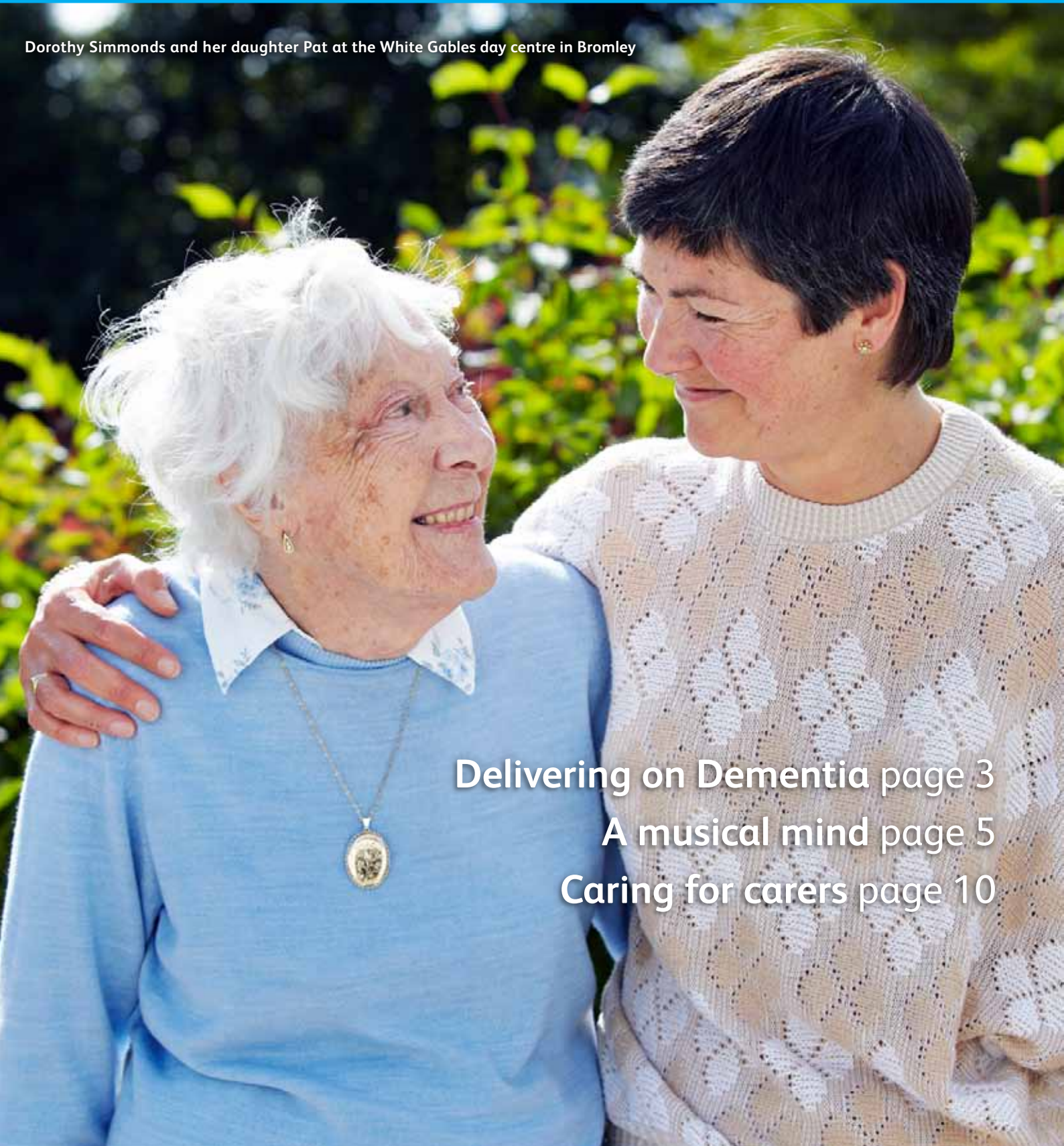


# Volunteer Voice

Issue 3 Spring 2012

Dorothy Simmonds and her daughter Pat at the White Gables day centre in Bromley



Delivering on Dementia page 3

A musical mind page 5

Caring for carers page 10

# Spring 2012



Welcome to the Spring edition of Volunteer Voice. In this issue you will find stories that celebrate the time and effort our volunteers give so readily, from new initiatives on page 11, to the support one volunteer gives from 3,000 miles across the Atlantic on page 10.

