

Dementia together

April/May 2019
Alzheimer's Society's magazine

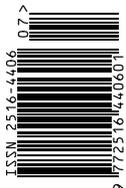
Join the club
Golf in Society

Not a frightening place
St Teresa's Hospice

Each day as it comes
Staying connected

Also in this issue
Dementia Action Week
Hearts of gold
Time and place

40 years
2019



Beginning again
Musical bond

**Have you ever left
the house without
trousers on?**



**Ask us anything this
Dementia Action Week**

20-26 May

All it takes is a conversation to see
we're still us

#AskUsAnything #DAW2019

alzheimers.org.uk/DAW

Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity no. 296645.





Welcome

We're encouraging people to start conversations for Dementia Action Week, 20–26 May, because keeping in touch can mean a huge amount to people affected by dementia.

This magazine is all about keeping in touch, of course. Every issue is full of ideas about ways to make a real difference – to your own and other people's lives. If you know anyone else who could benefit from receiving the magazine, make sure they know how to subscribe (see below).

We hold our poetry competition every two years, and I'm very pleased to announce our 2019 competition in this issue too – see p27 to find out how to take part.

Danny Ratnaike, Magazine Editor

Questions about dementia? See p38

This is the April/May 2019 issue of Dementia together, the magazine for all Alzheimer's Society supporters and people affected by dementia.

Subscribe or update your details

Use the form on the inside-back cover, visit alzheimers.org.uk/subscribe or call **0330 333 0804** to subscribe.

To update your details or to get the magazine on audio CD, call **0330 333 0804** or email enquiries@alzheimers.org.uk

Read or listen online

See alzheimers.org.uk/magazine for online articles, PDFs and podcasts.

Contact us

magazine@alzheimers.org.uk, **020 7264 2667** or **020 7423 3676**
Magazine Editor, Alzheimer's Society,
43–44 Crutched Friars, London EC3N 2AE

Copyright ©2019 Alzheimer's Society – please ask us if you'd like to copy our content or use it elsewhere.

Inside

News

Dementia Action Week 4



Each day as it comes
Staying connected 8

Society

Hearts of gold 12
'All that she was' 13
Try something new 13
Best possible life 14
A lasting gift 15
In your area 16

Beginning again

Musical bond 18

Join the club

Golf in Society 22

Not a frightening place

St Teresa's Hospice 24

Letters 26
Q&A: Sylvia Bouskill 28
Life with Ma 28
Time and place 30
Professional attorneys 32
Questions and answers 33
Extreme caring 34
After a fall 36
Making cupcakes 37
Competitions 39



Phenomenal afterGLOW

A massive thank you to over 5,000 glow-getters and volunteers who united against dementia after dark for Ready Steady GLOW in March. Three night walks in Manchester, Bristol and London raised a phenomenal £210,000 and counting.

This autumn, a new Memory Walk challenge will also offer exciting opportunities to take part in extended walks across the country, so look out for details in the coming months.

For more about Memory Walk, visit memorywalk.org.uk

Cupcake Day: Bake a difference

Cupcake Day returns on 13 June, so join us whether you're baking or buying for an event at work or home. Last year, Cupcake Day raised £1.4 million for people affected by dementia and this year we need you to help us raise even more! Our fresh new fundraising kit is filled with delicious goodies and decorations to help you host your big day. Sign up for your free fundraising kit at cupcakeday.org.uk

Dementia Action Week: Start a conversation

Take part in this year's Dementia Action Week from 20–26 May by keeping in touch with friends, relatives and neighbours living with dementia.

Despite almost all of us knowing someone affected by dementia, two-thirds of people with the condition report feeling isolated and lonely. Having dementia shouldn't mean an isolated life, which is why we're encouraging people to start a conversation. Even in the later stages of dementia, when having a conversation might become difficult, keeping in touch means a lot.

Dementia Action Week unites individuals, businesses and communities to improve the lives of people living with dementia. Events will be taking place in your communities, so why not get involved and join an event or volunteer?

Our Alzheimer's Society Annual Conference is also on 21–22 May, a great way for people affected by dementia to influence professionals and policy-makers – see alzheimers.org.uk/conference to find out more.

To find or register a Dementia Action Week event, order materials or access specialist guides, visit alzheimers.org.uk/DAW or call 0330 333 0804.



The Dementia Superheroes

Alzheimer's Society has created a comic book series to make dementia a little less scary for primary school-aged children.

The Dementia Superheroes features Violet Volunteer, Carl Carer and Sophia Scientist to help teach children about dementia in a fun and child-friendly way.

Once a month they will be sent a pack in the post including activities, collectable cards and the comic, which shows how dementia can make people feel differently. Children can become a 'dementia superhero' themselves by showing greater kindness and understanding towards people living with the condition.

Call 0330 333 0804 (local rate) or visit alzheimers.org.uk/superheroes to donate and sign up for your child.



Time for a Dementia Fund

Alzheimer's Society is calling for a special Dementia Fund to help tackle the immediate gap in social care funding for people living with dementia in England.

The fund would improve care in the community and access to care homes that can support people with dementia, leading to fewer emergency hospital admissions. The fund could come from NHS money announced last summer and earmarked for 'community care', and it could be given directly to individuals.

We believe the government must make funds available to support people affected by dementia, who currently shoulder two-thirds of the cost of dementia care, while longer-term decisions are made about proper funding for social care.

We've been ramping up our Fix Dementia Care campaign by meeting with MPs and Lords about the importance of better quality social care and the need for increased dementia care funding. We'll continue to have these crucial conversations, and the more supporters who sign up to our campaign, the stronger our voice will be.

Visit alzheimers.org.uk/fixdementiacare to call for extra social care funding.

Trek26: Take on dementia

Join us this summer for an epic 13 or 26-mile trek in one of six breath-taking locations in England and Wales. Join hundreds of others who've experienced how tough dementia can be – every pound raised will fund vital support and bring us closer to a cure.

Sign up now at alzheimers.org.uk/trek26

Cheer on the Dementia Revolution

Make a stand against dementia at this year's Virgin Money London Marathon by taking to the streets to cheer on our runners. Over 1,600 Dementia Revolutionaries running on 28 April have raised over £1 million already, with more to come.

Dementia Revolution, the event's Charity of the Year, is our partnership with Alzheimer's Research UK to raise money for the UK Dementia Research Institute.

We need volunteers at 10 cheer points throughout London to give our team the support and encouragement they deserve.

Visit dementiarevolution.org/volunteer by 21 April to add your voice.

Dementia affects a huge number of us, whether we're living with a diagnosis or have a close friend or family member who is. What's more, one in three people born today will develop dementia during their lifetime. In some way or other, dementia is a part of all of our lives.

This will be evident at this year's Virgin Money London Marathon, where the Dementia Revolution is the official charity. Not only are hundreds of runners raising money for our UK Dementia Research Institute, cast members of EastEnders have also got the nation's attention by supporting their fellow actor Barbara Windsor, who is living with dementia. Thanks to all for your fundraising and publicity.

We'll also see people uniting to fight dementia in Dementia Action Week, when thousands more will join almost 3 million Dementia Friends. They'll help to tackle some of the isolation and despair that too often comes with a diagnosis. If you're one of our amazing Dementia Friends Champions who run information sessions, then thank you. If not, why not find out more about this role and help spread the word? (see p 13).

Jeremy Hughes
Chief Executive Officer



A healthy mouth

A study, reported in the media, has looked at whether a type of bacteria that causes the gum disease gingivitis could increase a person's risk of developing Alzheimer's.

The study found high levels of proteins made by these bacteria in the brains of people with Alzheimer's disease, though this might be because good mouth hygiene can become a challenge as dementia progresses. The same proteins were also found in the brains of some people who didn't have Alzheimer's.

Looking at mice, the researchers showed that these bacteria could cause changes in the animals' brains that are similar to young-onset Alzheimer's. A drug that blocks infection by the bacteria also prevented this damage in mice. They are now testing to see whether this drug could be safe and effective in reducing the risk of Alzheimer's for people with gum disease.

Dr James Pickett, our Head of Research, said, 'There isn't clear evidence yet that this infection can cause this damage in humans or result in Alzheimer's.

'Success of this new drug depends on whether the infection really does play an important role in Alzheimer's disease. The upcoming clinical trial will be a crucial test to see if this can be a potential treatment for Alzheimer's.'

The study also gives us another good reason to keep fit and healthy – looking after our teeth and gums is an important part of that.

Visit alzheimers.org.uk/research to find out about our research programme.

Technology at home

A new £20 million programme at the UK Dementia Research Institute will investigate how technology can help to support people with dementia in their own homes.

The Care Research and Technology programme, housed at Imperial College London, will look at technology that enables people to live better and for longer at home. People affected by dementia will be involved to ensure that the work is fit for purpose.

The UK Dementia Research Institute now comprises seven centres working together to combat dementia.

Find out more about the institute at www.ukdri.ac.uk

Wales commitment

The leader of the Welsh Government has reaffirmed his cabinet's commitment to improving the lives of people with dementia in Wales. First Minister Mark Drakeford gave the keynote speech at our Alzheimer's Society Cymru conference, held at Cardiff City Hall in March.

Attendees saw films about the Society's dementia-friendly communities work across Wales and heard from scientists at Cardiff University, part of the UK Dementia Research Institute.

Jim Ibell, who opened the conference, said, 'It was wonderful to see so many people like me – living with dementia – hosting and participating in discussions.

'As a person living with dementia, I can feel very lonely, but at the conference everyone came up to talk to me. It was brilliant from start to finish.'

Deprivation of liberty: New code

The government has invited Alzheimer's Society to help draw up a code of practice for a new Deprivation of Liberty Safeguards (DoLS) system. This is the set of checks for when a person has their independence or free will restricted in some way, if they lack the ability to decide for themselves and it's in their best interests.

