, and there is optimism that this investment will result in substantial improvements to the lives of people with dementia. However, Professor de Strooper is under no illusion that this is the end of the story.

‘The £250 million is the budget for the next seven years, and includes funding for an iconic dementia research facility in London. These funds over seven years only begin to close the gap with cancer and AIDS funding. It would be a mistake for the government and other funders to think they have done their job.’

Plans to establish the Dementia Research Institute hub at UCL are being developed, and we expect to see scientists starting work there by the end of 2017.



Interpreting our genes

Isabel Castanho, a second-year PhD student at the University of Exeter Medical School explains how her research focuses on a gap in our understanding of how genes contribute to Alzheimer's disease.

To find new treatments that can slow or stop Alzheimer's disease, we need to know more about the underlying mechanisms that cause the disease to start and to progress over time. My research aims to help understand changes in how our genes are interpreted as the changes in the brain associated with Alzheimer's progress.

Scientists have already learnt a lot by studying the brains of people who have died with Alzheimer's disease and donated their brain for research. For example, we know that Alzheimer's is characterised by two proteins called amyloid and tau, which build up to form plaques and tangles in the brain. However, this type of study is only possible after the person has died, which means it is hard to understand the very early stages and changes over time by studying human brains alone.

Research involving animals that show characteristics of Alzheimer's disease can establish new approaches for diagnosis and treatment. Animal research is tightly regulated in the UK, and only allowed when there isn't an alternative method, but using animal models makes it possible to study how detailed mechanisms of the brain change as Alzheimer's progresses from early to later stages.

In my research as part of the Complex Disease Epigenetics Group, I am using mouse models of Alzheimer's to understand the changes in brain cells associated with the disease's progression. Our genes are important for these processes, but there is more to genetics than our DNA. I study epigenetics and gene regulation – how, when and where in the body our genes are turned on and off. I am studying this in the mouse brain, using mice that develop amyloid plaques and mice that have tau tangles in their brains.

Discovering how different genes are activated and deactivated at different stages is an important part of understanding the disease's mechanisms in detail. This could provide evidence that is important to designing better treatments. The end goal of my research is to help delay and reduce the consequences of Alzheimer's disease for people and their families.

In order to get there, we need to make new discoveries in mice, and check whether they translate to humans. As part of my PhD, I will take the specific changes that I find in mouse brains and see whether they translate to the extensive data from human brains available in our research group. Combining findings from mice and humans in this way will help us to better understand Alzheimer's disease.

I am very fortunate to be part of the Exeter Doctoral Training Centre, which is funded by Alzheimer's Society with generous support from the Garfield Weston Foundation. We are all working towards improved diagnosis and treatment for people with dementia, and the fact that we come from different backgrounds and are working on different aspects is very beneficial. Our interaction, co-operation and regular discussion improves our research as a group and our growth as individual researchers.

Learning from experience

This award-winning scheme is transforming attitudes for future generations by involving people affected by dementia in healthcare education.

Time for Dementia is a unique programme to help nursing, paramedic and medical students understand the experiences of people with dementia and those close to them. In order to give students a deeper appreciation of the challenges faced by people affected by dementia, students are paired with a person who has dementia and a family carer. The students visit them at home every three to four months over two years. It is hoped this will benefit students' knowledge, attitudes and behaviour.

The programme is now part of the curriculum at Brighton and Sussex Medical School and the University of Surrey, and is being formally evaluated so that the outcomes for students and families can be measured. If it proves to be effective, this evidence could persuade more educators to take it up. All the people who take part are given questionnaires when they start. For the students, these assess their knowledge of dementia and their attitudes to people with the condition. For the people with dementia and their families, questionnaires measure the severity of symptoms, the person's quality of life and the impact on carers.

These questionnaires are repeated as the programme progresses to measure the scheme's impact. Satisfaction surveys are used to gather feedback and additional interviews have provided more detailed ideas for future improvements. Students have also been invited to participate in focus groups. To date, 1,100 students have been involved and there are currently 350 families signed up.

Dr Stephanie Daley, Clinical Research Fellow at Brighton and Sussex Medical School, is leading the evaluation. She says, 'The feedback we've had so far has been very positive. Students say they have gained an understanding of the impact of the condition that they wouldn't have picked up in the classroom or on a clinical placement.'



