

# Care and cure

The Alzheimer's Society research magazine

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# What's in this issue of Careandcure

**Dementia affects many people in many ways, and it is important that research reflects this.**

This summer I heard researchers question whether there could be a single treatment for all people with Alzheimer's. They argued that its various symptoms and effects on the brain might mean we need different treatments for different types, just as for heart disease.

These differences can cause problems for clinical trials. It is easy to miss a positive result if it only helps some people. When results from failed trials are re-examined, they can appear more successful when limited to, for example, people in the early stages of the disease.

A one-size-fits-all approach is even less suitable in providing support to people with dementia and their families. As our feature article demonstrates, the experiences and needs of the children of people with early-onset dementia are very different to the assumptions behind many support services.

Sahdia Parveen (page 8) describes her work to understand differences between ethnic communities in their willingness to provide care for family members. Again, their needs can be so different that research like this helps us to understand how best they may be supported.

The more we recognise that dementia affects us all differently, the sooner we can find better ways to help everyone.

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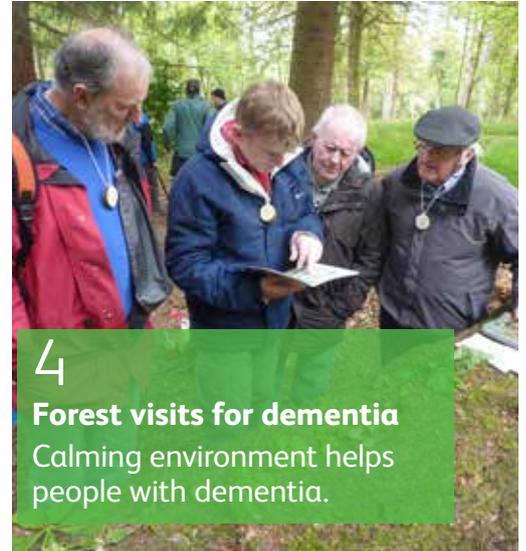
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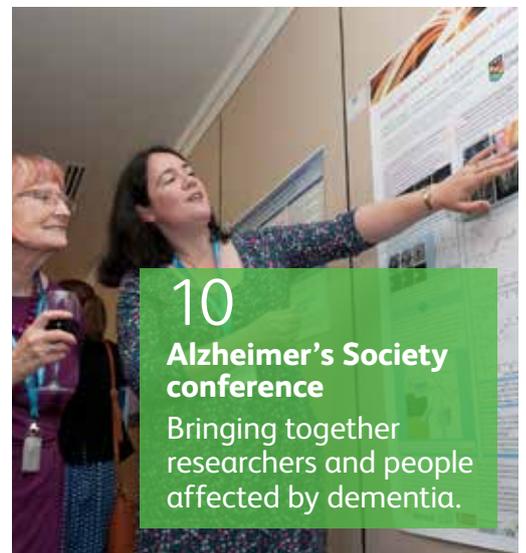
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# Latest drug trial results

The world's largest dementia research event, the annual Alzheimer's Association International Conference (AAIC), was held in Washington in July with over 4,500 dementia researchers gathering to share their latest findings.

The biggest announcement at AAIC was about a trial of the drug solanezumab, produced by Lilly. The results suggest that this drug could be the first to tackle the disease rather than simply treating the symptoms. However, the way that the trial was carried out meant that its findings can only be considered as preliminary. A larger trial with a more robust design is expected to announce its results in 2017.

Results for similar drugs from other pharmaceutical companies were also presented. An analysis of data from a trial for Roche's gantenerumab, which was stopped late last year, indicated there was an effect in people whose disease progressed more quickly. This suggests that the dose given may not be high enough and the duration of the trial not long enough to see effects in everyone given the drug.

Additional results from an early-stage trial of aducanumab from Biogen showed that a moderate dose

helped to reduce the side effects seen with a higher dose, but did not show an improvement in thinking and memory. This is now being fast-tracked to a phase three trial with more people, where any effects on cognition will be more apparent.

Academic researchers also presented their results across a wide range of research. A popular topic of study was risk factors, with research into type 1 diabetes, physical activity, loneliness and low grades at school to see their effects on dementia and cognition. Physical activity was a popular area and researchers also presented findings that it is beneficial for people

**'This drug could be the first to tackle the disease rather than simply treating the symptoms.'**

who already have dementia or mild cognitive impairment.

