

United Against Dementia

Annual Report
Overview 2018/19

alzheimers.org.uk



**‘Anytime you
need anything,
Alzheimer’s
Society are
always there
for you.’**

**Raymond James
who is living with dementia and
featured on our front cover**

Welcome

At Alzheimer's Society, 'united against dementia' is more than a slogan. Bringing people together and putting those affected by dementia at the heart of everything we do makes our work possible.

2018/19 was the second year of our five-year New Deal on Dementia strategy to transform the lives of everyone affected by the condition – people with dementia, their families, friends and carers.

Looking ahead

We're immensely proud of what we achieved in our 40th year. Now, as ever, we're looking to the future. This year, we'll scale up Dementia Connect and continue to innovate in all areas of our work. And we'll give our supporters new ways to get involved so we continue to grow our income in an uncertain climate.

Thank you

None of what you read in these pages would be possible without our people. Our phenomenally loyal employees have worked tirelessly towards our vision, always striving to do better. Our volunteers have shown up in rain or shine to make our events and campaigns a success. And the public have rewarded our efforts with their trust, passion and support.

To increase our fundraising income by 9% to more than £84 million, when much of the sector is facing challenges, is an incredible achievement. We don't take it for granted for a second. Every Memory Walker, marathon runner and bucket shaker enable us to do more for people affected by dementia and lead the way towards a cure.

With our health and social care services in crisis, and the number of people with dementia in the UK set to hit a million by 2025, it's never been more important to be united against dementia. Our sincere thanks for everything you do.



Stephen Hill, OBE
Chair of trustees



Jeremy Hughes, CBE
Chief Executive

Why we are here

Dementia is the biggest health and social care challenge of our time.



Dementia is now the UK's **biggest killer**



Every **three minutes**
someone in the UK develops dementia.



There are **over 850,000**
people living with dementia in the UK.
This is set to rise to over **one million** by 2021

Alzheimer's Society is the only UK charity focused on addressing the growing dementia crisis from all sides. We fund research into care and cure, provide support and training, and campaign for the rights of people living with dementia.

We are united against dementia.

New Deal on Dementia Strategy



Support

Our wide range of support means that nobody should have to face dementia alone.

We're developing our innovative Dementia Connect service which will make sure people with dementia get the right support, in the right way.



Society

We will fight for a future where nobody is excluded from their community or denied the care or support they deserve.

We are calling on the Department of Health and Social Care and NHS England to 'Fix Dementia Care' by committing to invest in tackling the social care crisis and giving people with dementia a fair deal.



Research

Dementia is caused by diseases of the brain which means that through research we will beat it.

We are the only UK charity to fund research into how to prevent and cure dementia as well as research to improve care for people living with dementia today. We are investing more money than ever in dementia research and attracting more talented researchers to the field.

Brand

Our brand identity was built from the idea of protest, from change coming through people demanding it from the grass roots up.

It is bold, vibrant and confident, to ensure we are seen and known by those who need our help or want to unite with us.

Fundraising

Thanks to our amazing fundraisers, donors and partners, we have become the largest and most influential dementia charity in the UK.

With a powerful movement, we will make dementia history. United against dementia.



Our year in numbers



218,000

people affected by dementia **supported directly** by our work



5.5mil

interactions with people affected by dementia accessing vital information **online and in print**



