

Annual Research Review

Our impact
in 2018/2019



Foreword

This year we've seen our strategy make a substantial impact in dementia research. Researchers supported by Alzheimer's Society have published more than 450 scientific articles, each making a critical addition to our knowledge of dementia. These publications are the foundation of progress in dementia research and at Alzheimer's Society we're determined to transform this knowledge into real change for people affected by dementia.

When I joined Alzheimer's Society earlier this year as the Chief Policy and Research Officer, I knew that growing the research community and developing partnerships to widen our reach would be critical to our success. I'm pleased to say the number of people and organisations uniting with Alzheimer's Society continues to grow. With our combined expertise in research, support and societal change, Alzheimer's Society is leading from the front to change the landscape of dementia forever.

In my previous role as Deputy Chief Scientific Officer for NHS England I had the privilege of leading and advising on science in national health policy and strategy. However, it is only now as I focus my full energy to supporting people affected by dementia, that I have realised so little innovation was being brought into NHS dementia care and diagnosis. It's clear that the historic underinvestment in dementia research has held us back, but now the tide is starting to turn.

Our researchers are making significant advances across the board, from prevention, through diagnosis and treatment, to care and support. Key to success in my role will be moving these innovations forwards so they can be adopted across our health and social care system.

Thanks to our supporters, I firmly believe that our research programme is poised to make a step change in the support and treatment available to everyone affected by dementia.

FIONA CARRAGHER

Fiona Carragher
Chief Policy and Research Officer



Research that makes a difference

Alzheimer's Society is the UK's leading dementia support and research charity – since 1990 we have invested over £70 million into dementia research.

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We fund research into all forms of dementia, tackling the issues that matter most. Our researchers are investigating how to help people reduce their chances of developing dementia, how to make diagnosis faster and more accurate, and they're making fundamental discoveries about the diseases that cause dementia to develop new treatments.

At the same time, we know that the 850,000 people currently living with dementia need the best support possible. We lead the way by identifying where research can make a difference, and funding high quality-studies that deliver real improvements to dementia care.

In 2018/19 we invested £11.7 million in research, including £7.4 million on new grants and £2 million towards ground-breaking work at the UK DRI. We also started our new stream of innovation projects working with entrepreneurs, designers and companies to develop products and ideas that help people live better with dementia today. Additionally our team have supported translation of knowledge into practice and, through the Research Network, meaningfully involved people affected by dementia at all stages of our research projects.



We are the only UK charity committed to funding research into the cause, cure, care and prevention of all forms of dementia.

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Our 2018/2019 research programme in numbers

£11.7 million
spend on research activity

Our Dementia Research
Leaders programme supported
28
new early career researchers

£7.4 million
invested in 49 new grants

167
active projects worth over
£37 million

£2 million
contribution to the UK DRI



A discovery every day

Our researchers published over 450 scientific articles – more than one for every day in the year.



16,000 GameChangers united

Over 16,000 people united with us and Oxford University to support dementia research by playing brain games.



Innovation for the nation

Our innovation team launched two new products that are now being used to tackle everyday challenges for people affected by dementia.



Dementia friendly, healthy homes

We announced a new £20 million UK DRI Care Research and Technology centre, part funded by Alzheimer's Society, which will find ways to keep people safe and healthy at home for longer.



Our Research Network grew by **25%** to involve **317** people with experience of dementia to guide our research