Learning what people with dementia really need. Mary and Eddie Wood share their experiences to train medical students.

Preliminary findings suggest that the families taking part value the project too. Eddie Wood, who was diagnosed with mixed dementia four years ago, says, 'It's been brilliant. The beauty of this project is that people training to be doctors, paramedics and nurses are given an opportunity to go into the world of someone with dementia to learn what they really need.'

Alzheimer's Society has played an important role in recruiting families to take part. Our involvement also means that families are supported and any issues raised during student visits are followed up.

Laura Green, the Society's Network Manager supporting the project, says, 'People's experiences of healthcare vary widely depending on where they live or the attitude of the professionals supporting them. This programme is so exciting because people living with dementia themselves are changing the perceptions of others.'

We will have to wait until 2018 for the full results to be presented, but the programme has already won the Best Dementia Training Initiative 2016 award at the 7th National Dementia Care Awards and the LaingBuisson Award for Excellence in Training. With these accolades behind them, the team hopes to expand into more areas of Sussex and Kent over the coming years.

Capacity for success

We launched our flagship Dementia Research Leaders programme in January 2014 to boost capacity among dementia researchers.

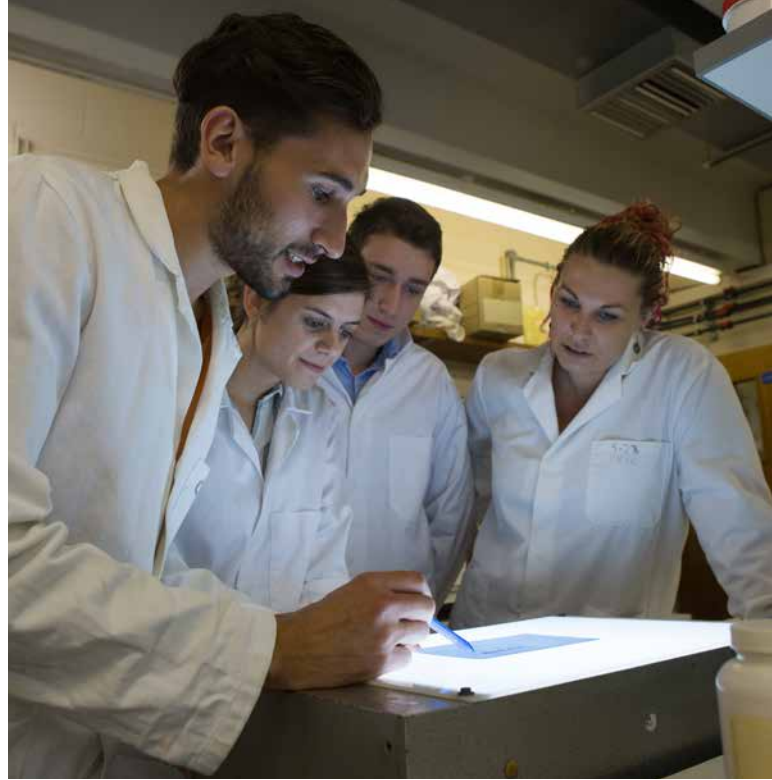
Three years on, our funding, mentorship and training continues to support the greatest minds to work on the brain's greatest problem.

Research is essential to improve care for people living with dementia today and to find a cure for tomorrow. Addressing these challenges is a formidable task, and to make progress we need to have a strong research workforce. However, too few researchers choose to work in dementia and those who do often find they can't stay. In fact, recent research revealed that 70 per cent of PhD students have left the field within four years.

We established the Dementia Research Leaders programme three years ago to bring more researchers into the field of dementia, and help those already in it to achieve their career goals. We do this by providing funding for promising early career researchers and setting up mentorship, skills training, information and opportunities at key points in their careers.

The earliest point of support for a budding dementia researcher is an undergraduate research bursary. These small pots of funding provide resources for students in the middle of their first degree to get their first taste of what research is really like. We have supported 30 students in this way since 2014, and many of our undergraduate bursary holders have gone on to choose a career in dementia research.