Although research on imaging and trials for Alzheimer's disease filled a large portion of the schedule, the prominence of other fields signified the need for attention to all areas of dementia research.

There were sessions devoted to frontotemporal dementia and to psychosocial interventions, while those on dementia care research and practice covered health economics, epidemiology and psychosocial factors among other subjects.

The technology and dementia 'preconference' drew its biggest ever crowd to discuss big data, assistive technology and even smartphone apps to motivate lifestyle changes.



For more information about popular topics at AAIC visit [alzheimers.org.uk/aaic2015](http://alzheimers.org.uk/aaic2015)

# Forest visits for dementia

Researchers at the University of Dundee have found that visiting forests can improve the wellbeing of people with dementia by providing a place of mental and physical enrichment.

The study developed a pilot scheme for people in the early stages of dementia to visit forests, along with their carers and local park rangers in order to engage with nature. They found that this was a very positive experience for both people with the condition and their carers.

One person with dementia said, 'I enjoyed it thoroughly and missed it when I wasn't there.' A carer said that the environment provided 'an escape from the noise that some people with dementia find so distracting and very difficult to filter out'.

Mandy Cook, the PhD student who organised the research, said, 'The pilot woodland activity programme can be seen to contribute to the care and support of people with early-stage dementia by enhancing positive mental wellbeing and broadening social networks.'



## Signs of dementia seen 18 years before diagnosis

**A study of over 2,000 people has shown a test of memory and thinking can reveal differences in people who go on to develop Alzheimer's disease up to 18 years before diagnosis.**

Based on tests completed 13 to 18 years before the study ended, a lower score in a cognitive test was associated with an 85 per cent greater risk of future dementia.

This suggests that the development of Alzheimer's disease may begin

**'This could mean there is a long window of opportunity for treatment.'**

**Dr Brown**

many years earlier than expected before symptoms are recognised.

'Dementia often causes changes in the brain years before the symptoms become apparent. This study shows

that there may be subtle indications of Alzheimer's disease in thinking and memory as many as 18 years before a formal diagnosis could take place,' says Dr Doug Brown, Director of Research and Development at Alzheimer's Society.

'This could mean there is a long window of opportunity for treatment in which we could one day halt or slow dementia.

'Although these tests cannot accurately predict who will develop dementia, they could potentially be used to identify people at higher risk.'



# Diabetes drug shows promise

**A diabetes drug that is currently being tested to see if it could treat Alzheimer's disease might also be used to prevent it, according to a new study using mice.**

Diabetes drugs have gained a lot of attention in recent years in attempts to treat Alzheimer's disease as research has shown the importance of the effects of insulin in the brain. In Alzheimer's, brain cells become less responsive to the presence of insulin, similar to pancreas cells in diabetes.

The drug in this study, liraglutide, is already on the market for treating diabetes. Researchers at Imperial College London are trying to recruit 220 volunteers around the country to take part in a study of its effects in mild Alzheimer's disease.

This new study, led by Professor Christian Hölscher and funded by Alzheimer's Society, has shown that liraglutide may also show promise as a preventative treatment. The researchers studied mice with genetic mutations that made them certain to

develop Alzheimer's disease. When the drug was given from a young age it prevented or reduced much of the damage normally seen in the condition as well as preserving memory recall.

Liraglutide has recently been licensed as a weight-loss drug and demonstrated to be safe for people who are not diabetic. Hölscher is now investigating new drugs that may work even better than liraglutide, by acting in two ways to achieve the same effect.

Separately, researchers in Denmark presented results at a conference from a small clinical trial involving 38 people with moderate Alzheimer's disease. These suggest that liraglutide helps to prevent the decline in how glucose is metabolised in the brain, which is a hallmark of Alzheimer's disease. This raises hopes for the outcome of the larger trial taking place in the UK.

