

Leading the fight  
against dementia

Alzheimer's  
Society

# Seeing dementia

Annual review 2014/15

I want people to see me rather than the dementia. I want them to take time to find out what I still love to do.

Joy

We are the UK's leading support and research charity for people with dementia, their families and carers.

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## Chair and Chief Executive's introduction

**During 2014/15 we delivered greater change for people affected by dementia than ever before. We supported hundreds of thousands of people affected by dementia including through our information services, National Dementia Helpline and local services. We had a record investment in research, and reached our first 1 million Dementia Friends.**

Making it all possible was the generosity of our supporters and the passionate engagement of our volunteers and staff.

Core to all our work during the year was enabling people affected by dementia to have their voices heard. One expression of this was securing a place for a person with dementia on the World Dementia Council. That place was filled by Hilary Doxford, one of our Research Network volunteers. In the pages that follow you will hear from four people affected by dementia about their experiences and how Alzheimer's Society has helped them.

Thousands of people each month benefit from our local support services, such as our Dementia Cafés and Singing for the Brain groups. In the

last year we have also started Side by Side, where people with dementia and volunteers take part in hobbies and activities out in the community, reducing the social isolation which can be felt. Our Home Focus service also brings together volunteers and home care staff to enable people to carry on living in their own homes.

Whether from our local Dementia Advisors and Dementia Support Workers or through our Helpline and The dementia guide, we can ensure that expert information and advice is there when people need it, seven days a week.

It's not just through our efforts, but also by inspiring others, that we can transform the lives of people affected by dementia.

Our Dementia Friends programme is now being copied around the world, and by the end of the year almost 100 towns and cities signed up to becoming dementia friendly. Companies and national organisations have also keenly come on board and played their part, for example developing dementia-friendly charters for their sectors.

The year saw the completion of the first Prime Minister's Challenge on Dementia and we were keen to ensure the momentum in Government was not lost. In February, the Prime Minister's Challenge 2020 was published and its implementation became a commitment in the Conservative manifesto. The other main political parties also committed to action on dementia. Meanwhile, our campaigners helped focus attention on the number of people not getting a timely diagnosis of dementia and being left in the dark. The national average diagnosis rate in England increased to just over 60% – there is still work to be done.

Hope for the future remains a key part of our work, and in the year we funded a record number of researchers finding out more, not just about preventing

and curing Alzheimer's disease and the other forms of dementia, but also about how to provide better care and support.

We are proud of our wonderful supporters. Whether it is the generosity of legacies, the enthusiasm of corporate partners, the energy of our sponsored runners and walkers, or simply saying there must be a better future for people affected by dementia by making a donation, you all play a vital part.

Thank you.



*Ann Beasley*

**Ann Beasley**  
Chair



*Jeremy Hughes*

**Jeremy Hughes**  
Chief Executive

**Everything we do is about making life easier for people living with dementia, their families, carers and friends.**

Over the following pages, you will hear from Val, Bhikhu, Keith and Joy about how dementia affects their day-to-day lives, the challenges they come across, strategies they use to cope and how support from Alzheimer's Society has helped them to keep living their lives as they want to. Because life doesn't end when dementia begins.



# Seeing dementia

At my worst point, it was like I was living in a different world. Because of the type of dementia I have, I started to lose my balance and have spatial awareness problems. I couldn't cook very well anymore and would drop things and bang into furniture.

One of my neighbours saw me walking into the village one day and told me I was veering into the middle of the road towards the traffic. After that, I had to give up my job as an Avon lady, which I'd been doing for 31 years, and my voluntary caring for two local older ladies. I'd always been very sociable, but I became very anxious and didn't go out for a whole year.

Val

# Seeing dementia

My daughter found Alzheimer's Society's services on the internet. I was worried about meeting the Side by Side volunteer Jen at first. But all the time that we talked I had this feeling of pleasure. We really hit it off. We've been to the garden centre, as we both love gardening, to National Trust houses and out for coffee.

Jen took me to Singing for the Brain, which is great. I also went to a local memory café, where I met Dave. I wasn't expecting it, but we've found love and are planning our wedding.

Some of the older people were more reluctant to join in at the café but we got them laughing and joking. I feel like I'm half back to where I used to be, when I was doing jobs and helping others.

Meeting Jen lifted me up and my confidence is back. After a whole year of not going out, I now can't imagine staying indoors.

