

Dementia together

August/September 2019
Alzheimer's Society's magazine

Art from the heart
Pottery pals

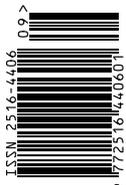
Home comfort
Leaving hospital



Whole new world
Navigating change

Also in this issue
Social care crisis
Memory Walk
Music and radio

40 years
2019

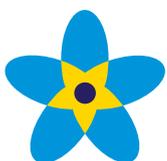


How I am now
Finding acceptance



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An Alzheimer's Society initiative



**Alzheimer's
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Dementia



Welcome

September is World Alzheimer's Month, and as we come together for Memory Walk this autumn, it's another reminder that dementia can affect anyone. By recognising this and uniting against dementia, we can make a difference for people living with the condition and, ultimately, beat it.

Our magazine shares ideas and real-life stories to help us do that. We want everyone who could benefit from this magazine to be able to get it, so make sure your friends, family members and colleagues know how to subscribe (see below).

I'm sad to say that this issue includes the final instalment of Life with Ma, our popular column from Dilly, a daughter-in-law, that we've featured since May 2012. We're planning to introduce some new types of article at the end of the year, and of course your feedback and ideas remain welcome in the meantime.

Danny Ratnaike, Magazine Editor

Questions about dementia? See p38

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

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Dementia: Disability rights

A report by MPs and Peers from across the political spectrum is highlighting how the rights of people with dementia are not being met.

This follows an inquiry by the All-Party Parliamentary Group (APPG) on Dementia – a cross-party group supported by Alzheimer’s Society. It found that people living with dementia are treated differently to people with other health conditions or disabilities. This is despite dementia being recognised as a disability, with the rights that come with that, in our own laws and internationally.

The report says that everyone needs to recognise the rights of people with dementia, including the public, employers, governments and public bodies.

Hilary Doxford, a Society Ambassador who has Alzheimer’s, attended the launch of the report at Westminster. She is one of the members of the 3 Nations Dementia Working Group who also take part in the APPG.

We will campaign with national and local decision-makers to deliver the report’s recommendations, which cover transport, housing, employment and more.

For more about the APPG and the report, see alzheimers.org.uk/appg



Social care crisis

A photo exhibition at Parliament has shown MPs the human cost of the social care crisis.

Dementia care: The crisis behind closed doors, organised by Alzheimer’s Society, featured the images and stories of 12 families who have struggled to access affordable, good quality care.

After walking through the exhibition, 94 MPs signed a letter to the future Prime Minister, asking them to address the issue of dementia care by including a Dementia Fund in the next Spending Review.

Alzheimer’s Society is calling for a £2.4 billion Dementia Fund to cover the additional social care costs that people face because of the complexity of dementia and its impact.

Alzheimer’s Society secured a new commitment from the Labour Party front bench in support of the fund, when the Shadow Minister for Health and Social Care called for its introduction during a recent debate.

Help make the Dementia Fund a reality by signing a public letter to the future Prime Minister at alzheimers.org.uk/fixdementiacareletter

Music memories

We want to bring music to more people with dementia for this year’s BBC Music Day.

Taking place on 26 September, BBC Music Day is an annual celebration of the power of music to change lives. It features live events and performances across the UK involving famous musicians, choirs and local community music groups.

To mark the event, Alzheimer’s Society will be encouraging the people we support to use BBC Music Memories, a website that uses music to help people with dementia reconnect with their most powerful memories.

Visit www.bbc.co.uk/musicmemories

Santander support

Since launching in January, our partnership with banking firm Santander UK has gone from strength to strength.

Santander employees have raised over £200,000 and counting, taking part in team and individual challenges, as well as holding Cupcake Day events. Many will also join this year’s Memory Walk, where Santander is our lead sponsor. Hundreds of the bank’s employees have also become Dementia Friends.

Over the next three years, we’re helping Santander to better serve people with dementia as the bank works to make its online and branch services more dementia friendly.

Dementia Connect: Here for everyone

Our new Dementia Connect service, designed so that everyone affected by dementia can get the right support at the right time, is on track to be available across all of England, Northern Ireland and Wales by 2022.

Dementia Connect combines our face-to-face, telephone, print and online support and advice, and we keep in touch as people's needs change. It also brings people with dementia together with volunteers through Side by Side, so they can continue doing the things they love in their community.

We've been introducing Dementia Connect gradually to make sure we're implementing it in the right way, beginning with East Lancashire, Birmingham and Solihull, and selected areas of Wales.

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

Bring Dementia Out

Alzheimer's Society is sharing what we've learnt from an innovative project to help lesbian, gay, bisexual and trans (LGBT+) people affected by dementia get the information and support they need.

Earlier this year, we involved LGBT+ people with dementia, carers and a range of organisations in Bring Dementia Out – a project that explored how best to address the unique challenges that dementia brings for LGBT+ people.

A video featuring real-life stories, an advice booklet and a website, with links to advice and support, were tested in Brighton and Hove and in Greater Manchester. This reached LGBT+ people affected by dementia, increased awareness within LGBT+ communities and improved understanding among health and social care professionals.

Partner organisations such as LGBT Foundation and National Dementia Action Alliance are now exploring the best way to build on this work more widely.

Patrick Etnenes, a gay man with dementia who was involved in the work, said, 'I feel excited about Bring Dementia Out and that it will be the new path that sets the wheel of change in motion.'

On the one hand, we know that exercise and social contact are good for people with dementia and their carers. On the other, Alzheimer's Society has our biggest ever programme to fund research into dementia. How do these two facts come together?

You've got it – it's Memory Walk, with events across Wales, England and Northern Ireland this September and October.

Whether it's a 2–10km Memory Walk, a longer Memory Walk Plus, a nighttime GLOW walk or one of the hundreds of smaller walks held by our amazing supporters, all have three things in common.

First, they are not about being super-athletic (unless you want to be). Young and old, living with dementia or not, everyone is welcome to join in healthy exercise at a speed and length to suit you.

Second, the walks are an opportunity to meet old friends and make new ones. You can be very sure that everyone there wants to make a better world for people affected by dementia.

Third, they are vital fundraisers. Only through your contributions can we keep expanding the support we offer today and fund more research to offer hope for the future.

So, for your health and wellbeing and to help support everyone affected by dementia, I look forward to seeing you at one of our Memory Walks – **sign up at memorywalk.org.uk or call 0300 330 5452 (local rate).**

Jeremy Hughes
Chief Executive Officer



In the press

Food for thought

A recent interesting piece of research used blood samples to examine the chemicals that our bodies produce as they break down the foods we eat. However, the way it was reported in some of the press could have left people confused about how these chemicals might be linked to a reduced risk of developing dementia.

Clare Walton, Research Communications Manager at Alzheimer's Society, said, 'There is a lot of research on the effect of your diet on brain health, but what's particularly interesting about this is its focus on the chemicals our bodies make when we eat certain foods rather than on food itself.'

'Drinking coffee or eating citrus fruits may be linked to a lower risk of cognitive decline, but it's important to stress that overindulging in coffee and sugary fruit juice isn't the answer to protecting yourself against dementia. Likewise, while a weak link was found between drinking red wine and lower decline, those who drank less overall still had a lower risk – so don't rush to crack open another bottle!'

Some of the reporting about this research got things back to front, saying incorrectly that the study showed oily fish, red wine and dark chocolate could help fight dementia, when really these were the weakest links in the study. It also wrongly concluded that a meal someone ate 12 years ago could affect your dementia risk.

What the research did indicate was that long-term diet and exercise habits are important in affecting dementia risk.

Find out how to reduce your risk of developing dementia at alzheimers.org.uk/reducemyrisk



Dementia Friendly Awards

Nominations for the 2019 Dementia Friendly Awards are closing soon, so get yours in now! Our awards celebrate the individuals, organisations and communities who are making a real difference to the lives of people affected by dementia. Categories include a new Lifetime Achievement Award to mark the Society's 40th year.

Nominate now at alzheimers.org.uk/dementiafriendlyawards

Research Network turns 20

Alzheimer's Society is marking 20 years of our Research Network with a series of events across England, Wales and Northern Ireland.

Research Network volunteers have personal experience of dementia, and they work with us and researchers to ensure that our research looks at the right areas and makes an impact.

Talks and presentations from researchers and Research Network members, including several during our annual conference in May, are celebrating the network's achievements while sharing the latest dementia research.

