

Our history: 40 years of Alzheimer's Society

40 years
2019



In 2019 Alzheimer's Society will celebrate 40 years of improving the lives of people affected by dementia, through delivering care, campaigning for a fairer society and driving groundbreaking research.

We will use this opportunity to reflect on how far we have come and the changes we have made, whilst recognising there is still much to do until we have a world without dementia.

As we look back on 40 years of achievements, we will also highlight how those achievements have laid the foundations for our current strategy, The New Deal on Dementia, and how they complement the three pillars of the strategy.



**The new
deal on
Support**

**The new
deal on
Society**

**The new
deal on
Research**

Fundraising

1979

A radio broadcast by Professor Davison on his research into Alzheimer's disease prompted Cora Phillips, a former carer, to contact him to set up a charity.¹ Professor Davison put Cora in touch with Professor Gordon Wilcock who had contacted him about the same suggestion. From then a small group of passionate and determined people who shared an ambition to make life better for carers of people living with dementia united to form the 'Alzheimer's Disease Society'.² The first Steering Committee took place on 6 November with official charity status commencing on 19 December 1979.³

Meanwhile, Morella Fisher, an ex-carer was interviewed in 'The Observer' and her article on 2 December entitled 'The Sad Quiet Epidemic' resulted in several hundred letters including one from Cora Phillips inviting her to join the Steering Committee. The aim of the new charity was to support families and carers with information about dementia, advise on the support available through social services, ensure adequate nursing care was available in the latter stages of the condition and to promote research and educate people about dementia.⁴

1980

The first AGM took place on 13 September with 98 member attendees⁵ to establish the aims of the Society.⁶ Our first branch was set up in Oxford.⁷

1981

There were 370 official members by the next symposium in February 1981.

Our first annual conference took place, launching the findings of our first ever survey about day care available in London and to create a holiday relief fund for respite for carers.⁸

Our first newsletter appealed for volunteers to set up local services.⁹

A grant from the DHSS, funded the salary of a Development Officer and a small office.¹⁰

The second branch was set up in Bromley.¹¹ World in Action met Cora Phillips and the Bromley branch to film 'The Quiet Epidemic' documentary for Granada TV.¹²

1982

First appearance on a news bulletin when ITN filmed people affected by dementia in Bromley.¹³

Subcommittees set up: liaison, fundraising, information, development group, legal and financial advice service, finance and social work.¹⁴

1 The Foundations of the Alzheimer's Disease Society by Anne L Hunter

2 Eileen Winstone presentation . Charity established at Steering Committee attended by Cora Phillips, Dr Anne Hunter, Brian Hunter, Prof Gordon Wilcock, Ceri Powell, David Newmark and Morella Kayman on 6th November 1979. Official charity status on 19 December 1979.

3 Eileen Winstone presentation

4 Foundations of the Alzheimer's Disease Society by Anne L Hunter

5 Eileen Winstone presentation

6 The Foundations of the Alzheimer's Disease Society by Anne L Hunter

7 The Foundations of the Alzheimer's Disease Society by Anne L Hunter

8 Eileen Winstone presentation

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14 The Foundations of the Alzheimer's Disease Society by Anne L Hunter

1983

Publication of 'Caring for the Person with Dementia: a Guide for Families and Other Carers.' We sold in excess of 9,000 copies which speaks for itself.¹⁵

The Society's first video was produced, called 'The Silent Epidemic'.¹⁶

In the summer, the Caring Fund was established to help families cope better with their caring duties. The sum was £15,000 to begin with and people were encouraged to apply.¹⁷

The Society started funding a small number of research projects and fellowships and a Medical & Scientific Advisory Committee was appointed to review applications and prioritise for funding.¹⁸ The committee's first two grants were directly from Society funds and from Dr Rickman's family trust.¹⁹ The appointment of the first Counsellor and the first Counselling course was introduced.²⁰

In the summer, with a grant from Manpower Services Commission, Regional Development Offices opened in nine areas with the task of establishing relatives groups providing practical and social support; contacting local government and agencies to ensure better understanding of and provision for people with Alzheimer's and raise awareness of dementia to the public.²¹

1984

Abingdon Day Centre in Oxfordshire was opened and run by volunteers, Community Psychiatric Nurses and Abingdon Social Services.²²

For the first time someone runs the London Marathon to raise money for the Society.²³

1985

Bromley Day Centre opened.²⁴

1986

The Alzheimer's Disease Society branch in Northern Ireland was officially opened in early 1986. The first paid full time member of staff started, Collette McCrory. Colette would sit with individuals and their carers and discuss issues - anything from how the person was coping to practical issues such as enduring power of attorney.²⁵

1987

The first scientific conference on dementia research was held in July at Southampton University.