For me, the fantastic contributions of our volunteers are reinforced during my visits to the Hammersmith dementia café where I volunteer once a month. It was there that I was put in touch with Julian Shuckburgh, a volunteer who plays the piano for the clients at their day support centre. His story features on page 4 and is a great example of how much volunteers give to the Society and what they get from it.

Thank you to everyone who took the time to send in your feedback about Volunteer Voice. It was great to hear from so many of you and I hope you see your comments reflected in this issue.

There are some exciting new ventures on the agenda for volunteers in the year ahead, not least our new five year strategy which some of you will have received with this magazine. As ever, I am keen to hear what's important to you. Please do write in and let me know your ideas about what you would like to read in the next issue.

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## Investing in volunteering

**Brett Terry, Director of People and Organisational Development**



Many of you will be used to seeing Rachael Bayley's smiling face here and as you can see, this month, you've got mine! I'm providing leadership to the volunteering development team, following the departure of Rachael who has recently left the Society to pursue other interests and we wish her all the best in her next role.

Rachael took the time to talk with some of you and we want to make sure we continue and extend this dialogue. For this reason, we will soon be setting up a volunteer forum so that, in each region, we are able to directly hear about your

experiences and expectations, so that we can use these to inform our work in the future. Please do look out for more information on the forums.

As Director of People and Organisational Development, my focus is supporting our people. At the moment I am writing our 'People Plan' – a five year plan which explains how we can make the best use of the brilliant people who work with and volunteer for the Society. We want to be able to attract the best new staff and volunteers, to retain those people who are already bring so much

# Delivering on Dementia



This year has already seen a whirlwind of activity as we prepare to launch the Society's new five year strategy, Delivering on Dementia 2012-17.

We all know that people affected by dementia don't get the same level of support that those living with other diseases do, and our ambitious plans aim to bring dementia to the forefront and address this. Every volunteer and member of staff will receive a booklet explaining more about Delivering on Dementia and what we aim to achieve over the next five years. If you have received a personal copy of this

magazine, you will find it included. Please have a read and find out more about the part you can play.

During the last three months, I've been lucky enough to meet many of you on the Delivering on Dementia tour which has travelled across England, Wales and Northern Ireland. I, and other senior managers and trustees, wanted to talk to staff and volunteers directly about our new ambitions for the next five years and hear your views about how we make it all happen. Everyday, volunteers do remarkable things and everyone I have met has been so passionate to find out more about what they can do to make life better for people affected by dementia.

Volunteers are crucial to the Society and to the delivery of our plans. Did you know that by the end of the decade there will be over one million people in the UK living with dementia, an increase of 25% in ten years?

To put our ideas into practice and really make a difference, we need all of you. We also need more funds than ever before. It seems almost everyone knows somebody affected by dementia and if there is one thing we can all join in, it's raising awareness of what the Society does and doing a bit of fundraising, however big or small that role is.

Some of you will already be dedicated fundraisers, organising events and mobilising others which is fantastic! But even if your role isn't specifically all about fundraising, we can still join together and make a difference. Dementia Awareness Week™ is a great time to get involved and raise both funds and support in your local community. For ideas on how, turn to page 9. We need to pull out all the stops this year. Thousands of people are relying on us to do so.

Thank you.

**Jeremy Hughes, Chief Executive**

to the Society, and to ensure our people receive quality training and support so that together, we are able to achieve our vision of a world without dementia.

Our new strategy outlines the most important things for us to do over the next five years, and how we will achieve it all. Part of this is about improving ways of working across the Society as well as with other organisations; but it is also about increasing our investment in research so that one day we eradicate dementia and do ourselves out of a job. The strategy also focuses on how we can improve our services and develop other ways of reaching people who need us, for example through our helpline, so that we can offer more

people affected by dementia better quality services and support. This is an incredible time to be part of the Society but what excites me most is the emphasis the strategy puts on our people, as without them we simply will not be able to achieve any of it.

