

# Impact review 2011/12

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Zalihe Hassan cares for her mother, Halide Eames, 81, who was [diagnosed with dementia](#) in Spring 2012. Their local dementia adviser Steve Reading visits the family regularly, offering a range of information and support.



## How did you first hear about Alzheimer's Society?

'When mum was first diagnosed with the early stages of dementia, I couldn't really take it on board. You hear the terms '[Alzheimer's](#)' or '[dementia](#)' but you don't know what they really mean. I'd never met anyone with the condition. The doctor gave me a leaflet about Alzheimer's Society and I called them for some advice. That's how I met Steve, my [dementia adviser](#).'

## What kind of information and support have you had?

'Steve has helped with lots of different things for me and mum. He sat down with my daughter and I and went through mum's diagnosis, explaining [how the brain works](#) and that dementia is not just an old age thing, it can happen to anyone. It helped me understand what was happening to mum and prepared me for what's coming in the future. I now know that things are not going to get better physically with mum's [Alzheimer's disease](#), but there are lots of things that can be done to help her live with it. Steve has sorted out practical things too, like arranging for someone to look at adjusting the bathroom so it's easier for me to get mum in and out of the bath. He helped me get a grant for [carers](#), something I wouldn't have known about. The extra money pays for things like petrol to come back and forward from mum's.

'He referred me to social services for day care and lunch clubs for mum, and I'm also finding out about day trips for her so she can get out and meet people. If I don't take her, she doesn't go out anymore and she was so independent before. He's helped me to arrange a disabled parking badge too - without one I have to drop mum off and leave her while I go and park the car.'

## What difference has this support made to your family?

'It's been so helpful. If you don't know anything about dementia, you're in the dark. But having information and help from Alzheimer's Society can take a lot of worry off your mind. As soon as I met Steve it was like we'd known each other for years and I felt really comfortable asking him questions. If it wasn't for Alzheimer's Society, I'd have gone round and round before getting the information I needed. I appreciate everything they've done for me. They're helping me to make mum's life a bit more comfortable.'

## During the year

- We hosted the 27th [International Conference of Alzheimer's Disease International](#) (ADI), which brought together people affected by or working with dementia to share advances in knowledge and good practice, and was an outstanding success.
- We achieved the Department of Health's [Information Standard](#) accreditation for our health and social care information. This recognition means those who use our information can feel confident that it's up-to-date, evidence-based and relevant to them.
- We published a [guide to healthy eating](#) for people with dementia, a [guide for homecare workers](#), a series of information cards in Urdu and Punjabi, an introduction to dementia DVD in Bengali, Gujarati, Hindi, Punjabi, Urdu and English, and factsheets on [urinary tract infection](#), and [exercise and physical activity](#).
- We introduced volunteers to our [National Dementia Helpline](#) to provide basic information, freeing up our advisers to deal with more complex enquiries. Funding from Tesco and the February Foundation will allow us to extend our weekday opening hours and open at weekends. Our Northern Ireland helpline and our main helpline are now an integrated 'virtual' helpline service.
- We secured local funding to continue to provide 11 of the 16 Dementia Adviser services in England that were set up under a Department of Health pilot. We now run 40 Dementia Adviser services, providing vital information and signposting to people with dementia.

## Access

Wigan-based GP, Dr Alex Turnbull, has worked closely with Alzheimer's Society for several years, helping to develop a local dementia strategy and raise awareness of early [diagnosis](#) among colleagues.



### **What difference can an early diagnosis make to the lives of people with dementia and their carers?**

'It can make a great difference - the earlier the assessments take place, the earlier [treatment](#) and advice can be given. A big plus of early intervention is that you deal directly with patients, allowing them to make decisions about their future care at a stage when it's easier for them to understand the issues. At a later stage, it can end up that the [person with dementia](#) is talked about by relatives and doctors, rather than being central to decision-making.

'Early diagnosis allows people to plan ahead as well as deal with the present. They can make decisions such as whether to move near family or stay in the community they know, and they may need to make [financial decisions](#).

'Evidence shows that you get the best results if you intervene at the earlier stages. You can keep people with milder forms of the disease stable for longer and perhaps slow down the rate of



deterioration, so quality of life for the person with dementia and their [carers](#) and families is often a lot better.

'We should be approaching early diagnosis positively. Once a diagnosis is made, [GPs](#) can continue to be supportive, adding to the good work of Alzheimer's Society and other health professionals in the field. GPs are increasingly rising to the challenge.'

### **Less than half of people with dementia are diagnosed. Why can diagnosis be difficult or take a long time?**

'[Diagnosis rates](#) vary around the country - and things are improving. In Wigan, the figure for people with a dementia diagnosis has gone up from around 1,000, three or four years ago, to 1,500. That's a reflection of more people being referred and assessed.'

'Many doctors are now more inclined to ask people about their [memory](#) or take note if it's not so good and refer people at an earlier stage for initial investigations, rather than perhaps sympathising but not doing anything about it.'

'However, many people who start to have [memory issues](#) don't go to the doctor. They think they're just being a bit forgetful and worry they're wasting the GP's time. You also have to consider [depression](#) in older people. That can mask or confuse diagnosis because people who have depression can have poor mental responses.'

'Professionals dealing with people who are ageing and getting forgetful need to encourage them to be tested for [dementia](#). People need to know it's not okay to put up with memory problems; it's important to be tested, and there's help available.'