15 AS milestone by theme document
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25 The History of AS in NI

1988

A Channel 4 documentary, 'What is it Worth?', on family carers jammed all 20 of the Society's phone lines from the time it aired to the time they closed, and generated nearly 5,000 requests for information packs, highlighting how little support was available then.²⁶

The Society advised carers on how the newly introduced Social Fund would affect them and how to correctly apply for it from the Department of Social Security (DSS). The Griffiths Report on NHS reform marked a political turning point as charities realised how much they'd have to do as responsibility for continuing community care moved from the NHS to local authorities - he used the analogy of social care as 'everyone's relative but nobody's baby'.²⁷

1989 (10 year anniversary)

In September we stepped up the lobbying of MPs on key issues such as Poll Tax exception for people with dementia, the need for an increase in the income support grant and the recognition of Alzheimer's disease as a terminal illness.²⁸

In October we successfully campaigned for people with Alzheimer's disease to be exempt from paying Poll Tax.²⁹

The first ever Dementia Awareness Week was held, led by Alzheimer's Society.³⁰

1990

HRH Princess Alexandra became our Royal Patron.³¹

The NHS and Community Care Bill became an Act and Alzheimer's Society continued to highlight how the Government had not laid out its plans on how it was going to finance it, or stated the size of the Mental Illness Specific Grant. On a positive note, we had a campaign win with the government agreeing to raise Income Support by £45 for people in nursing homes, by £15 for those in residential care homes and an extra £10 in London.³²

We reached 10,000 members.³³

The Society advised the writers on an EastEnders dementia storyline.³⁴

We ran our first ever Christmas Appeal.³⁵

The Society sent information about dementia to every GP in the country.³⁶

Our Income topped £1million.

Our first legacy was received.³⁷

'Not Enough Care', a survey commissioned by Alzheimer's Society, showed patchy and non-existent respite care.³⁸

The Society announced our official research programme (NB we have been funding research grants since 1983 and have been championing research right from the start).

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28 Sophie's campaign timeline
29 Newsletters 1988-91
30 ADS Newsletter 1989
31 From 1979 to 2009 history document
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34 Newsletters 1988-91
35 Annual Report 1990-91
36 Annual Review 2003/4
37 Eileen Winstone timeline
38 Annual Report 1990/91

1991

Cora Phillips was awarded an MBE for founding Alzheimer's Society.

In February Dr John Hardy and Dr Michael Mullan at St Mary's Hospital Medical School, London, established a link between the development of early onset dementia and chromosome 21. This research was funded by the Society.³⁹

The first national study conference on Younger People with Dementia drew attention to the special needs of this group.⁴⁰

1992

In July we held our first ever parliamentary meeting during Awareness Week to coincide with the launch of the Alzheimer's Disease Report which pulled together information on caring, research, health and social care.⁴¹

The longest-serving member of staff, Marion Howell, began working for the Society.⁴²

1993

In April we launched £1.25 million of Post-Doctoral Research Fellowships to support talented scientists and doctors over the next five years. 26 applications were received and the panel awarded four research fellowships.⁴³ In 2016 we found out where the four are now.⁴⁴

Community care legislation changes meant local authorities began purchasing care packages from Alzheimer's Society branches.⁴⁵

The Society attended all three major political party conferences for the first time.⁴⁶

We appointed our first Parliamentary Officer.⁴⁷

Virginia Bottomley, Secretary of State for Health, officially opened our new central office in Victoria.⁴⁸

1994

An open learning programme was introduced for people to study in their own time – a carers resource pack aimed at new carers of people with dementia, and the care workers course to encourage good practice in care homes.⁴⁹

Our members topped 20,000.⁵⁰

World Alzheimer's Day (WAD) launched on 21 September by Alzheimer's Disease International.

39 Annual report 1990/91

40 Annual report 1991/92

41 Annual report 1992/3

42 FP Doc pitch

43 Newsletter April 1993

44 <https://www.alzheimers.org.uk/blog/research-fellowship-awardees-where-are-they-now>

45 Annual report 1992/93

46 AS Milestone by Theme document

47 Annual report 1992/3

48 Annual report 1993/4

49 Annual report 1993/4

50 AS Milestone by Theme document

1995

We launched a major fundraising campaign, 'Don't forget the flowers', in September with a £1 donation from florists from the sale of bouquets from Paula Pryke.⁵¹

1996

Our new leaflet 'It's enough to blow your mind' explained dementia to teenagers.⁵²