A bill – currently in its final stages of being debated in the House of Commons – is set to amend how DoLS operate. We've been lobbying government to ensure that anyone deprived of their liberty is provided with information about their rights, and that the public should be consulted on the code of practice.

We'll be getting the views of people affected by dementia about what should be in the code in the coming months, to ensure that it will help professionals and families to understand how the new system is meant to work.

Dementia Connect: The right support

Dementia Connect has passed an early milestone as we mark a year since its launch in Birmingham and Solihull, and we're looking forward to introducing it elsewhere. Existing services are also in East Lancashire and parts of Wales.

Dementia Connect combines our face-to-face, telephone, print and online support and advice, and we keep in touch to make sure people get the help they need as their needs change. It also brings people with dementia together with volunteers through Side by Side, supporting them to continue doing the things they love in their community.

Dementia Connect is key to us realising our ambitious five-year strategy to be there for everyone affected by dementia in England, Wales and Northern Ireland by 2022.

This new service isn't available nationally yet – to find support near you, visit alzheimers.org.uk/getsupport

Northern Ireland airport audits

Alzheimer's Society is helping to make Northern Ireland's airports as accessible as possible. We've been supporting people with dementia to attend meetings at Belfast City, Belfast International and Derry-Londonderry airports, joining representatives from a range of disability organisations

During tours of the airports, people fed back about how staff could improve the experience of travellers with dementia, based on their own experiences.

Further meetings will follow every six months at both Belfast airports, with plans for Derry-Londonderry to be announced.

Alzheimer's Show: 50% off

Get half-price tickets for this year's Alzheimer's Show at Olympia London on 7–8 June, showcasing practical advice, information, products and services for people affected by dementia.

Use the code ASOC19 to get 50% off on-the-door prices – standard tickets become £10 per day and concessions £7.50 per day. People with dementia get free entry, as do under-16s accompanied by an adult. **Book now at www.alzheimersshow.co.uk**

Dementia-friendly sport and leisure

A new guide will help organisations to support people with dementia to enjoy more active lives. Launched in partnership with Sport England, our Dementia-friendly sport and physical activity guide will educate gyms, leisure centres, sports clubs and others about how dementia can affect people. It also includes ideas and tools to make their activities more suitable for people with the condition.

Download the guide at alzheimers.org.uk/sport

In briefs

Your voice heard

Help to improve dementia services in England by sharing your experiences. The Department of Health and Social Care would like people with a dementia diagnosis to complete a short questionnaire about living with the condition.

Complete the survey at www.ors.org.uk/surveys/dementia2020 or call 0800 311 2126 for a print version.

This is me: Updated



You can now get an updated version of our popular 'This is me' leaflet, which can be used to record details about a person with dementia who can't easily share information about themselves. 'This is me' is for a person whether they are at home, in hospital or in a care home.

Visit alzheimers.org.uk/thisisme or call 0300 303 5933 (local rate) for a free copy of 'This is me'.

Our own kind of music

The music and dementia charity Playlist for Life is training our dementia advisers to harness the power of playlists for people living with the condition. They will then help people to explore someone's life story and find the music that resonates with their memories and promotes their wellbeing.

For more about Playlist for Life, visit www.playlistforlife.org.uk or call 0141 404 0683.

Each day as it comes

Living in a remote spot, Pam Wood appreciates her continued connections with other people.

Gareth Bracken meets a woman with dementia focusing on what each day brings.

Quick read

Pam Wood, diagnosed with Alzheimer's in 2016, is staying connected and involved through family and volunteer support.

Pam, who no longer drives, lives in a remote village on the Cornish coast and relies on her daughter for shopping.

Pam enjoys trips with volunteer Sue, who she met through Alzheimer's Society's Side by Side service.

The two get on extremely well and Pam says their outings leave her feeling 'on top of the world'.

Life in an idyllic coastal village has plenty of perks for Pam Wood. The beautiful scenery, nearby beach and friendly locals are among the many reasons she loves Holywell Bay in Newquay, Cornwall, her home for the past four decades.

However, since her dementia diagnosis a few years ago – difficult enough to contend with in itself – Pam has found herself extremely grateful to her daughter and the Society. Their support has helped her to remain connected while living in such a remote spot.

Fell in love

Pam, 76, was born in Cheshire and lived in Crewe, where many in her family worked on the railways. One of her grandfathers was a wheelwright – making and repairing wooden train wheels – while her father was a coppersmith. Her other grandfather was a train driver who once recorded the fastest journey time from London to Glasgow on the Flying Scotsman service.

Pam worked as a legal secretary before running a newsagent with her late husband Arnold. Around 40 years ago, they sold the business and moved to Cornwall with their young daughter Julie, where they opened two more shops.

‘We used to come here twice a year to a holiday home and just fell in love with the area,’ says Pam. ‘So we packed up, came down and I’ve been here ever since.’

‘I haven’t got a Cornish accent yet, though I’ve been here long enough to have one!’

Pam has fond memories of working in the shops.

‘It was brilliant – you met the public,’ she says. ‘We had good relationships with everybody.’

Pam describes herself as an outgoing person who always wants to be doing something, whether indoors or out.

‘I like to be on the go all the time. I like walking on the beach and going to a craft club,’ she says. ‘I do knitting, crosswords and tapestry work. I’m into my jigsaws at the moment – it’s a big country scene one.’

Feeling embarrassed

Long before her dementia diagnosis, Julie noticed that Pam had begun to repeat herself during conversations.

‘If I said something to her I’d say the same thing a quarter of an hour later,’ says Pam. ‘She would say, “You’ve told me that once,” or, “You told me that yesterday.” I just put it down to my nerves, being on my own, but it started getting worse.’

Pam visited a GP and took memory tests, while a brain scan came back clear. Six months later, with her repetition becoming more regular, she returned to the doctor and was eventually diagnosed with Alzheimer’s disease in mid-2016, around two years after her first appointment.

Julie recalls the news being delivered to her mother in an unsympathetic manner.

‘The doctor just said, “You’ve got Alzheimer’s, bye-bye.” It was very harsh, very blunt. There was no explanation or advice on who I could get in touch with for help,’ she says.

Pam, who had never even heard of dementia, became more self-conscious about potentially making mistakes or repeating herself during a conversation.

‘I think I was embarrassed about it, to be honest,’ she says. ‘If I’d say something to somebody and they’d look at me, I’d think, “Did I say something wrong there?” I tried to hide the embarrassment somehow.’

Family lifeline

Pam gave up her driving licence around six years ago after others noticed her driving becoming more erratic.

Meanwhile the only shop within walking distance closed down, and she isn’t keen on using the local bus service, leaving her to rely on Julie for food and supplies.

Pam isn’t fazed by living in an out-of-the-way area, but acknowledges that she would be more isolated without the support of Julie, who lives next door.

‘I had my own independence with going shopping, but giving up driving was the right thing to do,’ she says. ‘I don’t really miss it because I’ve got Julie, her partner Kevin and the boys – but it’s very important that she’s around. I don’t know how I’d cope without her, to be honest.’

‘If Julie wasn’t here, then life would be really hard with things like shopping and the mail. I couldn’t cope with the mail – she takes all that off me. Kevin is a DIY man, he’s brilliant and checks everything for me.’

Pam used to join Julie for the shopping but stopped after it became too much for her.

Julie says, ‘I saw a vague look across Mum’s eyes. The shop was far too big and there were far too many people for her. So I had to take her out of that situation.’

Pam starts waving her arms frantically. ‘You walk in and everybody is like this,’ she says. ‘They’re always in a hurry’

– they’ve got the trolleys and are pushing at you. Everybody’s around you all the time. It’s overpowering.’

Top of the world

Julie has struggled to get the right support for both Pam and herself from local services, a process that she says is ongoing.

‘You’re completely forgotten about,’ she says. ‘If I didn’t live next to Mum, I don’t know what sort of state she’d be in now.’

The main source of support the family has received has thankfully been a great success. This is Side by Side – the

Alzheimer’s Society service that helps people with dementia to keep doing the things they love with the support of a like-minded volunteer.

Pam was matched with local volunteer Sue Morey and the two have met weekly for the past year. They’ve become good friends during visits to garden centres, walks along the beach and even a trip to a cider farm.

‘I hate being bored. I’m here on my own and there’s only so much telly you can watch,’ says Pam. ‘It’s just getting out for a couple of hours.

‘Sue is just good company, all through. We get on like a house on fire. We have a good laugh wherever we go, I always look forward to it. We have such a good time and I feel on top of the world afterwards.’

Sue feels that their trips help her as much as Pam.

‘Everyday family life can be stressful and it gives me that two hours of chill – no one else matters,’ she says. ‘I get a lot of enjoyment out of it – it’s just so rewarding and Pam is so appreciative.

‘We’re just so alike, especially in the things we like to do. Someone thought we were sisters last week!’

Day by day

Pam also keeps herself busy by working for a friend’s cleaning business.

‘I help them clean the holiday homes – it can be three or four times a week in the summer,’ she says. ‘It’s nice to clean it all the way through and think, “That looks really nice.” It gives me a boost because I’m not just sitting in the house vegetating. I love it.

‘My friend gives me a bit of pocket money. It makes me feel good, particularly when he takes me for coffee and cake!’

Pam’s desire to keep active and involved means she wants to continue living in the moment.

‘I’m determined to face up to Alzheimer’s. That’s why I keep carrying on and trying to cope, because I hate sitting in this chair 24/7,’ she says.

‘I don’t sit thinking that in another five years I won’t be able to walk or whatever. That’s not me.