Working together to take on dementia

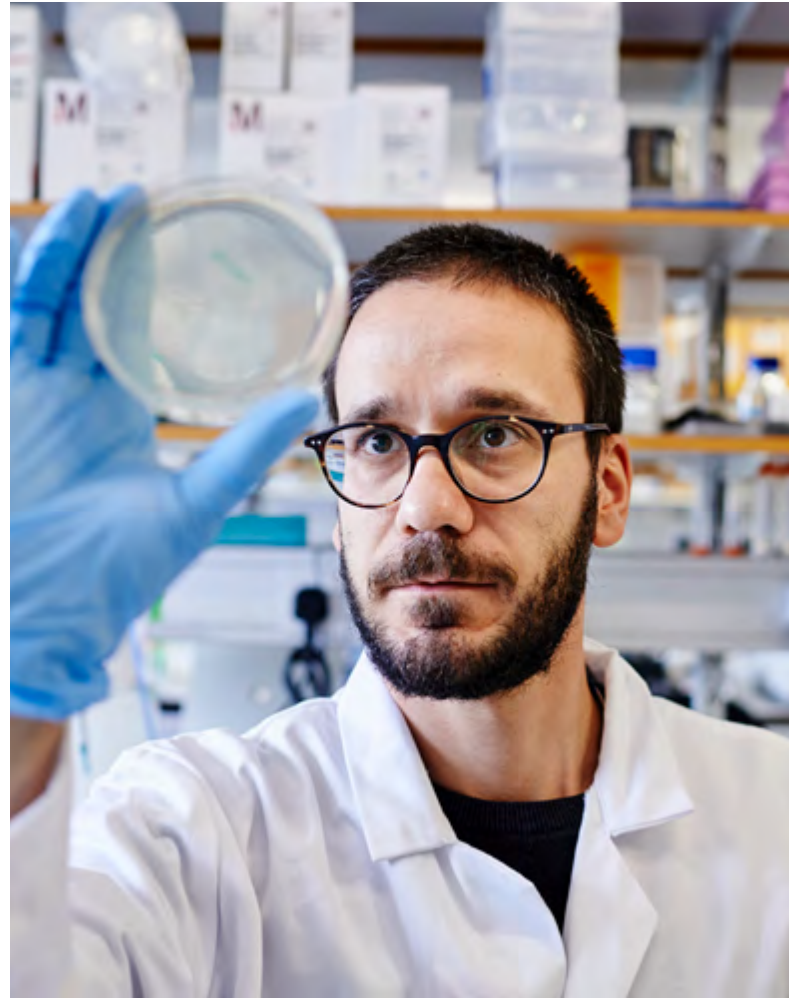
When the Alzheimer's Disease Society was founded 40 years ago, dementia research was at best rudimentary. There was little to no interest or investment in research and no large-scale university programmes. Right from the start, our newly-founded society began to drive development and champion dementia research. Our official research programme launched in 1990 and whilst our name has changed to Alzheimer's Society, our dedication to research into all forms of dementia continues to grow. Thanks to our supporters, we have now invested more than £70 million in over 400 research projects and supported hundreds of researchers.

Our research programme has played a part in some of the biggest developments in dementia research to date. One of our first grants supported a fundamental breakthrough in the genetics of Alzheimer's disease, helping to identify the genetic cause of a rare inherited form of the disease. This genetic understanding has provided important clues to guide research uncovering the causes of Alzheimer's.

'We are building on our 40 years of supporting dementia research, and stepping out further than we ever have before to ensure we recognise and maximise the clinical and human impact of all of our research.'

Dr James Pickett,
Head of Research at Alzheimer's Society

We have made significant progress in care research too. For example, we heard that too many people in care homes were being prescribed antipsychotic medication inappropriately, bringing a risk of severe side effects. We funded researchers to develop and test specialist training to address this, resulting in a programme that improved quality of life and reduced the use of antipsychotics by 50%. Most recently this training has been developed into an online course to train professionals worldwide.



Looking forward to the next 40 years, we will continue to build on our success, directing our efforts to make the biggest difference for people affected by dementia. Our Research Delivery Plan lays out how we will advance research towards better care for today and a cure for the future. It shows our approach to accelerate progress by developing the research community, partnering with people affected by dementia and supporting collaboration between research and our wider society.

We're working tirelessly to understand more, to turn scientific breakthroughs into new treatments, to improve care, find ways to prevent dementia and, ultimately, to find a cure.

Read our Research Delivery Plan:
alzheimers.org.uk/researchdelivery



This year our innovation team worked alongside people affected by dementia, national and local organisations, and LGBT+ communities on Bring Dementia Out: aiming to meet the needs of LGBT+ people affected by dementia.

Innovation for dementia care

We are the largest charitable funder of dementia care research in the UK. By teaming up with researchers and drawing on expertise within Alzheimer's Society and beyond, we accelerate work to find, evaluate and deliver solutions that make a real difference to people's lives.