Income for the Society passed £10 million.⁵³

The first general election manifesto was produced by the Society, 'Challenging Dementia'.⁵⁴

1997

Aricept is licensed in the UK and the Society appointed a specialist information officer to answer queries about the new drug. A year later, Exelon received its licence. However, only a minority of health authorities prescribed it. We campaigned for equitable prescribing arguing that withholding drugs from people with dementia amounts to discrimination against older people.⁵⁵

In May we released a groundbreaking survey on standards in residential care which helped persuade the government to bring nursing homes in line with residential homes by publishing their inspection reports.⁵⁶

Tom Kitwood published his seminal book 'Dementia Reconsidered: the person comes first', which was recognised as the theoretical basis for putting the person with dementia at the focal point of care.⁵⁷

With funds from the Society, Professor Nick Fox developed an MRI analysis technique to quantify changes in brain structure, which is now commonly used in clinical trials in dementia.⁵⁸

1998

TV presenter Anne Robinson launched the National Dementia Helpline in April. In its first year it received 24,000 calls.⁵⁹

We launched alzheimers.org.uk, including information about dementia, availability of help for carers, details of press releases, news of events and general information about the Society.⁶⁰

51 Annual report 1995/96

52 AS Milestone by Theme document

53 Annual review 1996/97

54 NHS70 briefing

55 Annual report 1996/7

56 Annual report 1997/8

57 Dementia research and policy timeline

58 AS Research Impact Report 1990-2012: Cause, care, cure and prevention

59 Annual report 1998/9

60 Annual report 1998/9

1999 (20 year anniversary)

The Alzheimer's Disease Society changed their name to Alzheimer's Society.⁶¹

Quality Research in Dementia launched in October and brought together doctors, scientists, carers and people affected by dementia to set the research agenda.⁶²

The National Institute for Neurology at Imperial College was awarded the tender to host the QRD programme and Dr Richard Harvey, Consultant Psychiatrist, was appointed as the first Alzheimer's Society Director of Research. By the end of the year, more than 100 people with dementia, carers and former carers had joined the QRD, later known as the Research Network, eager to help shape the growing research programme. Since the Research Network was founded in 1999, the number of active volunteers has more than doubled from 120 to over 300.⁶³

In February the government produced a National Strategy for Carers which set aside £140m over three years to support carers who need respite from caring – the first of its kind and in response to the efforts of the Society.⁶⁴

In June, ITV aired a documentary, 'Malcolm and Barbara: a love story', a first fly on the wall documentary about a happily married couple and the effect Alzheimer's had on their lives. Barbara later became an Ambassador for the Society.⁶⁵

2000

The first dementia café opened.⁶⁶

Dembase, a database of information about dementia, became available to branches.⁶⁷

The Gay and Lesbian Carers Network was established.⁶⁸

We launched 'Same Difference', a three-year campaign exploring how the charity could reach BAME communities with two videos produced for the African Caribbean community and the South East Asian community.

2001

We became the first organisation in the world to have a person affected by dementia on their board, Peter Ashley.^{69 70}

Following a Society campaign, the government implemented a five year ban on using genetic tests in setting insurance premiums for policies under £300,000.⁷¹

The 'Learning to Live With Dementia' project launched, working with people affected by dementia to develop better ways to meet their needs such as producing information that answers questions from people with dementia, developing appropriate local services, enabling people to become involved in decisions about their life and care and increasing understanding about what it is like to live with dementia.⁷²

National Institute for Clinical Excellence (NICE) announced its decision to support the availability of dementia drugs on the NHS following a three year campaign by the Society.⁷³

61 AS milestone by theme document
62 Annual report 1998/9
63 Celebrating 15 years of the Research Network
64 Annual report 1998/9
65 Annual report 1999/00
66 Ed Shrager – Alzheimer's Society history timeline
67 Eileen Winstone presentation
68 Annual report 2001/2
69 Eileen Winstone presentation
70 <https://www.dementiaallianceinternational.org/peter-ashley-life/>
71 Annual report 2003/4
72 Annual review 2001/2
73 Annual review 2000/1

2002

Talking Point was launched as an open discussion forum.⁷⁴

The Research Network prioritised funding the FITS (Focussed Intervention Training and Support) trial, which asked whether enhanced care could reduce the severity of behavioural symptoms, improve quality of life and reduce the use of antipsychotic drugs in people with dementia. Three volunteers were appointed to the project steering group. Results from the 12 participating care homes revealed that training staff asked to deliver person-centred care reduced the use of antipsychotics by 40%. The steep decline in negative behaviours showed that care staff who develop their knowledge and skills could greatly increase quality of life both for people with dementia and themselves. This resulted in an evidence-based training manual and CD of the FITS programme. ‘Evidence-based approaches for improving dementia care in care homes’ that was published in 2007.⁷⁵