Find out more about the Research Network at alzheimers.org.uk/researchnetwork

Memory Walk: Almost here

Make memories and soak up the atmosphere this autumn at one of our Memory Walks, coming to a town or city near you across Wales, England and Northern Ireland.

Our supporters make a huge difference to people affected by dementia, and Memory Walk brings us closer to a cure with every step that you take. Gather your nearest and dearest and join thousands of others who are walking for loved ones and a better future.

You could even walk some extra miles and make extra memories by taking on a bigger challenge at one of the longer Memory Walk Plus events. Sign up now at memorywalk.org.uk or call 0300 330 5452 (local rate).



Cupcake Day: Deliciously good

This year's Cupcake Day has raised over a £1 million and counting in the fight against dementia. It was the biggest Cupcake Day yet, with 32,000 of you joining us to bake a difference.

A huge congratulations and the biggest of thank yous to everyone who hosted or attended a Cupcake Day this year. We hope you all had a deliciously good day!

Cupcake Day will be back next year – sign up to get your free fundraising kit at cupcakeday.org.uk

Carers: Dementia and cancer

Earlier this year Dementia Talking Point, our online community, introduced a special area for the carers of people who have both dementia and cancer.

Part of a Leeds Beckett University research project, carers have used this special area to share practical and emotional support with others who understand what they're going through. We also hosted two Q&A sessions with the only Macmillan dementia nurse consultant in the UK.

One Dementia Talking Point member said, 'It's comforting to know that others are going through similar issues and to feel part of a community that I wouldn't encounter in normal everyday life.'

Dementia Talking Point is free and open 24/7 – join the community at alzheimers.org.uk/talkingpoint

Sharing our research with the world



Researchers funded by Alzheimer's Society have been sharing their work with international experts at the Alzheimer's Association International Conference (AAIC) in Los Angeles.

AAIC brings together some of the world's leading clinical and care researchers to share discoveries that could lead to the future

prevention and treatment of dementia.

Riona McArdle (pictured), one of our researchers, has been using body-worn monitors to find out whether looking at the way a person walks could help identify different types of dementia, including Alzheimer's, dementia with Lewy bodies and Parkinson's disease dementia.

She said, 'Attending AAIC has provided an amazing opportunity to share my research with an international audience and open discussions about how to keep moving this research forward.'

In briefs

Marathon milestone

The Dementia Revolution has surpassed its fundraising target of £3.5 million, with more still to come!

Thank you to everyone who ran, donated or volunteered for the cause at this year's Virgin Money London Marathon. The money raised will fund vital research at the UK Dementia Research Institute (see www.ukdri.ac.uk).

Dementia Revolution was the official 2019 Charity of the Year partnership between Alzheimer's Society and Alzheimer's Research UK.

DCan: The Dementia Choices Action Network

A new collaboration to make dementia care in England as personalised as possible has met for the first time.

The Dementia Choices Action Network (DCan) met in London recently, with speakers including Ronald Amanze, a poet and musician who has vascular dementia, and Jeremy Hughes, the Society's Chief Executive Officer.

Made up of representatives from Alzheimer's Society, NHS England and others, DCan will look at what makes good care that's tailored to each individual's needs and preferences. Importantly, it will also recommend how this can be made a reality for more people.

The many voices of dementia advocacy

An Alzheimer's Society Ambassador and member of the 3 Nations Dementia Working Group has appeared in a short film alongside other people with dementia around the world. 'The many voices of dementia advocacy' shares advice on public speaking, attending meetings and talking to the media.

This is part of a joint project between the Society, 3 Nations Dementia Working Group and Dementia Alliance International. It aims to inspire and encourage people who have dementia to build their confidence in these areas.

Contributors include Hilary Doxford of the 3 Nations Dementia Working Group (see www.3NDWG.org) – a network of people living with dementia in Wales, Northern Ireland and England.

Watch the film at www.tinyurl.com/advocacyfilm



Quick read

Margaret Willis, 77, has learned to accept and even embrace life with vascular dementia, following her diagnosis three years ago.

Margaret, a former publican now living in Flint, North Wales, says the diagnosis felt like her world had ended.

Boosted by support from Alzheimer's Society and a move to sheltered accommodation, Margaret is now managing much better.

She finds that people are very understanding once she opens up to them about her condition.

How I am now

Stunned by her dementia diagnosis, Margaret Willis had to battle her fears to reach a point of acceptance. **Gareth Bracken** meets a woman embracing who she is now.

I've always been a positive person – that's what helped me get through this,' says Margaret Willis, reflecting on a challenging three years since her unexpected diagnosis of vascular dementia.

Initially shocked by the news, Margaret has strived to accept and even embrace her situation as best she can, an approach made possible by the strong support she's received from Alzheimer's Society.

Pulling pints

Although living in Flint in North Wales, 77-year old Margaret is originally from the north west of England – she was born in Blackpool and grew up in Bootle, Merseyside. A mother of five, she ran pubs with her late husband Ron in Liverpool, Carlisle, Manchester and London.

'I wasn't one of those landladies sat at the side of the bar, I was there pulling pints,' she says. 'I loved it. There was a social side and it was just full of life, plus I could be there for my children 24/7.'

'I insisted on a good service and good manners. I was quite bossy!'

Margaret was also the first female bingo caller in Liverpool and at one point owned and ran her own taxi business.

'I was always happy with a microphone in front of me!' she laughs.

Biggest bombshell

Although she was experiencing some memory problems a few years ago, Margaret put it down to old age and didn't seek any professional advice.

Things took an unexpected turn when she visited the hospital with an ear problem. A consultant there sent her for a brain scan, which showed that Margaret had at some point experienced a mini-stroke and now had vascular dementia. However, she thought she was given her diagnosis in a frustrating and roundabout way.

'The biggest bombshell was the way I was told,' she says. 'After the scan, the consultant asked me how I'd got there. He said, "You drove here?!" Then he told me to bring a family member along next time. But because I wasn't aware of anything the matter at this stage, I'm thinking, "This fella is an idiot – why is he asking me all these questions?"'

'I asked for the results of the scan, but he still wasn't really telling me. He was mumbling on about everything, so I asked him to write it down. I got into the car and read this word "dementia". It was like my world had ended.'

'I hadn't smoked for years, but the first thing I did was stop at the garage and get a packet of cigarettes.'

The diagnosis caused great worry to Margaret, who not long afterwards got low scores on a test at a memory clinic.

'I thought I'm not going to know my kids, my friends, my grandchildren. This is what's going through your head,' she says.

Dementia can cause Margaret confusion and frustration when doing everyday tasks. She has put food in the fridge instead of the oven and put clothes on back to front. She has also struggled with sense of direction, fatigue and a loss of appetite.

'You get your good days and bad,' she says. 'Some days I don't want to see anybody, so I just stay at home.'

Uplifting experience

Margaret has received valuable support from Alzheimer's Society, in particular David Allmark, a Dementia Support Worker who has developed strategies to help her cope with the challenges of the condition.

'I'd make a cup of tea and forget to drink it, or leave windows open, but David made me laminated cards with reminders,' she says. 'It gave me the confidence that I wasn't forgetting as much.'

'He was able to reassure me that something like forgetting my family isn't going to happen overnight.'

Margaret is also supported by a volunteer, Nerys, as part of Side the Side, our service that helps people with dementia stay active and involved.

'I absolutely love her to bits – she's like my best friend'

now,' says Margaret. 'We're like teenagers, going out and buying clothes!

'She picked me up an awful lot, because at the time I was really low. She just uplifts me.

'The difference these people can make to someone with dementia is amazing.'

The Society has also supported Margaret with her power of attorney arrangements and helped her find new accommodation last year.

'Alzheimer's Society have been marvellous, I couldn't fault them,' she says.

Best move

Margaret now lives in sheltered accommodation, in a complex that has staff on call day and night.

'I try to stay independent but I've had major surgery and could become very ill, so I was glad to come here where someone is there for you at the press of a button,' she says.

'It suits my needs. If I want to go out or talk to people I can, if not I can stay here. My meals are cooked for me and I feel safe and secure, whereas I didn't before. What more can I ask for?

'It's been absolutely brilliant – the best move I've ever made.'

Margaret has a supportive network of friends and family who she sees regularly, but it was particularly important that her beloved dog, an 11-year old pomchow named Milly, was allowed to join her in the new home.

'Wherever I go, Milly comes with me,' says Margaret. 'She has become a service dog. She takes me home and she understands every word I say. I know she would fight to the death for me.'