As well as funding research in universities, we have an in-house innovation team that takes a novel approach to find new solutions for people affected by dementia. They follow the Learn, Investigate, Find and Experiment (LIFE) pathway to develop new services and products over a 6 to 12 month period. Through our Accelerator Programme we also partner with engineers, innovators and designers who have great ideas, offering funding and support to bring their ideas to life. This year, two products developed by our innovation team hit the shelves of our online shop – Lift the lid and the Fidget Widget Toolkit.

Fidget widgets

What is the Fidget Widget Toolkit? Five beautifully made, wooden, handheld, tactile tools specially designed to create repetitive actions such as turning, twisting, rolling, pulling and flicking movements.

Judith Bower, one of the inventors based at Alzheimer's Society, said, 'Carers often described fidgeting as a negative and disruptive behaviour. We wanted to create something that would tackle this idea, while, at the same time, creating something engaging that people with dementia could benefit from.'



The Fidget Widget Toolkit is a partnership between Alzheimer's Society, the University of Central Lancashire and Active Minds.

Lift the lid

The words of a carer surely resonate with most of us. He said, 'I love my wife dearly, I would like intimacy to continue, holding hands, a kiss on the cheek, having a cuddle lying on the bed together, these things have always been important to us.'

Gestures of love may not be so easily given or received in a care home. Our innovation team developed a 'workshop in a box' to help care professionals, sector experts and people affected by dementia to tackle taboo subjects such as sex and intimacy needs.

Centres of Excellence

Whilst our innovation team deliver new solutions in-house, our funding for university research tackles deep-seated issues in the health and social care system.

The IDEAL study based at Exeter University sheds new light on the factors that important for maximising wellbeing and quality of life. Since becoming an Alzheimer's Society Centre of Excellence in 2018, the IDEAL study has been extended, making it possible to follow the experiences of participants for several more years.

Dr James Pickett, Head of Research at Alzheimer's Society, said, 'We are already starting to see results from the IDEAL programme. After looking at several factors, they have found that psychological health has the biggest impact on people affected by dementia living well. Interventions that improve self-esteem, challenge negative perceptions towards ageing and reduce depression or loneliness could all help improve the psychological health of people affected.'

Harnessing technology

This year we were thrilled to announce a new £20 million research facility, the UK Dementia Research Institute (UK DRI) Care Research and Technology Centre, which will be part-funded by Alzheimer's Society over the next 6 years. Researchers at Imperial are working on a range of approaches to enable people with dementia to live safely and independently in their own homes.

Professor David Sharp, head of the new centre, said, 'The new technologies we develop ... will allow us to intervene at an early stage, to prevent the crises that so often lead to hospital stays, or a move to a care home. What's more we'll be able to improve our understanding of dementia onset and progression.'

A combination of sensors placed around the home and wearable devices will monitor sleep quality, behaviour, blood pressure, physical movement and brain activity. Computer analysis of the data will alert doctors and health teams to any potential problems and give an overview of general health.

'[This will deliver] valuable data, direct from patients, that will provide insights into the underlying causes and progression of dementia. We look forward to seeing this innovative, patient-centric, technology-based programme develop to deliver transformational changes to how we care for people with dementia.'

Prof. Bart De Strooper,
UK DRI Director



Researchers at the Care Research & Technology Centre will develop and test new solutions to help people stay safe and healthy in their homes.

Fundamental discoveries

UK DRI researchers in the six established centres are using cutting edge technology and working more closely together than ever before. They are already making discoveries that could fundamentally change how we diagnose and treat dementia, bringing us ever closer to the day we find a cure.

In Cambridge, a team led by Professor David Rubinsztein discovered that felodipine, normally prescribed to treat hypertension, may be effective in treating forms of dementia. A study, published in *Nature Communications*, showed felodipine prevents the build-up of misfolded and potentially toxic proteins in several neurodegenerative conditions.

In another example of the power of collaborative working, UK DRI Associate Director Professor Julie Williams at Cardiff University led an international team scrutinising more genetic data than any other study of Alzheimer's disease to date. Analysing data from more than 94,000 individuals to search for underlying causes, they identified five novel genetic variants or changes that influence the risk for Alzheimer's disease. These genetic variants provide crucial insights into how and why Alzheimer's starts in the brain, helping researchers find new ways to stop the disease.