96%

of people affected by dementia agreed our **services met their needs***



85,000

campaigners helping to influence local and national government



+500

Dementia Friends recruited **every day** across the three nations



950

researchers driving new scientific discoveries across care and cure



£112mil
total income



9%

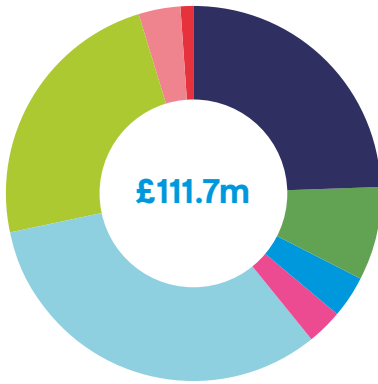
rise in **fundraised** income



40yrs
since the Society was **formed**

* based on survey of 7,600 service users

Where our money comes from

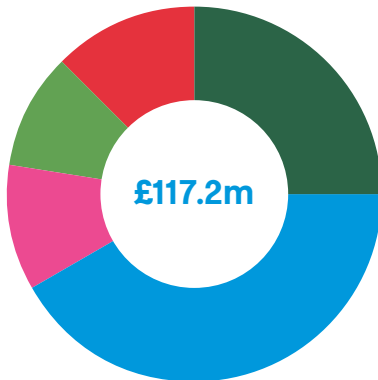


Our income by source for 2018/19

- Legacies (£27.5m)
- Individual giving (£9.1m)
- Corporates (£4.2m)
- Philanthropy (£3.2m)
- Community Fundraising (£36.7m)
- Charitable activities (£26.4m)
- Other trading activities (£3.7m)
- Investment income (£1m)

More than £73 million of our income came from individual supporters taking part in events, making one-off or regular donations, and recognising us in their wills

How we spent our money



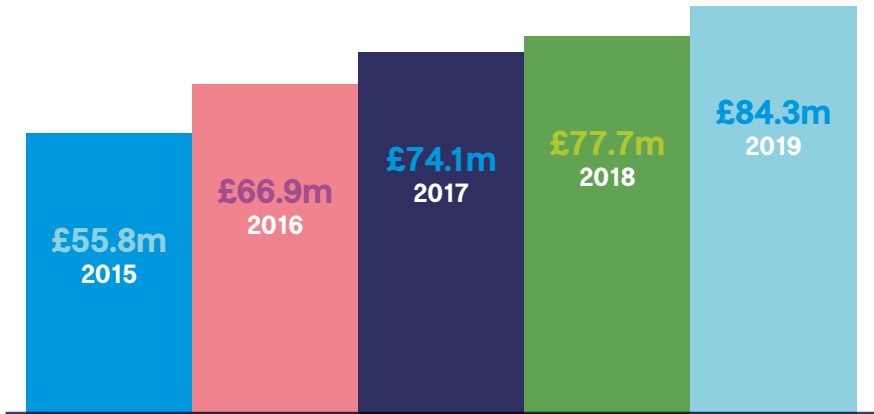
Our expenditure by activity for 2018/19

- Fundraising costs (£29.4m)
- New Deal on Support (£49.3m)
- New Deal on Research (£12.1m)
- New Deal on Society (£11.9m)
- Support costs (£14.5m)

For every £1 we spent directly on raising funds this year, we generated £2.89 in return

Charting our growth

Total fundraising and trading income over five years



This information has been taken from our Annual Report and Accounts 18/19. Audited by Crowe U.K. LLP. For more detail, please see our Annual Report and Accounts at alzheimers.org.uk/about-us/annual-reports

88p

We spent 88p of every £1 we earned this year on improving the lives of people with dementia, generating awareness and raising funds

£84 mil

The continued support and generosity of our supporters helped to bring in over £84 million through fundraising and trading activities, a 9% increase on the previous year