Embrace it

Although she still has difficult days, Margaret tries to be as positive as possible about living with dementia.

'Getting the news was a blow, for the first six months it was really bad,' she says. 'But then I realised that if I was more positive and didn't let it get a grip, I should be able to lead near enough a normal life.'

'I'm trying to just embrace it – it's the only way that I feel I'm handling it.'

This approach has seen Margaret speak about her Side by Side experience at events

and conferences. She is also a member of the North Wales Dementia Friendly Reference Group, helping to make Flint more dementia friendly. She has benefited from hearing other group members' experiences of living with the condition.

'Flint is very dementia aware and dementia friendly. The shopkeepers have contributed to that,' she says. 'Some people elsewhere aren't so understanding, although when people know I have dementia they're really good – it's about opening up.'

For Margaret, this has meant learning to accept her situation.

'It's nothing to be ashamed of,' she says. 'When you get over that bit you can embrace it – this is how you are, this is you now.'

'There's also nothing I can do about it other than try and manage it the best way I can without it causing too much stress.'

Chance of a lifetime

One area of lingering anxiety is the possibility of Margaret one day not recognising her children.

'Although I'm not going to know anything about it, I do worry,' she says. 'It must be heartbreaking for a daughter if their mum says, "Who are you?"'

Right now though, Margaret is very excited about a forthcoming holiday to China with her daughters.

'I was always a great organiser but I'm not anymore, so I've told them, "Just book it!"' she says.

'It's the chance of a lifetime – I'm not going to stop living because I've got dementia.'



Hear Margaret's story
Listen to this and previous stories
at alzheimers.org.uk/podcast



Next steps

- Volunteer with Side by Side – go to alzheimers.org.uk/volunteer or call 0300 222 5706 (local rate).
- Your donation could help more people benefit from Alzheimer’s Society support – see alzheimers.org.uk/donate or call 0330 333 0804 (local rate).
- Visit alzheimers.org.uk/dementiafriendlycommunities for more about dementia-friendly communities.

A huge impact

In our 40th year, we celebrate the people who are making a real difference for people affected by dementia in their communities.

From a condition never discussed and little understood 40 years ago, Alzheimer's Society has brought dementia out of the shadows. Our founders were determined to transform the landscape of dementia forever, and more people than ever are turning this vision into reality.

Nearly 3 million Dementia Friends and over 400 recognised dementia-friendly communities are making changes – big and small – so that more people with dementia can feel included and involved.

Without fear

In August 2014, Brecon received official 'Working to become dementia friendly' recognition from Alzheimer's Society – the first community in Wales to achieve this.

Dementia-friendly Brecon, known as Brecon Area DFC, is mobilising all sections of the community to challenge stigma, increase awareness and make sure that the voices of people affected by the condition are heard.

'We're helping people to keep on being part of the community by making places welcoming and accessible,' says Joan Brown, a Dementia Friends Champion who is chair of Brecon Area DFC.

This has included auditing how local businesses operate and advising them on how to make their environments more dementia friendly.

Joan also set up four intergenerational projects with weekly visits for schoolchildren to care homes and a community day centre.

'Raising a dementia-friendly generation is hugely important, because there are kids growing up without the fear and stigma,' she says.

Rural dimension

Dave Coombs, a volunteer for Brecon Mountain Rescue Team, became a Dementia Friends Champion after colleagues found they were searching for more missing people with dementia.

The rescue team is about 50-strong, but Dave hopes the message spreads into the wider community too.

'I believe in a lot of people doing a little to make a difference,' he says.

Dave also works for the Welsh Ambulance Service, where he is helping to support emergency services across Wales to better serve people affected by dementia.

'I've seen the difference a bit of awareness can make in interactions with people. Small things are noticed when I go into someone's home,' he says.

Dave is on the Brecon Area DFC steering group and recently helped organise a local event during Dementia Action Week.

'Brecon being a rural community adds an extra dimension,' he says. 'We're looking at being creative to get people to events or groups.'

Kindness and recognition

Sue Barker is a mental health nurse and lecturer who sits on a Champions Forum – a group of local Dementia Friends Champions who meet to support each other and share ideas with Alzheimer's Society.

She holds Dementia Friends sessions at Cardiff University, where she works, and more locally in Brecon.

'The drop in the ocean of Brecon does not need to be as big as the drop at the university to make a change,' she says. 'Behaviour breeds behaviour, and if one person starts to behave differently others tend to follow.'

Sue wants her sessions to make people think twice before becoming irritated by someone's behaviour.

'I hope they take a few seconds to think why someone might be doing that, rather than automatically responding as if everything is about and because of them,' she says.

'Dementia Friends is a brilliant vehicle to share a message of kindness, consideration and the recognition that small changes can make a huge impact.'

Visit alzheimers.org.uk/dementiafriendlycommunities to see how you can make a difference in your community.





‘Of course I will’

If there isn't already a Memory Walk event near you this autumn, you can still host your own, as Christine Bridges discovered last year.

When Christine and Kevin Bridges saw a Memory Walk ad on TV last year, he asked her if it was talking about his condition. Kevin was diagnosed with vascular dementia two years ago, aged 65.

When Christine confirmed that Memory Walk was all about helping people like him, he surprised her with a request she won't forget.

'He said, "You should do that for me." I looked at him and said, "If you want me to walk for you, then of course I will."'

Your walk. Your way

Christine checked online and, even though Alzheimer's Society organises many Memory Walks, she couldn't find one near to them in Worcestershire. Fortunately, she found the perfect solution.

'There was a tab that said "Your walk. Your Way", so I clicked on that and registered to host my own,' says Christine, who works for a local bus company.

'I decided to walk one of our well known bus routes, the 58 service that covers most of Redditch and is 8.3 miles long.'

After confirming a date for her Memory Walk, Christine promoted it on social media.

'I went onto Facebook and created an event, and invited family and friends to join me. I bought T-shirts for my team and set up a JustGiving page, which I shared on Facebook and Twitter.'

Walk and talk

Not only did Christine raise almost twice her £500 target, her walk also united people in doing something meaningful.

'I was joined by family and friends, as well as a local councillor and a couple of police community support officers.'

'One lady joined us who had lost her husband to this dreadful condition three weeks before. She had seen my walk advertised and decided to do something in his name.'

'It gave us all the chance to walk and talk about our memories. Doing this will stay with me, knowing it was Kevin who asked me to do it. You will be surprised at how many people know someone who has some form of dementia and want to be involved.'

Christine wants everyone to join their nearest Memory Walk or to host their own, regardless of how much you're able to fundraise.

'Every penny counts, so don't worry about not raising hundreds – it's about raising awareness as well.'

Try something new



Organise Your Own

Organising a fundraiser? If you sign up to Organise Your Own and let us know what you'd like to do, we'll send you everything you need to set up your event. From bake sales to bungee jumps, we're here to help make your fundraising fabulous!

Check it out at alzheimers.org.uk/organiseyourown

Read Care and cure



The summer issue of our research magazine, Care and cure, looks at 20 years of the Research Network, the impact of air pollution, life at a brain bank, and much more.

Visit alzheimers.org.uk/careandcure

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



Who will you walk for? Join us at a Memory Walk this autumn – visit memorywalk.org.uk or call 0300 330 5452 (local rate).

Delight and a side of chips

Side by Side has brought joy to a volunteer in County Armagh, as well as to the person – now friend – who she supports.

Susan McNickle has been supporting the same person with dementia, Dorothy, through Side by Side for a couple of years now. For all the highlights during that time, she doesn't hesitate when asked to pick one.

'Bringing her to see her friend, who lives in a nursing home,' says Susan. 'They used to be neighbours and I brought Dorothy to visit. The delight on both of their faces was fantastic!

'They were so pleased to see each other, as it had been some time since they last met. To know that I helped make this possible brought me so much joy.'

Tea and chat

Side by Side volunteers help a person with dementia to carry on doing the things that are important to them. For Dorothy in Portadown, County Armagh, Susan's weekly visits make it easier for her to get out and about to run errands and stay in touch.

'It helps her remain independent, get out and meet people, and get all her messages for the week,' says Susan, who lives nearby in Lurgan.

'She gets treats for her grandchildren, posts her letters and from time to time we call into the bus depot to pick up the latest timetables.

'Plus we get a wee cup of tea and a chat, and share a sausage and chips between us – we've gave up trying to be healthy!'