Val



## Meeting needs: We demonstrate the way in dementia care and support.

**We make sure people with dementia, their families and carers get the support they want and need – at home and in their communities. Every month thousands of people across the UK benefit from our high quality, innovative services. We also use our expertise to train health and social care professionals and help other organisations develop and improve their services.**

During the year we set up the Side by Side service, which Val and Jen are part of. It tackles the social isolation people with dementia often experience and helps them to live as independently as possible. We set up 14 pilot services across the UK. People with dementia and their carers help us develop and evaluate Side by Side, and make sure it truly meets people's needs.

Side by Side is just one of many innovative community-based services we have to reach and empower people affected by dementia, which range from Singing for the Brain groups to Dementia Cafés.

These support services are all made possible by the generosity of tens of thousands of people who donate or raise money. Last year we received more than £800,000 as one of six charities chosen for ITV's Text Santa appeal. And our flagship community event Memory Walk raised an amazing £2 million in 2014, as well as bringing together thousands of people to share stories and experiences, and celebrate the lives of loved ones.

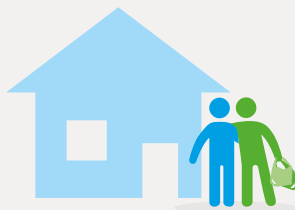
### Highlights from the year

87,000



We supported over **87,000** people affected by dementia through our one-to-one support and group-based services.

We set up our **Home Focus** service to help people stay in their own homes. Staff provide personal care, while volunteers help with things like shopping, housework and gardening.



1,673

We gathered feedback from **1,673** people with dementia and their carers about the services they use. We will use these findings to see what's working well and continue to improve our services.

We delivered dementia training to more than **3,200** people from organisations including charities, NHS trusts and arts organisations.