‘Free long term care’ was the Society’s longest and most successful campaign of the year. Free nursing care was introduced for people in nursing homes in 2001 in England and Wales in 2001 and NI in 2002 but personal care continued to be means-tested. The Society lobbied major political parties. A call to supporters resulted in hundreds of letters to MPs expressing their anger and disappointment at people affected by dementia having to pay for their long-term care.⁷⁶

2003

Our first national event for people with dementia was held at the Café Royal London, encouraging people living with dementia to say what they want the Society to do in the future.⁷⁷

The first ever Singing for the Brain group started.⁷⁸

Many people with dementia were still being denied prescriptions. The Society had a major campaign success when the Department of Health confirmed that NICE would issue guidance on the use of dementia drugs being freely available on NHS for anyone who needed them.⁷⁹

Memory Walk fundraising began. 55 walks raised £55,000.⁸⁰

2004

We launched a highly successful three-year initiative to raise awareness of vascular dementia and to develop a roadmap of research priorities. Since the completion of the project, Alzheimer’s Society has funded new research projects investigating the causes and diagnosis of vascular dementia and launched a major clinical trial co-funded with The Stroke Association.⁸¹

11,500 CD Roms were distributed to GPs to help diagnose people with dementia.⁸²

2005

NICE recommended that no one with Alzheimer’s disease should have access to Alzheimer’s drugs on the NHS, citing cost reasons. We led a robust campaign, Hands Off Dementia Drugs, challenging NICE’s decision. 9,000 people wrote to NICE to protest and over 600 supporters gathered in London to lobby Parliament.⁸³

74 Ed Shrager – Alzheimer’s Society history timeline

75 Celebrating 15 years of the Research Network

76 Annual review 2002/3

77 Annual review 2002/3

78 Ed Shrager – Alzheimer’s Society history timeline

79 Annual review 2002/3

80 Annual review 2003/4

81 Cause, cure, care and prevention: Impact of Alzheimer’s Society’s dementia research programme 1990–2012

82 Annual report 2003/4

83 Annual review 2004/5

Years of campaigning and lobbying paid off when MPs voted the Mental Capacity Bill through its final parliamentary stages. The new Mental Capacity Act marked a major turning point in the legal rights of people with dementia and carers. For the first time, people with dementia couldn't legally be presumed incapable of making their own decisions. Carers, too, would benefit from new rights under the act: implementation of the act in 2007 meant that they must be consulted about decisions relating to the health and welfare of people who have lost capacity.⁸⁴

One Society programme was launched to provide more and better services for people with dementia wherever they live in England, Wales and Northern Ireland to ensure that the Society could continue to improve the quality of life for all those touched by dementia well into the future.⁸⁵

We launched our first ever nationally accredited training course aimed specifically at improving the quality of care given to people with dementia. 2,500 carers completed the course in its first year.⁸⁶

2006

The 'Hands Off Dementia Drugs' campaign included a judicial review against NICE – a first for the Society; there were 30 mass protests nationwide and more than 30 organisations joined forces to create the Action on Alzheimer's Drugs Alliance. NICE performed a significant U-turn and said that people in the moderate stages of Alzheimer's could have the drugs on the NHS. It was a victory for the campaign.⁸⁷

The Society made 11 new awards to research projects totalling £1.8m.⁸⁸

2007

Sir Terry Pratchett announced he had a rare form of dementia, posterior cortical atrophy (PCA).

The Society's Dementia UK report with King's College and London School of Economics was published and established the cost of dementia in the UK to be £17 billion, with over 700,000 people affected by dementia.⁸⁹

Our 'Living with dementia' magazine was launched designed to respond to the needs of our members.⁹⁰

We rebranded with a new logo and strapline – 'Leading the fight against dementia'.⁹¹

The All-Party Parliamentary Group on Dementia (APPG) was established to raise awareness of dementia amongst parliamentarians and to influence legislation and policy-making in order to improve the lives of people with dementia and their carers.⁹²

Brains for Dementia Research was launched in partnership with Alzheimer's Research UK. It was a network of six brain banks across the country to collect high-quality donated brain tissue for dementia research. Over 3,200 people signed up and 600 brains were donated from those who have passed away.⁹³

We launched of a Vice-Presidents, Patrons and Ambassadors' programme which united key supporters in the fields of business, the arts, science, politics, the media, sport and those living with dementia, who were able to use their skills to ultimately beat dementia.