The next step in funding is a PhD studentship. We've funded 91 PhD students through the programme, a commitment of over £6 million. These students have made a fantastic contribution to dementia research across a wide range of topics, from understanding how brain cells use energy when affected by Alzheimer's disease to investigating whether we can help people retain short-term memories. Our eight doctoral training centres represent a huge step forward in our ambitions to bring more people into dementia research. Due to extra funding from



participating universities, these groundbreaking centres have allowed 52 new PhD students to begin their career in dementia research in an interactive and collaborative atmosphere.

After their PhD, people who are heading towards a career as an independent researcher may take a number of postdoctoral research positions. One way we support people at this stage is by awarding junior and senior fellowships. This is often the researcher's first experience of applying directly for funding and having the freedom to manage their own projects. These are skills that will be essential when they run their own research group. Healthcare professionals who are interested in getting research experience can also benefit from specialised clinical training fellowships. In the last three years we've supported 39 fellows with funding of just over £8 million.

We are keen to support our fellows as they continue to pursue their research topics, but it can be challenging to maintain a career in academia. For this reason we created a mentorship scheme to help them develop their careers and obtain permanent academic positions, so that they have job security and can continue their vital research.

We are proud to support so many passionate and talented researchers who really care about the work they do and how it will help people affected by dementia. It is their work that will deliver the insights required to understand the causes of dementia, learn how to prevent it, provide the best care and eventually find the new treatments that we so desperately need.

Making research a reality

How we are working to get care innovations put into practice.

At Alzheimer's Society, we were challenged by our Research Network volunteers to make sure that findings from care research get used beyond specialist studies. In response we started working hard on moving findings from research settings into the real world, a process known as research translation.

Implementing research findings in the real world can take time. On average, it takes around 17 years from the development of an initial idea to it being actively used in health and social care. We think this is far too long and our aim is simple – we want to make sure that improvements in care that are identified by research are made available for people with dementia, their families and carers much more quickly.

What are we doing about it?

One step we have taken is to look at the route that research follows before interventions are put into practice. Within this pathway, we are identifying actions we can take at pivotal stages to encourage professionals in frontline care to use research findings. This includes considering who pays for care services, influencing government policies and focusing on how we influence people to use what we learn from research.

We have also introduced implementation research grants, which aim to move research along this pathway to put findings into practice. These grants enable researchers to work with frontline health and social care professionals to build up practical evidence about interventions that have shown promise in research settings.

We know these interventions could improve quality of life, but it is important to gain evidence about how to introduce them in practice. The first two implementation grants were awarded in late 2016.

Namaste Care

Professor Dawn Brooker, Director of the University of Worcester Association for Dementia Studies, was



awarded an implementation grant to study a care programme called Namaste Care.

Namaste Care was first developed in the USA to enhance the quality of life of people with advanced dementia in care homes using physical, sensory and emotional approaches.

The research team will test different aspects of Namaste Care to see which work best to support people with advanced dementia in UK care homes and to understand how to introduce it most effectively. The researchers will also create a professional network to share learning from the project.

Life through a lens

Our second implementation grant will test non-drug therapies to support people with a learning disability who have developed dementia. Many different forms of therapy will be tested, including music, reminiscence and technology. Led by Dr Karen Watchman, Senior Lecturer at Stirling University, the research team will include co-researchers who have a learning disability.

They will make use of Jenny's diary, a resource that helps conversations about dementia with people who have both learning disabilities and dementia. They will also use photographs taken by family, staff and people with a learning disability to help understand their experiences of the interventions, capturing a 'digital story' of the work.

Altogether, our implementation research grants and our work on the research translation pathway mark the start of a movement to get evidence-based innovations used in real-world care. By bridging the gap between research and care, we will help people to live better with dementia.



Research Network

One distinctive feature of our ground-breaking research programme is the integral involvement of people with dementia and carers.

Our Research Network volunteers, who have direct experience of dementia, inform every stage of our research programme.

If you are living with dementia or have been a carer for someone with dementia and are interested in joining the Research Network, please contact Anna Grinbergs-Saull, Research Engagement Manager, at researchnetwork@alzheimers.org.uk

Found out more at alzheimers.org.uk/researchnetwork

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

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Call 0300 222 1122 and ask about Join Dementia Research.

Find out more

alzheimers.org.uk/research

General enquiries

enquiries@alzheimers.org.uk

Tim Shakespeare

Research Communications Officer

tim.shakespeare@alzheimers.org.uk

020 7423 1077

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