

# Volunteer Voice

Issue 4 Summer 2012

Caroline, 55 is a keen walker, a capella singer, Radio 4 fan, gardener and lives with dementia.

**PM launches Challenge  
on Dementia**

**Do we really pull  
together in bad times?**

**Giving people the choice**



# Summer 2012

The political world's growing awareness of dementia and its desire to address dementia issues has grown significantly in recent times. This has culminated with the tremendous publicity generated by the Prime Minister's Challenge, meaning that dementia is now in the public eye more than ever before, bringing with it huge opportunities to improve the lives of people living with the condition. From the Queen recognising dementia in her speech to Parliament in May, to support from celebrities like our new ambassador, actress Carey Mulligan, dementia is being recognised as a challenge for society as a whole.

This increased awareness is in no small part due to the hard work and support of our volunteers. We now need your help more than ever to take hold of this shift in awareness and understanding of dementia, to continue to push for the improvements in care and support that people affected by dementia rely on. There are now 800,000 people with dementia in the UK and an estimated 670,000 family and friends acting as primary carers.

In this issue, we hear from just some of the many volunteers who answered our call to tell us about activity in their local community. From Olympic races to vintage tea parties, we are all campaigners in all that we do for the Society. Together we can make the public profile of dementia higher than ever.

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## Delivering on Dementia



Our new strategy, Delivering on Dementia, is all about working together to make lives better for people affected by dementia both now and, through research, in the future. One part of working together is with people in the NHS and care services. Our campaigning work has shown what enormous improvements can be made here, though there is still far to go. An important next step is to create dementia friendly communities, working together with businesses large and small, local councils, emergency services, voluntary groups and others. Alzheimer's Society volunteers are so crucial to enabling this to happen.

Working together is also about our volunteers collaborating with our

employees. Previously, we've asked for your views on what we should be doing separately to employees. This year we are surveying you at the same time. The aim is to produce one plan for what we should be doing over the coming year, informed by the views of all our people as a whole. I look forward to hearing your views and sharing our plans with you.

Times are hard for many people but those living with dementia often have a particularly challenging time. As a volunteer you bring hope and support, whether directly through our services, through our campaigning or through our vital fundraising. Thank you for the difference you make.

**Jeremy Hughes, Chief Executive**

# PM launches Challenge on Dementia



The Prime Minister has set a challenge the Society must meet

David Cameron has become the first ever British Prime Minister to issue a call to action on dementia. At a Society conference in March to announce our Dementia 2012 report, Cameron launched the Prime Minister's Challenge on Dementia. He has called for improvements to health and social care, dementia friendly communities, increasing public understanding of dementia and greater funding for research.

The Society is leading the work on dementia friendly communities and public awareness. Jeremy Hughes, Chief Executive,

and Alzheimer's Society Ambassador, Angela Rippon, are co-chairing the Champion Group, which is made up of representatives from a wide range of influential organisations including Aviva PLC, Saga, Lloyds Banking Group and the Women's Institute.

This is a major development to enable people affected by dementia to live the lives they want. Through influencing government policy, we can help to change the lives of hundreds of thousands of people. Find out all the latest on page 6.

## A busy Spring:

**The All-Party Parliamentary Group on Dementia Inquiry** into how to improve diagnosis rates held two discussions in the House of Commons.

**The Queen's Speech** outlined the government's plans for a draft Care and Support Bill.

**The Welsh Assembly cross-party group on dementia** has been established to discuss dementia and related issues which could change policy in Wales.

## Aricept research – a Research Network Volunteer's perspective



Investigating the benefits of Aricept

Research co-funded by the Society has shown that the drug donepezil (Aricept) can be effective in the later stages of dementia. Aricept is currently used to treat mild

and moderate Alzheimer's disease. The study investigated the benefits of taking Aricept beyond the stages where it is currently licensed for use. Lead investigator Professor Robert Howard, from the Institute of Psychiatry at King's College, London explains the findings:

'We observed that patients who continued taking donepezil were better able to remember, understand, communicate and perform daily tasks for at least a year longer than those who stopped taking the drugs.'