The Department of Health announced its plan for a National Dementia Strategy with the aim of improving public and professional awareness, ensuring early diagnosis and intervention, and improving the quality of care for people with dementia and support for carers. The charity's CEO joined the Department of Health's own committee working on this strategy.⁹⁴

84 Annual review 2004/5

85 Annual review 2004/5

86 Annual review 2004/5

87 Annual review 2005/6

88 Annual review 2006/7

89 Annual review 2006/7

90 Annual review 2007/8

91 Ed Shrager – Alzheimer's Society history timeline

92 Dementia research and policy timeline

93 <http://brainsfordementiaresearch.co.uk/our-progress/>

94 Annual review 2007/8

2008

Sir Terry Pratchett's foreword and active support helped us to win attention for our report 'Dementia: Out of the shadows'. The report described the experiences of people leading up to and following a diagnosis of dementia. It provided people with dementia with an opportunity to explain what it is like to live with the stigma associated with the condition.⁹⁵

'The Dementia Tax: Charging people with dementia for inadequate care: The evidence for change' report looked into the types of care that people with dementia received and the amount that they paid for care.⁹⁶

We rolled out 'Worried about your Memory?' campaign, encouraging people to ask for help if they were worried about their memory, or concerned about someone else's, this prompted over 100,000 requests for information for this campaign over the years with over 2 million leaflets in 12 languages distributed.^{97 98}

2009 (30 years anniversary)

The government's National Dementia Strategy for England and equivalent developments in Wales and Northern Ireland were published – our members' personal experiences influences the Strategy's development.⁹⁹

Our Dementia Advisor service was launched providing high quality information, signposting and support in communities in response to the expressed needs of people with dementia and their carers.¹⁰⁰

Together with the All-Party Parliamentary Group on Dementia, we investigated the use of antipsychotic drugs given to people with dementia in care homes and urged an end to what MPs called 'dangerous over-prescribing'. The Department of Health in England conducted its own investigation and The National Dementia Strategy for England advised against inappropriate medication.¹⁰¹

Our report 'Counting the Cost' highlighted the huge human and economic costs of poor hospital care that people with dementia often received.¹⁰²

A new leaflet, 'This is me', supported people with dementia going into hospital and had a huge response with hospitals across the country taking steps to improve dementia care.¹⁰³

2010

We launched 'Fit for the Future', a restructure programme of our branches.

Over 100,000 messages posted on the Talking Point online forum in 2009/10.¹⁰⁴

41 national organisations (that went on to form the Dementia Action Alliance [DAA] which now stands at over 150 members¹⁰⁵) asked people affected by dementia, and other key stakeholders, what type of care and support they would hope to receive in the future. Informed by these conversations, they created the National Dementia Declaration, a set of seven expectations or statements of what life should be like for people with dementia. These statements were used to inform the Prime Minister's Challenge on Dementia published by the Department of Health in 2012.¹⁰⁶

95 Annual review 2008/9

96 NHS70 Briefing

97 Annual review 2008/9

98 Annual review 2011/12

99 From 1979 to 2009: the first 30 years

100 Annual review 2009/10

101 Annual review 2009/10

102 Annual review 2009/10

103 Annual review 2009/10

104 AS Milestone by theme document

105 https://www.dementiaaction.org.uk/assets/0003/5966/DAA_Annual_Report_17_18_online_final.pdf

106 Turning up the volume: unheard voices of people with dementia 2017

In April 2017 the Statements, after being reviewed and refreshed by the DAA and people affected by dementia, were welcomed and endorsed by the Dementia Programme Board that monitors and supports the implementation of the Prime Minister's Challenge on Dementia 2020 across the NHS, social care, the research sector and wider society. Alzheimer's Society is committed to taking them forward.¹⁰⁷

Alzheimer's Society gathered an expert panel in partnership with the BBC to review the evidence for lifestyle factors in reducing the risk of dementia.¹⁰⁸

2011

The Dementia Community Roadshow was launched, funded through our partnership with Tesco. The Roadshow helped over 37,000 people with questions about dementia in the first year.¹⁰⁹ (As of October 2018 we have reached over 240,000 people).