‘Every day is a day, and that’s it. I just take a day as it comes.’





Next steps

- Make your community a more inclusive place this Dementia Action Week (20–26 May) – see alzheimers.org.uk/daw to see what you can do.
- Visit alzheimers.org.uk/sidebyside to find your nearest Side by Side service, and visit alzheimers.org.uk/volunteer or call 0300 222 5706 (local rate) to volunteer.
- For our Keeping active and involved (1506) booklet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Hearts of gold

As the Society turns 40, we meet some of the incredible fundraisers whose achievements make our work possible.



Since 1979, Alzheimer's Society has fought to bring dementia out of the shadows, and we want everyone to unite with us to create a better future. Of course, we wouldn't be where we are today – and couldn't plan for tomorrow – without our amazing fundraisers.

Mark Richards, who leads an inspiring volunteer fundraising group (pictured) in south Wales, says, 'Most people these days know somebody who has the condition or is affected by it. I'm amazed there's not greater public money going into it.'

The group raised over £28,500 last year by involving their community in Radyr and Morganstown, Cardiff.

'By the end of 2019, we'd like to have raised £40,000 for the Society's 40th year,' says Mark. 'I'm confident we'll go past that.'

Involving everyone

After his wife, Heather, was diagnosed with dementia five years ago, at the age of only 53, Mark was determined to do something positive.

'Initially we were involved in various research projects,' he says, 'but as her condition advanced she was less able to participate, and I became involved in the newly formed community fundraising group.'

Supported by Society staff, the group meets every couple of months to organise anything from a coffee morning or beetle drive to a brass band or choir concert. Involving everyone in their networks has been a key to success.

'We encourage others – schools, Scouts, Women's Institute – to fundraise for us.'

Heather now lives in a care home, but Mark feels far from alone in the group.

'Many of us have relatives who are living with the condition, or have lost someone through dementia.'

As much as I can

Sue Lewis's motivations are just as personal – now 67, she was diagnosed with early-onset Alzheimer's in 2016.

'I know there's no way of finding a cure in my lifetime,' she says, 'but for the younger people, I want to try and raise as much as I can.'

Sue describes herself as the 'mouthpiece' of a fundraising group in Caerphilly, which grew out of a panel of people affected by dementia.

'I'm very passionate about it,' says Sue. 'I ought to have a soapbox to raise the importance of fundraising!'

The group makes teddy bears and knits flowers to sell, and Sue has also raised over £2,000 through two shows at social clubs. These featured tribute acts and a comedian, and Sue is impressed by everyone's level of support.

'We're aiming to do three events a year – the artists are willing to give up their time, they don't want paying. It's wonderful for them to do that.'

Natalie de Maid, our Regional Community Fundraising Manager in Wales, has no doubts about the impact that Sue and Mark's groups are having.

'They're worth their weight in gold. They're creating a long-term legacy and making a difference for generations to come.'



Fundraise to create a better future – visit alzheimers.org.uk/fundraise or call 0330 333 0804 (local rate) for information, ideas and support.



Become a champion

Dementia Friends Champions give people the information and encouragement they need to make a difference for everyone affected by dementia. Champions attend an induction and get support when needed to help create dementia-friendly communities everywhere. Find out more at dementiafriends.org.uk

Read Care and cure



The latest Care and cure, our quarterly research magazine, looks at using artificial intelligence to help diagnose Alzheimer's earlier, Namaste care for people with advanced dementia, and much more. Visit alzheimers.org.uk/careandcure



Be a GameChanger

Help us understand more about how the brain works, and so fight dementia, through GameChanger by playing fun daily brain games for a month using a smartphone app. Anyone over 18 who doesn't have a dementia diagnosis can join in. Sign up at alzheimers.org.uk/gamechanger



'All that she was'

A supporter in Northamptonshire brought Dementia Friends and Cupcake Day together last year.

Nicky Smith's mother, Kate Goshawk, lived in Suffolk for most of her life before moving close to Nicky in Earls Barton, near Wellingborough. Kate, who had Alzheimer's, was living in Grangefield, a local care home, by the time she died in 2017. Nicky decided to hold an event at the home the following Cupcake Day as a way to commemorate and celebrate her life.

'Mum was a keen baker – one of her first jobs was in a bakery – so it was appropriate,' says Nicky.

Holding an event at the care home also meant it could involve people who knew Kate in later life, but who hadn't been able to travel to her funeral in Suffolk. As well as supporting us, Nicky wanted to raise awareness about how to help people affected by dementia to live as well as possible.

'I really wanted to bring in Dementia Friends,' she says. 'Mum was someone who always wanted to support charities and do good things.'

A full room

Promoting the event through her local church and village magazine, Nicky arranged a Dementia Friends information session at Grangefield followed by tea and cake for Cupcake Day.

'It went down very well,' says Nicky. 'The cupcakes were obviously popular! We had a full room, with friends from the church, the local community and Grangefield staff. The care home was very happy to support the event and very helpful.'

'Pretty much everyone who went said to me, on the day or afterwards, what a great event it had been.'

Nicky's daughter Julia, who works at the Society in London, helped as well.

'I created a photoboard full of pictures of Gran to share with everyone there,' says Julia. 'People were so generous, both donating and buying cakes from the stand. It was such an easy way to fundraise and a lovely way to remember my gran.'

Nicky agrees, 'It just felt like a really nice celebration of Mum's life and all that she was.'

Encouraging all

As well as the fun of baking, sharing and eating cupcakes, Nicky hopes this kind of event encourages everyone affected by dementia to seek support.

'It's getting as many people as involved as possible, because this is something that affects so many families.'

Cupcake Day is on 13 June, though you can host an event on any day that suits you – visit cupcakeday.org.uk or call 0300 222 5770 (local rate) to order your free fundraising kit.

Best possible life

How a Dementia Friendly Community Champion in Northern Ireland is making a positive impact on people's lives, from home care to shopping.

When Lynne Bulled's employer chose her as one of 300 staff to focus on improving services for people affected by dementia, she approached the Society for help. That was in December 2016, and it's safe to say that she's succeeded in making a real difference since then.

'I'd like to think if I had dementia, people would go the extra mile for me,' she says. 'I'll do whatever it takes to make sure someone has the best possible life.'

Community champion

Lynne, Homecare Officer at Northern Health and Social Care Trust, manages the kinds of community services that many people with dementia rely on.

After becoming a Dementia Friendly Community Champion – Northern Ireland's equivalent of a Dementia Friends Champion – she delivered workshops for her staff.

She says, 'I wanted to build staff understanding, knowledge and skills, engaging and motivating them to improve the quality of care we provide.'

The impact of this has been evident when Lynne talks to the people with dementia who they support, as well as with their families.

'Our staff have become more confident, feeling more empowered to support and enable people to live life to the full. They're also better equipped to signpost people to other services.'

Shopping challenge

Lynne didn't stop with her own work though. Knowing that shopping can become a challenge for many people affected by dementia, she contacted the Junction shopping centre in Antrim.

'I sent an email to the two managers of the Junction, and it snowballed from that. Both managers have family experience of dementia and they invited me along to speak to them. They got my passion.'

As a result of rolling out workshops to staff at the Junction, they are better able to support people affected by dementia. Many have become Dementia Friends, and staff dementia awareness is now a requirement for all the centre's shops. People with the condition have also been involved in improving facilities and signage.

'It has been a privilege to work alongside individuals with dementia and learn from their experiences.'

After seeing what the Junction has achieved, other shopping centres in Northern Ireland are now also working to become more dementia friendly.

Not only was Lynne recognised as Dementia Friendly Community Champion of the year in our Dementia Friendly Awards last year, her son Samuel was also one of three winners in the Inspiring Young Person of the year category.

'That was such a reward for me as well – I'm very proud!'

Lynne (right) with Danny Brown, who has vascular dementia, and Leona Barr, manager of the Junction.



See dementiafriends.org.uk to find out more about becoming a Dementia Friends Champion.

A lasting gift

Siân Gregory, Will to Remember Executive, on the importance of legacies and how we can help you to plan for the future.



You may have heard about the recently announced legacy of Lady Saunders – better known as actress and TV presenter Katie Boyle – who died last year. She left a staggering £8 million to charity, including a sizeable donation to us.

Most of us can't leave anywhere near as much as she did, but her generosity highlights the power of gifts in wills, which are vital for us to be able to plan ahead and support longer term research.

Although family and friends come first when writing a will, once you're happy they're provided for, a gift to Alzheimer's Society has far-reaching impact. Before working here, I benefitted from what the Society does as a young carer, and I intend to leave a gift in my will to help us create lasting change.

Our Will to Remember scheme means that making or changing your will is easier and quicker than many people expect. You can seek advice from our network of trusted solicitors and you'll receive our free will guide pack, which

gives invaluable guidance. You'll also get £150 off the cost of writing or updating your will. There's no obligation to leave a gift to us and no charge to us either, as the solicitor covers the cost of the discount.

Dementia is a cruel, complex condition, but we can all unite to fight it. Gifts in wills help to make that happen. Visit alzheimers.org.uk/willtoremember or call 0330 333 0804 (local rate) to find out more.



Get your regular copy by completing the form on the inside-back cover, visiting alzheimers.org.uk/subscribe or calling **0330 333 0804**

**Subscribe to
Dementia together
magazine today**

40 pages of real-life stories, support, information and ways to get involved. Delivered to your door every two months.

Although there is no fixed subscription fee, we do ask that you make a donation to support the magazine and our vision of a world without dementia.



In your area

First-rate friends

Gladstone Primary Academy in Stoke-on-Trent is the first primary school in Staffordshire to become a dementia-friendly school, and pupils from nursery and reception to Year 6 have taken part in a series of memory walks throughout the year.