**'Liraglutide may also show promise as a preventative treatment.'**

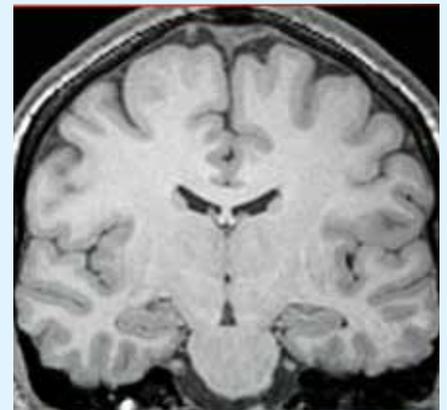


To find out more about participating in the liraglutide trial, visit [alzheimers.org.uk/liraglutide](http://alzheimers.org.uk/liraglutide) or call 020 8383 3704

## News in brief

An analysis of proteins found in the blood has reaffirmed the validity of two key 'markers' for Alzheimer's disease. The analysis, funded by Alzheimer's Society, looked at several markers that were thought to be associated with the build-up of amyloid-beta in the brain. This result could be useful in helping to predict the onset of Alzheimer's disease.

Scientists have created a high-resolution 'atlas' of the brain from MRI scans of healthy people. The hope is that it could help doctors to diagnose Alzheimer's by being a reference to compare with people suspected of having dementia. This could make it easier to differentiate changes that are down to ageing from the early signs of dementia.



Regular physical activity could help to protect the brain from cognitive impairment as well as helping people with dementia to live better, according to the results of three trials. They showed that exercise can improve behavioural symptoms of dementia and reduce levels of a protein that is a key hallmark of some forms of dementia.



# Still Mum and Dad

**While most people with dementia are aged over 65, more than 40,000 younger people are thought to have the condition in the UK. A particular challenge that faces younger people with dementia is the effect that it can have on their families, especially their children.**

**P**rofessor Pat Sikes was inspired to learn more about the effect of dementia on young people by her own children, as their father was diagnosed with early-onset dementia when they were aged 13 and 15. She realised that there are very few resources to help younger people in a similar situation to her family.

Professor Sikes and her post-doctoral research associate, Dr Mel Hall, are being funded by Alzheimer's Society to interview young people between the ages of seven and 31 about their experiences of having a parent with dementia. The conversation between the researchers and participants has a flexible approach, with volunteers being given the chance to share their stories freely.

## **Isolation and frustration**

Interviewing began last year and themes are already emerging from the project. For example, a recurring

aspect of conversations so far is that young people are reluctant to take on the role and identity of a 'carer'.

As Dr Hall explains, 'The participants feel out of place at events that are aimed at carers, because they are often much younger than everyone else.'

One participant, 17-year-old Harriet\*, told the researchers, 'I just started going to a support group for carers but it is all husbands and wives, loads older than me. I'll go because they might have some advice but it's different, you can get a new husband. I can't get a new Dad.'

Another recurring theme is marginalisation from peers and other family members.

'We have found that children of people with early-onset dementia can feel very isolated and that no one

understands what they are going through,' says Professor Sikes. 'They can also feel a lot of guilt and frustration arising from their feelings about their parent and the situation that they are in.'

As awareness of dementia increases, there has been a reduction in stigma about the condition. However, due to the common use of images of older people in the media and information materials, it is not well known that younger people can also have dementia. The study has found that the children of these younger people with dementia do not feel that most portrayals of dementia reflect the experience of either themselves or their parent.

'Our participants feel that their experience is not well recognised. They are often fed up because in the public perception it often seems that dementia is always Alzheimer's and

the people affected are always “old”. This is not their situation and the lack of representation makes them feel very alone,’ Dr Hall explains.

Elizabeth is 17 and her dad has frontotemporal dementia and lives in a care home. She told the researchers, ‘I feel so out of place at the home because there’s elderly people, their families and I’m just there... a resident’s family will go in and they’ll say, “Oh, are you here seeing your grandad?” “No I’m seeing my dad.” “But how old are you?” “17.” “WHAAAAAT?” They’ve, like, never heard of that.’

Another participant, 21-year old Madison, has a similar experience. ‘I literally don’t know anyone my age who has any similarities. Like I felt very isolated at first, literally don’t know anyone who has remotely a similar experience.’

### Still Mum

A striking aspect of the research so far is participants feeling that they have lost their parent as a caregiver, supporter or provider. In some cases, a loving, gentle parent can become aggressive or emotionally distant.

The researchers have termed this experience ‘still Mum and Dad’ after the film Still Alice, about how a woman’s diagnosis of early-onset



Alzheimer’s disease at the age of 50 affects her and her family, including her children.

Professor Sikes explains, ‘The participants often express frustration that their parent is not the same person that they knew. They are not “still Mum”, as even though their parent looks like they always have, they are not the same person.’