Research on the views and experiences of patients and carers in using dementia drugs proved crucial in Alzheimer's Society's campaigning work against the decision of NICE to restrict dementia drugs to the moderate stages and contributed to a reversal of their decision.¹¹⁰

Our Ambassador, Lord Fellowes launched our innovative Drug Discovery programme in the House of Lords. The programme has the potential to bring better treatments to hundreds of thousands of people with dementia sooner.¹¹¹

2012

We worked with David Cameron to develop the Prime Minister's Challenge on Dementia, with three champion groups set up to focus on the main areas for action:

1. Driving improvements in health and care
2. Creating dementia-friendly communities
3. Improving dementia research.¹¹²

We rolled out our Carers' Information and Support Programme (CRISP) to help carers of people with a recent diagnosis in their caring role and to plan for their future.¹¹³

As part of the Care and Support Alliance, we lobbied Parliament to demonstrate public anger about the failing social care system. Over 1,000 people attended, alongside our Ambassador Sir Tony Robinson.¹¹⁴

We launched a five year strategy, Delivering on Dementia. This had four aims:

1. Demonstrate the way in dementia care and support
2. Be the foremost point of contact for anyone dealing with dementia
3. Lead partnerships and investments in research to improve care, advance prevention, and move closer to a cure
4. Campaign for people affected by dementia to be able to live the lives they want.¹¹⁵

We launched our first annual assessment of how well people with dementia are living in the UK.¹¹⁶

107 Turning up the volume: unheard voices of people with dementia 2017

108 <http://news.bbc.co.uk/1/hi/health/8484868.stm>

109 Annual review 2011/12

110 Cause, cure, care and prevention: Impact of Alzheimer's Society's dementia research programme 1990–2012

111 Annual review 2011/12

112 Annual review 2011/12

113 Annual review 2011/12

114 Annual review 2011/12

115 Annual review 2011/12

116 Annual review 2011/12

2013

The Dementia Friends programme began with the aim of creating 1 million Dementia Friends by 2015. It was the biggest ever social action initiative to change people's perceptions of dementia aiming to transform the way the nation thinks, acts and talks about the condition.¹¹⁷

'The Dementia Guide' was published to give people affected by dementia all the vital information they need at the point of diagnosis. 'Living well with dementia after diagnosis' information pack in Wales was also released.¹¹⁸

The User Involvement Plan was launched to ensure that all our work is truly informed by people affected by dementia.¹¹⁹

We played a key role in developing and following up on the 2013 G8 Dementia Summit, bringing together government and charity organisations from around the world to improve understanding and collaboration in dementia research.¹²⁰

Peter Dunlop, an Alzheimer's Society Ambassador, shared his experience of dementia at the Summit.¹²¹

The Dementia Friendly Communities (DFC) recognition process launched in September so that people with dementia, no matter where they live, could continue to be active, engaged and valued in their community. Everyone, from local businesses to schools and religious groups, has a role to play. Over 225 communities were recognised by the DFC recognition process by 2017.¹²²

2014

We launched Join Dementia Research, in partnership with the National Institute of Health Research and Alzheimer's Research UK. In the first month, more than 5,000 people signed up to take part and over 500 had been matched to trials.¹²³

The 'Right to Know' campaign aimed to improve diagnosis rates and post-diagnosis support. The campaign helped us recruit 60,000 more e-campaigners to influence decision makers.¹²⁴

We committed to £100 million investment in dementia research over the next 10 years.¹²⁵

We delivered dementia awareness training to all 2,000 staff of the Care Quality Commission (CQC). (We also looked at developing new training aimed at inspectors so that the needs of people with dementia are a priority when judging standards of care and suggesting improvements).¹²⁶

A national awareness campaign encouraging people to become a Dementia Friends featured the likes of Chris Martin, Lily Allen, Ray Winstone and Pixie Lott¹²⁷ and the programme is now being replicated around the world. By the end of 2014 almost 100 towns and cities signed up to becoming dementia friendly. Companies and national organisations also keenly came on board and played their part, for example developing dementia-friendly charters for their sectors.¹²⁸

117 Annual review 2012/3

118 Annual review 2012/3

119 Annual review 2012/3

120 Annual review 2012/3

121 <https://www.gov.uk/government/publications/g8-dementia-summit-global-action-against-dementia/g8-dementia-summit-global-action-against-dementia-11-december-2013>

122 Turning up the volume: unheard voices of people with dementia 2017

123 Annual review 2014/15

124 Annual review 2014/15

125 https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/extended_history_of_the_research_network.pdf

126 Annual review 2013/4

127 https://www.huffingtonpost.co.uk/2014/05/07/dementia-celebrities-advert-alzheimers_n_5278504.html#gallery/348389/10

128 Annual review 2014/15

2015

We reached 1 million Dementia Friends target.