Apart from raising over £4,000 towards vital support and research, the children have learnt about dementia and involved many members of the local community – their own families but also local police and fire fighters – in their activities.

Year 5 children decided to visit people with dementia living in a local care home and sang songs with them. Pupils also took part in paying their respects to the late Society Ambassador Gordon Banks, who played for Stoke City FC.



Belfast celebration

People with learning disabilities spoke about the benefits of taking part in dementia-friendly community workshops at a recent celebration event in Belfast City Hall.

Tracy Smith, Dementia Support Worker at the local Society, has held workshops with 35 people with a learning disability and staff from four day centres in Belfast.

Services Manager Fiona Brown said, 'This work will continue with the other two day centres in Belfast. Two people with learning disabilities will become Dementia Friendly Community Champions along with one staff member.'

'This is just the beginning of developing services for people with learning disability and their families.'



Our winners

The Wales Walking Football over 50s and over 60s teams helped to kick off our Blue Shoelace campaign in Wales, wearing the special Alzheimer's Society laces while taking on England in March. Although they didn't win at St George's Park in Burton-upon-Trent, they certainly won the day for us by raising both funds and awareness.

Paula Langston, Regional Fundraising Manager, said, 'I want to say a massive thank you to the Wales Walking Football over 50s and over 60s teams for wearing their shoelaces with pride. We plan to roll this exciting campaign out to other sports – cricket, bowls, rugby and others.'

To get involved in Alzheimer's Society Cymru's Blue Shoelace campaign, contact claire.carwardine@alzheimers.org.uk or call 029 2047 5572.

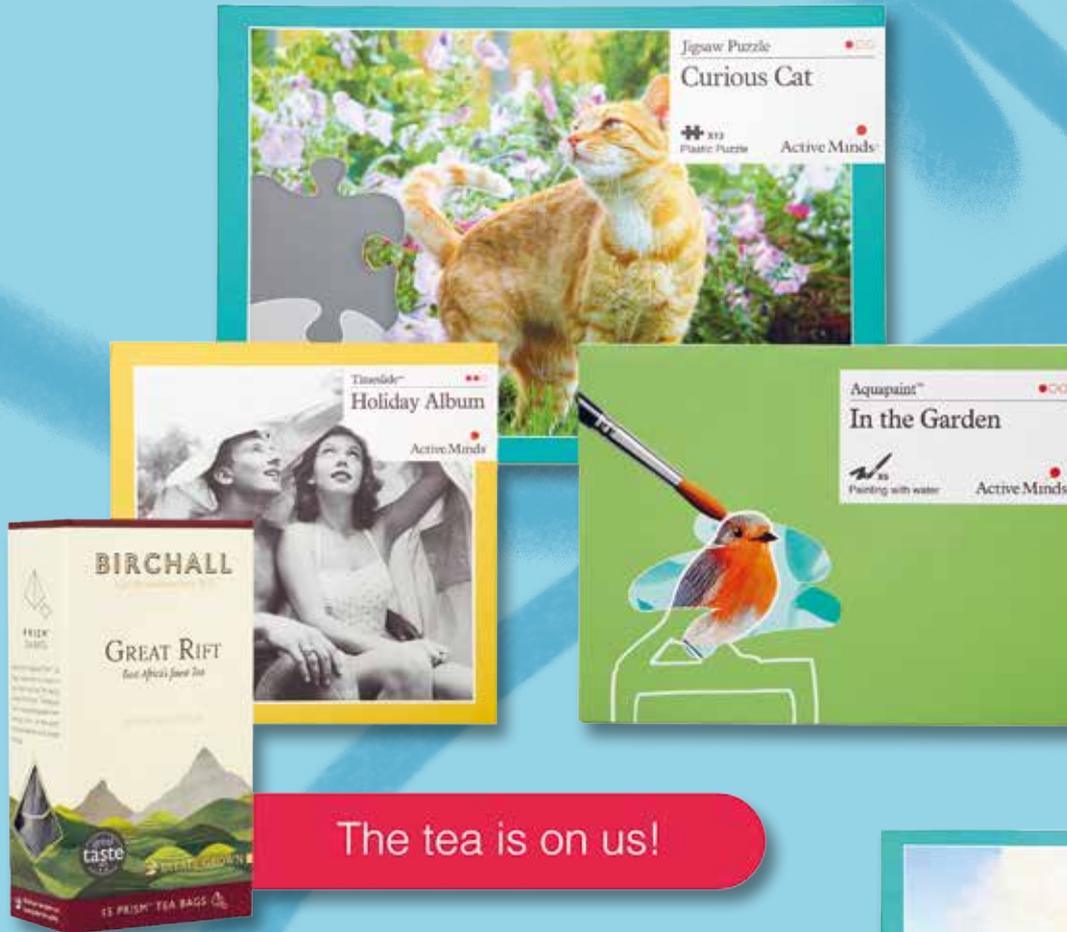
Bring Dementia Out

Alzheimer's Society has been working with people affected by dementia, LGBT+ (lesbian, gay, bisexual and trans) communities and organisations, and the National Dementia Action Alliance on Bring Dementia Out.

This innovation aims to raise awareness of the additional challenges faced by LGBT+ people affected by dementia, and to help them feel more comfortable in getting the support and information they need.

A series of resources with signposting to further support has been tested in Brighton and Hove and in Greater Manchester, and this is now being evaluated to see what impact it has had. For our LGBT: Living with dementia (1511) booklet and Supporting a lesbian, gay, bisexual or trans person with dementia (480) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).





The tea is on us!

Time well spent!

Each pack contains a selection of products, that will help encourage conversation and improve communication and wellbeing, as well as a pack of deliciously strong breakfast tea. They are the ideal way to spend memorable time together.

100% of our profits go straight back into our work, supporting people affected by dementia and ultimately finding a cure.



The tea is on us!

Shop now
shop.alzheimers.org.uk



Registered with
**FUNDRAISING
 REGULATOR**

Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645 19030SO

Beginning again

Music and theatre have provided a valuable focus for Diana Smith-Harris's positive approach since her husband's dementia diagnosis. Gareth Bracken meets a carer with a message of hope.



Quick read

Diana Smith-Harris has been sharing a message of hope and positivity following her husband's dementia diagnosis.

Eugene Harris, 66, who lives with Diana in Leeds, West Yorkshire, was diagnosed with Alzheimer's disease in September 2016.

The couple were curators for Every Third Minute, a festival of theatre, dementia and hope organised with Leeds Playhouse.

Diana, who is holding further sessions in care homes, wants to show that life doesn't end with a dementia diagnosis.

‘We understand that this is happening and we can't change it, so we just need to embrace it.’

Rather than be distraught or even downbeat about her husband's dementia, Diana Smith-Harris wants to approach it as simply another step on their journey together. Through music and theatre, the couple have been demonstrating what people can still achieve after a diagnosis of dementia.

Musical bond

Diana, 58, was a social worker for 31 years before retiring, partly to ensure that she could best support her husband Eugene, who has Alzheimer's, at their home in Leeds, West Yorkshire.

Eugene Harris, now 66, came to England aged four from the Caribbean island of Saint Kitts. He was a self-employed upholsterer, building a successful business through word-of-mouth recommendations.

‘He was a perfectionist,’ says Diana. ‘He didn't want anything coming back.’

Eugene is also a classically trained pianist who plays the keyboard and steel pan, while Diana is a singer. They met around 20 years ago after Diana filled in for another singer in Eugene's steel band.

‘I ended up staying in the band and we got together – the rest is history!’ says Diana, who has been

married to Eugene for 15 years. ‘Music was what really pulled us together.’

Feeling of relief

Eugene was diagnosed with Alzheimer's disease in September 2016, following memory problems that had started two or three years before.

‘I noticed he was forgetting things. He'd leave his van down the road and forget he was driving not walking,’ says Diana. ‘He also couldn't recall which customer each piece belonged to.’

Eugene took himself to the GP and underwent various tests over a couple of years, with a brain scan eventually leading to a diagnosis.

At the time, Diana was keen for the consultant to understand how cultural factors might affect Eugene's performance in some of the tests.

‘He was asked to recognise different types of gate, but because Eugene spent his early life abroad, his memories might be different. He may not have known different farm gates and garden gates,’ she says.

‘The consultant assured me he was sensitive to these things and had a lot of experience with patients from the Caribbean.’

Diana was actually quite relieved following her husband's diagnosis.

‘We thought it was Alzheimer's and we now knew – at least it was official,’ she says. ‘We could now



move on and look at medication to keep him going. I started to find out what groups were out there.'

No illusions

Eugene and Diana attend a peer support group run by their local authority in partnership with local cultural groups. This involves things like trips to museums and visits from music students. They are part of a monthly dementia choir and weekly walking group, and took part in last year's Memory Walk. Diana also goes to carer support sessions.

'We've just thrown ourselves into whatever's out there, life hasn't stood still,' she says.

Since Eugene's diagnosis, Diana has maintained a very positive attitude and outlook.

'I don't know where this resilience comes from, but I take it all in my stride,' she says. 'I'm under no illusions that things will get worse, but if so I'll come up with a new strategy.'

Eugene likes walking and goes out on a set route two or three times a day. He recently had a fall, which concerned Diana, but she remains determined that he be supported to keep doing the things he enjoys.

'Although I obviously wondered if he was going to be OK, I'm not going to stop him going out,' she says. 'We've just got to move on

to another day. It's nice that he can go out for the moment.'

Diana and Eugene have the support of neighbours, friends and even local businesses.

'I'll often get phone calls from people looking out for him,' she says. 'If he goes into the bank but gets a bit agitated, they'll ring me and I'll come and get him.'