Meant to meet

Susan volunteered with Side by Side after seeing the difference that support from Alzheimer's Society and others made to her family when her father had vascular dementia.

'My dad was my whole world and sadly he passed away four years ago. After losing him, I wanted to give something back and help someone.'

Susan hasn't looked back since then. 'Dorothy and I are great friends,' she says. 'We were just meant to meet each other.'

'I enjoy her company immensely and look forward to visiting her every week. We're quite similar in our personalities, in that we've a good sense of humour and we both like to help people. I love to hear her stories and find out how her week has been.'

Two-way street

Susan makes clear that it's not only Dorothy who benefits from Side by Side.

'The partnership is definitely a two-way street,' she says. 'I get just as much out of it as she does.'

'I have gained a fantastic friend who is so appreciative of my help; it's heartwarming. I have a lot of respect for the older generation and I hope someday, if I'm ever in a similar situation, someone will be there to help me.'

'I would urge anyone to volunteer for Side by Side. In today's society, where everyone is so busy with their own lives, I wanted to give something precious back – time. I do all this in memory of my dad.'



See if Side by Side is available near you at alzheimers.org.uk/sidebyside

Call 0300 222 5706 (local rate) or email volunteers@alzheimers.org.uk to find out more about volunteering.

Welsh language support

Dementia Adviser Mair Watkins on the immeasurable value of getting support in Welsh through Dementia Connect in Wales.



When dementia affects how well you communicate, it can isolate you from family, friends and community. If Welsh is your first language, you might even lose your ability to communicate in English. Either way, getting support in your language of choice makes a huge difference.

Dementia Connect – the new service we’re introducing to more areas in coming years – includes support in Welsh for people in Wales, where the language has official status alongside English.

As a Dementia Adviser and Welsh speaker, I feel privileged to be welcomed into the lives of people using this service. People need information about local support and a myriad of other topics, as well as practical help with day-to-day challenges.

The saying ‘Cenedl heb iaith, cenedl heb galon’ means ‘A nation without a language is a nation without a heart’, and Welsh remains at the heart of our national culture.

For someone with dementia, being able to use their own language is a key that can unlock the world to them again. When they realise they can express themselves and be understood, this is an incentive to foster relationships and gain the care that’s so vital.

What more motivation could I need to do what I do?

Dementia Connect isn’t available nationally yet, but to find support near you, visit alzheimers.org.uk/getsupport If you live in Wales, you can call our Welsh-speaking phone line on 0330 094 7400 (local rate).



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

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In your area

£s on the pillow

Hotels, B&Bs and guest houses in Wales have been raising thousands of pounds through Alzheimer's Society Cymru's '£s on the pillow' campaign.

The initiative, supported by electricity operator Western Power Distribution, has raised over £1,200 through leaving donation envelopes on guests' pillows so they can help to fund dementia support and research.

Elaine, owner of Rebleen Guest House in Tenby, said, 'It is often a talking point between guests and myself when they ask me why I put the envelopes on the pillows. I was amazed by how much I had collected in such a short time.'

Hotels, guest houses or B&Bs in Wales can get involved by calling 029 2047 5572 or emailing claire.carwardine@alzheimers.org.uk



Communities together

Dementia-friendly church services in the Causeway area of Northern Ireland are bringing communities together to support people affected by the condition.

Dementia-friendly workshops (pictured) at St Patrick's Church of Ireland in Coleraine led to the first service in April. Monthly dementia-friendly services are now co-celebrated with nearby St Malachy's Catholic Church and open to all, inspiring other communities to get involved too.

The work was prompted when local people said they had experienced a lack of spiritual support after getting a dementia diagnosis.

Aoife McMaster, Dementia Support Worker at the Society, said, 'It is great to have a service where people with dementia can come and know their needs will be met, and where they can practise their religious and spiritual beliefs and remain a part of their local community.'



400km in three days

A team from Wilsonart UK, a company that makes worktops and other surfaces, cycled over 400km in three days in their latest bid to raise funds to fight dementia.

From their Shildon office in County Durham, 21 employees biked to the company's site in Perth over a very hot weekend at the end of June, taking in Alnwick Castle and the Angel of the North along the way.

Wilsonart UK chose Alzheimer's Society as its charity of the year and is now well over halfway to reaching its fundraising target of £10,000.

Chai, chat and true leadership

A women's community group in Northampton have surprised themselves with their own success after choosing to support Alzheimer's Society this year.

Chai and Chat, set up by the town's Indian Hindu Welfare Organisation, has been hosting presentations, creating Dementia Friends and building a community where people affected by dementia feel more able to speak out and get support.

Although donations are still coming in from a sponsored walk and picnic in Abington Park in June, they have already smashed their £1,000 target.

Neelam Aggarwal-Singh, the group's Chair, said, 'We had three generations taking part in the walk and we're still reeling from excitement – it exceeded our expectations.'

'Dementia affects all of us. If people are able to accept and acknowledge it, they are more likely to get the help they need.'





Join team Alzheimer's Society!

Keep fit and look great this year with our branded clothing range. Whether you are taking part in Memory Walk, or completing one of our sporting challenges, look the part in our branded Team Alzheimer's clothes. As well as looking great, you will be bringing us one step closer to finding a cure for dementia.

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

Shop now

shop.alzheimers.org.uk



Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645 19256SD

Whole new world

Alzheimer's Society support has made a huge difference to Hanish Shah since his mother's dementia diagnosis. **Gareth Bracken** meets a carer doing what he can to navigate through continued change.

'Everything changed that day,' says Hanish Shah, recalling the stroke his father had in February last year. Hanish's mother, Kanta, had been diagnosed with Alzheimer's in 2017, and it soon became clear that she wouldn't be able to cope living alone after her husband moved into residential care.

Now Kanta's main carer at his family home in Northampton, Hanish is calling on people in a similar position to make sure they take full advantage of whatever help is available.

'I was between a rock and a hard place, because everything happened in one hit,' he says. 'But if you get the right support, it can open up new avenues and make a big difference.'

Quiet type

Kanta Shah, now 78, came to England from Kenya with her husband Jayantilal in 2001. Hanish arrived the following year.

'Mum was always a quiet type. She wasn't outgoing, though she did attend cultural festivals and meetings,' says Hanish. 'She was also a very good cook – I always remember the food she made.'

In 2017, the family noticed Kanta becoming more forgetful, though from a distance it was difficult to judge just how bad things were.

'She would mix up a lot of things and not remember tasks that had to be done,' says Hanish. 'You would mention something to her today, but by tomorrow she would have forgotten it.'

'Because we weren't there 24/7, we couldn't say exactly what was happening. We saw they needed help but could only do so much due to Dad's stubbornness. He was always there saying, "I know what I'm doing with her."'

Later that year Kanta was diagnosed with Alzheimer's disease, only a few months before her husband's stroke.

Hanish used to work in customer services for the council, but left around 10 years ago after being denied flexible hours. He had been preparing to return to the workplace when his parents' health problems forced a change of plan.

With his wife Avani working full time, Hanish stayed at home to care for Kanta, who moved into the house.

Here to help

It wasn't until Kanta came to live with them that Hanish saw the full impact of her dementia. He thinks the situation was made even more difficult because his mother had become used to 'tagging along' with her husband.

Quick read

Hanish Shah cares for his mother Kanta, who has Alzheimer's, and wants people to ask for help whenever they need it.

Hanish became Kanta's main carer last year, when she moved in with his family in Northampton after her husband's stroke.

Hanish says Alzheimer's Society has been a vital source of support – opening up a 'whole new world' for him.

He says it's important for carers to take the first step and ask for help, even if others don't approve.



'It was worse than we envisioned,' he says. 'When she moved in with us, we found that she was not her own self – she was waiting for direction on what to do.'

The family took immediate steps to improve Kanta's wellbeing.

'We had to build everything from scratch and bring in small changes,' says Hanish. 'She thought that, if she made a mistake when cooking, people would judge her, so we've tried to take that fear away. We told her she has dementia but that it's not bad to forget things. We say we're here to help, not criticise or judge.'

'It's not easy, but now she's bright and bubbly, whereas she wasn't before.'

The family try to get Kanta out of the house at least two or three times a week, including for regular yoga sessions.

Getting adult colouring books has been particularly successful, and Kanta now spends hours a day colouring pictures in while listening to music.

'I've also reinforced that there are things she has to do for her health – like eating properly and good hygiene,' says Hanish.

Same situation

Hanish acknowledges that being a carer can be frustrating at

times, as he and his wife strive to maintain a balance between work, caring and family life.