Our campaigning secured election manifesto commitments from all five main parties, a new Prime Minister's Challenge on dementia, and a commitment to invest £6.25 million in improving dementia care and support in Northern Ireland.¹²⁹

Side by Side began, reducing the social isolation that can be felt by many people living with dementia.¹³⁰

We helped influence the government to commit £150 million to a world leading UK Dementia Research Institute (UK DRI).¹³¹ As a founding partner, in early 2016 we committed to raising £50million¹³² with six hubs selected. The UK DRI unites over 700 world-leading researchers across six leading UK Universities, with the headquarters at University College London.¹³³

Hilary Doxford, a Society Ambassador and Research Network volunteer, secured a place for a person with dementia on the World Dementia Council, which was set up in 2014 to support the delivery of commitments made at the G8 Summit.¹³⁴

The number of Memory Walk participants hit 50,000 with funds raised exceeding £4million.¹³⁵

The Dementia Community Roadshow attended our first LGBT+ event, the Manchester Pride show, to show our support and get a better understanding of the needs of LGBT+ people affected by dementia.¹³⁶ We now attend Pride events across the country.¹³⁷

2016

We launched our hard-hitting 'Fix Dementia Care' campaign. The first part of the campaign focused on radically improving dementia care in hospitals. As a result, more than 10,000 people emailed the Chief Executive of NHS England calling for action.¹³⁸ The second and third parts of the campaign focused on fixing dementia care in home care and care homes.¹³⁹ 'The Fix' campaign inspired over 30,000 people to unite against an unfair social care system.¹⁴⁰

To help people affected by dementia find local dementia services more easily we launched our Dementia Connect search engine, with 100,000 searches for support in its first year. These developments led to more than 35 million page views of our website.¹⁴¹

Oscar-nominated actress and Ambassador Carey Mulligan became the UK's Global Dementia Friends Ambassador to help bring attention to dementia, encourage people worldwide to become Dementia Friends and to be more dementia-friendly.¹⁴² In her role she delivered a keynote speech at the 2017 UN Official Commemoration of the International Day for the Elimination of Violence against Women.¹⁴³

Simon McDermott and his Dad, Ted, aka 'The Songamminute Man' won a Pride of Britain Award for raising awareness of dementia and over £130,000¹⁴⁴ for the Society after receiving support from our Helpline.¹⁴⁵

129 Annual review 2014/15

130 Annual review 2014/15

131 <https://www.alzheimers.org.uk/research/researchers/UKDRI>

132 <https://ukdri.ac.uk/about-us/our-funders>

133 <https://dementiarevolution.org/blog/uk-dri-what-it-means-people-affected-dementia>

134 Research Network History PDF

135 Annual review 2015/16

136 <https://www.manchestereveningnews.co.uk/news/greater-manchester-news/alzheimers-society-take-part-manchester-9796340>

137 <https://www.alzheimers.org.uk/blog/alzheimers-society-pride-2017-supporting-lgbt-people-dementia>

138 Annual report 2015/16

139 <https://www.alzheimers.org.uk/our-campaigns/fix-dementia-care>

140 Annual review 2016/17

141 Annual review 2015/16

142 <https://www.alzheimers.org.uk/about-us/policy-and-influencing/global-dementia-friendly-movement/global-dementia-friends-ambassador-carey-mulligan>

143 <http://webtv.un.org/watch/player/5655220030001>

144 <https://www.justgiving.com/fundraising/songamminute>

145 <https://www.alzheimers.org.uk/blog/songamminute-man-wins-pride-britain-award-raising-dementia-awareness>

Over 150 dementia-friendly communities were developed with our support, reaching an estimated 18 million people and 1.5m Dementia Friends.¹⁴⁶

Cupcake Day was launched. People can bake, buy and sell cupcakes to defeat dementia. Since its launch, over 77,000 people have taken part, raising over £2.7m.¹⁴⁷

2017

Memory Walk had 80,000 walkers and raises £6.7million.¹⁴⁸

Our one-to-one and group services have improved the lives of 266,250 people affected by dementia during Delivering on Dementia 2012-17, the Society's five year strategy. In that time we responded to 170,500 National Dementia Helpline enquiries and had 116,000 Memory Walkers raising £16.7million.¹⁴⁹

By 2017 we were running over 2,500 one-to-one or group based services supporting people affected by dementia and their carers.¹⁵⁰

The New Deal on Dementia, Alzheimer's Strategy 2017-2022 began. The strategy built on what had come before, but looked to deliver our ambitions through three key 'pillars' of activity, underpinned by fundraising, digital and a new brand, with the strapline United Against Dementia.

Our new brand and United Against Dementia campaign created thousands of new supporters and a network of tens of thousands of campaigners. It challenged people to put aside their differences and play their part in the growing dementia movement. United Against Dementia is now at the core of everything we do, from bringing researchers together globally to uniting people in fixing a broken care system.¹⁵¹

For the first time ever, our annual income rose to over £100 million.