Hope keeps coming

One of the partner organisations of their peer support group is Leeds Playhouse. Last year the theatre, then known as West Yorkshire Playhouse, brought together a group of curators – people with dementia and carers – to create a special dementia-related theatre festival.

Diana and Eugene helped plan and deliver Every Third Minute, which included theatre performances, live music, debate, workshops and training, held at the theatre and local care homes.

'People think dementia is all doom and gloom, that people's lives are ended after a diagnosis, but for me it's people's lives just beginning again,' says Diana. 'The word "hope" kept coming up. We wanted to give that positivity.'

The festival curators took on tasks such as vetting plays, turning to the Leeds Playhouse team when they needed help with aspects such as publicity.

'Things weren't done to us, we were involved in making them happen,' says Diana, who valued the spirit of teamwork among the curators.

'Everything was decided as a group, we gelled as a group. We made really good friends.'

The festival won a National Dementia Care Award and got great feedback from audience members.

'People said to us, "That story you told could have been my sibling or parent." They took it to their hearts and could identify with it. They liked our positivity about dementia.'

Here and now

Not wanting their work to end when the festival came to a close, some of the curators have visited care homes to hold further sessions. Eugene and another group member played music while Diana and her fellow curators led residents through singing exercises and simple activities, including a mirroring game.

'It was very well received,' says Diana. 'Care home staff said residents who never usually interact were clapping and cheering.'

'We now want to adapt it for specialist dementia groups for those with complex needs.'

In the meantime, Diana wants to continue to be as upbeat and optimistic as possible in supporting her husband.

'It's like we're going through another journey within our life,' she says. 'There's an issue but we've got to embrace the moment and live with it.'

'I just work here and now, to make it as pleasant and comfortable for Eugene as I can.'



Photograph: Anthony Robling



Photographs: Paula Solloway

Next steps

- For *Caring for a person with dementia: A practical guide* (600), see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Use our online directory to find dementia services near you – go to alzheimers.org.uk/getsupport
- Our arts guide includes practical advice for venues such as theatres to become more dementia friendly – see alzheimers.org.uk/arts

Join the club

A golf project in Lincolnshire is offering sport and social stimulation to people with dementia. Gareth Bracken swings by to find out more.

Quick read

Golf in Society is a project that provides weekly golf sessions for people living with dementia.

Players at Lincoln Golf Centre receive support and advice from trained volunteers while on the driving range and main course.

Alan Dawkins, who has mixed dementia, says he loves attending the sessions and feels very good when he's playing.

Carey, the wife of group member John Cowham, has received great emotional and practical support from the other carers.

A group of people with dementia are heading out onto the driving range at Lincoln Golf Centre to begin their weekly session. Their relatives stay behind to socialise or enjoy time together, knowing that their loved ones are happy and well looked after.

This is Golf in Society, a social enterprise that aims to improve the lives of people affected by dementia through the health and wellbeing benefits of golf.

The project, which also offers sessions for people with Parkinson's, was started in September 2015 by social entrepreneur Anthony Blackburn. He worked on the idea with England Golf – the governing body for amateur golf in the country – and Alzheimer's Society. Lincolnshire was chosen because of its low diagnosis rates and a need for programmes for people in the earlier stages of dementia.

'I doubt there are many people who would think about golf after a diagnosis, so this is quite groundbreaking,' says Anthony.

Feeling good

The group are hitting balls on the driving range, where specially trained volunteers, known as golf activators, are on hand with helpful advice about footwork

or club position. They also offer supportive comments – with the occasional exception.

'A load of rubbish! Is that the best you can do?' jokes volunteer Pip after a shot from Alan, who responds by pretending to prod him with his club.

Alan Dawkins, 82, was diagnosed with mixed dementia – vascular dementia and Alzheimer's – in May 2015.

'I've been playing with these lot every week. I love it here,' he says. 'I feel very good when I'm playing.'

He breaks off as one of the players hits a big shot. 'Oh my godfather!' he cries, as the ball flies through the air.

'Right then, gladiators,' shouts volunteer Richard Phipps, a retired mental health nurse. 'Time to go out on the course and play a bit of real golf!'

Sense of purpose

Alan has been playing golf for decades, but other group members like John Cowham are newer to the sport.

'Good grief, no!' he laughs when asked if he's always been a golfer. 'I played rugby.'

A retired teacher who was diagnosed with mixed dementia, again both vascular dementia and Alzheimer's, in July 2017, John particularly enjoys the social side of the sessions.



Photographs: Dean Atkins

'It's just good fun,' he says. 'You're with other people and they're cheerful. If they weren't, I'd be out the door like a shot.'

The men split into three groups to play a golf game called Texas Scramble, which keeps them all involved.

George Scrini, who used to play football and cricket, marked his Golf in Society debut last week by taking home the trophy for the day's 'champagne moment' – the best shot or achievement.

'I enjoy what I'm doing,' he says. 'It's people who are out here to enjoy themselves.'

Richard feels a sense of purpose among his fellow volunteers, who feel they are achieving something.

'It's so positive to see the players leave with a big grin on their face, having been able to recall some of their previous sporting or work achievements and walk out with their arms around each other's shoulder,' he says.

Pip Sykes adds, 'I don't view it as a carer taking out a patient – I greet them as friends. They're human beings, not Martians.'

Happier lives

After a successful session, the players head back to the clubhouse to be reunited with their partners for lunch and some social time.

'A lot of courses have barriers or elitist views, but we're a different kind of club,' says Andy Randall, Manager at Lincoln Golf Centre.

'This group just fell perfectly under our umbrella.'

'The plan is to be a blueprint for other golf clubs to follow.'

Alan's wife Chris agrees that some clubs can be unsuitable for people with dementia, describing them as 'intolerant'. However, this project has had a positive impact on both her and her husband.

'This is by far the most stimulating time that he has in the week,' she says. 'It might also be the only three hours that I get. Dementia is very claustrophobic – it's really hard. This is the one thing in the week that I don't want to miss.'

John's wife Carey has also felt the benefits.

'I've found it incredibly supportive. It's a group of new friends,' she says.

'Dementia carers can feel stressed. You need to be able to share that with other people. I get a huge amount of emotional support from it and practical tips from others in the same position. People understand what you mean.'

Anthony has now run over 400 sessions in Lincoln, Harrogate and Glasgow, and wants to help create dementia-friendly golf clubs in every county of the UK.

'We're on a journey that's going to make our social dream a reality,' he says. 'So many people living happier lives – that's a fantastic legacy.'



Next steps

- For more about Golf in Society, visit www.golfinsociety.com
- Use our online directory to find dementia services near you – go to alzheimers.org.uk/getsupport
- Visit alzheimers.org.uk/dementiafriendlycommunities for more about dementia-friendly communities.

Not a frightening place

A hospice in Darlington has been improving its care and support for people affected by dementia. **Gareth Bracken** visits an organisation embracing a new culture.

Quick read

St Teresa's Hospice in Darlington has improved its dementia care and support by focusing on a series of commitments.

The hospice has been working with its staff so they can provide more individualised care, as well as making changes to the environment.

Many staff and volunteers have completed specialist training, and over 300 have also become Dementia Friends.

One carer felt relaxed when their loved one was at the hospice because they knew he was being looked after.

As part of its aim to reach as many people as possible with its support and services, St Teresa's Hospice, in Darlington, launched a dementia strategy last year.

Using guidance published by the charity Hospice UK and feedback from patients with dementia, carers and its own workforce, St Teresa's created key commitments to focus on.

'I remember hearing 20 years ago that hospices don't care about people with dementia, but that attitude has completely turned around as the condition becomes recognised as a palliative illness,' says Jane Bradshaw, Chief Executive at St Teresa's.

'We put this strategy together to show our commitment to helping people instead of writing them off.'

Better care

Since last summer, St Teresa's has made great progress in educating and raising awareness among its staff.

Ongoing training in areas such as communication and patient assessment has been introduced, including a programme delivered by Alzheimer's Society. Dementia Friends is also now a requirement for all staff and volunteers, with over 300 having joined so far.

'There was maybe a fear among some staff and volunteers that all people with dementia were aggressive and challenging,' says Alison Marshall, Head of Care.

'But they are now confident that they have the skills and awareness to support patients in different areas. Our care has improved and we're seeing how we can meet people's needs differently.'

Being flexible

The hospice has also been finding ways to help its staff recognise people's individual and changing needs, and to be able to meet them.



‘There are simple things you can do, like finding out whether the person wants to be in a quiet or busy room, or not overloading them with questions,’ says Sheila Dawson, a Nurse Consultant. ‘You try different ways to communicate.’

Most of the hospice’s patients with dementia use their day hospice, but some in the later stages of the condition come in for help in managing symptoms.

‘Usually after a few days a person will go back home, but sometimes we’ve kept people here for weeks because it’s too stressful for them to move – it’s being flexible,’ says Sheila.

Carers are also offered services such as support groups and complementary therapies.

Just the start

Externally, St Teresa’s is part of a group of hospices who share education on dementia. It has also developed links with the Society and local care homes, making each other more aware of their respective services.

Hospice staff have also delivered specialist training to care home workers.

‘This is just the start for us,’ says Diane Farrell, Head of Workforce Development.

‘People have realised we’re open for business but now we’ve got to make more links within the community.’

Another commitment has been to make the hospice a more dementia-friendly environment. Better and brighter signage has been introduced in parts of the building, with plans to extend this throughout.

Such a difference

Feedback from the families of people with dementia who have been at the hospice shows that all of this work is making a real difference.

One carer said, ‘When he went into the inpatient unit, the board on the wall had a drawing and welcome message. It was such a good idea and made such a difference when we arrived.’

‘I felt relaxed when he was at the hospice, as I knew he was getting looked after.’