Local relatives have been helpful when Hanish and Avani have needed a break, while Alzheimer's Society has been a major source of support.

'The Society opened up a whole new world for me,' says Hanish. 'We started getting a lot more information about what to do and how to deal with things. They told us what benefits Mum and I would be entitled to.'

Hanish and Kanta also attend a support group through Alzheimer's Society.

'There are so many carers in the same situation – when you go to a group you can relate to them,' he says.

'I talk to them and get bits and pieces that we could use to help our situation, and Mum enjoys the activities for an hour.'

Foot in the door

Hanish is keen to raise awareness of dementia, especially among communities where greater stigma can be attached to the condition.

'It's not just a particular group that can get dementia, it is right across the board and could affect anybody at any time,' he says.

'I don't know if it's a taboo thing, especially as we are a minority group, but a lot of people don't want to accept it could happen to them or their family.'

'But if people see changes in elderly relatives, follow it up with a doctor. If they do get a diagnosis, it will be better for the lifestyle of the person with dementia in the long term.'

Hanish says it's important that carers get the advice and support they need following a diagnosis.

'Family members might not approve of external support, they might say, "Keep it hush, let's deal with it our way,"' he says. 'But there's a lot of help out there, it's just taking that first step, putting that foot in the door and saying, "I need help."'

Dignity and respect

With Hanish once again seeking a return to work, the family are considering what further support Kanta might need from social services. Although she is managing at home at the moment, Hanish knows his mother might require residential care as her condition progresses.

'With a situation like ours, we have to start planning for the future. We couldn't just do it when it happens,' he says. 'We're looking into replacement care and day care, so as not to burden Mum with a last-minute rush into full-time care.'

Whatever Kanta and her family's next steps, Hanish wants to ensure that his mother lives as well as possible, with the understanding she deserves from other people.

'We want people to see that she is still a person and still needs to be treated with dignity and respect.'





Next steps

- Our support ‘opened up a whole new world’ for Hanish – donate to support others at alzheimers.org.uk/donate or call 0330 333 0804 (local rate).
- For *Caring for a person with dementia: A practical guide* (600), see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- For our publications in a range of languages and formats, see alzheimers.org.uk/accessibleresources or call 0300 303 5933 (local rate).

Art from the heart

A Derbyshire pottery group is making a difference for local people affected by dementia. **Gareth Bracken** visits a creative community helping its members to find new ways to flourish.

‘I’d never done any pottery before, but it’s my life now,’ says carer Mick Smith. ‘It’s all come from this really.’

Mick is a member of the Wabi Sabi Pottery Group, held weekly at the Derbyshire Eco Centre.

Launched in 2014 by adult education services in Derbyshire with support from Alzheimer’s Society, the sessions give people affected by dementia the opportunity to develop new skills and socialise with others facing similar challenges.

Quick read

A pottery group in Derbyshire is helping people affected by dementia learn new skills while socialising with others in a similar situation.

Designed to reduce isolation, the Wabi Sabi Pottery Group allows members to get involved in all aspects of the pottery process.

Carol Hill, who has frontotemporal dementia, says they have all become friends who accept each other for who they are.

Mick Smith, whose wife has vascular dementia, says pottery has made his life more bearable.

‘We wanted to do something to reduce isolation,’ says Sue Mulroy, the adult education tutor, potter and qualified art therapist who runs the group. ‘I’m a real believer in peer support through creating a community where people understand each other’s experiences.’

Sue feels the group is ideal for people living with dementia.

‘They’re able to learn new skills through body memory, where the brain isn’t so important,’ she says. ‘People with dementia often learn to throw pots more easily, maybe because they’ve lost the critical part of the brain that tells them they can’t do it.’

Members can also benefit from the opportunity to think differently about their situation.

‘I’ve always said the group is about loss and adjustment, because dementia is a progressive illness,’ says Sue.

The sessions are designed so that everyone can feel involved, even if their dementia is more progressed.

‘One lady who taps a stick as communication also uses the movement to decorate the clay,’ says Sue. ‘Even watching me pack the kiln can help someone feel involved.’

Really worthwhile

Group members are busy working on their respective projects, each of which is at a different stage of the pottery process.

Ian Emslie, 70, was diagnosed with frontotemporal dementia in 2010. He has been attending the group for the past five years with his wife Lesley.

Today, Ian is putting the finishing touches to a wall planter before beginning work on another with fresh clay.

‘We started off simple then progressed to making more intricate things,’ he says.

‘I feel it’s really worthwhile, it’s really good. I like the feel of the clay, it feels very tactile.’

A bowl that Ian made is waiting in the cupboard, ready to be painted.

‘I’m going to try different texture paint,’ he says. ‘We always experiment with colour and different textures.’

‘I get really absorbed and time passes so quickly.’

Not ashamed

Carol Hill has been throwing pots on the wheel – the process of shaping the clay as it turns – before switching to moulding pieces with her hands.

‘I know it sounds silly but I always say the clay talks to me. With a lump of clay, it’s surprising what you can turn out,’ she says. ‘I take my time and gather my thoughts.’

Diagnosed with frontotemporal dementia around six years ago, 61-year old Carol attends the group with her husband Chris.

‘You meet other people with similar problems,’ she says. ‘It’s interesting talking to them about what they used to do with their lives.’

‘We’re all friends and all accept each other for what we are.’

Carol says the sessions take place in a supportive environment.

'You share your skills. If someone is struggling, we say, "Why don't you try doing it this way?" and vice versa.'

Being around other people while picking up new skills feeds into Carol's positive outlook.

'I tell people I've got dementia, I'm not ashamed of it,' she says. 'You get on with life – life is for living. Don't give up, that's my theory.'

Lose yourself

Perhaps the biggest beneficiary of the group has been Mick. He cares for his wife Carol, who was diagnosed with vascular dementia eight years ago.

'I don't know how life would be without it,' he says. 'You can actually live with the difficulties of dementia.'

Carol is being supported by volunteer Jennifer to make a large pinch pot.

'Carol loves it here – she makes pinch pots with her fingernails,' says Mick, who is modelling a clay hare.

The couple have been attending the sessions for the past four years.

'I find the group beautiful really,' he says. 'The carers lose their soulmate, the person they loved and married. The people who understand it best are those who live with it.'

'If there's been a bright spark that's come out of the dementia, it's this group. They're lovely people and Sue is such an inspiration to us all.'

Mick has even turned a room at home into his own full-scale pottery, where group members meet to do additional work.

'It's just something you can sit and do, and lose yourself,' he says. 'The end product isn't that important, it's the journey doing it.'

'You can lose yourself in the pottery – it makes life bearable.'



Photographs: Dean Atkins

Next steps

- For our **Keeping active and involved (1506)** booklet, go to alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Use our **Dementia Directory** to find dementia services near you – see alzheimers.org.uk/dementiaconnect
- Join **Dementia Talking Point**, our online community, at alzheimers.org.uk/talkingpoint

Home comfort

Unnecessarily long stays in hospital are especially difficult for a person with dementia. Gareth Bracken reports on a scheme getting people home as soon as it's safe.

The Home First scheme in Somerset is giving hospital patients who are healthy enough the chance to return home to finish their treatment.

In the past, people – including those with diagnosed or suspected dementia – would have stayed in hospital for assessments and to plan for their rehabilitation. This can now take place at home or during a

temporary stay at a specialist reablement unit, care home or community hospital.

Covering four hospitals in the county, Home First enables nurses and occupational therapists to liaise with patients, families, social workers and other professionals to ensure that the person can leave hospital safely.

'It's not about hurrying people out of hospital, it's about getting them home as soon as they don't need hospital intervention,' says Tim Baverstock, Strategic Manager for Commissioning in Adult Social Care at Somerset County Council.

People still get the assessments and support they need, but in an environment where these can be more effective.

'You get a much better idea of people's ability out of hospital,' says Tim.

Once a person returns home, they are supported by visiting homecare staff to become more able.

'It means people are less likely to come back into hospital,' says Iona Brimson, Senior Commissioning Officer at the council.

'Our priority is, "How can we help you be at home and also keep you there?"'

Joined-up support

Lorna Brown is Home First and Discharge Lead for Musgrove Park Hospital (pictured) in Taunton, overseeing and co-ordinating people who leave hospital under the scheme.

'We know people with dementia do better in their home environment, so if we can support them at home then we should be,' she says.