Ella, 28, put her experiences of her mum’s dementia in very frank terms. ‘It is just so weird because she looks like Mum and she sounds like Mum and she’s saying stuff like Mum. But she’s not. It’s just really weird,’ she said.

‘It’s not her fault, but yeah... she doesn’t remember what I do, she’s rude, always talking about herself, really negative, bringing the conversation down... talks over you and doesn’t let you talk to anyone else.’

People in this situation need the right kind of support to help deal with changes in a parent’s personality and behaviour.

### Resources for the future

One participant, 25-year old Sarah, sums up the feelings of under recognition that have been identified by many people in the study.

‘Dementia is a terminal illness and I don’t think many people see it like that, I think most people see it as “that’s just what an old person does”. Not that cancer is better than dementia, but people would be like “gosh I’m so sorry, what can I do to help you?”’

While the current experiences and perceptions of young people who have a parent with dementia are dominated by feelings of frustration and loneliness, research such as this will help people like those in this study to cope with their situation and realise that they are not alone. The study is due to continue until

**‘I literally don’t know anyone my age who has any similarities.’**

**Madison, 21**

October 2016, and Professor Sikes and Dr Hall are looking for more people to participate so they can get a clearer idea of the challenges and experiences that young people in this situation face.

The researchers will use their findings to develop resources that are attractive to other young people who are having a similar experience. These resources will hopefully be available through social media and existing support sites. They are also aiming to produce an animated film.

Dr Hall says, ‘It has been an incredibly enlightening but difficult journey in our understanding of how young people are affected by dementia.

‘We want to use our research to find out how best to help young people facing this incredibly difficult situation and to alleviate some of the isolation that these people are experiencing.’

\*names of participants have been changed



**The researchers are looking to speak with people under the age of 25 who have a parent with dementia. If you are interested in participating in this study or know someone who is, please visit: [www.cypdpd.group.shef.ac.uk](http://www.cypdpd.group.shef.ac.uk)**

**If you are affected by any of the information in this article, please call our National Dementia Helpline on 0300 222 1122 or see [alzheimers.org.uk/helpline](http://alzheimers.org.uk/helpline)**

# Research driven by personal experience of dementia

Dr Sahdia Parveen is an Alzheimer's Society junior fellow at the University of Bradford and was recently awarded a Dementia Research Leader award (page 11).

My grandmother was diagnosed with vascular dementia when I was 13 years old and we found out that my grandfather had leukaemia when I was 15. I helped my mother look after my grandparents, and the experience of trying to support each of them was very different.

Whereas healthcare professionals helped us cope with the various stages of my grandfather's leukaemia, with my grandmother's dementia we learned by muddling through it. My mum, determined that we should be one step ahead of my grandmother's condition, would often send me off to the library to 'do research on dementia'. I guess this was the start of my dementia research career!

While I was studying for my master's degree in clinical psychology, a lot of research was being done in the US about how minority ethnic groups' experiences of dementia compared with other people's. They found

that African American and Hispanic groups had strong cultural obligations to provide care for family members, and that this influenced how they used services, how they coped and their wellbeing.

What researchers couldn't agree on was whether a carer's sense of cultural obligation was a positive or a negative. Some found that cultural obligation was related to more positive experiences of being a carer, whereas others found it caused carers to feel more distressed. This made me think that the link researchers were missing was how willing these carers were to provide support.

My Alzheimer's Society junior fellowship will focus on how a carer's sense of cultural obligation, willingness to care and preparedness change over time, and how they influence carer wellbeing. The research will help us develop interventions for carers to help them feel more prepared and in control,

**'A third of young people know someone living with dementia.'**

**Dr Parveen**

and this will enable carers to better support the person with dementia.

Perhaps as a result of my personal experience, I have been very keen to raise awareness of dementia among young people. I felt inspired by the Dementia Friends initiative and developed a workshop specifically for young people called Dementia Detectives. The goals of the workshop are to bust the myths surrounding dementia and encouraging young people to develop ideas to create dementia-friendly communities.

Currently, a third of young people know someone living with dementia and this number will increase. We need to involve young people more in order to reduce stigma as they approach adulthood and build their confidence in supporting people with dementia in the community.