We know that volunteers are vital for our success. Some of you have already shared your views on how we deliver our strategy at the Delivering on Dementia tours. You have told us we need to get better at communicating with you - so we have set up an email address, **[tellvolunteering@alzheimers.org.uk](mailto:tellvolunteering@alzheimers.org.uk)**, so that you can share your opinions quickly. If you don't use email then please write to the address above. Do contact us with

any questions you have, or any good ideas you think we should know about. As a charity, we have a responsibility to innovate and try new ways of doing things so please do get in touch.

Finally, thanks to those of you who took part in our last volunteer survey. My colleagues in the Volunteering Development Team have put together a plan to put some of your feedback into action. We will be repeating the survey again at the end of 2012, both to see how we are doing and to find out where we need to improve. I'm looking forward to listening to and learning from you to ensure that we get things right.

# People and places

## If I'd known what I do now



Shahida (centre) with colleagues Ruth Amesbury, Sian Aubrey and Karen Edwards

**Shahida Khan started volunteering with the Society at Dar ul-isra Mosque in Cardiff. She now works as a Befriending Manager.**

Shahida's background as an interpreter and her extensive language skills in Punjabi, Hindko, and her native language Urdu, together with her long standing involvement in her local community, formed the foundations for her volunteering experience with the Society.

'I interpreted information about dementia for Muslim families to raise awareness of the support available. It's vital that people are aware of it in their own language. In our culture, care of an elderly relative typically falls to the family. Some do not recognise the signs of dementia, attributing symptoms to the natural ageing process: in English you say someone is 'losing their marbles', in Urdu we have a similar phrase, 'they are acting 60'. Families try their best to manage alone without any understanding of dementia, or knowledge about the help available.'

It was only after she started volunteering for the Society that Shahida realised her mother's forgetfulness was in fact dementia. Unaware of the condition, her family had developed their own method of coping. 'Mum used to get up in the night and fell once. We attached some bells to her duvet so that when she got out of bed we'd be alerted. She was often confused and didn't recognise us. If I'd known what I do now, it would have been easier to handle.'

Shahida's experience was like that of many worshippers at the Dar ul-isra Mosque. 'That's exactly what my auntie used to do!' was a common response to explanations of her experience.

Shahida says, 'Volunteering my skills and experiences to help others was perfect for me. I'm so pleased to now have a permanent role with the Society.'

## Stepping out to fight dementia:



Emma (centre) at the 2011 Staffordshire Memory Walk

**Emma Fletcher, Fundraising Volunteer**

'I began my fundraising journey with Alzheimer's Society in 2008 aged 13. Within no time at all, I became a regular volunteer and a fixture in my local office, helping with anything from fundraising to office admin.'

Alzheimer's Society is a charity very close to my heart. My grandma passed away having had Alzheimer's for over 10 years, and over that time I learned the devastating effects dementia can bring.

As part of the new South Staffordshire Fundraising and Awareness Focus Group, I helped organise our local Memory Walk, the Society's annual flagship fundraising event, which took place in September 2011 on Cannock Chase. We held a cake sale for walkers to recharge

their batteries after their stroll around the woods and devised nature trails and other games for the children, which soon became quite competitive between both children and adults alike! We had 107 two-legged walkers as well as an abundance of four-legged walkers – including two horses donned in blue and green ribbons. The day was a huge success and so far we've raised £4,475.37!

Hearing people's personal experiences of dementia is always the most poignant part of Memory Walk. For me this just reinforces the importance of volunteers and fundraising. The knowledge that you are doing even the slightest thing to try and combat dementia is something that simply can't be beaten.'

**For information about Memory Walk visit [memorywalk.org.uk](http://memorywalk.org.uk) or contact your local Alzheimer's Society office.**

# A musical mind

**Julian Shuckburgh, 71, volunteers for the Hammersmith Day Support Centre in West London and has dementia. Twice a week he plays the piano for the day clients.**

For 40 years Julian was head of a large publishing house. In 2008 he was diagnosed with fronto-temporal dementia, which affects the part of his brain responsible for words. Now, although remembering lyrics has become difficult, the piano keys remain the same and even without sheet music Julian never misses a note.