Early detection

Research has shown that biological changes linked to Alzheimer's may begin 15–20 years before people show symptoms. This insight has driven interest in early diagnosis because the right treatment given at the right time could halt Alzheimer's disease before it takes hold. This year we've funded research and made discoveries that bring early detection a step closer. We boosted our funding for the PREVENT study, which is currently recruiting middle-aged participants to investigate the earliest changes. With over 400 people taking part already, initial data suggests that particular aspects of spatial memory may be early indicators of Alzheimer's disease.

We are especially interested in funding research that explores how new markers of disease can move from useful research tools to diagnostic tests used in clinic practice.

Researchers at King's College London have advanced the conversation on developing a blood test for Alzheimer's disease. Researchers reviewed many published studies describing different ways to use blood tests as a diagnostic tool. There is still work to be done to develop a usable test, but they identified several key challenges and made important recommendations for future research. The ultimate goal is to find a blood test that could be used as an accessible, low cost and accurate way to diagnose dementia at an early stage.

Dr Antoinette O'Connor of the Institute of Neurology at UCL started work on an Alzheimer's Society funded Clinical Research Fellowship this year, which



will take that work further. Dr O'Connor is leading a study using the latest technology to detect changes in the blood when people have a rare form of inherited Alzheimer's disease. Her unique study will help to find the earliest detectable changes in the blood and could pave the way for a diagnostic test.

Also this year, Dr Ashwin Venkataraman was funded by Alzheimer's Society to develop cutting-edge brain scanning and artificial intelligence. His project at Imperial College London explores the effect of tau and amyloid on mitochondria (energy-producing batteries of cells) and on synapses (connections between brain cells) in people with Alzheimer's disease. Scans taken at the start of the study and again a year later will be compared with scans from healthy volunteers to examine the impact on brain cells. The new technology will help to track disease progression and may support the development of new treatments in the future.

Partnering with people affected by dementia

At Alzheimer's Society we champion the value of involving patients and the public in research. Our research benefits from a dedicated group of Research Network volunteers who are all carers, former carers, or people with dementia. When we set up the Research Network in 1999, the concept of involving non-scientist 'experts by experience' in research was revolutionary. Since then the Research Network has gone from strength to strength, and this year the number of volunteers grew by 25% to include over 310 people. Keeping the voices of people who have personal experience of dementia at the heart of our work ensures that the research we fund is relevant, credible and has an impact for everyone affected by dementia.

2019 marks the 20th anniversary of the Research Network. Together with our volunteers we are hosting a series of celebration events across the UK. These 'Research Uncovered' events are open to the public and will involve researchers, Research Network volunteers and the Alzheimer's Society team to raise the profile of dementia research and the impact volunteers can make.

Over the last year, we have showcased the impact of the Research Network. We were delighted to lead a special issue of the academic journal 'Dementia' showcasing successful examples of involvement and sharing learning from these projects.

In this journal, one group of researchers and Research Network volunteers shared how they worked together to design and carry out a study comparing the views of those who care for people with dementia from white British and South Asian communities. They reported that involving people affected by dementia had a significant impact on study outcomes and meaningful relationships developed between researchers and volunteers. The article also shared their experience on the flexibility and time needed to make this approach successful.

Our future direction is to continue growing the Research Network and broadening its appeal. To support this we've created a new role for volunteers who aren't able to commit to regular reviewing of research applications or meetings. People who choose this flexible role can share their personal experience in one-off opportunities such as telephone discussions, email or postal surveys and face-to-face meetings, taking on as much or little as they like. This has already increased appeal for people who have a dementia diagnosis or are in full-time work.

With the dedication of our volunteers we're sure that the Research Network will continue to thrive, and we're looking forward to working together to shape our research and bring about real change for everyone affected by dementia.



Keep up to date with the latest news from our Research Network on our website alzheimers.org.uk/research-network-news

Developing the dementia researcher community

To reach our goal of beating dementia, we need to attract the most talented people into the field of dementia research. Our Dementia Research Leaders programme supports researchers ranging from undergraduates to senior fellows. We offer opportunities and funding at an early stage in their career to help them develop into the dementia experts of tomorrow.