5 years

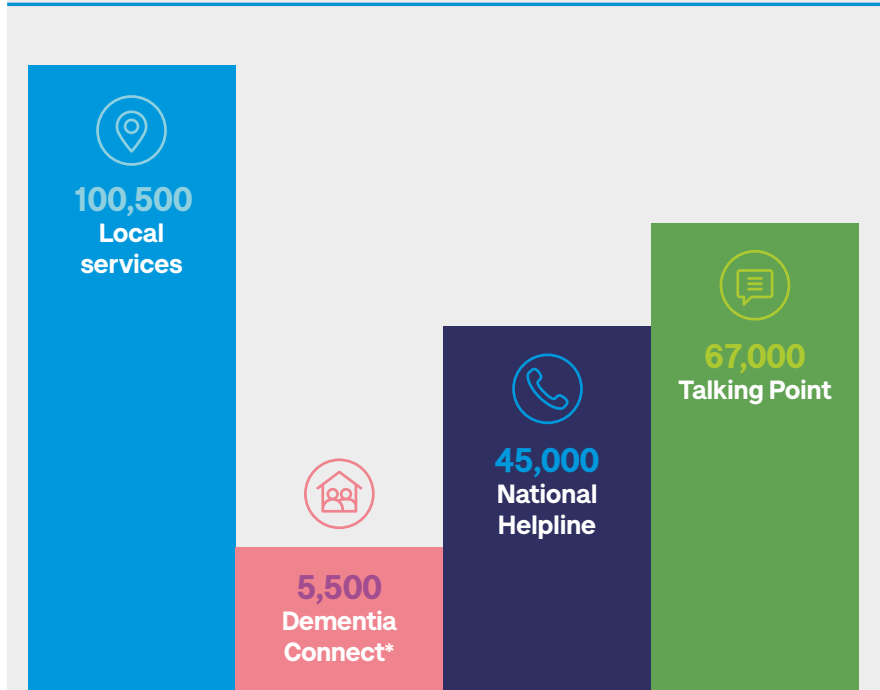
We raised £28.5 million more this year than five years ago

The New Deal on Support

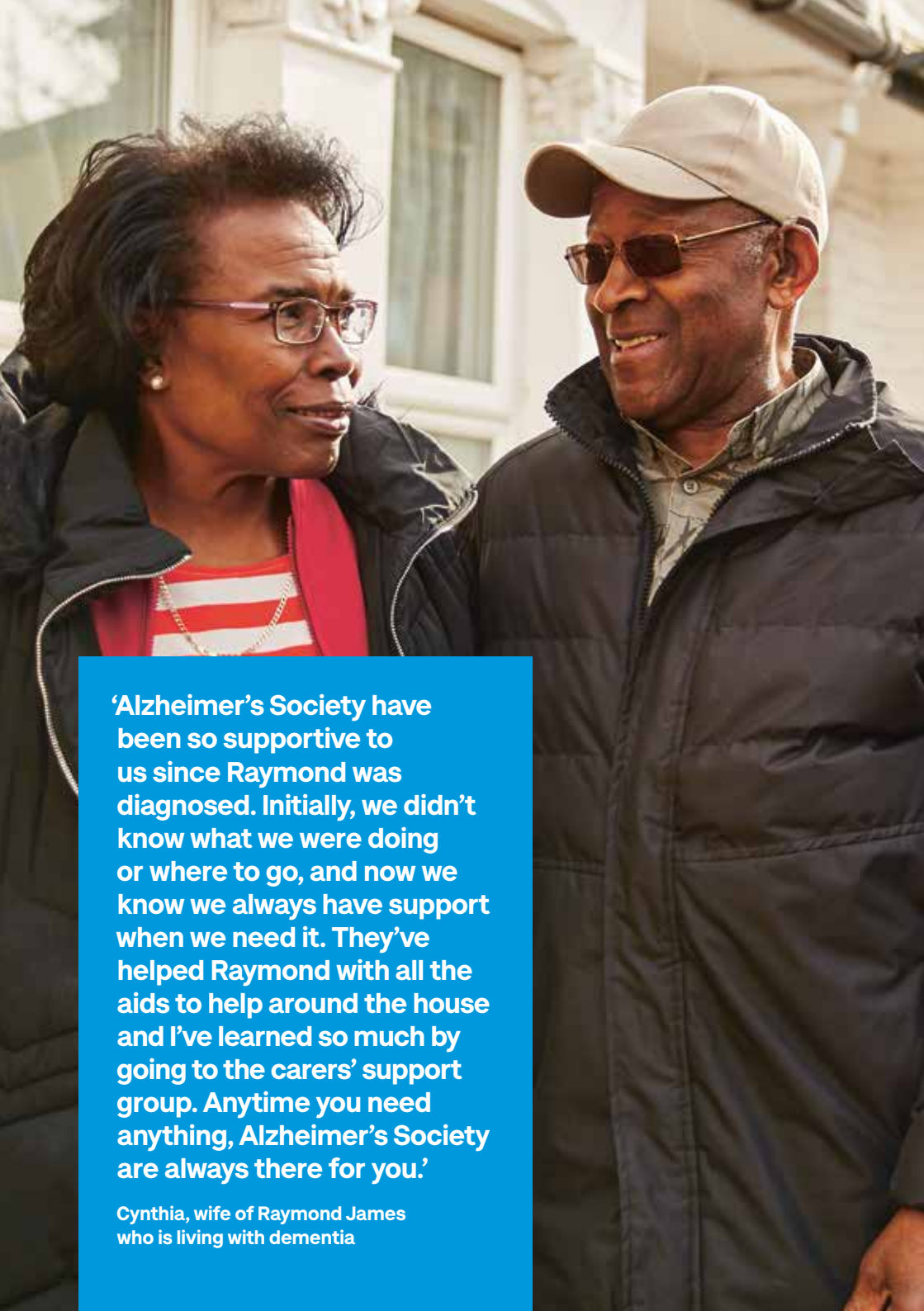
In 2018/19, our wide range of services supported even more people affected by dementia, in a way that worked for them.