‘It was my daughter’s idea. The day centre had to get rid of their old piano and we thought it would be nice to buy them a new one’, says Julian, who started learning the piano aged four. He went on to sing with the world-leading Bach Choir, and wrote a book about the composer’s life. ‘I thought it was so touching that the Society wanted me to come and play and I soon realised that it was keeping me going. Playing to people is so enjoyable. As well as helping others, I’m also helping myself.’

Julian volunteers for reasons many will recognise. ‘I feel useful, like I have a job. I enjoy it and feel like I’m giving something back. It’s so satisfying to know that the songs are meaningful to others. Everyone has an association with a particular piece of music and it’s lovely to see them smile as they recognise the song.’

As well as classical pieces, Julian plays 1940s songs like A nightingale sang in Berkley Square, and he has also composed a jazz piece. The clients at the day centre really look forward to his visits. One lady in particular, Lil, likes to sit close by so that she can sing along and always asks if he can stay longer. ‘His playing is my favourite thing about the day’, she says, ‘and I look forward to him coming every week.’



Julian’s playing brightens everyone’s day



Brenda has spread the word for the Society to hundreds of people

## Flying the Society flag

**Brenda Brown is an Information Support Volunteer from Belfast. Her mother has Alzheimer’s and Brenda volunteers as a result of their shared experience of the Society’s carers’ support group.**

‘Volunteers are the lifeblood of most charities. Here, they carry out roles that are needed to develop the work of the Society as it continues to lead the fight against dementia.

One of my roles is raising awareness of the Society. As well as handing out leaflets in my local community, I campaigned for all GP surgeries and chemists in my local area to have Alzheimer’s Society leaflets. It’s so rewarding to signpost the services the Society provides to those who need help.

I meet a lot of different people at these events. Sometimes, people need a listening ear and reassurance; others are students looking for volunteering opportunities to enhance their CV and improve their career prospects. This is where my recruiter role comes in!

The truth is, I really enjoy volunteering for the Society. I hope I can help people cope with and manage the impact of dementia on their lives.’

# William Brooks Award

Back in November, we celebrated the contributions of 10 volunteers who have improved the lives of people affected by dementia. They attended an event at Buckingham Palace and met the Society's Royal Patron, Princess Alexandra, and Society Ambassador, Sir Michael Parkinson.



Our 10 very special volunteers and the people who had nominated them, travelled from all parts of the UK to attend the reception at the Palace. Joanne Duffy from Barrowford in Lancashire, the youngest winner at 22, was nominated by Stephen Hughes, a Support Services Manager. He said, 'Joanne is a fantastic volunteer. She is a great listener, and the carers who come to our support groups value her calm and friendly approach. Nothing is ever too much trouble, and she is a real asset to our team. We are delighted that has now secured a job with the Society as a Dementia Support Worker and wish her lots of luck.'

Jo said, 'I'm thrilled to have won the award, volunteering is so rewarding. I have made friends, built up my confidence and improved my knowledge about dementia.'

## So what happened on this very royal day?

### 13.00 – Lunch at Piccadilly

Lunch at the Royal Society – hotpot followed by sumptuous chocolate cake. Sir Michael presented each winner with an engraved plaque.

### 15.15 – Enter Buckingham Palace

Walking along the huge gravel forecourt and under the Royal Balcony was a surreal experience. We smiled and waved at tourists taking our picture!

### 15.30 – Gather in the Green Room

We were led across a red carpet and up a spiral staircase to the Green Room. Tea was served in royal china cups and saucers and sipped in a genteel fashion.

### 16.00 – HRH Princess Alexandra arrived

She was charming and took lots of time to ask each winner about themselves.

### 16.15

Sir Michael formally introduced each winner to the Princess, who presented them with a framed certificate.

### 17.00 – Depart

At the end of a lovely day, we were escorted out to the front gates and through the empty forecourt.



Drinking from the royal china, winner Angela Clayton-Turner was accompanied by her daughter, Catherine

# s for Volunteers 2012



The Princess met each volunteer individually at the reception

Other winners included Susan Lawrence from Plymouth, who helped establish the new Singing for the Brain service across Devon and Cornwall and Alan Chandler, Redbridge's 'man in a million', who for nine years has driven younger people with dementia to visit local places of interest. These trips to the seaside and nearby parks make such a difference as people really enjoy the exercise and meeting others.