A detailed assessment of a person at their home is vital.

'It's really key to involve the family,' says Lorna. 'When we're assessing a person's care needs, we'll include carer support in that.'

A person remains supported by Home First until their needs are met or further support is sourced.

'We track and maintain them through the system – it's joined up and is better for the person,' says Lorna.

For people with dementia or delirium, a more specialist range of staff and community support services can also help. This could include the Intensive Dementia Support Service (IDSS) – a crisis team that supports people with dementia whose behaviour is challenging.

'We aim to stabilise and prevent admission into mental health in-patient beds, while Home First and its care providers continue to support the individual,' says Emma Norton, IDSS Service Manager.

First class care

One of the reablement units in which patients can stay before returning home is Woodlands Farmhouse, a respite home run by homecare provider Ruby Care. Specially trained staff consider a person's capability and work closely with them on a daily basis to help them regain skills and independence.

Quick read

The Home First scheme in Somerset is helping patients – including people with dementia – to return home as soon as possible to finish treatment.

People still get the assessments and support they need, but in an environment where these can be more effective.

Most people return straight home while others first spend a spell in a specialist residential unit, care home or community hospital.

Stanley, whose wife stayed at one of the units following time in hospital, says it provided a better environment for her recovery.

‘We provide reasonable goals to ensure that people are supported to take risks, but won’t set unachievable tasks that may hinder their reablement,’ says Julie Lawrence, Care Manager at Ruby Care.

Stanley, whose wife recently had a short stay at Woodlands after spending a month at Musgrove Park Hospital, says it provided a better environment for her recovery.

‘It was first class – very good. They gave her the care she needed and they even looked after me,’ he says.

His wife speaks equally highly of her stay.

‘The food was nice and the staff were brilliant – they would do anything for you,’ she says.

In charge

Ruby Care also provide a short-term homecare service for people returning home. They meet the person at home for a safety assessment and produce a detailed report of their care needs. This means a smoother handover process if long-term

homecare is required from another provider.

‘We believe that the support we are providing will reduce, or at a minimum delay, the need for long-term residential or nursing care,’ says Emma Purvis, Registered Manager at Ruby Care.

Helen, who is 93, spent 10 days at a short-stay home before receiving support at home from Ruby Care.

Her niece Jo says, ‘My aunt was going downhill but Ruby Care ensured she was drinking plenty of fluid, getting proper meals and taking her medication. They have been absolutely phenomenal – they’ve gone above and beyond on so many levels.’

Luckily, Helen didn’t need a hospital stay, and Jo says her aunt has appreciated the opportunity to remain at home.

‘Helen can still do so much for herself. Rather than taking that away from her, they’ve given it back to her,’ she says.

‘She feels like she’s in charge of her life because she’s in her own home.’



Next steps

- For our Hospital care (477) factsheet, go to alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- The Dementia-Friendly Hospital Charter gives advice on how hospitals can become dementia friendly. To view the charter, see dementiaaction.org.uk/dementiafriendlyhospitalscharter
- Visit alzheimers.org.uk/dementiafriendlycommunities for information about dementia-friendly communities.



Your letters, emails and messages on social media and through our online community.

Letter of the month

Sleep and dementia risk

On a radio programme in June, a scientist said that everyone who sleeps less than six and a half hours a night will definitely get dementia. He didn't say that they might, but stated that the statistics show that they definitely will suffer this.

I find this worrying, because since having some difficult experiences at the dentist fairly recently, I continue to wake up about four in the morning and find it hard to get back to sleep, so I get considerably less than six hours sleep a night.

A Wills, Greater London

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

Society response

Researchers are still finding out about how sleep affects our health, including our risk of developing dementia. We know that our bodies' cells and tissues are repaired while we sleep, and it's also when our recollections are established as long-term memories.

Studies have linked not getting enough good quality sleep when we're middle aged to experiencing cognitive decline – including Alzheimer's – when we're older. However, we don't yet know that poor sleep actually causes this, and there's no basis to say that a person will definitely develop dementia because they don't have a certain number of hours' sleep each night.

Since sleep is important for our health and wellbeing, it makes sense to do what we can to sleep

well. This could include looking at how much physical exercise and exposure to natural light we get during the day, what we eat and drink (and when), and what we can do in the hours before sleep to help ourselves wind down and sleep comfortably. See www.nhs.uk/livewell for advice from NHS Live Well on sleep and tiredness.

If you regularly have poor sleep, then it's worth getting medical advice. A doctor will be able to check if it's a side effect of any treatment you're on, if it's related to some other condition, and if there are helpful things you can try that don't involve drugs, such as relaxation and deep breathing exercises or a talking therapy. If these don't work on their own, using sleep medication when required could help some people.

For our Dementia: Reducing your risk (35) booklet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Your turn

Tell us what you think – write to Magazine Editor, Alzheimer's Society, 43–44 Crutched Friars, London EC3N 2AE or email magazine@alzheimers.org.uk Letters for the August/September issue to arrive by 9 September. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Poetry competition 2019



Our shortlisting panel is looking at the over 120 entries to our poetry competition, and our guest judge – award-winning poet Colette Bryce (pictured) – will be selecting winners soon. Look out for the winning poems in our October/November magazine!

Seen elsewhere...



Jaded'n'faded, a Dementia Talking Point member, shared how our online community had made a difference to her:

“ It is an incredible resource and unique in content. When I started to suspect my mother had dementia, I read everything I could on the subject (and I mean everything!) But the ‘medical’ descriptions of the disease didn’t give me enough detail somehow, though I did learn a lot. One day I came across Talking Point and it was a complete revelation – real people describing real experiences. ”



Melanie Grigg, a Dementia Friends Champion in Surrey, shared a photo on Twitter of local police officers who had taken part in a Dementia Friends information session:

“ I recently had the pleasure of making 14 members of staff from @SurreyPolice Dementia Friends. Such a good feeling to know they can take that knowledge into their work on a daily basis. ”



We shared Julia’s story on Facebook, saying how she needed extra care at night to help care for her husband Bob and asking people to sign a letter to the new Prime Minister to deal with the social care crisis (see p4). Many people added a comment to show their support, including Joan Naxton:

“ Signed, let’s hope they read and listen to all of us who have and are involved with dementia. ”

Blue Badge progress

Changes in England and Wales should make it easier for people affected by dementia to get a Blue Badge, which helps people to park nearer their destination.

It has been difficult for people with dementia and other ‘hidden disabilities’ to get a badge in many areas because the focus is often on mobility, rather than challenges such as feeling anxious in unfamiliar places or road safety concerns.

In England, the Society shared the problems that people faced in a consultation in March 2018, and later that year the government committed to extending the scheme to people with hidden disabilities. From 30 August, local authorities will need to follow national guidance and take better account of dementia symptoms, though a diagnosis still won’t guarantee a badge.

In Wales, Alzheimer’s Society Cymru submitted evidence to a committee looking at how the scheme is implemented. The Welsh Assembly has since published recommendations including for a parking scheme for carers, more consistent training for assessors and automatic renewals for lifelong conditions.

To check your availability and apply for a Blue Badge, visit www.gov.uk/apply-blue-badge

Travel research

Researchers at the University of Plymouth, supported by Alzheimer’s Society, are seeking people living with dementia and their companions to share challenges and positive experiences of air travel. Findings will promote safe, comfortable air travel for people with dementia and their companions by providing helpful advice. To find out more, email joanna.dixon@students.plymouth.ac.uk



Dessie Ferguson
Ballymena, aged 66 with vascular dementia

What's changed most since your diagnosis?

Medication since diagnosis has helped to slow down my memory loss. I had planned to spend my retirement farming beef cattle. At the moment, my livestock consist of a gander and two geese. They are not what you would call cuddly pets, but they know I look after them and in turn they guard the farm as well as any dog would do. Working outside is still important to me and I might get cattle next year. Until then I keep busy cutting firewood and will take each day at a time.

How has Alzheimer's Society helped you?

Our local Society provided practical support and literature about living with dementia. This was greatly appreciated by my wife and family. I've also been accompanied to several activities, including a question and answer session with final year pharmacy students and attending Kilrea Livestock Mart to be interviewed by Radio Ulster.

What helps you relax?

I enjoy watching Sir David Attenborough's nature programmes as well as science and history documentaries by Brian Cox and Alice Roberts. The Blues Brothers movie always makes me laugh – it includes a great scene about the music from Rawhide, and features singers like Aretha Franklin and James Brown.