This year, we supported 218,000 people affected by dementia, across our range of services. This was up from 210,000 people in 2017/18. In addition we had 5.5 million interactions with people affected by dementia accessing vital information online and in print.

We've provided direct support to 218,000 people through our frontline services:



*(including Side by Side)



‘Alzheimer’s Society have been so supportive to us since Raymond was diagnosed. Initially, we didn’t know what we were doing or where to go, and now we know we always have support when we need it. They’ve helped Raymond with all the aids to help around the house and I’ve learned so much by going to the carers’ support group. Anytime you need anything, Alzheimer’s Society are always there for you.’

**Cynthia, wife of Raymond James
who is living with dementia**

Dementia Connect – an offer of support to anyone with a diagnosis

As part of our five-year New Deal strategy, we focused our resources on developing our Dementia Connect service.

In 2018/19, we rolled out our third early adopter Dementia Connect service across Wales. The rollout saw 70% of health and social care commissioners who fund the Society across Wales agreeing to switch to Dementia Connect. (For more information on Dementia Connect please see our full Annual Report and Accounts 2018/19)

This year, our total number of Dementia Advisers and Dementia Support Workers increased from 659 to 684.

Through Side by Side, we supported 4,455 people with dementia this year, with a combined total of 63,000 hours of volunteer support.

Supporting anyone in need

Our National Dementia Helpline received 45,000 calls in 2018/19 (42,000 in 2017/18).

Through face-to-face local services, we supported 106,000 people across England, Wales and Northern Ireland

Our online forum Talking Point makes dementia support available globally 24/7, 365 days a year. 1.3 million people accessed Talking Point this year, with 67,000 people formally registering for increased levels of support.

Supporting people with information and guidance, wherever they are

We had 5.5 million interactions with people affected by dementia through sharing our expert knowledge online and on paper.

Our website continued to be a life-changing resource for people affected by dementia, once again attracting a total of 11 million views.

We provided essential print materials to people where and when they needed them, distributing 823,000 copies this year.

To increase awareness and improve support for people affected by dementia, we reached more than 7,900 people with dementia training this year.

Improving our services by asking people for their opinions

More than 7,600 people affected by dementia who had used our services gave us feedback through Making Evaluation Count.

Overall, at least 96% agreed our services met their needs

Feedback from 164 people using Dementia Connect showed high satisfaction, with the Dementia Adviser understanding their needs (99%), providing useful information (96%) and allowing enough time to discuss their concerns (97%).

Overall, 97% said they would recommend Dementia Connect to others.

‘I used to be ashamed of having dementia. I’m not anymore.’

Person with dementia, feeding back on our Side by Side service

‘Our Dementia Adviser’s listening skills should not be underestimated as she was brilliant at understanding our needs and our lifestyle. She wanted to know and understand our experiences and a day-in-the-life of both of us. I felt supported in my needs.’

Person with dementia, feeding back on our Dementia Adviser service

‘When you feel like you are wading through a sea of treacle, the support service feels like a comfort blanket giving you the support and encouragement to tackle things head on.’