Sir Michael said, 'I am delighted to offer my congratulations to these 10 volunteers. Their commitment to improving the lives of people affected by dementia is inspirational. Alzheimer's Society relies on volunteers to continue their vital work, and as the number of people with dementia rises they will need volunteer support more than ever.'



Sir Michael was with the group all afternoon



Back row: Alzheimer's Society Chief Executive Jeremy Hughes, Susan Lawrence, Alan Chandler, Angela Clayton-Turner, Sir Michael Parkinson, HRH Princess Alexandra, Society Chairman Alastair Balls, Eileen Harrington, Joanne Duffy, Society Vice-Chairman Eileen Winston

Front row: Pat Bentley, Audrey Welch, Judy Roberts, Wendy Oldfield and Lynne Ramsay



Finding new treatments will bring us another step closer to defeating dementia altogether

## A thirst for knowledge

Tesco will fund two dementia scientists to conduct vital research and increase our understanding of potential life-changing treatments.

In addition, Tesco will partially fund a research project to test existing drugs that could be used to treat dementia and establish an inexpensive drug treatment.

Eight candidates were interviewed at the end of February and the successful researchers will be announced soon.

# Tesco Charity of the Year: One year on

Last month saw the conclusion of our Charity of the Year partnership with Tesco. In this whirlwind year, together we've raised an amazing £6.5 million to support people affected by dementia and money is still coming in!

It's not just Society volunteers and staff who have gone all out to get the most out of the partnership. Tesco staff across the UK have gone above and beyond their usual day jobs, volunteering hundreds of hours of their time to fundraise and raise awareness. The last two months have seen staff leaping from planes and abseiling down 400ft towers as part of our Leap Year Challenge, as well as showcasing their talents in Tesco Distribution's Got Talent and Strictly Come Dancing events, and dressing to impress as part of our Rock'n'roll week.

One Tesco employee who has particularly immersed himself in the partnership is fundraiser and local charity champion, Pete Tomkins from Lichfield, Staffordshire. Pete is well on his way to breaking his £10,000 individual target by conquering Africa's highest peak, Mount Kilimanjaro. The team he's walking with has already beaten their target of £35,000, a staggering achievement. Pete said, 'I found a photo of my dad, who passed away a year ago, looking out over the Pyrenees. This photograph epitomised his life. I feel privileged to have an opportunity to pay tribute to him by climbing Kilimanjaro, as well as it being a fantastic way to raise as much money as possible for a great cause.'

We now know that the Tesco funded Dementia Community Roadshow has reached more than 20,000 new people on its travels around the UK. One visitor said, 'I saw the van as I drove into Tesco. It was the answer to my prayers – I have been worried for my aunt and uncle and had no idea where to turn. I do now. Thank you.' The Roadshow will continue to travel around Tesco car parks in the UK to reach those who need us for a further two years.

Funding from Tesco is also enabling us to open our National Dementia Helpline at weekends as well as funding additional Helpline advisers during the week. This means that no call should go unanswered when people need us most.

Overall the partnership has been a massive success and the money raised is already making such a difference. Thank you to everyone who has been involved.

## Reaching those in isolated areas

**Pamela Frazer is one of the new Dementia Support Workers funded by Tesco. She works in Mourne, a rural part of Newry and the latest place in Northern Ireland to open a dementia café.**

Pamela works alongside volunteers who are already raising awareness about the support she provides. Leaflets, posters and brochures in GP surgeries all help to promote her contact details and role.

'Without the Tesco funding it wouldn't be possible to reach the people I'm helping now. Isolation is a real problem for many people in Mourne. One man who attended one of my carer groups could only attend because it was close to his home. He's the main carer for his mother who has dementia and wasn't aware of the support available. He had to reduce his working hours to give her the care she needs so we talked about financial support and other services that might be available. A lot of people are unaware of what's out there. Their lives or the lives of their loved ones change but they just learn to cope with it. It's great that I can build on the work which has already been established to ensure no one goes through dementia alone.'



Pamela (left) helping people to improve their sense of well-being

# Dementia Awareness Week™ 2012

This year Dementia Awareness Week™ will take place from 20–26 May, running simultaneously across Northern Ireland, England and Wales for the first time.