### **Why is it important for GPs to have information and support from organisations like Alzheimer's Society?**

'It's vital that we get the support and resources we need to help people to the best of our ability. I find the Alzheimer's Society literature, particularly the [training programme](#) that was developed with the British Medical Journal, to be very informative and helpful.'

'As a GP, you have to keep up-to-date with all aspects of medicine. In terms of a GP's time, [dementia](#) is an ever-growing area. It should have priority over many other issues because it's becoming more important to make a diagnosis through early assessments.'

### **During the year**

- We continued our [Worried about your memory?](#) campaign, sponsored by Eli Lilly for a second year, targeting all GP practices with information about the early signs of dementia. Over 100,000 people worried about their memory contacted us as a direct result of this campaign.
- We worked with the Prime Minister to develop a series of government commitments on dementia as part of the [Prime Minister's Challenge on Dementia](#). His public backing and influence add significant weight to our fight.
- We published [Dementia 2012](#) - a landmark report on how well people with dementia are living in the UK. The discrepancy we highlighted between prevalence of dementia and diagnosis rates was also of concern to the [All-Party Parliamentary Group on Dementia](#) (APPG), which launched an inquiry aimed at improving diagnosis rates across the UK.
- Building on the success of our campaign for access to dementia drugs for people with Alzheimer's, we published information about the legal duties of primary care trusts (PCTs) to follow the [NICE guidelines](#). Our [local campaign groups](#) have worked hard with PCTs to make sure that these guidelines are implemented.

- Our continuing [campaign to improve hospital care](#) for people with dementia helped to convince the government to introduce the [National Commissioning for Quality and Innovation \(CQUIN\) dementia target](#), which encourages hospitals to identify patients with dementia in their care.

## Support

Linda Willis, 62, lives in Newport, Wales, and attends Alzheimer's Society art classes, [choir](#) and Memory Café. She also speaks at events about what it's like to live with dementia.

### **Watch Linda Willis talk about what it's like to live with dementia**

[You can also read the transcript of this film](#)

### **What difference do the art classes, [choir](#) and Memory Café activities make to your life?**

'They're all brilliant for boosting my confidence. I come away from my art classes and [choir practice](#) feeling like I've really achieved something. The choir has helped with my speech and memory too - I'm amazed that I can remember all the songs. Without the Alzheimer's Society group I definitely wouldn't socialise so much either. When I was first [diagnosed with dementia](#) it was so easy to go into myself and not to talk to anyone because it was difficult to say what I wanted to say. I'd worry people were judging me. I think I could have become reclusive if it wasn't for the group. It has helped me so much.'

### **How important is it for you to spend time with other people who also have dementia?**

'The communication with other people who have similar problems is really important to me. We can help each other through the bad days because we understand each other - we have a bond. The group and the [activities](#) give us a chance to have conversations without our befrienders or carers, which is good sometimes. And it's important for the [carers](#) to spend time together too.'

### **Do you and your husband get any other support?**

'I have a befriender, Leah, who comes once a week to take me out. We go shopping, to the pictures or for a walk or a coffee. It gets me out into the community and I feel safe with Leah. It's nice for my husband too. I can feel like I'm a burden on him sometimes and this gives him time to see his friends and do his own thing. He doesn't have to worry about me when I'm with Leah.'

### **Do you think it's important to help other people understand what it's like to live with dementia?**

'Definitely. Our choir performances help raise awareness of dementia and what people with the condition can achieve. People come up and talk to us afterwards and we tell people about the [support](#) that's available. When I've spoken about my experiences at Alzheimer's Society events, people have told me that they didn't realise what people with dementia go through. They've seen a different side. I speak from the heart. I tell them it's hard. I talk about the way other people treat you, how some try and take over and how frustrating that can be. I'm still a person, I can still think and still do things, maybe not so well but I can always ask if I need help. And I've had amazing support, which I'm really grateful for.'

## **During the year**

- We continued to grow our [support services](#), and now have 2,143 across England, Wales and Northern Ireland. This includes 316 dementia cafés (236 on 1 April 2011), and 144 [Singing for the Brain®](#) groups (85 on 1 April 2011). 114,659 people benefitted from our services - an increase of 15% on last year.

- We evaluated six of our 53 (at 31 March 2012) befriending services in England and Wales and found that 90% of people who used the service said it helped them to feel less alone; 84% that it helped them feel listened to; and 81% that it helped them maintain or improve their independence.
- We continued to work with [commissioners](#) to demonstrate the need for dedicated services for younger people with dementia, such as our new and thriving service for this group in Gwent and Cardiff and the Vale, attended by Linda, featured here.
- We funded 23 new dementia support worker posts through our partnership with [Tesco](#), helping over 840 more people during the year. At 31 March 2012 we had a total of 330 dementia support workers, providing one-to-one support for people with dementia and their families.
- The number of people using our online community, [Talking Point](#), offering information and support for anyone affected by dementia, increased by 40% (there were 19,535 Talking Point members on 31 March 2012). We redesigned Talking Point to simplify the registration process and make it easier to navigate around the site.

## Rights

Susie Troake, 30, from Liverpool, [cares](#) for her mother who has [dementia](#). She also [campaigns](#), [fundraises](#) and raises awareness of the issues faced by people with dementia and their carers.