Another relative said that their wife ‘loved coming to the day hospice’, where she could have a manicure and a massage. She later had a hospice befriender who she looked forward to seeing.

A different carer said that his loved one enjoyed the hospice

experience, as she could mix and interact with people, and talk to staff if she needed anything.

‘The staff cared for me as well,’ said a fourth carer. ‘As soon as they had seen to my mam they looked after me and made me comfortable.’

Culture change

Jane believes that the hospice’s dementia strategy has brought about positive change at St Teresa’s.

‘Our staff have always been incredibly caring and extremely patient-centred, but I do notice that some of the conversations about dementia have changed – there’s greater sympathy,’ she says.

Diane agrees. ‘We’ve changed the culture,’ she says. We still have a long way to go, but we’re heading in the right direction.

‘We’re blowing away myths. People now come to the hospice and realise that it’s not a frightening place.’



Next steps

- Our ‘This is me’ leaflet shares a person’s preferences – visit alzheimers.org.uk/thisisme or call 0300 303 5933 (local rate) for a free copy.
- Become a Dementia Friend or Dementia Friends Champion – find out how at dementiafriends.org.uk
- For our End of life care (531) factsheet, go to alzheimers.org.uk/publications or call 0300 303 5933 (local rate).



A letter about unfair travel insurance premiums, and posts from social media and our online community.

Letter of the month

Unfair travel insurance

I am writing to enquire whether other readers have experienced what I consider to be grossly unfair penalties for people with dementia who wish to travel abroad.

My husband, who has dementia, and I have booked to go to France by train to stay with our daughter for a week in April this year. Investigating travel insurance, I found that my husband is uninsurable as a single traveller, even though he would be accompanied at all times. Most companies would only insure us on a 'single trip' policy, rather than annual cover, and some refused to insure us at all. The cheapest premium for me was £10, while the cheapest for both of us was £176.

My mother, who is 84, with multiple sclerosis and using a mobility scooter, travelled to Israel for 10 days last year with a single traveller insurance premium of just over £100. She needed someone with her, is more overtly disabled, and was travelling for a longer period, over a greater distance and to a more challenging country.

I am really saddened by this. The insurance has cost almost more than the travel tickets, and it makes me question whether I will be able to take my husband to see our daughter again, at a time when contact with the family is so precious. I would like to know if others have had similar experiences.

Mrs Suzanne Martin, Kent

Congratulations to our letter of the month writer, who will receive a bouquet of flowers.

It's frustrating when we know how beneficial it can be for people with dementia to continue to travel, only to be discouraged by increased costs. We're working with many sectors, including the financial sector, to help them become more dementia friendly and remove unfair barriers.

In the meantime, MoneySavingExpert.com includes information on travel insurance for those with pre-existing conditions. For our **Travelling and going on holiday (474)** factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Pension age change: Impact on benefits

A rise in the state pension age will mean that fewer people can claim Attendance allowance (AA) or Pension credit, though those already receiving them will continue to do so.

Since December 2018 the state pension age for both women and men began to increase, and it will reach 66 by October 2020. People starting a new claim for AA or Pension credit must be over the state pension age.

People under this age may be able to claim Personal independence payment (PIP) if they need help with daily activities or moving around.

If someone is eligible for a disability benefit such as AA or PIP, their carer may be able to claim Carer's allowance and they might be able to pay less Council tax. Extra money (premiums) in Guarantee pension credit is also linked to disability benefits.

Contact Citizen's Advice or Age UK for a benefits check, and for our Benefits for people affected by dementia (413) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Your turn

Tell us what you think – email magazine@alzheimers.org.uk or write to the address on p3. Letters for the June/July issue to arrive by 7 May. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Seen elsewhere...



When members were still able to make light-hearted asides in the midst of a serious discussion on Talking Point – see alzheimers.org.uk/talkingpoint – Maryland, a member of the online community who lives in County Durham, said:

“Thank goodness for this site. Sometimes when I have had a bad day like today, it does you good to know that you are not alone with this. Thank you everyone. ”



On Twitter, Dementia Friends Champion Patrick Gray thanked staff at Lantern Coffee House in south London following an after-work information session:

“Thanks to the lovely staff of @lantern_coffee house in Raynes Park who welcomed me last night for an after-hours @DementiaFriends session. A real commitment from them to help make their community more dementia friendly. ”



After we shared the sad news about the death of Gordon Banks, England's World Cup winning goalkeeper and Society Ambassador, on Facebook, Emily Woodward in Derbyshire commented:

“I had the great pleasure of working alongside Gordon during my time with the Society and I can say he was truly one of the kindest, most humble people I have ever come across. He had time for everyone, a true gentleman. ”

**We want your lines,
Whether they rhyme
Or not.**

Poetry competition 2019

Our fifth poetry competition is open to entries until 30 June, and we'd love to receive your poems in these three categories:

- **Change** – What do you want to say about dementia and the people affected by it that might challenge others to change?
- **Share** – What do you want people to understand about dementia's real-life impact?
- **Celebrate** – Honouring the life stories and memories of people with dementia.

Our panel will agree a shortlist, and winners will be selected by a guest judge and published in the magazine.

Each poem should take up no more than one side of A4 and should not have been published in print before. We can only accept one entry per category from each person, and poets retain copyright. The poet must have given consent if a poem is submitted on their behalf.

Email your entries – remembering to say which category each is for – by 30 June to magazine@alzheimers.org.uk or post to the address on p3.



Sylvia Bouskill
Lancashire, aged 74
with mixed dementia –
Alzheimer’s and
vascular dementia

What’s changed most since your diagnosis?

Initially loss of confidence, but now I’m fighting back. I’ve been trained as a ward sister to have control and it’s difficult dealing with uncertainty.

I’ve been a Street Pastor in my local town centre for 10 years – trained volunteers from local churches who care for, listen to and help people out on the streets at night. I don’t do it as often as I used to because I have physical health issues as well as dementia.

What would you take to your desert island?

Ella Fitzgerald on CD. She’s such a blessing to me, I love the way she sings.

How has Alzheimer’s Society helped you?

Alzheimer’s Society has made an incredible difference from the start by being available to listen, help and point me to things I might like to get involved with. They were there for me immediately after my diagnosis.

If you could go back in time, where would you go?

The 1950s, when I could hopefully do a lot of things better. One memory that came to me was my grandma and her second husband. I don’t have many regrets, but looking back I didn’t respect them as I should. It wasn’t that I didn’t love her – I just got tied up with my own life.

What is your most treasured possession?

My faith. It defines everything in my life – without God, I’d be nothing.

If you have dementia and would like to answer our questions for a future column, email magazine@alzheimers.org.uk or write to the address on p3.

It’s been a while since we’ve seen Ma, but her northern granddaughter keeps us up to date with stories and photos, including one of Ma beaming beside a snowman in their little yard – her complaints about lacking a garden dispelled temporarily at least.

Every Monday she sees her regular carer and friend, and they often go to the park for a walk and a cup of tea.

Her misconceptions seem to be on the increase, as she becomes convinced of increasingly unlikely scenarios.

Last Saturday she got up even later than usual, around midday, putting her in a really bad mood, glaring at everyone she came across. Her granddaughter usually gets the brunt of these, and Ma blamed her for ‘coming into my room in the morning and telling me to stay in bed!’

She often brings Ma a cup of tea in the morning, but she’d not that day. She thought Ma had been having confusing dreams and so let her rest instead.

On another occasion, Ma was keen to tell the family that she had bumped into Boris Johnson that day in Northern Ireland (where she lived at one time) and that he was ‘alright’.

Although these are often a source of some amusement, the family knows they are real to her. Ma continues to benefit from being part of a busy and loving household where people come and go, and she has a ‘real job’ that she can enjoy – endless ironing!

Dilly, a daughter-in-law

(continued next issue)



**Read more from Life with Ma
and many other blogs at
blog.alzheimers.org.uk**





Join an epic 13 or 26 mile trek this summer in one of six breath-taking locations.

It'll be tough, but you've got what it takes.

Sign up now
alzheimers.org.uk/trek26



Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity no. 296645

Challenge yourself.
Take on dementia.





People with dementia in Cambridgeshire look at new products being developed to help keep track of when it is and where you are.

Time and place

Peterborough’s Open Minds group tried out some reminder products for us last year, and Ravencourt – the manufacturer of one of them – is developing a new model in light of their feedback.

We returned to the Dementia Resource Centre, where this group of people with dementia meets every week, to show them a new version of the Rosebud reminder clock. We also took along a GPS locator device to see what they thought of that. Oli Story – Ravencourt’s Managing Director – accompanied us to answer people’s questions about both products.

Rosebud reminder clock

The Rosebud reminder clock has a large, clear display that shows the time and date in a number of formats. You can also set reminders with sounds, pictures and even video, choosing from those supplied or creating your own.

Open Minds had previously said the reminder sounds may not be heard in the next room, so the new version being developed by Ravencourt has a volume control. While people at the other end of the group’s long meeting room had to listen out for a reminder at its lowest volume, everyone could hear the loudest even when it was coming from a side room.

Whereas you could only set daily or one-off reminders before, the new Rosebud includes options for them to go off daily, weekly or on a future date, such as for a haircut in three weeks’ time.

It also now changes to British Summer Time and back again automatically. Norma wanted to know whether it would take leap days into account, and Oli assured her it would.

Frank said he has a clock with a similarly clear display at home and found it useful to see each morning. Colin was impressed with the Rosebud’s reminders, saying,

‘I think it’s brilliant – I get very confused sometimes.’

Oli wanted to hear what the group thought of a second version of the clock with a metallic instead of white plastic finish. Although people differed about how different the metal and plastic actually felt, most preferred how it looked.