Thousands of volunteers and staff will come together to raise awareness of both dementia and the Society, along with those much needed funds. For a number of years the theme has been Remember the person, putting people with dementia at the heart of the campaign. This will be our theme again this year but we're also going back to basics. We know that levels of understanding about dementia are still low, with many people reluctant to think and talk about the disease, so we want to tell the general public some key facts about dementia. These are presented in our new booklet, Five things you should know about dementia.



## What can you do to support Dementia Awareness Week™?

### Raise awareness

Why not create your own Remember the person poster? Get together with other volunteers and staff and display them in a public location to raise awareness of dementia. We want people to know that there is more to the person than their dementia.

### Fundraise

Whether it's afternoon tea or a tea dance, get creative. How about a 1940s tea dance held in your local community centre? You could charge for entry and sell tea and cakes. Or how about something completely different like arranging a Zumba class followed by green tea and sushi?!

Whatever you decide to do, you can reach out to people in your community and get them thinking and talking about dementia. To get involved and to help fundraise, please call 0845 671 8568 and we'll send you posters and leaflets to display in your area. We will also be holding fundraising collections so if you would like to join in, please do give us a call.

**Visit [alzheimers.org.uk/remembertheperson](http://alzheimers.org.uk/remembertheperson) for more information.**

## A will to help

### David Stanton, Legacy Team Volunteer

Before I retired, I worked for a firm of solicitors in the City of London, quite close to the Society's central office. I was keen to find a voluntary role in which I could use the experience I gained during my career. As my mother has vascular dementia, I decided to approach the Society and was pleased to be invited to join the Legacy Team in November 2010.

My part of the team deals with the legal aspects following the death of a supporter who has left a gift in their Will to Alzheimer's Society. This involves liaising with solicitors, checking the Will and the estate accounts and ensuring that the contribution to the Society is made in the most tax efficient way. Quite often the Society is left a property or another asset so we must consider the best way of selling that asset in order to raise the most money. I'm delighted to support the team in this way. Gifts in Wills are an important source of income for the Society, making up over 20 per cent of our total income. Last year, the Society received over £10 million in legacy donations. Thanks to people's kindness and generosity this year it will be £12 million.

**For more information contact the Legacy Team on 0870 0110 290 or at [legacies@alzheimers.org.uk](mailto:legacies@alzheimers.org.uk)**



Using his skills to give back to the Society

# Caring for carers

Alzheimer's Society understands that people supporting and caring for a loved one with dementia need quality information and advice, and someone to listen and understand what they are going through. Our new Carer Information and Support Programme has been set up to meet those needs and is being rolled out across England and Wales.

The sessions provide carers with invaluable peer support as well as practical advice on legal and financial issues, care services and coping strategies.

Volunteers are able to make the most of their previous skills and unique insight to help support the sessions. They can often use their own personal experience of dementia to enhance the expert knowledge and training of the staff member delivering the session.



Ensuring information about dementia is accessible for carers

## Drawing on experience

### Barbara Cable



Barbara, sharing the lessons she's learnt

**My mother had vascular dementia and I received a huge amount of support through the difficult stages of her dementia over the two years before she passed away, as well as the transitional period afterwards.** I received so much expertise, time and sympathy and once the clouds began to disperse I thought, what can I do now? To begin with, I started shaking a tin and handing out information leaflets. Then the Carer Information and Support Programme came to my home town of Burnley, and I thought, what a brilliant idea! I realised that this was a way that I could share my knowledge and experience and give back the support I'd received.

I really admire the Dementia Support Worker who leads the sessions. You don't know who's going to turn up, how people will react or at what stage their loved one's dementia is at. People can become upset, angry or even defeatist. With up to 12 carers present it can be quite

demanding for staff, so being on hand to chat to carers takes some of that stress away. I can often relate to a lot of what they say and realise that most people just need an ear to chew.

I feel useful and I want to help more. As well as keeping me active, I feel passionately devoted to Alzheimer's Society. I want to help people learn and share what I've learnt. I used to work as a trainer for Barclays bank and I'm very used to standing in front of a group of people for a length of time. I'd love to help take the sessions myself!

It's hugely important to me, having gone through it with my mum, that people know what to do when a family member gets dementia. The programme is a fantastic resource for carers and something that's never been done before. It's so exciting and I'm so glad to be a part of it.