Carer, feeding back on our Dementia Support service

The New Deal on Society

In 2018/19, we continued to bring together people affected by dementia to grow a movement for change.

We fight for a future where nobody affected by dementia is excluded from their community or denied the care they need. As always, we put people with dementia, and their families, friends and carers, at the heart of what we do, to change attitudes and improve lives.

Growing a movement for change



85,000
campaigners



160
MPs



2.8mil
Dementia
Friends




423
Dementia
Friendly
Communities

Influencing – fixing our broken health and social care system

Our Fix Dementia Care campaign gathered momentum, raising the profile of dementia care as a social justice issue.

We met face-to-face with government officials throughout the year, inviting people affected by dementia to make their voices heard and hold their decision-makers to account.



‘It was really good to speak to an MP who had an interest in dementia so that we weren’t starting from scratch. Some of the things I was able to tell him were things he hadn’t thought of about social care – I was able to put the meat on the bones.

It was very satisfying to see how quickly our visit to Parliament made a difference and that Derek Thomas MP spoke in a debate about social care for people with dementia. I had an anxiety about coming to London as I often do, but the Society did a good job, as always, of ensuring I had proper briefing and looking after me.’

Shelagh Robinson, member of the Three Nations Dementia Working Group

We worked with government and people affected by dementia to influence a review of The Mental Capacity Act. We met with Caroline Dinenage MP, Minister of State for Health and Social Care, to ensure that people with dementia would not be worse off under the new system.

We played a major role in the development of the first Government Dementia Action Plan in Wales, involving over 1,000 people affected by dementia.

We now hold five of the 14 seats on the working group that will oversee plans and the allocation of dementia funding in Wales

(including three people affected by dementia)

In January, we secured a reference to Dementia Connect in the NHS England Long Term Plan, recognition from national decision makers of how our service will transform dementia support, and ultimately save lives.

‘...We will continue working closely with the voluntary sector, including supporting Alzheimer’s Society to extend its Dementia Connect programme which offers a range of advice and support for people following a dementia diagnosis.’

NHS Long term plan

Dementia Friends – creating an inclusive society

This year, we made huge strides towards making the UK a dementia-friendly country.

We recruited more than 500 Dementia Friends every day, reaching a total of 2.8 million.

We grew the number of Dementia Friendly Communities in England and Wales to 423, far exceeding our target of 20

We hosted a Dementia Friendly London summit with the Mayor, Sadiq Khan, resulting in an ambition to make London the first dementia-friendly capital city in the world.

We reinforced our position as the UK's global leader on dementia. There are now 51 Dementia Friendly programmes in 46 countries, supporting people affected by dementia all over the world.

Creating a movement for change

In May 2018, our long-standing annual Dementia Awareness Week became Dementia Action Week to emphasise that awareness-raising alone isn't enough. Over 900 events took place across our three nations and over 22,000 people became Dementia Friends.

We have increased our campaigners to 85,000 people who have united with us against dementia. We also had the support of 160 MPs who engaged with our work throughout the year.

'For those Londoners living with dementia and their carers, we can do much more to make the capital a more welcoming and accessible place.'