GPS locator

Ravencourt had asked Alzheimer’s Society for feedback on a new safer walking GPS device they are developing. A person with dementia can carry this with them and use it to let someone else know where they are. This could be when the person needs help and presses an SOS button, or when they go outside an agreed area that they’re familiar with.

To test it, Jon from our online shop took the device outside and had a walk around. When he pressed the SOS button, Oli got an alert through an app on his smartphone, which everyone could





hear. This sounded very different to usual ringtones, so you'd know it was urgent even if you were ignoring most calls and messages.

When Jon pressed a button on the device to speak, we could hear him in the room through Oli's phone, and he could hear Oli's reply. Using his phone app, Oli could see where Jon was on a map.

The group had a closer look at the device after Jon returned. One member liked the fact that pressing the SOS button was easy if you needed it, but difficult to do accidentally – a problem he'd had with another device that kept going off in his pocket.

Everyone agreed the silver button was visible on the black device, and Valerie was pleased the locator would come in a range of other colours too.

Norma joked that carrying a similar device meant her daughter could tell when she was in the pub! This underlined a more serious need to be clear about

who you've said can see where you are – and if a person isn't able to decide this for themselves, that the decision made on their behalf is in their best interests.

Norma said she had got her device for free, and Jon said people should find out what they can get funded for locally before buying products themselves, as this varies widely.

The device can be kept on a keyring or in a pocket or bag, but Dougie was glad to hear it can also be worn on a lanyard around your neck – something he uses to avoid losing keys. Barry said he'd prefer to be able to wear it on his wrist, which Oli said his company is looking into.

One person asked where the device would work – how far from the person who it was set up to help find you? Oli said wherever the device's SIM card would work, so anywhere in Europe. If you went somewhere without a signal, then the person would be able to see

the last place you were that had one and when you were there.

Some people thought a 'safer walking device' sounded more like something to stop you from falling over. Their suggestions for other names included 'pathfinder', 'keep in touch' and 'keep safe'.

The safer walking device is still in development, but the new Rosebud reminder clock, with metallic finish and new features, is available from our online shop exclusively from April for an introductory price of £69.99 without VAT – the same price as the existing clock in black or white (you don't have to pay VAT if it's bought for use by a person with dementia or other condition). See shop.alzheimers.org.uk or call 0300 124 0900 (local rate).



See p39 for a chance to win a Rosebud reminder clock.



'I want to arrange my finances for when my dementia means I'm not able to deal with them, but I don't have anyone I could appoint through an LPA.'

Professional attorneys

In England and Wales, a lasting power of attorney (LPA) is a legal document appointing someone to look after your finances if you aren't able to do that in future (you can also create an LPA for health and care decisions). In Northern Ireland you can set up an enduring power of attorney instead, but only for finances.

Most people appoint a trusted family member or friend as their attorney. However, not everyone has someone suitable and willing to do this, or you might want to appoint someone who isn't involved in family disagreements.

Another option

It's possible to appoint a 'professional attorney', who would expect to be paid a fee. This would normally be a solicitor, accountant or financial adviser.

You could also appoint a professional attorney to act together with a family member, or to only take the role on if your first choice isn't able to.

A professional attorney can charge for their time as well as for expenses, whereas a family member or friend can only claim for expenses. The law also sets higher standards for how professional attorneys behave.

Who to pick?

It's important that you trust whoever you choose, as you are agreeing to give them control over your money and property.

You may have a solicitor, accountant or financial adviser who already knows you well, but you can choose someone new if you prefer.

It's a good idea to meet them – at least once – to see what they're like, and to allow them to get to know you and understand what is important to you.

You could also ask about their skills and any experience they have of acting as an attorney.

How much?

Appointing a professional attorney is a big financial commitment. You should ask for detailed information about costs, which could include examples of typical fees in different scenarios. Bear in mind that their rates may change over time.

Don't hold back – ask as many questions about fees as you need to in order to feel comfortable about what you are committing to pay.



For our Lasting power of attorney (472) factsheet or NI factsheet: Enduring power of attorney and controllership (NI472), see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Solicitors for the Elderly could help find a solicitor with relevant experience – visit www.sfe.legal or call 0844 567 6173 (call costs vary).

The Society of Later Life Advisers may help in finding an accountant or financial adviser – go to www.societyoflaterlifeadvisers.co.uk or call 0333 2020 454 (local rate).



Photograph: Georgi Malhele



Q&A sessions on our online community are an opportunity to get an expert opinion about a situation.

Questions and answers

Talking Point, our online community, is a place where you can share experiences and advice – or simply let off steam – with other people affected by dementia. You can also ask experts questions through the community’s Q&A sessions, which focus on a different subject each time.

These sessions happen live at a scheduled time and date, but you can also take part by asking questions in advance, and you can read answers and comments afterwards as well.

Chance to ask

Q&A sessions provide a great opportunity to get an expert’s take on a specific question.

For example, in a recent session Angelo Makri from our Knowledge Services team, who focuses on wellbeing, answered questions about how carers can look after themselves. People asked him about coping with guilt, organising replacement (or respite) care, communicating how you feel to family and friends, and caring for someone else when you have a health condition of your own to manage.

Other Q&A sessions have looked at paying for residential care, loneliness, medication, lasting powers of attorney and managing money.

The expert is often someone from the Society, but we include people from other organisations too – another recent session about living with dementia and cancer featured a Macmillan nurse who specialises in dementia.

Free to join

Upcoming sessions are usually announced on Talking Point a week beforehand.

Anyone can see all of the questions and answers, not only while the session is happening but also after it’s finished. To ask a question and take part, you need to become a member of the online community – this is free, and it’s perfectly fine to use a made-up name to do this.

You can post a question either before or during the session, and the expert will reply directly on the day. If you’d prefer to ask a question anonymously, you can email the Talking Point team for them to ask on your behalf.

Whether or not you join Q&A sessions, you will find plenty of support on Talking Point from thousands of people who understand what you are going through.



Take part

Talking Point is free, open day and night, and you only need an internet connection to read conversations and start your own. Visit alzheimers.org.uk/talkingpoint



We hear about a husband's account of caring for his wife, whose stroke was followed by a diagnosis of dementia.

Extreme caring

Stuart Donnan wrote this book – *Extreme caring: You have to go on* – to share his experiences of caring for his wife Beryl after her stroke and later dementia diagnosis. It was published three years ago, in the same year that Beryl died.

Caroline Branney, who manages our Dementia Knowledge Centre, says, 'When his wife had a stroke in 2000, Stuart started on a journey of learning to understand and manage her needs and the complex side effects of the stroke. Beryl was also diagnosed with dementia 10 years later. This book is Stuart's account of how they lived with the impact of these health issues.'

Stuart, a medical academic, first met Beryl in Australia, where they both grew up. They moved to England together in the 1960s, where they eventually settled after spells back in Australia and in Hong Kong.

'A large proportion of the book describes the life they have led since 2000 and the practical and emotional issues they faced,' says Caroline. 'The second half is more reflective, exploring the meaning and ethics of this experience.'

Janet Sellars, a reader in East Yorkshire, says, 'It was both easy and difficult to read! It was well written about his wife's problems, with some funny bits and some heart-breaking parts too.'



The book's detailed contents page and clearly marked chapters and sub-sections make it easy to pick up again and refer to.

'It allows the reader to dip in and out of the book easily and return to bits to re-read quickly,' says Caroline.

Words and silence

Beryl's stroke impaired her ability to process language and produce speech – known as aphasia – but she still found ways to express herself.

'Although her aphasia slowly improved,' says Caroline, 'she never recovered her fluency. Beryl was recorded in an interview in 2005 and much of the book is based on that.'

When Beryl was diagnosed with dementia, she and Stuart had to face additional challenges of stigma and lack of awareness.

'Stuart admits that, even as a medical academic, he didn't like the term "dementia" and its associations. He is aware of the stigma that can still surround the condition,' says Caroline.

'Themes covered include the importance of music and art in their lives and how even silence – such as in a meditation session – can be enjoyed together. 'There are some examples of how Beryl regularly surprised others by her choice of apt words and her responses even though she could hardly speak.

'Although Stuart does talk briefly toward the end of his book about how Beryl was before her stroke, I think it would have been more interesting if we had learnt more about her at the start.'

Endurance and help

The book's title underlines the stresses of caring, and Stuart's story demonstrates the need to get whatever help and support is available.

'The term "extreme carer" has been taken from the idea of extreme sports,' says Caroline. 'Stuart describes caring as a feat of endurance, with many ups and downs.'

Janet says, 'He doesn't hide the fact that both his patience with and his love for his wife of many years was stretched to almost breaking point at times over the years of "extreme caring".'

'He acknowledges how this can be unsustainable,' adds Caroline. 'He found that the stress meant he had to seek help and respite at various stages, and eventually Beryl was admitted into a care home.'

A Lee in Greater London, speaking from her own experience of dementia, says, 'The book is very good, and I will tell a friend who has a family member with Alzheimer's to read it.'

Extreme caring: You have to go on, by Stuart Donnan (DestinWorld, 2016), 252 pages, £9.99, ISBN: 9780995530706.

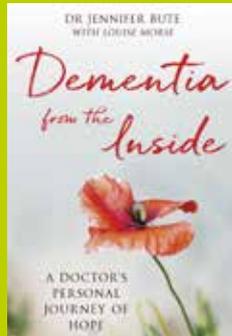


Your turn

For the next issue, we invite you to read *Dear Alzheimer's: A diary of living with dementia*, by Keith Oliver (JKP, 2019), 352 pages, £12.99, ISBN: 9781785925030.