People we fund join a fast-growing and dedicated national research community. We have a fantastic track record of recruiting and retaining top researchers. Bringing together expertise from a broad range of disciplines, this community is united by a common purpose: to defeat dementia.

Supporting people with dementia and cancer

Mollie Price, a psychology PhD student at Leeds Beckett University, is working with Alzheimer's Society to support carers of people with both dementia and cancer. Little is known about what life is like for people living with these two chronic conditions.

This year Mollie teamed up with Serena Snoad who manages the Alzheimer's Society online community forum called Talking Point. Together, they created a dedicated space where people can provide support for each other.

'We hope that, by creating a designated area, these carers can access a social support network of others who understand the unique challenges they face.'

Mollie Price, Psychology PhD student at Leeds Beckett University

Interviewing the carers of people with dementia and cancer has helped Mollie piece together a better understanding of their challenges and needs. We hope this will lead to advice on strategies that improve care for people in this situation.

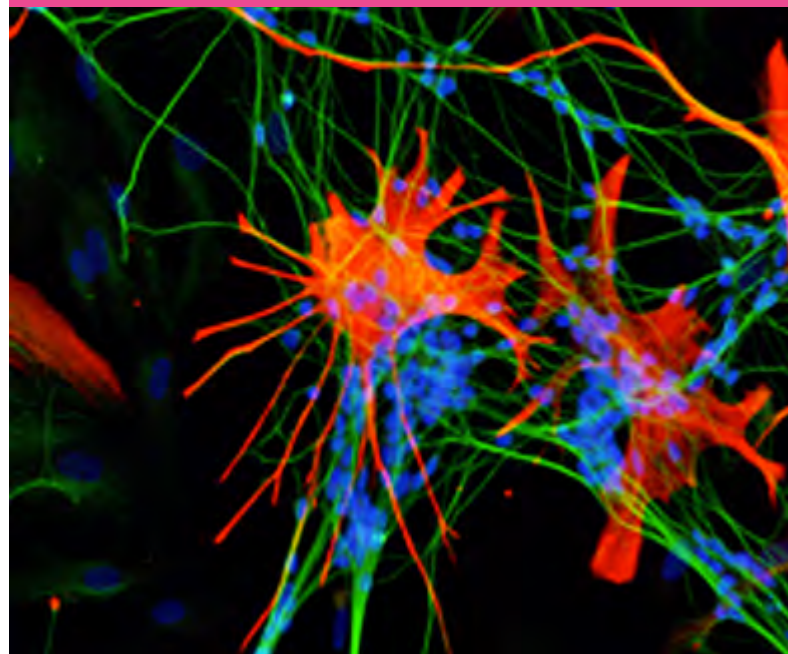
Stars of the show

Dr Claire Garwood is a research fellow based at the Sheffield Institute for Translational Neuroscience. Alzheimer's Society funded her PhD which focused on understanding the role that astrocytes play in the development of dementia. Astrocytes are star-shaped brain cells which provide essential nutrients and other chemicals to neurons.

Claire said, '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.' She has examined what this change in insulin response means for astrocytes – how do they make energy and, critically, do they still provide support to neurons? Her research was published in the European Journal of Neuroscience last year.

There is an urgent need for more research into the care and treatment of all types of dementia. New researchers, including those currently working in other fields, bring fresh ideas that help expand the boundaries of dementia science and accelerate discovery and learning. Our Dementia Research Leaders scheme has begun to address the shortage, but there is still work to do.

Dr Garwood's research found cells called astrocytes (red) stop supporting neurons (blue and green) in Alzheimer's disease. Fixing this could help keep our neurons healthy.





**We build strong
partnerships to
take on the biggest
challenges in
dementia research.**

Connecting research and society

We are committed to achieving a world without dementia but we know we can't do it alone.

We bring researchers, people affected by dementia and funders together to work collaboratively, and our support for research goes far beyond funding. Our partnership programme allows researchers to tap into our experience and reach to make their project a success. Researchers can get support from our Research Network, get advice on new projects or share exciting new research with our supporters. Together we can take on the biggest challenges in dementia research.

Join Dementia Research

Dementia research can only go so far without participants. People are vital to bringing new interventions and treatments to everyone affected by dementia. To get more people taking part in research we support Join Dementia Research in partnership with the National Institute for Health Research, Alzheimer's Scotland and Alzheimer's Research UK.