We invested over £10million into research for the first time, as we pushed harder than ever to investigate cures, better methods of care and ways to prevent dementia. This took our total active research grants to 182, our highest ever.¹⁵²

Over 50,000 people are signed up to our online discussion forum Talking Point, where they can share their knowledge and experience of dementia and our website receives over 11 million views.¹⁵³

'Turning Up the Volume: unheard voices of dementia' was published, taking an unprecedented look at the real picture of living with dementia today, from the people who know those living with dementia. Statistics included that more than half (54%) of the public agreed the government should pay for their care and support if they develop dementia.¹⁵⁴

Our income grew to over £100million with donations from philanthropists and grant-making trusts reaching over £5 million for the first time and legacy donations totalling £22.8 million, accounting for over a quarter of our voluntary income.¹⁵⁵

We announced our biggest-ever single investment in dementia care research, with £6 million awarded to three 'Centres of Excellence'. The 'Centres of Excellence' will focus on key priority areas within dementia care research over the next five years.¹⁵⁶

Exercising our influence as the 'critical friend', we committed to making sure the Dementia Statements, created by people living with dementia, framed the dementia movement for change. We ensured the voices of people affected by dementia are heard by policy and decision makers in

146 Annual review 2015/16

147 Gaby Morgan, Cupcake Day team

148 Annual review 2016/17

149 Annual review 2016/17

150 Annual review 2016/17

151 https://www.alzheimers.org.uk/sites/default/files/2018-08/Trustees_Report_and_Annual_Accounts_17-18.pdf

152 Annual review 2016/17

153 Annual review 2016/17

154 https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/turning_up_the_volume_unheard_voices_of_people_with_dementia.pdf

155 Annual review 2016/17

156 <https://www.alzheimers.org.uk/news/2018-05-03/alzheimers-society-centres-excellence-could-make-life-changing-difference-people>

England, Wales and Northern Ireland. We gathered evidence and real life testimony to highlight how the social care crisis is a dementia crisis, and worked with parties from across parliament to put dementia at the heart of the social care reform agenda.

2018

UK Dementia Research Institute opened in London (UCL, King's College London and Imperial College London), Cambridge, Cardiff and Edinburgh.

More than 90,000 people took part in Memory Walk raising over £7 million.

Seventeen insurance industry leaders pledged to raise £10 million for Alzheimer's Society.

More than 23,000 people took part in our second Cupcake Day, raising over £1 million.

We reached 2.5m Dementia Friends in July.

The total number of people affected by dementia we directly reach and support through our services increased from 206,000 in 2016/17 to 210,000 in 2017/18.

The number of interactions with people affected by dementia we indirectly reach through our expertise and information increased from 6.1 million in 2016/17 to 6.5 million in 2017/18. We continue to be the leader in reach and quality of support to people affected by dementia, with 2,846 local services helping 105,000 people.

Alongside this, 42,000 people were supported by our Helpline, 60,000 gained support by joining Talking Point and our website attracted 11 million views.

We started our new strategic service, Dementia Connect, that over the coming years will help people wherever they live in our three nations. The first 'early adopter' service opened in Pennine Lancashire and had more than 1,200 referrals in the first 12 months. Our second early adopter site opened in March 2018 covering Birmingham and Solihull.

We are the key charity partner to the government and the NHS in implementing the Dementia Strategy in England and this year were central to establishing a similar plan in Wales. On top of that we have invested a further £10 million in new research grants and other research activity. This includes £1 million to the UK DRI. We developed and tested a new model for innovation, selecting research and development demonstrator sites for 2018/19 that will prove new approaches to care and support, have impact, and are scalable.

We are also developing our capabilities through collaboration. Having forged new partnerships with the Global Brain Health Institute and Optum Labs, we are leading the UK's delivery of the EU-wide Joint Programming in Neurodegenerative research 2018.

Led by us, the Dementia research roadmap for prevention, diagnosis, intervention and care highlights issues that are being tackled through the Economic and Social Research Council/ National Institute for Health Research Dementia initiative 2018 and we are using our partnerships programme to find opportunities to collaborate on applications.

In October we released 'Dementia – the true cost: fixing the care crisis'. This report highlighted the experiences of people affected by dementia who rely on health and social care support, who often have to face horrendous costs to pay for their care. It set out how people often struggle to access vital care and the care that they do access is often of poor quality. It set out recommendations for the government on how to fix the social care crisis. We will be campaigning on these issues to ensure that dementia is a key focus in the Green Paper on Social Care. We will continue to campaign on this in the coming months.¹⁵⁷