**Watch Susie Troake talk about how she cares for her mother and helps support the Society**

[You can also read the transcript of this film](#)

### **Can you tell us about your campaigning work for Alzheimer's Society?**

'Recently, I've been [lobbying MPs](#) on the health and social care changes that are happening in Liverpool. They're going to close nine day services for older people and replace them with three larger centres in the city. People have built up trusting relationships with staff and service users at their current services and I'm raising awareness of the impact that such a change in routine can have for [people with dementia](#).

'Because of my experience, I know how being able to pick up the phone to someone who really understands can make such a difference when you or a family member is [diagnosed with dementia](#). So I go in to speak to practice managers at GP surgeries to make sure they have information about the support that's available.

'I've been interviewed on BBC Radio Merseyside about my experience of caring for my mother. And I've taken part in a question and answer session at the UK Dementia Congress, led by broadcaster [Angela Rippon](#), who's an ambassador for Alzheimer's Society.

### **How important do you think it is to keep campaigning for the rights of people with dementia and their carers?**

'Without people [campaigning](#) and raising awareness, would David Cameron have mentioned people with dementia in his latest speech? It's so important that we keep fighting. The most vulnerable people always seem to get the worse deal. My mum is one of the lucky ones - she has relatives who will advocate on her behalf. But so many people don't have someone to do that for them, they're on their own. I don't just do it for my mum; it's about changing things for everyone.

### **Do you think attitudes to dementia are changing?**

'Not a great deal, unfortunately, but I do hope in time they will. Many people's attitudes seem to be "Well I don't need to worry about that because it only happens to old people" or "That's not going to happen to me". I come across that perception a lot when I'm [volunteering](#) or out collecting money for Alzheimer's Society. People are shocked to hear that someone as young as my mum has an illness like dementia. She was only 54 when she was diagnosed four years ago. I don't think people are educated enough about dementia and we still need to raise awareness of what it is and what it can do. I'd like everyone to be aware of the issues, to know a lot more about the condition, and for there not to be the same stigma and judgement that there is now.'

### **During the year**



- We worked hard to keep the issue of [funding](#) and [charging for social care](#) high on the public and political agenda, and were heavily involved in the focus and content of the [Prime Minister's Challenge on dementia](#), which launched in March 2012.
- As part of the [Care and Support Alliance](#), we helped to organise a lobby of Parliament to demonstrate public feeling on the issue of our failing social care system. Over 1,000 older and disabled people attended, alongside our Ambassador [Tony Robinson](#).
- We published a [report](#) presenting new evidence about the financial abuse of people with dementia and their carers, and launched a high-profile [campaign](#) to raise public awareness of this issue to protect vulnerable people from being targeted by scammers.
- With support from Comic Relief, we increased our number of local volunteer campaign groups from 23 to 31 in England and Wales. Together with our 5,000 plus e-campaigners, they form a lively and active [Campaigners' Network](#).
- With support from the Department of Health, the [Dementia Action Alliance](#) has continued to grow and, by the end of March 2012, had 90 member organisations working to transform the lives of people living with dementia. This is an increase of 30 organisations over the year.

## Research

Professor Christian Hölscher from the University of Ulster, in Northern Ireland, has been [researching](#) whether [diabetes drugs](#) could help treat [Alzheimer's disease](#). His work has seen extremely promising results.

**Watch Professor Christan Hölscher talk about his research**

[You can also read the transcript of this film](#)

### **Why are you looking to existing drugs to treat dementia instead of developing new ones?**

'The main advantage is that these drugs have already been rigorously tested. We know that they're safe to take and we understand the effects they have on patients. Getting to this stage is a long and expensive process. So, being able to jump straight to [clinical trials](#) with people with [Alzheimer's disease](#) saves around 10 years of research, as well as millions of pounds.'

### **Why diabetes drugs?**

'We have known for some time that diabetes is a risk factor for developing [Alzheimer's disease](#). When someone has diabetes, the cells in their brain can have problems growing and repairing themselves.'

'The results of our tests with mice show that these diabetes drugs can be very effective in protecting the cells and neurons in the brain and helping them to stay healthy and to grow. The drugs reduced the levels of a protein called [amyloid](#), which is a key feature of Alzheimer's disease, and protected against swelling in the brain. The earlier the drugs are used, the better effect they have, but even after extensive damage the drugs appear to be able to improve the situation.'

### **You've now been funded to test the drugs with people in the early phase of Alzheimer's disease - what do you hope to see?**

'If the results are as we hope, we will see that the drugs can slow down or even halt the damage to the brain that Alzheimer's disease causes. We also hope we'll see that they protect people from the degenerative effects of the disease, such as confusion and [memory loss](#).'

### **How will new treatments like this improve the lives of people with dementia now and in the future?**

'We have to wait for [clinical trials](#), but this has the potential to have a profound effect on people's lives. If the drugs can slow down the progress of the disease, as we hope, this will help people to live independent lives, interacting with their friends and families, for much longer. For the future, we hope that this work will spark a whole new wave of research. We're already starting to work on other types of drugs that look promising and I'm sure we will find better [treatments](#) and strategies to protect the brain and keep cells healthy.'

### **During the year**

- We funded £3.1 million of essential new [research](#) into the cause, cure, care and prevention of dementia, and our research was published in 50 academic publications. We worked closer

than ever with our [Research Network](#), a group of over 200 people affected by dementia who are integral to our research.