I feel very fortunate in the support I have had in building my research career and for my public engagement activities. I hope that these will help current carers and future generations to feel one step ahead.

 To read a longer version of this article visit [alzheimers.org.uk/careandcure](http://alzheimers.org.uk/careandcure)



Dr Sahdia Parveen, right, receiving her Dementia Research Leader award from Ann Beasley, Acting Chair of Alzheimer's Society.

# Improving care in hospital

Being admitted to hospital is an unpleasant experience for anyone, but for people with dementia it can be particularly distressing. Research into hospital care is already helping to make improvements.

Consultant and researcher Dr Liz Sampson was funded by Alzheimer's Society and Bupa UK Foundation to study the effects of hospitalisation on behavioural symptoms of dementia.

'We found that there were quite high levels of agitation and behavioural symptoms for people with dementia coming into hospital. It's a very difficult environment because it's very busy and noisy and they get moved around a lot.'

'A lot of the time you read a report and it would say that people with dementia stay longer in acute hospital because of their behavioural problems. We found that actually that wasn't making them stay longer; it was external factors that were beyond their control. Dementia always gets the blame.'

Although this kind of research is much needed, it can be very difficult to carry out. Dr Sampson worked with two research assistants who followed 230 people from the point they were admitted in A&E.

'It's a very fast-paced environment in which to be doing research; people are being wheeled in and out all the time. It's really challenging because you have to get consent from the families. I'm amazed actually at the way the people with dementia and their carers were happy to participate in research at such a difficult time in their lives.'

Part of the research was carried out at North Middlesex Hospital in north London, where Dr Sampson works with geriatrician Dr Sophie Edwards, the hospital's dementia lead. Dr Edwards has used their



Dr Liz Sampson, left, and Dr Sophie Edwards have applied research findings to improve care for people with dementia in hospitals.

observations of patients and carers to introduce dementia-friendly aspects onto the wards and was recently awarded the Kate Granger award for compassionate care.

Among these are a '10 things about me' document for each patient to help staff to understand the person's individual preferences and needs – similar to the Society's This is me – and a 'carer's passport' that allows carers to access wards outside of visiting times with free parking.

'The initiatives we have introduced are all about connecting with the patient as a person. We can learn more about a patient when we know more about them as people, about their life, and that, in turn, can improve the care we provide,' says Dr Edwards.

**'The initiatives we have introduced are all about connecting with the patient as a person.'**

Dr Edwards

They have also been able to use their findings to help other staff at the hospital. 'We've probably trained over 600 staff in dementia awareness and dementia care. We've been able to focus on the research findings, so we've been able to boost the amount of training people have in managing agitation and difficult behaviours,' says Dr Sampson. 'We really try to put them in the shoes of someone with dementia and realise what it's like.'

'I think we've realised that person-centred care is as important in hospital as it is in the care home setting. A lot of what this project has helped us to understand is that a hospital is what we call a toxic environment and that it's not the fault of the person with dementia. It's that we put them into this very stressful environment and make their behaviour change.'

'Therefore we need to change the environment around the person.'



For This is me, produced for people with dementia who are receiving care at home, in residential care or hospital, see [alzheimers.org.uk/thisisme](http://alzheimers.org.uk/thisisme) (available in English and in Welsh).

# Alzheimer's Society conference



**The 2015 Alzheimer's Society annual research conference was held in Manchester this summer. The conference was by far the largest to date, with 200 attendees including Research Network volunteers, researchers and Society staff.**

Over the two days, the diverse range of people engaged in many discussions and debates on how best to achieve our goals.

Posters were presented by researchers, focusing on everything from blood markers of amyloid to the sleep disturbances in people with dementia living in care homes. Rita Guerreiro, one of our funded research fellows said, 'Research is getting an increasingly significant role in the overall Alzheimer's Society programme, which was clear in the great scientific talks and posters.'

The first day focused on training for our funded researchers and volunteers. A career development session for early-career researchers gave them a chance to network and learn skills from one another. While this was going on, our Research Network volunteers were attending refresher training workshops.

The day ended with a gala dinner and the inaugural Dementia Research Leaders awards ceremony (page 11).

Jeremy Hughes, the Society's Chief Executive Officer, tweeted, 'Rising

stars recognised in first Dementia Leaders Awards at #AlzSocResearch conference last night.'