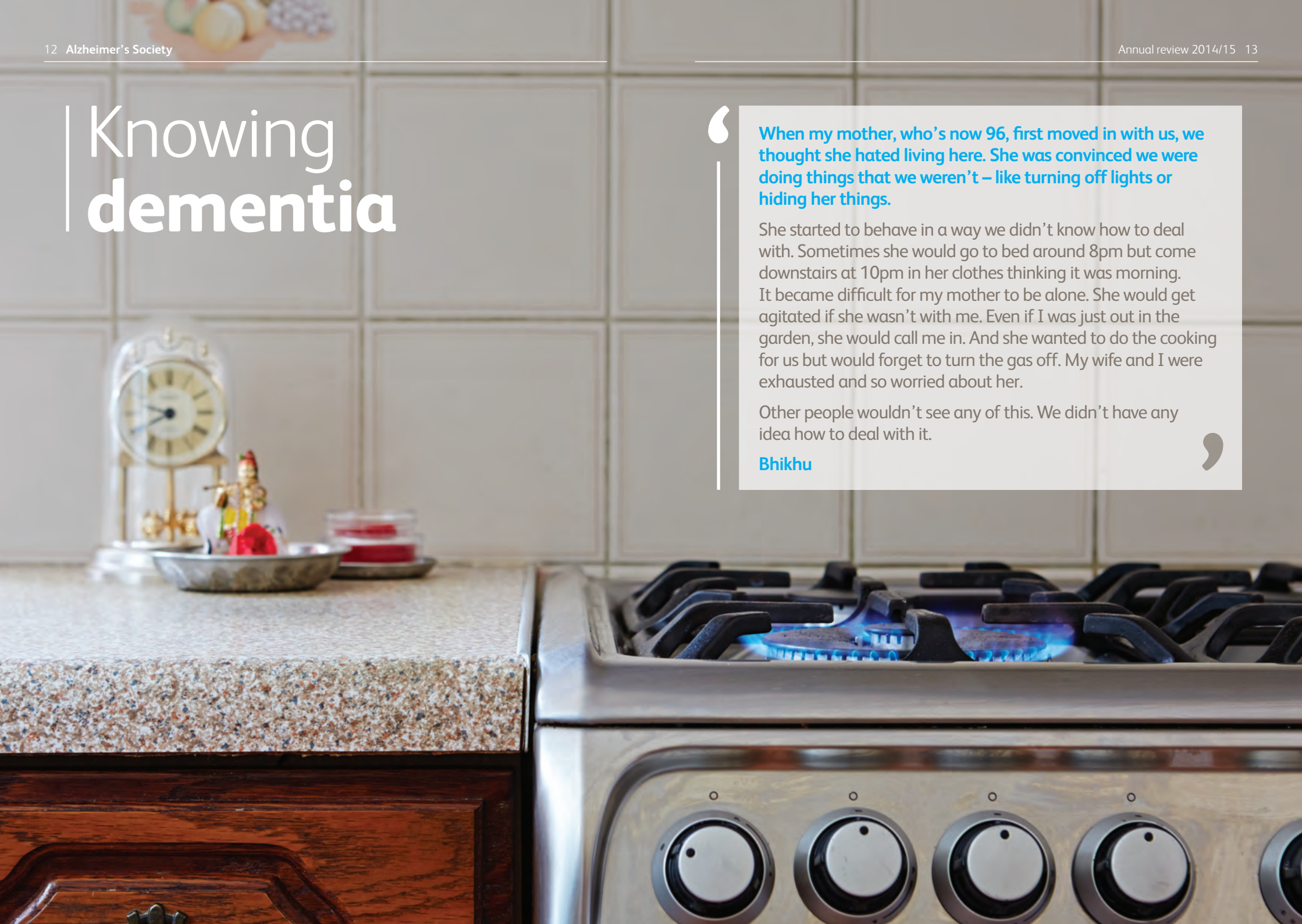
# Knowing dementia

**When my mother, who's now 96, first moved in with us, we thought she hated living here. She was convinced we were doing things that we weren't – like turning off lights or hiding her things.**

She started to behave in a way we didn't know how to deal with. Sometimes she would go to bed around 8pm but come downstairs at 10pm in her clothes thinking it was morning. It became difficult for my mother to be alone. She would get agitated if she wasn't with me. Even if I was just out in the garden, she would call me in. And she wanted to do the cooking for us but would forget to turn the gas off. My wife and I were exhausted and so worried about her.

Other people wouldn't see any of this. We didn't have any idea how to deal with it.

**Bhikhu**





# Knowing dementia

**If we hadn't got help to understand what was happening, I don't know how we'd all have coped.**

We attended Alzheimer's Society's training for South Asian families, which taught us about my mother's condition and gave us so many ideas on ways to cope. We talked to her about the things she could remember from back in India, and her eyes would light up. We'd look at old pictures and videos, and play old songs that she liked. They really motivated her. Our Alzheimer's Society Dementia Support Worker, Rani, found a day centre for my mother, which she really looked forward to going to.

Her condition got much worse and eventually she moved to a care home. In our culture, it's looked down on to put your parents in a home. We felt guilty and inadequate. That's something else that support from Alzheimer's Society has helped us deal with.

My mother has settled into the home really nicely. They're looking after her well and we have the peace of mind she's being cared for. We're all a lot happier.

**Bhikhu**



## Sharing information:

We aim to be the foremost point of contact for anyone dealing with dementia.

We want everyone dealing with dementia, like Bhikhu and his family, to know we're here for them, with information, advice and support they can trust. Whether they have dementia themselves, are family members, carers or health or social care professionals, we want to be the first place they turn to, whatever they need and wherever they live.

In 2014/15 we reached more people than ever before through our Helpline, online forums and information guides.

Overall, there were 20% more visits to our website than in the previous year.

We ran 10 of our Information Programmes for South Asian Families (IPSAF) – the service that helped Bhikhu understand and cope with his mother's dementia. It covers financial and legal issues, support services, looking after someone with dementia, and looking after yourself.

Our successful two-year corporate partnership with Lloyds Banking Group raised an incredible £6.5 million, part of which was used to develop and roll out IPSAF.

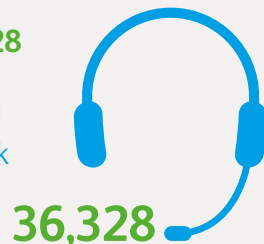
IPSAF is part of our wider programme of information and support for people affected by dementia. This includes the Carer Information and Support Programme and Live Well, which helps people recently diagnosed with dementia to manage their symptoms and live as well as possible.

### Highlights from the year



Over **6,000** people joined our online discussion forum, **Talking Point**, to share information and receive support. In our annual survey almost 80% of people agreed Talking Point helped them to feel less isolated.

Our **Helpline** responded to **36,328** enquiries, up by almost **40%** on the previous year, and our trained advisers started offering Facebook advice sessions.



**41,658** people came on board our **Dementia Community Roadshow**, which raises public awareness of dementia and encourages people worried about their memory to seek advice.

We distributed more than **260,000** printed copies of **The dementia guide** and launched online films and DVDs of the guide with subtitles and voiceovers in eight different languages, as well as British Sign Language.



# Understanding dementia

I was only 54 when I was told I was in the early stages of Alzheimer's. I was a head teacher and studying for an MA.

I wanted to keep working as long as possible, but it became hard to take in new ideas and retrieve them later. I found I could only concentrate on one thing at a time and it was difficult to respond to unexpected things – which is about 80 per cent of your work when you're a head teacher. Four days into the new school year, I had to stop working.