Angela Clayton-Turner, a Research Network Volunteer, said, 'My husband Ted, who has dementia, stayed on Aricept for some years after he entered the severe stages of the illness. My gut feeling is that the medication prolonged our quality time together. We were able to go on holidays abroad when his dementia was really advanced. The research confirms my instincts that Aricept can help in the later stages.'



# Local voices

## Going for gold

When Society volunteer Jessie Howell watches the 100 metre Olympic race on TV this summer, it will have more resonance with her than for others. Her daughter Kay experienced the excitement of being able to run on the 100m track inside the Olympic Stadium before the London 2012 Olympic & Paralympic Games in memory of her father, Grenville, who died with Alzheimer's five years ago.

'My daughter Kay, and friend Louise, were both awarded the opportunity of a lifetime to run the 100m, courtesy of Gold Challenge, the UK's Olympic & Paralympics based charity challenge.

Kay decided to do the Gold Challenge in memory of her father and raised £700 for the Society. The Gold Challenge event featured a number of celebrities and athletes competing in a range of events and provided a thrilling afternoon of entertainment. Events included a series of 100m sprints, relay races and a Gold Challenge Olympic themed parade.'



Kay and Louise, two of the first to enter the stadium



**Jessie Howell became involved with the Society over 12 years ago whilst caring for her husband. She says, 'Kay lived quite far away, and had a small baby, so couldn't help as much as she wanted to, so she decided to do this run in her father's memory. We are all extremely proud of her - it was amazing to see her run!'**

## Art Therapy

In March, Shropshire volunteer, Rene Roberts celebrated her 80th birthday. Rene has volunteered for Alzheimer's Society for many years, and for the last 12 has run an art activity group in Shrewsbury for people with dementia. Here, Art Therapist and Rene's friend, Elisha Maran-Barnell, celebrates a shared love of art and dedication to supporting people affected by dementia.

'Rene is one of a rare breed of volunteers who do much for nothing in a quiet way. Collecting money, leading carers' groups where she brings empathy and understanding based on her own experiences with her husband, volunteering at the art group and much more. All this is done with positivity and compassion.

Rene found her talent for landscape art late in life. When you look at her landscapes, you feel the wind and sun; you can smell the heather and touch the mosses. She has lived a long time in Wales and you can sense her love for nature, for the elements and for weather in her art which is uplifting and beautiful. As a mentor, she inspires the group members with her art, poetry and song. Her funny poems and songs are particular favourites and we all have a good laugh together – a very therapeutic activity. She brings back various cheeses from her travels to Wensleydale which we try in our sensory reminiscence special sessions which, needless to say are very well attended!'



Elisha Maran-Barnell with friend, Rene (right)



**Elisha Maran-Barnell is a trained art therapist and initially intended to work with cancer patients. However, when her mother developed dementia she found that art was their way to communicate. 'Through her illness she taught me much more than any training would be able to.'**

# In bloom

'Our medieval market town in rural Hampshire, Bishop's Waltham, retains its character with a lively High Street and local events. During the summer the streets are lined with vibrant hanging baskets and trips take much longer as Mum loves to pause at each tub, identify every plant and check its progress.

One spot of special interest is the square where the hanging basket competition entries compete for distinction and this year our dementia support group were invited to participate. Very quickly we embraced the idea of a red, white and blue theme. I even challenged mum to create a Union Jack design, but with a twinkle in her eye she told me she would love to but couldn't remember what it looked like. The resulting baskets may not have been the neatest ever created and I think we'll be sweeping compost from the corners of the halls for many weeks, but it was worth it. To watch the engrossed expressions as members dug fingers into the moist compost, tucking the tiny plants into their new homes, was magic. Time alone will tell how the colour schemes develop, but we all have a point of interest for the summer. Our members can proudly bring grandchildren to see them, but in addition they will promote our group, increase awareness of our work and what our members can still achieve. Who knows, we may even win a prize!'