Let us know what you think about this insight into life with dementia by 6 May, so we can share it in our next issue. Email magazine@alzheimers.org.uk or write to the address on p3. *Dear Alzheimer's* is also available in our online shop – see shop.alzheimers.org.uk

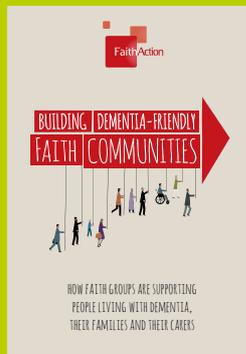
Spirituality and dementia



Dementia from the inside

Jennifer Bute was working as a highly-qualified doctor when she was diagnosed with early-onset dementia in 2009. In this book, she draws on her personal experiences and insight, interwoven with her faith, to offer hope to people affected by dementia. This is a rare insight into dementia by an experienced clinician.

Dementia from the inside: A doctor's personal journey of hope, by Jennifer Bute and Louise Morse (SPCK, 2018), 192 pages, £9.99, ISBN: 9780281080694.



Building dementia-friendly faith communities

This booklet is a collection of examples about how faith communities from different traditions are supporting their members who are affected by dementia, either directly or indirectly.

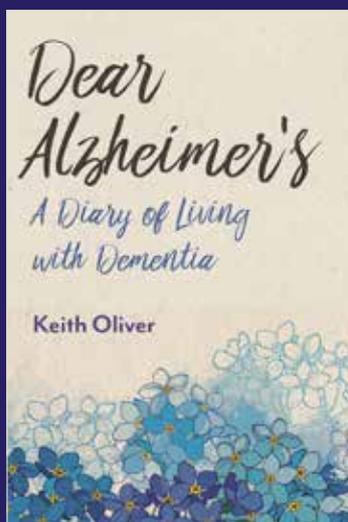
Building dementia-friendly faith communities: How faith groups are supporting people living with dementia, their families and their carers,

by Rodie Garland (FaithAction, 2018), 28 pages, £6.59 print or free download from www.faithaction.net/dementia

Dementia-friendly faith groups

Find out more about supporting people with dementia to continue practising their faith on our website, with links to specific information for different faith communities.

Visit alzheimers.org.uk/faith



Book giveaway

We have five copies of *Dear Alzheimer's* to give away – email magazine@alzheimers.org.uk or write to the address on p3 by 18 April quoting 'Diary' for a chance to win one (see p39 for terms and conditions).



Talking Point members and readers on supporting a person with dementia after they've had a fall.

After a fall

'These things happen – my wife has had a few falls while I've been right beside her. They can happen so unexpectedly that it's impossible to prevent them.'

'My wife fell heavily onto her knee a few days ago and that night woke up screaming, as she felt pain and had no idea what was happening because she hadn't any memory of any fall. Luckily, things have settled with my wife.'

'These things are tough to handle, and my heart is broken with it, but we can only do our best.'

karaokePete

'After a fall, arrange an examination by a GP who can review any medication to ensure he/she is not suffering any side effects from drugs and examine to exclude infection.'

'Referral to a falls clinic may result in physiotherapy and assessment for any walking aids. A home visit from one of the falls team can check the residence to make sure there are no tripping hazards. Grab rails, raised toilet seat etc can be fitted where needed to reduce the chance of further falls.'

A reader in London

'One or two falls last summer affected [my mum's] mobility, but... she would still try, and even in bed at night it looked like she was peddling on a bike or doing the can-can. This started in her last year, but at least she stayed in bed.'

'It was hard, but I had to accept that because of the restlessness there was a high risk of a fall, even though I had eyes on her 24/7. I did restrict her access to certain rooms and moved a lot of furniture into the garage, my aim being to make it as trip-free as possible.'

Tin

'At a minimum, speak to the GP as soon as possible to rule out any change in health that might be underlying the falls. I'd also speak to social worker and a community team [in case the person] may need extra support. Keep a diary of falls and when they happen.'

Careroncoffee

'My mother's care home is just dementia care, not nursing, but they deal with lack of mobility, continence requirements etc. There are residents there who are moved with a hoist, others who need a carer to help them mobilise, and there seems to be no problem with that. My mother fell and broke her hip during the summer and they had her back within 10 days to help her regain her mobility.'

Sirena

'The truth is that falls happen and, even with the best precautions and someone right there, they can't all be prevented. You could ask for a pressure mat or bed alarm.'

Amy in the US

Visit alzheimers.org.uk/talkingpoint to read the full thread and join our online community.

Next issue

What advice would you give someone caring for a person with dementia about making time for themselves? Email magazine@alzheimers.org.uk or write to the address on p3.



Making cupcakes



You don't need the skills of a Great British Bake Off winner to take part in Cupcake Day on 13 June. It can be an excellent way for a person with dementia to get involved in making and decorating cakes, even as the condition progresses.

People with years of baking behind them could revel in the chance to share their expertise. Others may have rarely been near an oven, but might enjoy trying something different. Even if a person isn't able to take part in the whole process, doing particular stages could be fun, whether on their own or with someone's support.

Icing and cake aren't the healthiest everyday foods, but they make a good occasional treat. If someone needs to take greater care with what they eat, you can also find healthier recipes online, including for low fat or low sugar cupcakes.

Cupcakes are versatile – you can flavour and colour the cake and the icing, and decorate them with all sorts of toppings. Choose these by taste and texture, or to suit a theme, such as favourite animals, travel destinations or even films.

Making an event out of eating cupcakes, with room or table decorations and even games, could also be enjoyable – see cupcakeday.org.uk for inspiration!

Many ideas are included in our guide *Taking part: activities for people with dementia*, at a reduced price of £10 plus postage from our online shop – see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

New carer's guide available free of charge

Caring for a person with dementia: A practical guide is for anyone who provides the main support for a person with dementia.

This guide will help you to:

- understand dementia
- support someone living with the condition
- learn about your own rights
- look after yourself.



To order call **0300 303 5933** quoting code 600 or email orders@alzheimers.org.uk

If you or someone you know has questions or concerns about dementia, we are here for you.

Talk to us

Our National Dementia Helpline can provide information, support and guidance.

Call **0300 222 1122** 9am–8pm Monday to Wednesday, 9am–5pm Thursday and Friday, 10am–4pm at weekends or email helpline@alzheimers.org.uk

Talk to others

Talking Point is our online community for anyone affected by dementia open 24–7.

Visit alzheimers.org.uk/talkingpoint

Find the information you need

Our wide range of publications provide information about all aspects of dementia and dementia care.

See alzheimers.org.uk/publications

Support near you

Search our online services directory by postcode, town or city to find information about services and support groups in your local area. Go to alzheimers.org.uk/dementiaconnect

alzheimers.org.uk
alzheimers.org.uk/facebook
alzheimers.org.uk/twitter

'I can't tell you how much it has meant to me to have good in-depth information. You have made such a difference in our lives.'

Carer





Rosebud reminder clock

We have the new Rosebud reminder clock, with metallic finish, for one lucky winner and Talking time pals – keychain devices that announce the time and date – for two runners-up drawn from correct entries received by 3 May.

Q: If you experience memory problems, it would not be helpful to:

- A. Try doing one thing at a time, breaking tasks down into smaller steps.**
- B. Keep the problems you're having to yourself, without ever telling anyone else.**
- C. See if memory aids or tools – whether high or low tech – could help.**

Send us your answers with your name and address – email magazine@alzheimers.org.uk or post to the address on p3.

Terms and conditions for competitions and giveaways Competitions are free to enter and open to residents, aged 16 and over, of the UK, Republic of Ireland, Isle of Man and Channel Islands. Winners will be drawn randomly from entries received by midnight on the end date and results are final. Winners will be notified soon after and announced in the following issue. Prizes are subject to availability, and will be sent by Alzheimer's Society or our supplier.

Nature pack competition

A Carroll in Lincolnshire won a Spring Nature pack, and K Murray in Greater Manchester, J Dandy in Lancashire, M Wilcox in Cardiff and C Cross in Cambridgeshire each won a Spring Nature Explorer. Answer: The pioneering Victorian and Edwardian era naturalist who campaigned for women to have full fellowship of learned societies was Marian Farquharson.

Running top competition

M Wilcox in Cardiff won an Alzheimer's Society running T-shirt. Answer: Records of competitive racing date back to the Tailteann Games in Ireland in 1829 BCE.

Extreme caring giveaway

The five readers who each won a copy of Extreme caring, by Stuart Donnan, were E Bernstein and A Lee in Greater London, S Breen in Greater Manchester, A Waspe in Suffolk and J Sellars in East Yorkshire.

Cupcake Day apron



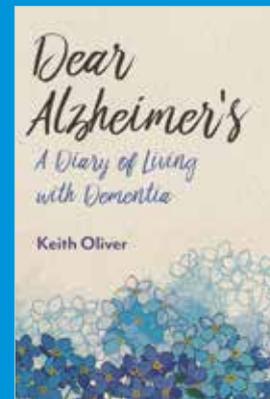
We have a Cupcake Day apron for one winner and Cupcake Day tea towels for two runners-up drawn from correct entries received by 10 May.

Q: Cupcake Day is on 13 June, and you can host a Cupcake Day event on:

- A. 13 June and no other day.**
- B. 31 June and no other day.**
- C. Any day that suits you.**

Book giveaway

See p35 for a chance to win a copy of Dear Alzheimer's by Keith Oliver.



Poetry competition

See p27 to enter our Poetry competition 2019.



Rise to the challenge and bake to beat dementia

Sign up for your free
fundraising kit at
cupcakeday.org.uk

0300 222 5770

cupcakeday@alzheimers.org.uk



Alzheimer's Society is a registered charity in
England and Wales (296645); the Isle of Man (1128)
and operates in Northern Ireland.



13 June 2019
**Cupcake
Day**