- Our innovative [Drug Discovery](#) programme was launched by Lord Fellows in the House of Lords in May 2011. The programme has the potential to bring better treatments to hundreds of thousands of people with dementia sooner. We've identified the top five drugs and are progressing towards the final pre-clinical laboratory testing before we start the clinical trial in 2014. A fundraising appeal, focused on the programme, raised £190,000.
- Following the call from the [National Institute of Health Research](#) (NIHR) for dementia-themed research proposals, we ran a unique networking workshop, attended by UK researchers and our research network volunteers. Advice from people with experience of dementia helped researchers to improve their research funding applications - 30 were ultimately supported by us and 10 were shortlisted by NIHR.
- We held a symposium on the treatment of behavioural and psychological symptoms of dementia at the Alzheimer's Association International Conference on Alzheimer's Disease (AAICAD). Leading researchers announced three groundbreaking clinical trials at the event, which was attended by over 200 researchers.

## Community

John Hall, 63, works on our [Dementia Community Roadshow](#), taking information and advice out into communities. Two Roadshow vehicles will tour Tesco car parks and other venues around the UK until 2014.



### What does the Roadshow aim to achieve?

'Its main purpose is to raise awareness about [dementia](#) and [Alzheimer's Society](#) - something I believe it does extremely well. As a great big blue vehicle, we really stand out when we set up in Tesco car parks.

'The [volunteers](#) and advisers are there to answer questions and discuss concerns. We have lots of leaflets and information on board, and a private space where we can talk to people confidentially.'

### Do you get a good response from the public?

'Yes, we do. There's still a certain stigma attached to dementia. But when people see the Roadshow vehicle, they seem to feel they can approach it much more easily than going into an office. Our volunteers and advisers are always open and friendly, which gives the Roadshow a relaxed feel.

'Sometimes people can be tentative to start with, but when you get talking they're usually happy to open up and let you know about their concerns. For those people who just pick up a leaflet on their way by, the [Roadshow](#) can be an important prompt. It means that when they are ready to talk to

someone about dementia, they'll be better informed.'

**What sort of questions and concerns do people have when they come and talk to you and the Roadshow staff?**

'Mainly people are [worried about their memory](#) and want to know more about dementia. Or sometimes they want to talk about their relatives. We get quite a wide age range visiting us, so sometimes it's young people concerned about their parents or grandparents, other times it's older people with worries about their partner.'

**Do you think the Roadshow will help change attitudes to dementia and encourage more people to do something if they're worried?**

'It's a really effective way to get information about dementia out into the community, and I know from speaking to people that it helps change attitudes. We understand that talking about dementia for the first time can be difficult. One man walked by the Roadshow five times without stopping or making eye contact, but eventually he came back and when he left us he was smiling. What we can do is alleviate people's worry - they walk away with peace of mind.'

**During the year**

- We launched our [Dementia Community Roadshow](#), funded for three years through our partnership with Tesco, in June 2011. The Roadshow takes dementia information and advice into the heart of communities, and helped over 37,000 people with questions about dementia in the first year.
- We disseminated the findings of our [report on care at home](#) widely, including running a seminar at the National Children and Adult Services Conference. We also published a [guide for homecare workers](#) to improve their dementia knowledge, which we promoted at the UK Homecare Association conference and the Care Show.
- We have begun to establish Community Dementia Forums and local Dementia Action Alliances across England. These will play a vital role in shaping and delivering the dementia friendly communities programme, which we launched in March 2012.
- We produced a [guide](#) for people with dementia and their carers on reducing the use of antipsychotic drugs, and a [best practice guide](#) for health and social care professionals to help them manage behavioural and psychological symptoms - a critical aspect of our work to reduce the use of antipsychotics. Endorsed by the Department of Health, the Royal College of General Practitioners and the Royal College of Psychiatrists, the guide has been translated into seven languages and is now in use across the UK and internationally.



## Challenge

Coronation Street actor Tony Hirst plays a character, Paul, whose wife has early onset [dementia](#). The soap opera storyline explores Paul's role as a [carer](#) and sees him start a relationship with another woman.



### How did Alzheimer's Society help you to prepare for the storyline?

'Coronation Street producers and scriptwriters were in constant contact with Alzheimer's Society. People there read all the scripts and gave their advice. They also put me in touch with some men and women who care for [partners](#) with dementia. I talked to a man in a similar situation to my character (Paul starts a relationship with another woman while caring for his wife, Lesley, played by actress Judy Holt). It was really helpful to talk to him about issues such as [guilt](#) and his concerns about his wife's care. What struck me about some of the carers I met was how they laughed and joked, were warm and affectionate, but just beneath the surface there was anger, frustration and grief for what they'd lost.'

### What sort of response have you had from fans?

'I've found that the fans with any experience of a family member or partner with [dementia](#) have been absolutely supportive. It was the ones with no knowledge or understanding of the condition that were judgemental.

'The scriptwriters made a conscious decision to make it [early onset dementia](#) because they wanted to challenge expectations and show that it's not just an old person's disease. A lot of viewers were surprised to see Lesley diagnosed, as she was a vibrant, healthy woman in her 40s. It was important to show the physical vibrancy being offset against the brain being so affected. To me, it shows a clear

example of the essence of the disease and what it can do.'