Brightening up the town and increasing awareness



**Jane Ward, 50, is a full-time carer for her Mum, Ella, who has had vascular dementia for almost three years. Initially Jane struggled to cope, but once dementia had been diagnosed, she became involved with her local carers group which she now helps to run.**

## Do we really pull together in bad times?



**Amanda Boulton, a volunteer from Lancashire, shares her honest reflections on looking after a family member diagnosed with Alzheimer's. We'd like to hear how other families deal with a diagnosis. If this strikes a chord, why not write in and share your story?**

'Coming from a close knit traditional family, I always thought that if one of us became ill, we would all pull together and support one another. But is that necessarily true? As devastating as it is, a diagnosis of dementia is not only the beginning of an unknown journey for that person, but also the start of an extraordinary journey for their family members. When my mum was diagnosed five years ago, I found that the most challenging thing to deal with was the changing dynamics of relationships with my immediate family members, alongside coming to terms with slowly losing our loving mother and daughter relationship.

I was both amazed and dismayed at how differently we all dealt with our new situation. Whilst some of us went into organisation mode, trying to control the situation, others went into what I call 'ostrich mode', head in the sand and unable or unwilling to deal with it. The journey was an emotional and complex one: we all experienced a massive learning curve whilst going through the grieving process. Much of this was tinged with the bitterness and disappointment at the way we all reacted, which often resulted in conflict. Little did we know that there is no right or wrong way to react. Our true challenge was to embrace our differences in dealing with the situation without judging one another. In reality, and with the benefit of time and hindsight, we can now see this and hopefully will face the next stage of our family journey together.'

# Dementia friendly action

The Prime Minister's Champion Group on dementia friendly communities has met twice since it was launched in March. The Group's task is to work out how the organisations involved and the sectors they work in can take part in helping to create communities in which people with dementia can continue to live well. This might be through raising awareness, getting involved in Alzheimer's Society partnerships or developing products and services that help people affected by dementia.

At the first meeting, Trevor Jarvis, who is living with dementia, talked about his problems getting money out of the bank when staff don't understand how to work with someone who has dementia. Angela Clayton-Turner explained how thoughtful strangers in shops had made all the difference to her and her husband Ted who now lives in a care home. This was followed by a speech by Ruth Girardet from Tesco who explained how effective last year's partnership with the Society has been in raising awareness with customers and employees. Many Tesco employees have a connection to dementia which is one reason why their staff were so enthusiastic about the partnership and the Dementia Community Roadshow, which continues this year.

At the second meeting, the Prime Minister visited the Society's offices in London to meet helpline staff and then to discuss with the Champion Group how to change society for people affected by dementia. On the day David Cameron said, 'I want to commend the Alzheimer's Society for the brilliant work they're doing' before adding; 'We've got to raise awareness



Photo courtesy of Rebecca Naden, Press Association.

Tackling dementia; the Prime Minister attends a meeting at Devon House

about dementia, about Alzheimer's, and make sure we build genuinely dementia friendly communities.' The Champion Group will report back to him in September on our plans.

A set of questions has been launched on the Department of Health website to get people thinking about and responding to how we can make communities more dementia friendly. The comments box is open until 13 July so why not log on and have your say?

**Visit: [dementiachallenge.dh.gov.uk/2012/05/28/dementiafriendlyquestion/](http://dementiachallenge.dh.gov.uk/2012/05/28/dementiafriendlyquestion/) or send your thoughts by post to the address on page 2.**



# You're already a campaigner

Have you ever...

Spoken to a friend or relative about dementia?

Wanted to improve things locally for people living with dementia?

Posted something dementia related on Facebook or Twitter?