The second day was filled with talks from a variety of researchers. Professor Giovanna Mallucci's talk on the repurposing of existing drugs to treat dementia caused a great deal of excitement and questions. Her presentation about work to prevent brain cell death even drew the attention of The Guardian.

Research Network volunteer Wendy Mitchell tweeted, 'so good to see promising research along with promising results – gives me

and my daughters hope' and Dr Claire Garwood tweeted, 'Really interesting talk by Giovanna Mallucci on targeting the unfolded protein response in neurodegeneration.'

The conference was closed by Ann Beasley, Acting Chair of Alzheimer's Society. She expressed her new found hope for the future of dementia research in light of what she had seen at the conference.

This sense of hope was felt by many of the attendees, with one saying, 'The whole atmosphere was uplifting which considering the subject was great.'



# Awards for rising research stars

**The Dementia Research Leaders awards were set up to recognise the contribution that early-career researchers make to dementia research and people affected by dementia.**

The awards from Alzheimer's Society were judged by a panel of Research Network volunteers and current dementia researchers.

The awards were categorised into the qualities expected of a Dementia Research Leader: academic achievement, using research evidence, patient and public involvement, and public engagement. The winners each received £1,000 to be used for their professional development. Due to the exceptional quality of the entries, the judges also decided to award runner-up prizes of £500.

## Winners

**Sahdia Parveen, University of Bradford, for patient and public involvement, and public engagement.**



The judges were impressed by Sahdia's work with young people and in engaging with minority ethnic communities. They commended the use of social media and the large geographical reach used in her research.

**Katie Lunnon, University of Exeter, for academic achievement.**

The judges felt that Katie demonstrated huge potential in her field of epigenetics, and was helping to build research capacity at an emerging centre of excellence

at Exeter by helping to develop the careers of those around her.

**Sebastian Crutch, University College London, for patient and public involvement, public engagement, and academic achievement.**

The judges commended Sebastian's sheer dedication and commitment to engagement activities and his sensitive approach to reaching different audiences.

**Rita Guerreiro, University College London, for academic achievement.**

The judges were impressed by Rita's (pictured) academic achievements in a short space of time, producing impressive and high impact results. They felt she demonstrated all the qualities of a dementia research leader.

## Runners-up

**Roxana Carare, University of Southampton, for academic achievement.**

**Karen Watchman, University of the West of Scotland, for using research evidence.**

## Implementation grant scheme launched

**Alzheimer's Society is one of the first medical research charities to launch an Implementation grant scheme to enable the scaling-up of non-drug treatments, programmes and services that will improve the health and wellbeing of people with dementia.**

Over the past few years, as research into the care of people with dementia has progressed, we have received lots of feedback that

more needs to be done to close the gap between research and practice.

Malayka Rahman-Amin, Research Translation Manager at the Society says, 'We have now entered an exciting phase of our funding journey where research knowledge is becoming mature enough to have potential impact, but we see blockages towards getting that research put to use in the real world.

'Our new Implementation grant scheme aims to unblock the research pipeline and enable research to have

a positive impact on the lives of people with dementia.'

Alzheimer's Society is offering grants of up to £400,000 to researchers to implement strategies that have been shown to improve the quality of care.

This scheme will generate new insights into what it takes to translate research into better outcomes for people with dementia. These insights will be useful for researchers and those who commission and deliver care.

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## About us

Alzheimer's Society is the leading support and research charity for people with dementia, their families and carers.

Since 1990, Alzheimer's Society has funded over £35 million of cutting-edge dementia research. We aim to increase our investment in our research programme to around £10 million a year by 2017 and £100 million over the next decade.

This money funds important research that will help us to improve the quality of life of people with dementia, by tackling questions related to the causes of dementia, investigating good practice in care and treatment, and pursuing a cure.

## Research Network

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

As part of our Research Network, volunteers with direct experience of living with dementia inform our research priorities.

If you have been a carer for someone with dementia or you have dementia and are interested in joining the Research Network, please contact Anna Grinbergs-Saull, Research Engagement Officer, for an application form or apply online at [alzheimers.org.uk/researchnetwork](http://alzheimers.org.uk/researchnetwork)

Alzheimer's Society maintains editorial independence over the content of this magazine.

Sunrise Senior Living is generously sponsoring the Research Network.

For more information please visit [www.sunrise-care.co.uk](http://www.sunrise-care.co.uk)



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