This online platform matches thousands of volunteers to research studies taking place across the UK. This year, Join Dementia Research reached a new milestone. 40,000 people with and without dementia have now joined the register and are supporting over 10,000 research studies across the UK, driving dementia research forward.'

'It's incredible that 40,000 people have now registered with Join Dementia Research. With their support we have the opportunity to drive advances to benefit the hundreds of thousands of people living with the condition.'

Caroline Dinenage, Minister of State at the Department of Health and Social Care

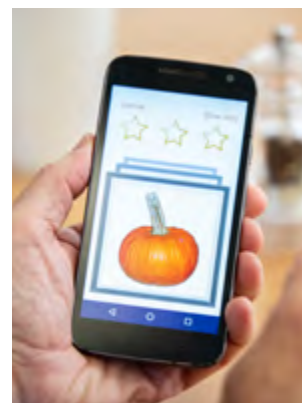


Smartphone technology: A GameChanger for dementia research

Alongside the University of Oxford, Alzheimer's Society launched GameChanger in September. GameChanger uses a series of smartphone games to test aspects of memory and thinking believed to be affected at the very early stages of Alzheimer's disease.

We had a fantastic response to the launch and over 15,000 people without dementia have donated 5 minutes day for a month to support dementia research.

Dr Claire Lancaster, part of the research team leading GameChanger from the University of Oxford, said, 'GameChanger is the first project of its kind. This smartphone technology could give future doctors a more accurate way to measure changes to our memory and thinking. We need to understand the healthy brain and how it changes before we can spot the early signs of dementia.'



Through GameChanger, researchers will be able to compare aged-related changes in the healthy brain with changes seen in people who have early stage Alzheimer's disease. Ultimately this will support research that could develop treatments to slow down or even stop the progression of dementia.

<https://www.alzheimers.org.uk/research/get-involved>

Thanks to you

Our volunteers

We're enormously grateful to all of the people who volunteer their time and experience to help us deliver a successful programme of research each year. This includes the 317 carers, former carers and people with dementia in our Research Network and the 47 academics and clinicians who make up our Research Strategy Council and Grants Advisory Boards.

We give particular thanks to:

- Professors Carol Brayne, John O'Brien, and all members of our Research Strategy Council
- Professor Paul Ince and all the members of our Biomedical Grants Advisory Board
- Professor Steve Iliffe and all the members of our Care, Services and Public Health Grants Advisory Board.
- Professor Ruth Boaden and all the members of our Implementation Grants Advisory Board
- 427 peer reviewers who submitted 544 reviews providing expert commentary on grant applications
- 31 trained mentors who are offering career development support to our research fellows
- 17 Area Co-ordinators and Deputy Area Co-ordinators who help develop the Research Network
- 30 lay members of the Grant Advisory Panels
- 130 Research Network monitors who help our funded researchers deliver their research
- 17 Research Network members who helped researchers improve the quality and relevance their project plans before applying for funding.
- All the volunteers with lived experience who support our innovation programme

Our donors and funders

Our research programme would not be possible without the generous support of all of our donors and funders. We would like to thank all those individuals who have donated to our research programme, our corporate partners, supporting trusts and those who remember us in their Will.

Our partners

Our research programme is delivered in partnership with several other organisations. We give thanks to the following for working with us to fund and deliver high-quality dementia research:

- Alzheimer Netherland
- Alzheimer's Drug Discovery Foundation
- Alzheimer's Research UK
- British Heart Foundation
- Design Council Spark
- Economic and Social Research Council
- EU Joint Programme – Neurodegenerative Disease Research
- Global Brain Health Initiative
- Medical Research Council
- LifeArc
- National Institute for Health Research
- Royal Air Forces Association
- Stroke Association
- All our partners on the 'Lift the lid', 'Bring Dementia Out' and 'Dementia Connections – Uniting with General Practice' projects



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Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

To keep up to date on the latest news from our research programme, sign up to receive our research magazine at **alzheimers.org.uk/careandcure**

All of the dementia research we support is fully funded by voluntary income. You can donate to our research programme online at **alzheimers.org.uk/donate**

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Alzheimer's Society operates in England, Wales and Northern Ireland.