Sadiq Khan, Mayor of London

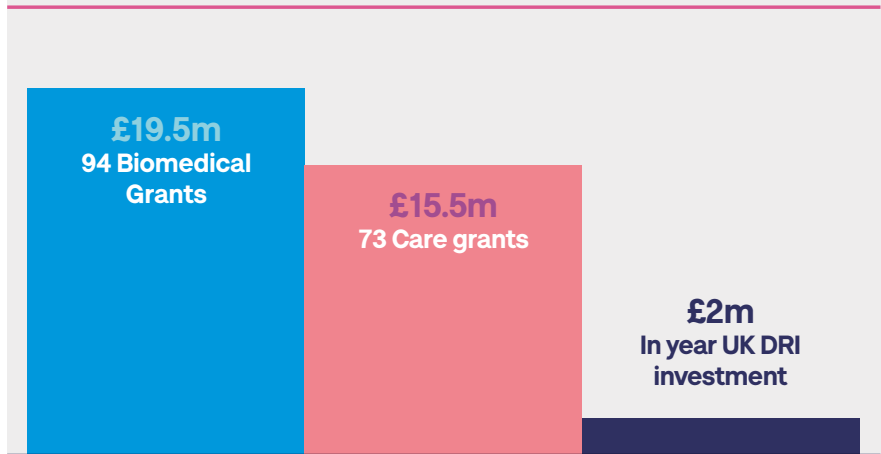


The New Deal on Research

In 2018/19, we took the lead in care and cure research to improve lives today and work towards a future without dementia.


Research has the potential to change everything for people affected by dementia. That's why we prioritise research into both care and cure – the only dementia charity to do so. People living with the condition will always be at the heart of both these areas of our work.

Society Core Research portfolio, £37m investment, 167 active grants



Putting people affected by dementia first

2019 marks the 20th year of our research network – 300 people affected by the condition who have equal decision-making power to the research experts in deciding what projects we fund.

A close-up portrait of an elderly woman with short, wavy, reddish-brown hair. She is smiling gently and looking slightly to the left of the camera. She is wearing a grey cardigan with a white and blue floral pattern. The background is a bright, slightly blurred outdoor scene with a blue sky and some greenery. A pink rectangular box is overlaid on the left side of the image, containing white text.

‘As the earliest member of the Research Network I have been enormously encouraged to see the ongoing effort made by researchers to understand more about dementia. They value our experiences as ‘expert carers’, to the extent of involving us as contributors, co-applicants and in every way they can think of in a joint effort on the difficult road to finding meaningful interventions for this appalling condition.’

Shirley, first research network volunteer

Research – a new discovery every day

Every day, we are leading the way in dementia research.

Our researchers published over 450 scientific articles in 2018/19 – more than one a day

This year, we invested £9.6m in funding research grants, of which £7.6m is new research that directly supported at least 253 researchers, with a total of £37 million in active research projects.

As well as supporting new research, our investments nurture researchers. Our Dementia Leaders programme helps mentor people to build a career in dementia research.

Success in research happens step-by-step. In 2016, we funded a PhD student who studied the presence of a new toxic protein in the brains of people with dementia. She even used samples of brain from the Brain Bank we fund. This year, her work was used as evidence of a new form of dementia, called LATE. This landmark discovery is re-framing the way we view the causes of dementia and was widely reported internationally.

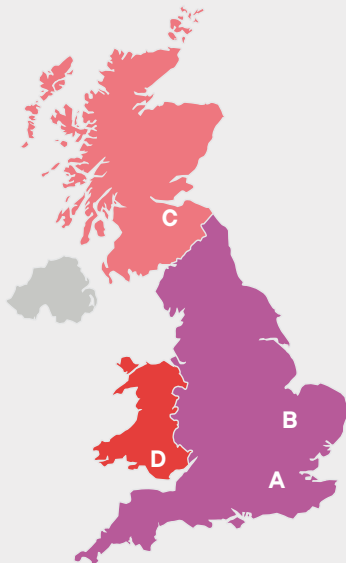
The UK Dementia Research Institute – changing the face of dementia research

In a ground-breaking collaboration with the Medical Research Council and Alzheimer’s Research UK, we established the UK Dementia Research Institute (UK DRI). This is the UK’s first dedicated institute for dementia research.

A network of 300 researchers are working tirelessly across the UK DRI to change how we diagnose and treat dementia and ultimately find a cure

This year, we invested £2 million in the UK DRI. We have committed to invest £50 million in the institute over eight years – our biggest ever single investment in dementia research.

UK DRI: seven research centres united



A. London based:

- UCL
- King’s College London
- Imperial College London
- Care and Technology Centre

B. University of Cambridge

C. University of Edinburgh

D. Cardiff University



Turning research into reality

After research comes development, putting research into practice. We believe the best way to do this is by involving care providers in research.