A major challenge now is staying connected with people. It can be hard to follow group conversations; I can feel isolated and tend to withdraw. And I have to keep a diary and weekly planner which I write everything into, from appointments to when to water the tomatoes or do the Hoovering. I tick things off as I go.

A year ago I thought I was bulletproof. Yes, it was hard some days but I thought I could handle anything. But when you have dementia you have fewer tools available to you to deal with difficult things. I've encountered depression for the first time in my life.

Keith

# Understanding dementia

Being an Alzheimer's Society Research Network volunteer helps me engage with people and contributes to keeping me going. I review funding applications for care and wellbeing research. Finding a cure is vital, but so is research on ways to help people live with the condition.

I also set up a creative writing project and published a book of writing by people living with dementia called Welcome to our world. We've sold nearly 1,200 copies to raise money for Alzheimer's Society.

I've learnt a lot through my research volunteer work. And when you have Alzheimer's, to be able to say you're still learning is really important. With this greater understanding and knowledge of dementia, I can exercise greater control over my life and health. I feel supported and part of a team, and that I'm doing something good. I'm challenging the perception that people with dementia can't do things. The challenges are significant, but with support, good relationships and communication, we can.

Keith



## Advancing research:

We lead partnerships and investments in research to improve care, advance prevention and move closer to a cure.

Thanks to research, we understand a little more about dementia every day. Research helps us find better ways to treat and prevent dementia, but also to improve the quality of life of people living with dementia, their families and carers. We're enabling more pioneering research than ever before, by increasing the amount of money we spend on research, collaborating with others and developing and supporting the next generation of dementia researchers.

We're the only funder of dementia research that includes people with dementia and their carers in all decisions about which projects to fund.

We believe the contribution of volunteers, like Keith, ensures our research funding is allocated to projects that address the real needs and concerns of people with dementia and their carers.

During the year, our Research Network grew to 269, strengthening the voice of people affected by dementia in our research programme. And we funded

more research grants in a single year than ever before (41 compared to 24 the previous year).

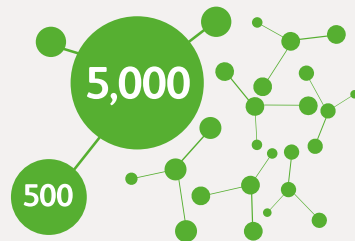
One key area of our research work is making sure what we find is put into practice. For example, we published and disseminated the outcomes of our Focused Intervention Training and Support (FITS) programme aimed at supporting care home staff to reduce the use of anti-psychotic drugs.

### Highlights from the year

£8.1m

We spent **£8.1 million** on new high-quality **research**, including tripling our investment in dementia care research from £1.1 to £3.7 million.

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.



We supported **53 new PhD students** to pursue a career in dementia research through our **8 new** doctoral training centres.



We awarded **10 fellowship grants** to support post-doctoral researchers and clinicians to advance dementia treatment and care through cutting-edge research.

# Recognising dementia



**I used to be an adrenalin junkie. I loved water-skiing and cycling, and my favourite thing ever was white-knuckle theme park rides. I could have spent all day on those.**

The dementia has affected my balance and spatial awareness. I can still go on the rides if my son goes with me, but I wouldn't be safe on my bike or in the water now.

I had to give up my work as a carer, which I loved. It was devastating. I still try to keep my independence, as much as I can. But I went to get something for dinner the other day and when I got into the shop, I couldn't think what I needed. I tried my hardest but my brain wouldn't let me formulate the thought.

The worst thing is being rushed. It builds up the stress and I drop my money and get lots of tuts from other customers. People look at me, a woman in jeans with purple hair, and they think I couldn't possibly have dementia. They have no idea what it's like to be me.

Joy



# Recognising dementia

**Dementia Friends is one of my passions. Going out and talking to people has given me more confidence and a purpose. Dementia is a lonely disease and my volunteering is a way of helping others.**

As an Alzheimer's Society Dementia Friends Champion, I've given talks to anyone and everyone – from the police to the NHS and local businesses. Some of the local shops have been brilliant. At the hairdresser, all the staff are dementia friendly. When they offer someone with dementia a coffee or a tea, they know not to fill it up too much in case, like me, they shake. And they're aware to speak clearly.

Dementia Friends helped them understand the things that make life easier for people with dementia.

I dyed my hair purple so people would know me as the lady with purple hair rather than just the lady with dementia. I want people to see me rather than the dementia. I want them to take time to find out what I still love to do, like the white knuckle rides, and that I want to stay independent. People can enable me to keep my independence but be waiting in the wings to help if I fall.

Joy



## Inspiring change:

We campaign for people affected by dementia to be able to live the lives they want.