What single thing would improve your quality of life?

Better weather would help, with less rain and storms. I like to be outside a lot but don't like getting soaked. Farmers need rain, but in Northern Ireland we often get far more than we need!

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.

Ma joined us on a two-week family trip to Cornwall. This involved several confusing train and car trips, and a brief stay in our house before setting off. We wondered how she would cope, given that she can't remember much about what's happening, but she seemed OK with our explanations.

Our biggest fear was that she might fall, given that her Cornish bedroom had several random steps up and down to the bathroom and kitchen. Yet she found her way around without mishap. In fact, if we hovered helpfully she seemed to become extra slow and hesitant – given more space, she was relatively sure-footed.

Ma spent her time between delightful play with her great grandson, asking where she was, and consulting her two diaries (my two sons gave her these so she uses both). The diaries appear to be lots of notes and crossings out as Ma tries to make sense of everything.

Memory loss works in her favour at times. She felt carsick on one drive along particularly winding roads and shouted angrily for us to stop. However, after a shaky start at our seaside destination, she sat happily on the beach, apparently having forgotten the incident.

We all loved her being with us and recognised her familiar ways, such as saying 'I'm not hungry!' as she quietly eats the meals put in front of her, or 'I remember going to Glastonbury!' when, as far as we know, she hasn't.

Maybe we'll do this again next year.

Dilly, a daughter-in-law

Sadly, this is the final instalment of Life with Ma. We wish Dilly, Ma and their family the very best for the future – and here's to Cornwall again next year!



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





Help someone with dementia to keep on doing the things they love

Side by Side is our fun, friendly, super-flexible volunteering opportunity for someone like you to help someone with dementia.

Sign up for Side by Side today:
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0330 333 0804

‘Side by Side has made a huge difference to his attitude; it’s helping to increase his confidence and he has regained some of his independence.’

Side by Side volunteer

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





People with dementia in Coventry offer their thoughts and feedback on three devices that play music and radio.

Music and radio

On the last Friday of every month, Coventry and Warwickshire’s Focus on Dementia Network group – made up of people with dementia – meets to have a say on local and national issues.

Facilitators Sharon and Tina kindly invited us along to hear the group’s opinions about radios and music players designed for people with dementia.

One button radio

First, the group looked at the One button radio, a retro-style AM/FM analogue radio. You can set the station and volume by lifting a magnetic panel, which is then replaced so the more complex controls are out of sight. This means that someone can turn the device on or off simply by using the single button on the outside.

Noel found the retro style a bit too convincing, initially thinking it

was an old style radio with music to match. ‘You instinctively think it’s going to be music from a long time ago,’ he said.

Tommy tried setting the radio before turning it on, and found it straightforward enough to use. ‘The thinking behind it is quite clear,’ he said.

Dave liked the idea of the panel covering up the station and volume controls.

‘That would be easier for me – then it’s set and you’ve got what you want,’ he said. ‘The panel hides the difficulty.’

John, who found the radio a bit big, wondered if the panel could be attached with velcro so it would be easier to use if someone wanted to adjust the controls beneath it.

Dave’s main concern involved the two plastic knobs that need to be placed on the station and volume controls to allow them to be altered. There is a different knob for each control and they aren’t

interchangeable, which he thought could be a problem if he had to set them himself.

‘I think I’d get confused and maybe end up damaging it,’ said Dave.

Simple Music Player

Next up was the Simple Music Player, which can play songs loaded via a USB cable. The music can then be played by lifting the lid and stopped by closing it, while pressing the button beneath the lid skips to the next track.

Dave liked the look of the device, while both Tommy and John praised the on-off lid.

‘You just move it to the next song – that’s quite good,’ added John, who again thought the player was a bit large.

To change the volume, the music player’s instructions suggest that someone can push a pencil into one of two holes on the underside of the machine.



Tommy didn't like the idea of having to do this, though he acknowledged that a carer could probably do this to set the volume overall.

Dave suggested having some pre-set volume levels on a small number of buttons. 'You could have something simple like one to four,' he said.

John wondered why the volume control couldn't be in a more accessible position.

'Why hide it away if the people with dementia aren't going to be using it anyway?' he said.

Simple MP3 Music Player

The final product for feedback was the new Simple MP3 Music Player.

Tommy was immediately impressed. 'This one looks ideal,' he said. 'It's more modern and up to date.'

Songs can be loaded onto the device via USB, though this didn't appeal to everyone.

Dave, who felt that the storage space of 8GB was a good amount for music, said that he uses USBs quite frequently. However, John and Tommy said they wouldn't know how to use one.

An arrow button on top of the device moves the player on to the next track, though Tommy initially tried to slide rather than press this.

'It could have a "go back a track" button, but that would obviously complicate it more,' added John.

The product has some smaller controls on the back – including the option to make the songs play in a random order – some of which Tommy found confusing.

It was noted that this may have been more straightforward with an instruction leaflet, which wasn't available at the time.

Different needs

John felt that all three players were expensive when other products, including voice-operated technology like Amazon Alexa, could offer more at a similar or cheaper price. However, the group also agreed that a person's needs and preferences would vary a lot.

'There's not a blanket solution for everyone, because dementia is so broad,' concluded John.



All three of these devices – along with a range of other helpful products and gifts – are available from our online shop, see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

Without VAT, the One button radio is £45.83, the Simple Music Player (in red) is £83.32 and the Simple MP3 Music Player is £70.83 (you don't have to pay VAT if it's bought to be used by a person with dementia or other condition).



'I've told my boss that I've been diagnosed with dementia and she's asked me to leave. What can I do?'

Asked to leave your job

Having dementia doesn't have to mean that you stop working. You may still have a lot to contribute, and working is important to many people's wellbeing.

Even if you're finding work too much of a struggle and you welcome the idea of stopping, you'll probably need to plan how you'd adjust financially.

What does the law say?

Under equalities law, you can't be sacked simply for having dementia, because dementia counts as a disability.

You can be dismissed if you can't do your job, but employers should first consider 'reasonable adjustments' to help you carry on. These might include providing a quieter environment, changing hours or even offering you a different role. What's considered 'reasonable' depends on a number of things, including the costs involved.

The main law in England and Wales relating to this is the Equality Act 2010, while in Northern Ireland it's the Disability Discrimination Act 1995, but what they say is basically the same.

Talk to your boss

Your employer might not have a good understanding of dementia or equalities law, and guidance from the Society or DEEP (the Dementia Engagement and Empowerment Project) could help them with this.

Try to discuss different options with your boss. You could take someone with you for support, such as a family member, colleague or union representative.

It can be useful to get some advice about your legal rights, so you know where you stand when talking to your boss.

What if they sack you anyway?

It all depends on the circumstances, but you might be able to make a claim to an employment tribunal for unfair dismissal if you are sacked simply because of your dementia and without 'reasonable adjustments' being considered.

You'd need to get legal advice and there are tight time limits for tribunal claims, so the sooner you get advice the better.

What if you stop work?

It may be that, despite adjustments being made, you aren't able to continue working – or you may decide that you'd prefer to stop anyway. If so, find out about any benefits you might be entitled to receive and the impact of leaving on any workplace pension you may have.

Legal advice

Try Citizens Advice or your union, if you are in one. ACAS (the Advisory, Conciliation and Arbitration Service) has a free helpline on 0300 123 1100, as does the Labour Relations Agency in Northern Ireland, on 03300 555 300.

You could also speak to a solicitor, though they will charge a fee.

Pension and benefits

You can get free advice from Pension Wise on 0800 138 3944. For our Benefits (413) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Guidance for employers

For our Dementia-friendly business guide, which has a section on supporting staff affected by dementia, see alzheimers.org.uk/business

For DEEP's Tips for employers who want to be more dementia friendly, please visit www.dementivoices.org.uk/deep-guides



Dementia Talking Point, our online community, helps many people to feel less alone and more understood.

It's not just you

Whether you're caring for someone with dementia or living with your own diagnosis, the condition leaves many people dealing with loneliness and isolation.

You might not know where to turn for support, and if you feel like nobody else would understand anyway, this could make you want to talk about it even less.

Each month our online community, Dementia Talking Point, holds a Q&A with an expert about a chosen topic. The focus of the most recent session was loneliness, isolation and how to stay connected.

This is one of the most talked about topics on the online community – you're definitely not the only person going through this, even though it can feel like that.

Time and distance

During the Q&A, people asked lots of questions about loneliness. A few talked about how their caring responsibilities mean they don't have the time to socialise or maintain friendships.