If you answered yes to any of these questions, you are already an Alzheimer's Society campaigner. As a volunteer you are in the fantastic position of being able to champion the rights of people affected by dementia.

Campaigning is not just mass marches and protests. It is as much about raising awareness and sharing information. Whether you can take two minutes to give someone a **Worried about your memory?** leaflet, or spare a day to attend a national lobbying event, every action makes a huge difference.

We campaign on a wide range of issues, from ensuring people receive an early diagnosis to pushing for reforms in the way that we currently pay for care. Improving the lives of people living with dementia is at the heart of everything we do.

**Make it official. Join the Alzheimer's Society Campaigners' Network by visiting [alzheimers.org.uk/campaignersnetwork](http://alzheimers.org.uk/campaignersnetwork)**



Gabriel Uzor, committed to raising public awareness of dementia

## A day in the life

**Gabriel Uzor, a Campaign and Media Volunteer from Cardiff, offers an insight into his role with the Society.**

'Campaigning has become part of my everyday life and I'll never pass up an opportunity to inform people about dementia and how the Society can help to make the lives of those affected as normal as possible. I'm particularly passionate about spreading the word of the Society's **Worried**

**about your memory?** and **Early Diagnosis** campaigns. Currently only 40% of people living with dementia receive a diagnosis. Both of these campaigns target GPs in the area and encourage people concerned about memory problems to approach their GP and get help quickly.

As part of my role, I've recently been contacted by Horn of Development Organisation who are organising our health awareness campaign programme for women from a wide mixed ethnic/cultural background in Cardiff. I hope we will be able to collaborate with their six month programme and let these women know more about our campaigns and in turn, they will share information with their families and communities. I've also recently made arrangements with a gospel group, who are organising a wonderful social event to show that people affected by dementia can live life to the full through the power of music and dance. It's all part of an event promoting dementia friendly communities in July at the Royal Welsh College of Music and Drama in Cardiff, which will enable people to contribute their comments and ideas about how we make Cardiff more dementia friendly.

The efforts of the other volunteers I work with, as well as an understanding and time commitment to people with dementia, are a constant source of inspiration.'

# Making millions aware of dementia

In May, all across the Society people got involved with our flagship awareness raising campaign, Dementia Awareness Week™.

Face to face events, media coverage and online activity all helped to spread the word.

Tea-drinking - that very British tradition - was the inspiration for our fundraising theme and there were many brewing, from vintage street parties to relaxing reminiscences. There were also some very original ideas, like a childhood memories art competition judged by a local artist and a fundraising dinner dance at the Bristol Marriott hotel. In Beamish, there was a 1950s picnic, with music and entertainment provided by local schools and bunting created by people with dementia and in Ballynahinch, Northern Ireland, a 50s and 60s tea party and balloon launch. Saga Homecare staff and volunteers also got involved as part of their sponsorship of the week.



Carey Mulligan is the Society's latest high profile supporter

The Carmarthenshire Singing for the Brain group took over the National Assembly for Wales' Senedd building twice during the week. The day formed part of the launch of new bilingual information packs which will be available to people with dementia across Wales when they receive a diagnosis.

In London, Bafta-winning actress Carey Mulligan added her voice to the campaign. The star has chosen to support the Society as her grandmother Margaret, whom she calls Nans, was diagnosed with Alzheimer's in 2004. She joined people with dementia and their carers at the Society's Rest Bite service in Kentish Town. Carey said, 'I am committed to helping the Society in any way I can. My family and I rely on the help of organisations like Alzheimer's Society to help us understand the disease and guide us in the care of my grandmother.'

## Tea for two



A teapot of money is presented to volunteers Joanne Tegerdine and husband Adam

In York, Dementia Awareness Week™ got off to a retro start. Volunteers and staff dusted off the china and rolled out the bunting for their own vintage tea party. As well as tea and cakes served from traditional English china, guests enjoyed a range of old-fashioned entertainment, with music, classic cars and stalls with vintage inspired items. Over £2,000 is expected to have been raised by the event.