### **What role do you think soap operas have to play in raising awareness of issues like dementia?**

'Coronation Street has an audience of over 10 million people. While it's not a campaigning show, the people making it are well aware that they have a real responsibility when tackling something as important as dementia.

'A soap opera is great for getting complex, uncomfortable issues that we'd sometimes prefer not to deal with, into people's living rooms - and in an accessible way. Even if it just skims the surface, it can be a stimulant to get people talking. The strength of the story has provoked opinions and challenged the ones people already held. I hope it will be a springboard for continued debate.'

### **During the year**

- We worked with the Department of Health to develop and roll out the early diagnosis [advertising campaign](#) across England. Post the campaign, research showed that 90% of the population now recognise the advantages of early diagnosis and 88% now believe the right treatment can slow down the progression of dementia.
- We continued the powerful Remember the Person theme for [Dementia Awareness Week?](#) 2011 - tackling fear and avoidance of dementia. We reached 91,000 people through local events and activities, 17.5 million people through our media coverage, and 8.3 million people had the opportunity to see our billboard advertising campaign.
- We worked with the producers of Coronation Street on a challenging storyline highlighting the issue of dementia to millions of households. Through advising the cast and scriptwriters, we were instrumental in making sure the issue was handled realistically and sensitively.
- We worked with the Royal College of General Practitioners to improve GPs' understanding of dementia, and collaborated with BMJ Learning to develop an [e-learning module](#) on the management of the behavioural symptoms of dementia, which was launched in March 2012.
- As part of the [Dementia Action Alliance](#), we worked with the NHS Institute to launch a call to reduce the use of antipsychotics. Many colleagues in health and social care signed up actively to review the prescriptions of everyone with a diagnosis of dementia who was on [antipsychotics](#).

## Choice

Tim Wilkins, an [Alzheimer's Society](#) Service User Involvement Officer, works with people affected by [dementia](#) in [West Sussex](#) to shape future services. His role is funded by West Sussex Primary Care Trust.



### **Why is it important to involve people with dementia and carers in developing and improving services?**

'I want to make sure we're doing everything we can to enable people with dementia to do the things that they want to do - and that they're getting the [support they need](#). I look at different ways of engaging with people affected by dementia. My aim is to make them aware that Alzheimer's Society and other organisations are here for them.'

'I've met some wonderful people [living with dementia](#), their carers and families, every one of them doing their best to live their lives, as well as they can, often without many choices. I've listened to their views, tried to understand their situation, and worked with them to bring about changes to [local services](#).'

'We try to give people ownership of the services they use. For example, in the Dementia Cafés, we find out what activities people with dementia would like to do. These are their services after all. Looking forward, I believe having services that respond to people's individual needs and offering them choice is vital.'

### **How do you make sure you reach people with dementia from all different communities?**

'It's an essential part of my job. I have found it so important in all communities to gain trust. So I've been along to groups, activities and organisations, speaking with many members of the community and community leaders to gain insights and respect. I make it clear that I'm not there to tick a box but to consult with them about long-term plans. I'm currently working on a leaflet about dementia for the gypsy and traveller communities, and have an ongoing working relationship with the Sussex Lesbian, Gay, Bisexual and Transgender telephone helpline.'

### **What improvements do you want to see in the future for people with dementia?**

'I want to see communities becoming [dementia friendly](#), where people living with dementia have more control over their lives and the choice to do the things they want to do. People with dementia have a voice, a voice that must be heard.'

Awareness of dementia continues to grow and this is something we must take advantage of. We need everyone to understand that people with dementia are just like you and me - and that we could end up with dementia. It's only right that we improve things for people with dementia, their families and carers, now and in the future.'

### **During the year**

- We began a significant programme of work to make sure that people affected by dementia are actively and meaningfully involved in influencing what we do, wider awareness-raising, and policy development. This includes training staff, speaking to the media, informing research and planning new services.
- We continued to explore new and better ways of engaging with people affected by dementia in black and minority ethnic communities. For example, our extensive and innovative work in East London has resulted in a significant increase in the number of families of Bangladeshi and Somali origin whom we support.
- We rolled out our [Carers' Information and Support Programme](#) in 17 places. This helps carers of those with a recent [diagnosis](#) to develop the skills and confidence they need to manage their caring role and plan for the future. We also piloted three new sessions in five places on issues that arise for carers [as dementia progresses](#), and this part of the programme launched in the spring.
- We have been responding to the introduction of Personal Budgets, where people are allocated a budget to pay for their own care, and the growing number of people paying for their own services, by making sure we are ready to deliver our services in this way. Personal Budgets are already in place in some areas of England.

## Chair and Chief Executive's introduction

- Jeremy Hughes - Chief Executive
- Alastair Balls CB DL - Chair

Welcome to our Impact review 2011/12.

This year has been a landmark one for the Society and people affected by dementia, with major achievements in all areas of our work: care, support, campaigning and research.

We ended the year with the [Dementia 2012 conference](#) and launch of our offirst [annual assessment](#) of how well people with dementia are living in the UK. The conference also saw the Prime Minister launch his [Challenge on Dementia](#) - the first time any Prime Minister has made dementia a key priority.