This year we launched Care Collaboration Grants of up to £300,000 to involve care providers in research and improve the delivery and implementation of care research.

Innovation – getting ideas to market quickly

To meet the needs of people affected by dementia and deliver solutions quickly, we built a new team focused on innovation.

We look for answers to challenges through three approaches:

1. Innovation Sprints

2. Accelerator Programme

3. Partnership

This year, our **Innovation Sprints** developed Lifting the Lid, our award-winning ‘workshop in a box’ to help care home employees address sex and intimacy issues for people with dementia.

Our **Accelerator Programme** funded Jelly Drops and How Do I?.

Jelly Drops are ‘sweets’ with high water content to prevent dehydration, a leading cause of hospital admissions for people with dementia.

How Do I? is an app that people in the earlier stages of dementia can use to record themselves carrying out daily tasks as a future reminder.

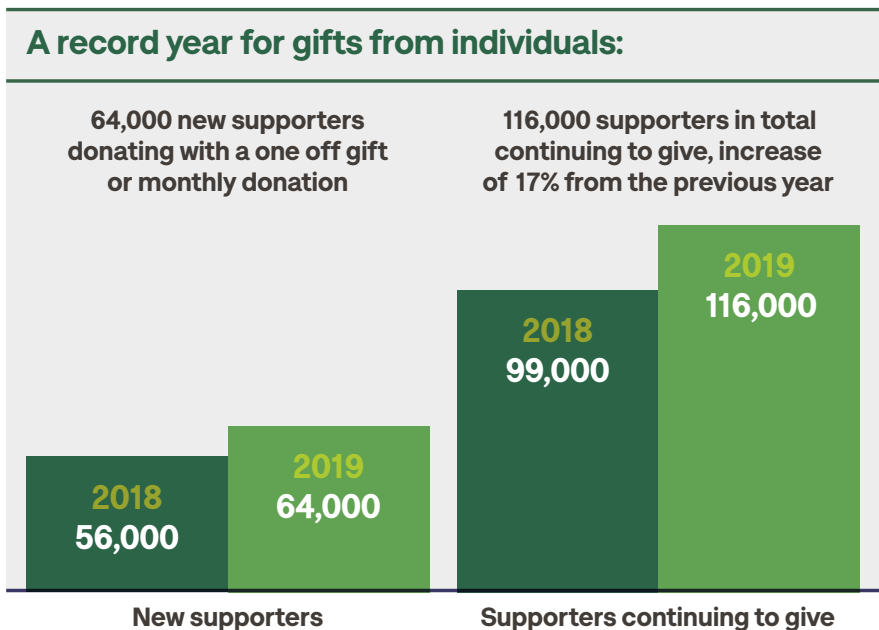
We **partnered** with the University of Oxford to create GameChanger, a memory game app. Over 16,000 people have downloaded the app and are supporting dementia research simply by using their smartphones.



Fundraising

In 2018/19, we gave you even more ways to get involved – day or night.

Our work simply wouldn't be possible without the money raised by our incredible supporters. This year, thanks to them, our fundraising income increased again, enabling us to change the lives of more people affected by dementia.



Our total fundraising income, which includes donations and legacies as well as money from trading activities, raised more than £84m in 2018/19. This is up by 9% on the previous year, which is remarkable given the current financial climate.



‘I hope my story will help other people affected by dementia.

Since my husband Scott and I went public with my diagnosis of Alzheimer’s disease last year, we’ve been overwhelmed by the reaction and all the messages of support we have received.

It’s made us realise that there are so many people going through the same thing.

I hope that by sharing my story, we can encourage more people to talk openly about dementia and support much needed research.’

Dame Barbara Windsor

Dementia Revolution – leading the race towards a cure

Our Dementia Revolution fundraising partnership with Alzheimer’s Research UK was the 2019 Virgin Money London Marathon charity of the year.

Over 40,000 people got in touch about a place and 1,600 runners signed up to take on the ambitious challenge with us

At the end of 2018/19, these supporters were well on their way to reaching the £3.5 million target.