**For more information contact your local Alzheimer's Society office**

# Far away but close at hand

**Joanne Moquin volunteers from the comfort of her home in Toronto, Canada. She is part of a team of online moderators for Talking Point, the Society's online support forum for anyone affected by dementia.**

I had already been an active member of Talking Point for several years before becoming a moderator, having received a great deal of support when my mother's Alzheimer's had been particularly difficult. Her dementia really compels me to volunteer. I want to help as much as I can and I like to know that I'm doing a good job and that my experience is helping others. In addition to Talking Point, I also run a carers' support group and I volunteer at my mother's nursing home.

I try to get online for at least an hour a day. Sometimes that means ten minutes here and there, other times I'm on for quite a while. I feel that I can make a real contribution on Talking Point, and it's so gratifying when I receive positive feedback. I've also received negative comments, but as Joe E. Brown says in the movie *Some Like It Hot*, 'Well, nobody's perfect'.

Being in another time zone can be frustrating as I often enter a discussion that's well advanced and can feel disconnected. On the plus side, the time difference allows me to reply to someone who is up late in the UK which means people can talk to someone day or night.

All of the eight Talking Point moderators have been affected by dementia. Some have finished their journey, others are at different stages. The moderators ensure that everything runs smoothly. Although we don't always agree on how to handle a problem, we agree to go with the majority. As a team, we work really well together.

**Have you discovered Talking Point? Join the discussion at [forum.alzheimers.org.uk](http://forum.alzheimers.org.uk)**



3,000 miles away, Joanne's experience of her mother's dementia inspired her to volunteer remotely

## Across the Board

### Pippa Gough, **Trustee**

Back in the 1970s, when I started my nursing career as a naive 17 year old with little life experience, dementia was seen as part and parcel of old age. We gave it scant attention in our training and certainly didn't think about how best to meet the needs of individuals and families who were struggling to live with the disease. I hope I responded with compassion to all the people who passed through my hands. To my shame, I am sure there were times when I didn't.

Twenty years later dementia would start to wreak its devastation upon my own family and I understood – in the sense of really knowing – how desperate the need was for good information about dementia and for accessible, quality support. By this stage I was Director of Policy with the Royal College of Nursing and in partnership with Alzheimer's Society and others we were pressing the government to fund expert nursing care for people in nursing homes. Politically, professionally and personally, dementia was part of my life. Alzheimer's Society provided the clearest leadership for the development of services that really mattered.

At the end of 2010, I became a trustee for the Society. I felt I had reached a stage in my career where I could offer my knowledge and skills and I wanted to be more involved in an organisation that was changing the face of dementia care. I was delighted to be appointed to the Board. It's been an exciting time to join given our new five year strategy and the ambitious new ways we want to reach people. I am now Chair of the Trustee Advisory Group for Services so will be spending more time ensuring our services become more accessible to everyone. We have all come to the organisation in different ways and as a trustee, so have I. I would love to hear any questions you have about the trustees and what our role is. Just send your questions to the address on page 2 and we will respond to some of them in the next issue.



Dementia has touched Pippa's life both personally and professionally

## Calling all volunteers... make your voice heard!

- Do you keep a diary or have you ever written a journal?
- Do you think you have a way with words?
- Do you like to know what's going on locally and sharing the news with others?
- Are you an avid reader who has thought more than once, I'd love to have a go at this?

## Even if the answer is no to all of the above - we have a great opportunity for you!

Volunteer Voice is going quarterly and we'd like you to help us write it. This magazine is the only means of communication we have to share news and stories across our volunteering community. It is therefore so important that it contains the stories that you want to read.

## What would I have to do?

All you have to do is send your name, contact details and an example of your writing. Please write 200 words on something that interests you in your local community - it doesn't have to be about the Society.

We will then choose two people from each Society region and country (North, East, West, Wales and Northern Ireland).

Please write to Georgie Day. See page 2 for contact details.

Find out more about the latest volunteering opportunities.

Go to **[alzheimers.org.uk/volunteers](https://alzheimers.org.uk/volunteers)** or contact your volunteering officer.

For details of your local office and services visit **[alzheimers.org.uk/localinformation](https://alzheimers.org.uk/localinformation)**