As a result of the PM's challenge, the Government has committed to more than double the funding of dementia research from £26m to £66m by 2015. Our own investment in essential [research](#) into the cause, cure, care and prevention of dementia continues to grow. Our programme of new grants and fellowships is uniquely informed and monitored by people affected by dementia, through our [Research Network](#) Volunteers.

Whilst working closely with the Government on its commitment to tackle dementia, we have also joined with other charities to highlight the need to address the overall funding crisis in social care and to seek to protect patient interests as the NHS in England is radically reformed. We were also central to the adoption of dementia plans in both [Wales](#) and [Northern Ireland](#).

This year, we continued to increase the [services](#) we provide and we continue to develop groundbreaking services for all people affected by dementia. Many of these - like [Singing for the Brain®](#) and Dementia Cafés (sometimes called Memory Cafés) - are provided locally by a record number of volunteers supported by our dedicated staff. Other services, like our [National Dementia Helpline](#) and [Talking Point](#) online community, support people wherever they live. And, thanks to the magnificent support we received from [Tesco](#) as their Charity of the Year, alongside [Alzheimer Scotland](#), our number of dementia support workers increased during the year.

Despite the UK recession, our supporters continue to be incredibly generous, and our voluntary income increased to £41.1 million from £32.1 million last year - a remarkable achievement, which





contributed greatly to our overall income of £71 million.

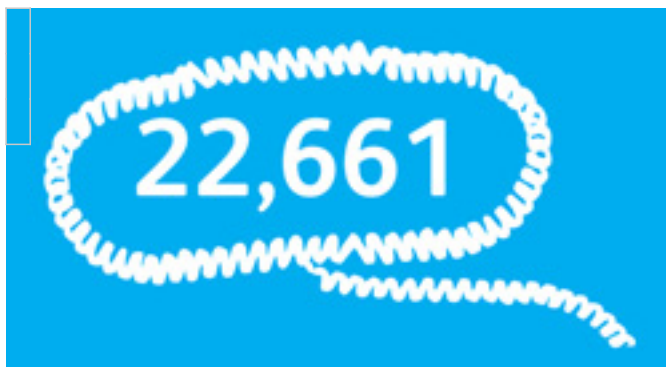
Towards the end of 2011, we involved many volunteers and staff across the Society in developing our ambitious five-year strategy, [Delivering on dementia](#). Through local meetings across England, Wales and Northern Ireland, we were pleased to meet with them at the start of 2012 to introduce the strategy and to witness their passion to do more in our services, our campaigning, research, and in our fundraising.

We were proud to end the year hosting the [International Conference of Alzheimer's Disease International](#) in London for the first time in its 27-year history. We welcomed 1,600 delegates from around the world, including a greater number of people living with dementia than ever before.

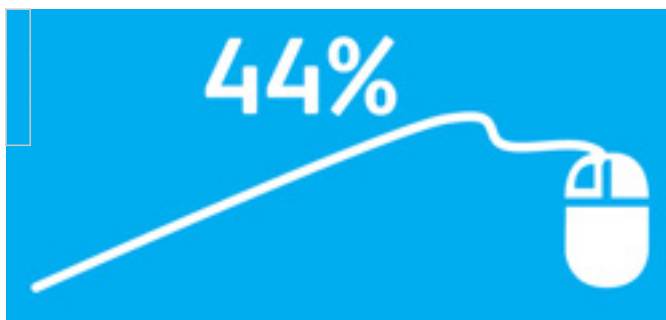
Of course, we could not achieve all of this amazing work without the support and guidance of our committed Board of Trustees, who are supported by the Senior Management Team.

Through the continued passion and dedication of our volunteers and staff, and the generosity of our many supporters, we are confident we will achieve all we have committed to achieve in the first year of our ambitious strategy to transform the lives of people with dementia, their families and carers.

## The year at a glance



Our national dementia helpline helped 22,621 people get the information and support that they need - that's an average of 90 people every working day and an increase of 19% on the previous year



Visits to our website increased by 44% during 2011/12, from 2.8 million to 4 million. In our most recent web survey, 98% rated the website as either good or very good.



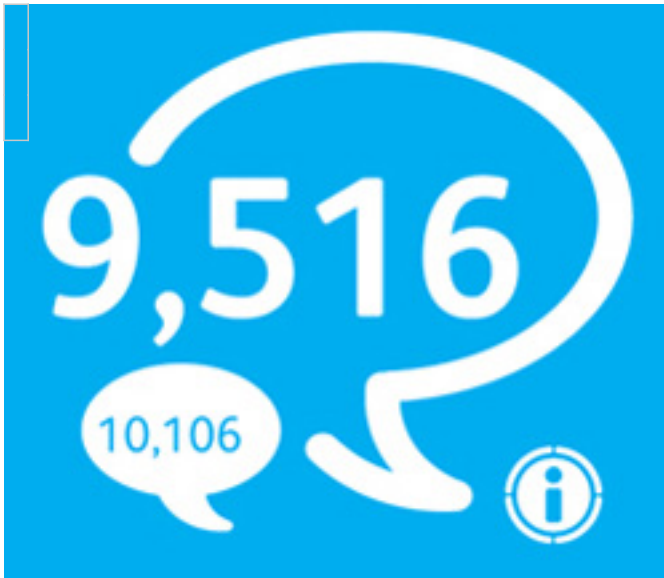
We distributed more than half a million leaflets, booklets and books through our local services as well as directly to people affected by dementia.