Volunteer, Joanne Tegerdine, who helped pull the event together said, 'We turned back time for a day! It was brilliant – people were coming in even as we were setting up – the support was amazing. Volunteers created the street theatre that went with the tea party and everyone from the helpers pouring the tea to singers, dancers and owners of classic cars who took them along made it happen.'

**Thank you to all the volunteers who helped pull out the stops for a fantastic Dementia Awareness Week™!**



# Walk with us this September

After a phenomenally successful Memory Walk 2011, plans for 2012 are well underway. Memory Walk is the Society's biggest annual fundraising event and last year raised over £880,000, the most we've ever raised! We couldn't have done it without many of our volunteers' hard work. We're looking forward to making this year's even more successful.

Memory Walk has grown dramatically over the years, and there are a range of events available to get everyone up and walking.

## Memory Walk Marathons

There are three challenging 26 mile treks to choose from, including a route that takes in the majestic stones at Stonehenge, the picture postcard Holy Island of Lindisfarne, or the spectacular coastal scenery of the Causeway Coast in Northern Ireland.

## Flagship Memory Walks

There are 16 high profile events attracting 500 or more walkers that take place in a variety of iconic locations.

## Local Memory Walks

These are smaller, community orientated walks, often organised by Society staff and volunteers. In 2011 we had over 90 local walks across the Society.

## Organise Your Own Memory Walk

If there isn't a walk in your local area, you may choose to organise one of your own with friends and family. The Memory Walk team can help get you started.



Memory Walk is a great way to bring together people across England, Wales and Northern Ireland

The money you raise will help us to run services in your community. The more people who take part and the more money we raise, the bigger the difference we can make to people's lives.

So ask your friends and family to sign up now and let's make it a day to remember.

**If you have any questions, email [memorywalk@alzheimers.org.uk](mailto:memorywalk@alzheimers.org.uk) or call 020 7423 3646.**

# Your Voice, your Society

The second Society wide volunteer survey is included with this issue. Quick, easy and anonymous, this is your opportunity to say what you think about volunteering for the Society. If you are able to complete the survey electronically to help keep our costs down, please do. Go to **[alzheimerssocietyvolunteersurvey.org.uk](http://alzheimerssocietyvolunteersurvey.org.uk)** and enter the password **volunteer2012**.



Brett Terry, Director of People and Organisational Development says, 'It's so important we hear your collective voice. Your comments will be used again to create a plan so that we can act on your experiences and expectations. The Society is 100% committed to this journey and we want to ensure that you are given the opportunity to play a lasting role in shaping your volunteering environment and the future of volunteering itself. Over 1,300 of you gave us your feedback in the last survey and having listened, we've been able to use your responses to really improve things for volunteers in the future.'

## Communication must get better

You told us that we need to get better at talking and listening to you, so we launched this magazine which is now produced quarterly, so that you can read about the things that matter to you. We've also invited our volunteers to help put together the magazine so that we can bring you more local stories.

During February and March some of you had the chance to meet your Chief Executive, Jeremy Hughes, and talk about the strategy in the Delivering on Dementia tour.

And because hearing directly from you is so important to us, we are setting up volunteer forums across the Society, to offer you an opportunity to make your voice heard and help inform the Society's work in the future.

## Improved management and support

You reminded us of your diverse skills and ability to be involved more in the Society so we have developed a training programme for all our employees to help them understand better the value of volunteers. New employees will learn about the role of volunteers as part of their induction, whilst staff who manage volunteers will attend a specialist training course.

## Learning and developing

You told us that you want to develop new skills so we have ensured volunteer training is relevant to you and as easy to complete as possible. For example, our Data Protection training can now be completed online, on paper, on an individual basis or as part of a group. As new roles emerge, we will continue to provide appropriate training and support.