Dame Barbara Windsor and her husband Scott Mitchell gave us their valuable support following her diagnosis, and ‘Barbara’s Revolutionaries’ (Scott and a team of Barbara’s EastEnders cast-mates) even ran the marathon.

Memory Walk’s biggest year yet

October saw our biggest number of Memory Walks to date. More than 90,000 people took part and over 2,000 volunteered in 34 events across the UK.

Memory Walk raised over £8 million this year, up from £7 million in 2017/18.



Memory Walk is the third biggest mass participation event in the country, and the fastest growing.

New ways to get involved

We launched two new fundraising initiatives:

1. Ready Steady GLOW – a series of night-time walks across the UK
2. Dementia Superheroes – a monthly comic that helps talk to young people about dementia

Legacies – leaving a lasting impact

Gifts in wills have a lasting impact and play a vital role in the search for a cure, with a third of all restricted gifts from legacies directly funding dementia research. We are now in the top five health charities for legacy donations.

Growing our corporate partnerships

Our corporate partnerships with companies including McKesson, E.ON, Buzz Bingo and HSBC UK went from strength to strength this year, and we built new partnerships with Sainsbury's Argos, BMW, William Hill, Santander UK, Principality, One Stop, Talent and Pure Storage. These multi-year partnerships will bring in over £6 million over their duration.

Insurance United Against Dementia (IUAD), raised almost £1 million towards the overall £10 million campaign target.

IUAD is also helping to create a more dementia-friendly industry. AXA has committed to help all 10,000 of its UK employees become Dementia Friends, and is 25% of the way through this process.



'It was important for us to do this walk together as a family to recognise the help we had received from Alzheimer's Society.'

Our ambitions for 2019/20

New Deal on Support:

- expand Dementia Connect and provide even more people with fast access to information and support from an expert Dementia Adviser
- embed Dementia Connect in Wales, the West Midlands and beyond, expanding our reach and impact
- increase referrals to Dementia Connect, working closely with healthcare providers.

New Deal on Society:

- reach and involve more people with dementia, especially people in later stages and from more diverse backgrounds
- continue to influence health and social care locally and nationally, to prioritise dementia and address the gaps in social care. Build on the commitment to Dementia Connect in the NHS England Long Term Plan
- support more individuals, organisations and communities to become dementia-friendly through our Dementia Friends and Dementia Friendly Communities programmes.

New Deal on Research:

- **invest £12 million in new research and innovation, listening to people affected by dementia to make sure we have the biggest impact**
- **our Innovation team will create new products and services that improve the lives of people affected by dementia**
- **lead the development of a national plan looking at how technology can help research into diagnosis, treatment and care.**

Fundraising:

- **we will recruit new supporters and keep the trust of our existing givers**
- **build relationships with two new strategic partnerships to raise funds and create new opportunities to support more people affected by dementia**
- **develop new ways to support us, based on people's feedback and preferences. We will aim to give every supporter the best experience possible.**

These are a summary of our ambitions. To read our full list of ambitions for 19/20 please see our Annual Report and Accounts 18/19.



‘Dementia doesn’t define you. For dad it’s about enjoying his life. It’s about not being put in a box. It’s about setting goals and having dreams and doing different things. Alzheimer’s Society have helped support dad in life changes and decisions that he’s made, to make life better for himself.’

Denise, daughter of Allen who is living with dementia

The background is a dark blue gradient with several glowing, bright blue circular and linear patterns. These patterns resemble stylized orbits or paths, with some forming complete circles and others as intersecting lines. The overall effect is a sense of movement and interconnectedness.

Thank you

We are the UK's leading dementia charity.

Every day, we work tirelessly to find new treatments and, ultimately, a cure for dementia. We provide expert information, training, and support services to all those who need our help. And we are creating a more dementia-friendly society so people with the condition can live without fear and prejudice.

Looking for information, support or advice about dementia? Our helpline is here for you on **0300 222 11 22**.

To read our full Annual Report and Accounts 18/19 please visit **alzheimers.org.uk/about-us/annual-reports**

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

Registered charity in England and Wales (296645) and Isle of Man (1128)

18014S0

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