Membership of Talking Point - our online community - increased by 40%.



We had 2,143 services providing care, information, support and training to 114,659 people (an increase of 15% on last year).



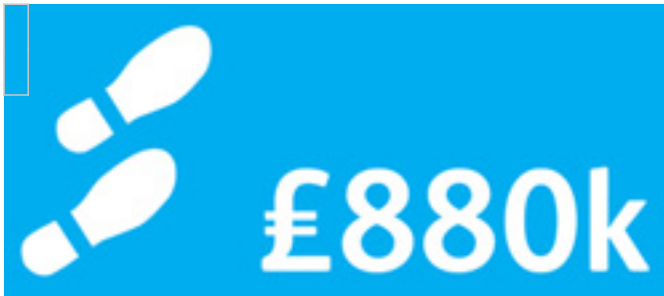
9,516 people with dementia and 10,106 carers and family members used our Dementia Advisor service.



We reached over 37,000 people through our Tesco-funded Community Roadshow, which takes dementia information and advice into the heart of communities.



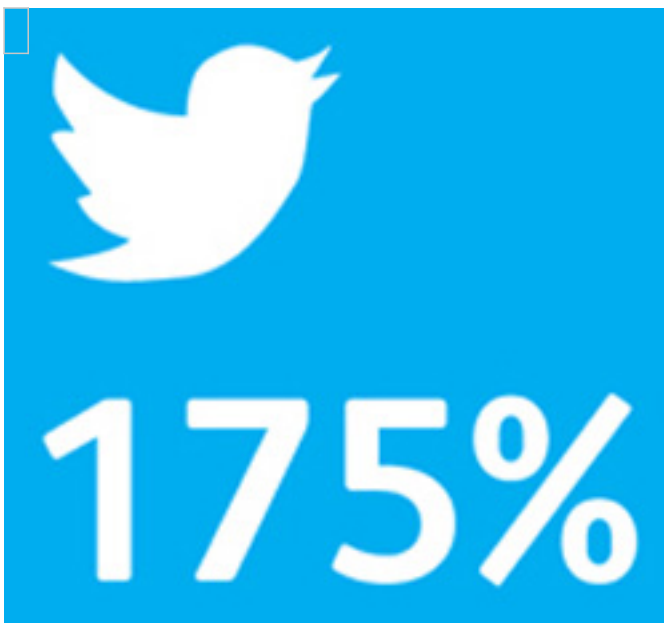
We raised a total of £7.5 million through our Charity of the Year partnership with Tesco.



10,000 people took part in our flagship community fundraising event, Memory Walk, raising a total of £880K.



increase in Facebook's fans;.



increase in Twitter's followers;.





During DementiaAwareness Week™ 2011 we reached 91,000 people through local events and activities.



We secured over 9,250 pieces of media coverage, and were a Times Christmas Appeal charity, reaching thousands of readers and raising £130,000.

## What we'll do in 2012/13

2012/13 is the first year of our ambitious five-year strategy, Delivering on Dementia, built around four strategic aims.

### 1. Demonstrate the way in dementia care and support

During 2012/13 we will:

- continue the detailed review of all of [our services](#) to make sure that we are providing exemplary information and support to people affected by [dementia](#) across England, Wales and Northern Ireland
- capture and explore emerging ideas that will improve the lives of people affected by dementia using [our services](#). This builds on our track record for service innovation and recognising the value of grassroots knowledge and creativity
- maintain and enhance our performance in relation to the standards under the PQASSO kitemark - the quality standard for third sector organisations - including equality and diversity, user involvement, environmental sustainability, and monitoring and evaluation
- continue to build strong working relationships with statutory bodies and policy makers at a local level, including Dementia Partnership Boards, Clinical Commissioning Groups and Health and Wellbeing Boards. These relationships will allow us to respond to service development opportunities and focus on the needs of people affected by dementia locally
- make sure that people affected by dementia have a significant role in shaping what we do and influencing the external environment by supporting a robust and sustainable culture of involvement across the Society
- continue to make our services responsive to personal budget holders and people paying for their own services. This includes running workshops across England to share tools and guidance with local managers. We are also collecting examples of best practice in helping people with dementia to access personal budgets, which will inform our own practice.

### 2. Be the foremost point of contact for anyone dealing with dementia

During 2012/13 we will:

- open the [National Dementia Helpline](#) at weekends from September 2012, allowing more people to get the information, advice and support they need. We will recruit additional volunteer helpline assistants to give our advisers more time to focus on the more complex enquiries
- launch a new online directory of all local dementia care and support services across England, Wales and Northern Ireland, designed to meet the needs of people with dementia,

their families and carers

- aim to deliver the [Carers' Information and Support Programme](#) to over 1,000 carers, and begin work to make the programme more accessible to people in Pakistani and Indian communities - the two largest minority ethnic communities in England
- continue to raise awareness of dementia and reach people [worried about their own or a loved one's memory](#) in their own communities, through our [Dementia Community Roadshow](#), funded by Tesco. This includes visiting community fairs, town centres, and rural areas.