As the leading authority on dementia issues, we use our position to improve all aspects of care and support. Through raising awareness and improving understanding of the condition, we work to ensure people with dementia can be active members of their community. We fight for dementia to be a political priority, locally and nationally. We also continue to use our influence internationally.


Our Dementia Friends initiative relies on volunteers like Joy to share their experiences so that the people around them know how dementia might affect their lives and what they can do to make it easier. This year we reached our ambitious target of 1 million Dementia Friends, and will keep developing the initiative until we reach 4 million by 2020.

We set up Dementia Friends schemes in Wales and Northern Ireland and worked on the launch of Dementia Friends in Scotland.

Our corporate partners play a key role. During our two-year partnership with the Home Retail Group (Argos, Homebase and Habitat) 10,000 of their staff became Dementia Friends and they've committed to creating 30,000 in total.

We continue to create dementia-friendly communities across the nations, so that people with dementia will feel included in their community, be more independent and have more choice and control over their lives.

### Highlights from the year

**1,000,000** 

We reached our target of **1 million Dementia Friends**. Our ambition is to have 4 million by 2020.

We now have **10 task groups for dementia-friendly communities**. They focus on different issues, such as power of attorney and data protection, helping the retail sector become dementia friendly, and meeting the needs of people in rural communities.



**£6.25m** 

Our campaigning secured 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.

We launched our **Right to Know** campaign to improve diagnosis rates and post-diagnosis support. The campaign helped us recruit **60,000** more e-campaigners to influence decision makers.

**60,000** 



## Society money

We are pleased to have increased our income to **£90.6 million**. Because of this success we have again increased our charitable expenditure, this year by **25%**. This means we're able to make even greater progress towards our vision of a world without dementia.

### Income

Income grew strongly to **£90.6 million** (2014: **£82.6 million**), a 10% increase on the previous year. Contract income for care services amounted to **£34 million** (2014: **£31.4 million**). Although the commissioning of care services is undergoing significant change, we have continued to be successful in keeping attention focused on the needs of people with dementia and their carers.

Voluntary income increased by 16% to **£52.3 million** (2014: **£45 million**), underpinning our strategy of delivering on dementia.

### Expenditure

89 pence in every **£1** of total expenditure was spent on direct costs towards improving the lives of people with dementia (2014: 89 pence in the pound).

The remaining 11 pence in every **£1** was spent to support our frontline activity including IT and premises.

Charitable expenditure increased during the year by **£15.5 million** to **£76.7 million** (2014: **£61.2 million**). Our spending on care services increased to **£57.6 million** (2014: **£50.4 million**). Research expenditure more than doubled, to **£9.1 million** (2014: **£4 million**) in line with our strategic objectives.

Expenditure on fundraising rose to **£14.6 million** (2014: **£12.4 million**) as extra investment underpinned our strong growth in voluntary income.

## 10%

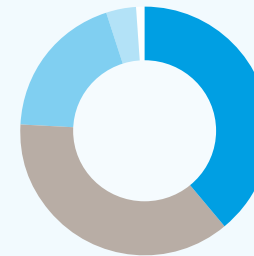
Our income grew to **£90.6 million** (2014: **£82.6 million**), an increase of **10%**

## £9.1m

Our research expenditure more than doubled to **£9.1 million** (2014: **£4 million**)

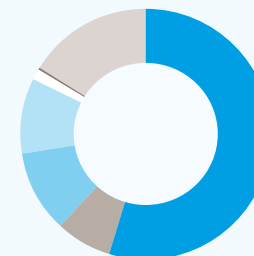
## 89p

From every **£1** of expenditure, **89p** was spent towards improving the lives of people with dementia



### Income by type

Donations	39%	£35.3m
Contracts	37%	£34m
Legacies	19%	£16.9m
Trading and other	4%	£3.4m
Investment	1%	£1m



### Expenditure by activity

Meeting needs	£50.9m
Sharing information	£6.6m
Inspiring change	£9.8m
Advancing research	£9.1m
Trading costs of subsidiaries	£1.4m
Governance	£0.3m
Fundraising	£14.6m

You can read our accounts in full at [alzheimers.org.uk](http://alzheimers.org.uk)

# Fighting dementia



## A big thank you

To all our supporters who helped us continue to fight dementia in 2014/15, including:

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\*Lynda Bellingham sadly passed away in October 2014. She remained one of our Ambassadors until she died and we are extremely grateful to her for her time and dedication to Alzheimer's Society.

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 The Childwick Trust  
 The City Bridge Trust  
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 the C Charitable Trust)  
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And to all our supporters who wish  
 to remain anonymous.

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AR1415

Leading the fight  
against dementia

**Alzheimer's  
Society**