## It's time to speak up again!

We hope you can see that a lot of your feedback is already being acted on, but we know there is still much to do. It's time to speak up! We'll let you know the initial findings in September. Thank you.

Email **[tellvolunteering@alzheimers.org.uk](mailto:tellvolunteering@alzheimers.org.uk)** or call **08455 049 300** for more information.



Look out for more information coming soon

## Celebrating our volunteers

Every year we celebrate just some of our amazing volunteers in our annual William Brooks Volunteer Awards. We will soon be opening up nominations for the 2012 awards and inviting you and our employees to tell us about any of the volunteers you know who make an exceptional contribution.

Why not have a think about who you believe deserves a special thank you for all that they do. Your manager or volunteering officer will be able to give you more information in the upcoming weeks.

# Giving people the choice

Personalisation is a new way of thinking about services and social care. It's about putting people's needs, wishes and choices at the centre of the support they receive.

One of the ways people can have more choice is through a personal budget. Anyone eligible for social care support can opt for a cash payment as an alternative to a direct service. This money can be used to purchase services that they can choose themselves. So for some, maintaining links with their local football club could be more beneficial than attending a local day centre. Personal budgets could help give them this choice.

Personalisation also emphasises the importance of early intervention and maximising choice and control for people looking for services. It also recognises the value of the support available outside of traditional statutory services through volunteering, peer support and other informal support networks like friends, families and neighbours.

Alzheimer's Society is supporting personalisation by making any changes to our local service delivery as simple as possible. In some areas our contracts with Local Authorities are already being replaced by personal budgets. In these services, we are making sure we charge a fair price whilst making sure our costs continue to be covered.

**For more information on how the Society is planning for personalisation, contact Ian McCreath at [ian.mccreath@alzheimers.org.uk](mailto:ian.mccreath@alzheimers.org.uk)**

**'There was a time when I was putting my husband to bed up to 15 times a night, and I was totally exhausted. I was visited by a professional who asked about the current situation and said she'd ensure an extra session of day care for my husband. But if she'd asked me what I wanted most, it would have been extra night cover, so that I could just have some sleep.'**

**Carer, England**

## Across the Board

### Ann Beasley, **Trustee**

When I became a volunteer for the Society's Audit Committee in 2006, I had no previous experience of the Society other than buying raffle tickets. It was only later when my father was diagnosed with vascular dementia that the issue really hit home. He had been a teacher in the army and an intellectual man – the condition left him not knowing who he or anyone else was. My mother became a full time carer, it took over her life. It struck at the whole family.

I knew a little about volunteering before I joined the Society. For my Masters in Business Administration in 2003, I wrote a dissertation on volunteering within the Metropolitan Police which focussed on two pilot volunteering initiatives to run two police stations that would otherwise have been closed to the public. The volunteering work I've been involved in with the Society has been particularly rewarding for me, whether I've been shaking a collection tin in Tesco or representing the Society at a beneficiary charity dinner, which I did recently. Both are as important as the other. The volunteers I've worked with are relentless in campaigning for quality patient care, and I'm excited at not only what the Society has achieved so far, but also at its ambitious five year strategy.

I became a trustee in September 2009, not only because I wanted to continue to use my skills and experience to support the growth of the organisation, but because I had seen how truly committed the people in the Society are and how they work so incredibly hard to make a difference. It's good to feel part of that. I like to think that we, as trustees, are real people with passion and personality who are motivated by a Society committed to growth and change, with ambitious objectives to meet the challenges ahead.



Motivated by a Society committed to growth and change





Do something **amazing** this year and sign up to an Alzheimer's Society fundraising event. We have lots of exciting events for you to choose from, whether you'd like to cycle, trek, run, walk or even jump.

Thousands of people took up the challenge last year and raised more than £5 million to transform the lives of people with dementia today and fund research to find a cure for tomorrow.

Visit [alzheimers.org.uk/events](https://alzheimers.org.uk/events) or call 0870 417 0192 to find out more.

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)