### **3. Lead partnerships and investments in research to improve care, advance prevention, and move closer to a cure**

During 2012/13 we will:

- continue to fund high quality [research into the cause, cure, care and prevention of dementia](#), including two clinical trials. This includes continuing to [work with people affected by dementia to inform and improve our research](#)
- publish an academic paper on initial work in the [Drug Discovery programme](#), announcing the names of the drugs to be investigated. We will also fund a research fellow to carry out the essential pre-clinical work that will allow us to move towards a clinical trial in 2014
- work in partnership on government-funded research
- launch the roll-out of an evidence-based training programme for care homes that has been shown to halve the use of dangerous [antipsychotic drugs](#).

### **4. Campaign for people affected by dementia to be able to live the lives they want**

During 2012/13 we will:

- work with the [All-Party Parliamentary Group \(APPG\) on Dementia](#) to publish the report on their inquiry into improving dementia [diagnosis rates](#), and work with other organisations, like the [Dementia Action Alliance](#), to make sure the report's recommendations are met
- continue to shape and direct the [Dementia Friendly Communities programme](#). This includes leading the Prime Minister's challenge group, and holding the Coalition Government to account on the implementation of the [Prime Minister's Challenge on dementia](#)
- continue to grow the membership of the national [Dementia Action Alliance](#) and the network of local Dementia Action Alliances across England to support the development of [dementia-friendly communities](#)
- respond to the White Paper on social care, [campaign](#) for a new settlement on funding, and be part of the wider debate to push more funding for social care overall
- work with the [Department of Health](#) to produce a new resource to help health professionals to assess cognition in older people in GP surgeries, memory clinics, hospitals and care homes, with the aim of improving [dementia diagnosis](#)
- establish new evidence on the experience of [people with dementia in care homes](#) by

producing a new care home report

- publish Dementia 2013 - the next of [our annual reports](#) on the state of the nation for people with dementia
- work with the Department of Health in England to further develop a national awareness campaign to run from 2012-15
- launch a cross-party group on dementia in the Welsh Assembly
- continue to grow and develop our [Campaigners' Network](#). We will establish more volunteer-led campaigners' groups, including the first in Northern Ireland, and grow our number of e-campaigners.

## Society money

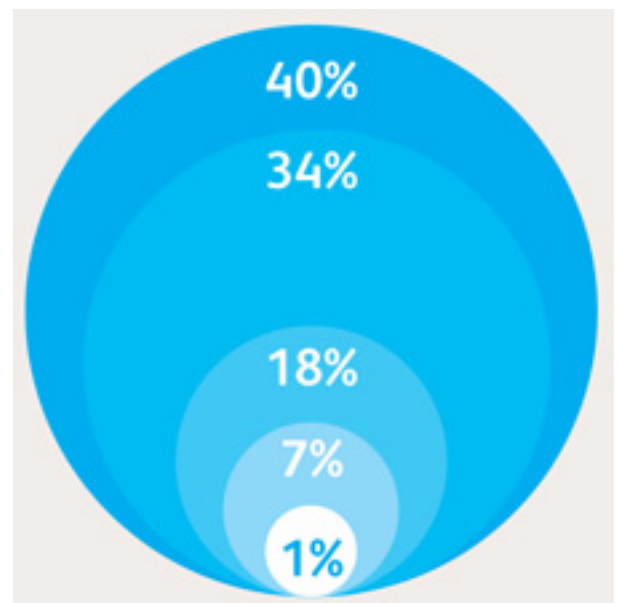
Despite the slowdown seen in the UK economy, we are delighted to report strong growth in income.

**£71m:** our income exceeded £70 million for the first time

**9%:** This enabled the Society to increase its charitable expenditure by 9 percent

**£1.1m:** The Society's reserves increased by £1.1 million

## Income



### Income by type

- 40%: £28.7m Donations
- 34%: £24.3m Contracts
- 18%: £12.5m Legacies
- 7%: £4.7m Trading and Other
- 1%: £0.9m Investment



Total income increased in the year to £71.0 million (2011: £61.6 million). Voluntary income, consisting of donations and legacies, amounted to £41.1 million (2011: £32.1 million). Much of the credit for this growth must go to all those supporting the successful Tesco Charity of the Year partnership. Income given specifically for research increased to £3.5 million (2011: £2.5 million).

## Expenditure



During 2011/12, 88 pence in every £1 of total expenditure was spent on direct costs towards improving the lives of people with dementia (2011: 87 pence in the pound). The remaining 12 pence in every £1 was spent to support our frontline activity, including IT and premises around the country. Charitable expenditure increased during the year by £4.7 million to £56.0 million (2011: £51.3 million) and of this 85 per cent was spent on care services (2011: 87 per cent). The investment in fundraising has increased to £12.0 million (2011: £9.8 million), to ensure funds are generated to continue the Society's work. £3.6 million was allocated to research during 2012 (2011: £2.8 million).

## Funds

# £29.1m

Total funds as at  
31 March 2012

Total funds as at 31 March 2012 were £29.1 million (2011: £28.0 million), of which £22.2 million (2011: £24.0 million) were unrestricted. It is the Society's policy to hold free reserves equivalent to at least three months of charitable expenditure. At 31 March 2012 the Society held free reserves equivalent to 4.3 months (2011: 4.7 months) of charitable expenditure. In the light of the economic uncertainty and the pressure on public spending at the present time, the Board of Trustees feels that the above reserves cover is prudent and also allows for future growth.

Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9.00am-5.00pm Monday-Friday

10.00am-4.00pm Saturday-Sunday

Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499.