Another described how, when he tries to speak to friends about his feelings – and despite them being

generally supportive – they either can't understand or don't seem comfortable talking about dementia. They sometimes change the subject completely, presumably because they don't know what to say.

Some said that because they live in a rural area, the nearest services and support groups are too far away, leaving them feeling cut off.

Different areas

On Dementia Talking Point, there is a place where you can talk privately with other community members about how you feel.

For when you need something lighter, there are also areas to talk about what books, films or music you're enjoying at the moment, or to share jokes and puzzles.

You might feel like nobody around you gets what you're dealing with, but there will be plenty of people on the online community who have a good understanding of this.

By opening up and talking about the difficult things, you can help to support each other through it – you don't have to feel alone in feeling alone.



Photograph: Freeimages.com/Gustavo Ribeiro de Mello



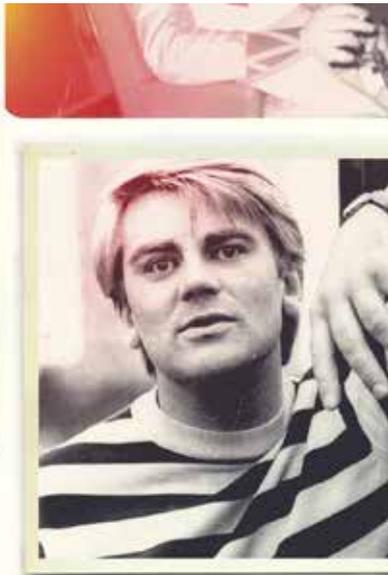
Take part

Dementia 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 what readers think about a carer's account of her late husband's dementia.

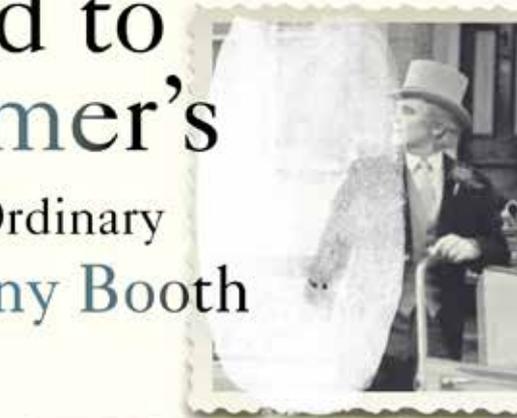
Married to Alzheimer's



STEPH BOOTH

Married to Alzheimer's

A Life Less Ordinary
with Tony Booth



Steph Booth began writing an Irish Times column about her husband Tony's dementia in 2013. He had been diagnosed nine years before that, and Steph continued the column until after he died in 2017. Her book, *Married to Alzheimer's*, developed from the columns, bringing her experiences from that whole period together.

Caroline Branney, who manages our Dementia Knowledge Centre, says, 'Steph was Tony's fourth wife and 24 years his junior. He was an actor and political activist with eight children. For much of the time that he had Alzheimer's, Steph cared for him at home.'

Although it doesn't shy away from dealing with the difficulties that they faced, Caroline says it remains an enjoyable book.

'I found this book a pleasure to read,' she says, 'and thoroughly enjoyable despite the serious subject. It combines a compelling biography with an interesting, practical view of caring for a partner with dementia and what this can entail.'

Karen Good, a reader in Suffolk, says, 'I have just finished the book and found it very enlightening. My mum has been diagnosed with Alzheimer's for two and a half years, but is still in the mild to moderate stages. It's a little sad to see what is to come.'

Karen feels it would be too close to the bone for her parents to read, but Gail Gregory in Lancashire, who has Alzheimer's, got a lot from the book.

'I found it to be a well-written read from a carer's point of view,' says Gail, 'with true representations of sad, funny and difficult times when caring for a loved one. An interesting life and a very heartfelt book.'

Rasila Mehta, in Greater London, adds, 'It was very interesting and educating, and very encouraging. After reading this book, I feel I am not alone.'

Constant tension

Caroline thinks the book comes across as a very honest account, with 'almost too much information sometimes'.

'Steph describes the constant tension between choosing between her own and Tony's wellbeing, her loss of confidence and emotional exhaustion,' says Caroline. 'She found the kindness of friends and family to be critical.

'She raises the need for meaningful long-term support after diagnosis, the continued need to destigmatise and understand dementia, the recognition of person-centred care and the validity of the carer's experience.'

This was something that resonated with Gail too, who says, 'It is such a shame that the care system still has flaws in helping carers and the person who has dementia.

'It's about time changes were made – someone actually needs to listen to people's needs, both the person with dementia and the carer.'

Useful section

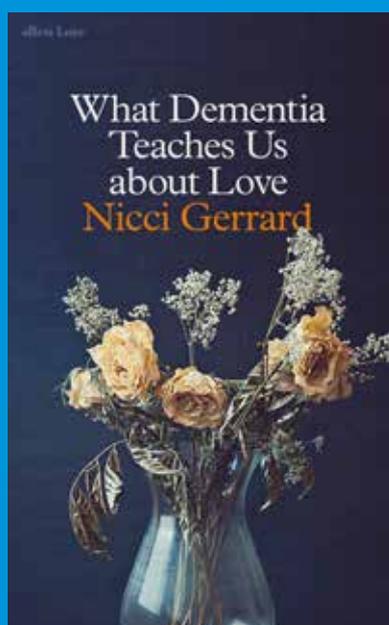
One section called 'Things I wish I'd known', towards the end of the book, stood out as particularly useful for Karen.

'I will definitely use this section,' she says, 'especially the part about powers of attorney, as I have been trying to do this with my dad for some time.'

Caroline agrees, 'When Steph started out as a carer – like most informal carers – she had general lack of awareness and limited knowledge, as well as a blind faith in her capabilities as carer. "Things I wish I'd known" makes a thought-provoking starting point for further discussion.'

Karen adds, 'A colleague at work has had her mother recently diagnosed with Alzheimer's, so I will definitely share the book with her. The strategies used in the book are helpful and it is humorous in places too.'

**Married to Alzheimer's:
A life less ordinary by Steph Booth
(Rider, 2019),
256 pages, £12.99,
ISBN: 9781846045752.**



Your turn

For the next issue, we invite you to read *What dementia teaches us about love*, by Nicci Gerrard (Allen Lane, 2019), 272 pages, £16.99, ISBN: 9780241347454.

Let us know what you think about this book by 6 September so we can share it in our next issue – email magazine@alzheimers.org.uk or write to the address on p3.



Book giveaway

We have five copies of Nicci Gerrard's book to give away – email magazine@alzheimers.org.uk or write to the address on p3 by 16 August quoting 'Teach' for a chance to win one (see p39 for terms and conditions).



Members of our online community, Dementia Talking Point, on handling anger or cruel comments caused by someone's dementia.

Anger and cruel comments

'A tip that I was told was to not say the word "no" when replying, but to start the sentence with the word "Yes" and then say what I needed to say. For example, "Yes, we can do that this afternoon" (when he wants to do it now), "Yes, you need to use your walker when you go outside" (when he wants to go out without it) or "Yes, your pants have to go on first."' **canary**

'I told her that I knew what she needed, to which I could see her rally for an onslaught, and then opened my arms and said "a hug". As always, the hug was accepted and the mood changed in an instant. I'm convinced that rage and cruel comments are often a manifestation of anxiety and confusion.' **karaokePete**

'I do think so often it is fear and anxiety that sometimes is the cause. Personally I try to nip things in the bud, I prune everything to give full attention, I slow down, I quieten down, I reassure how much I love him. Everything is put on hold. Tiring and exhausting, yes.' **AliceA**

'If Mum gets really verbally aggressive at home, I walk away (usually to the kitchen) and wait 10 or 20 minutes and let her calm down. I then go back to her, by which time she has calmed and we carry on as if it didn't happen.

'Very often reassurance in one form or another helps, sometimes it will be a smile and other times a rub on the back and sometimes a hug, which is difficult as I'm a big man of 6ft 4in and Mum is short and frail these days. But she loves a hug and laughs (I always manage to knock her glasses off), even after an outburst.' **Palerider**

'I've learned to spot the episodes long before they flare up, so I have to nudge my mum and remind her that it's about to happen and not to fuel the fire. Often the anger and cruel comments are there to engage an argument. By letting him have a purge, he always ends up calm and singing or whistling like nothing happened.' **InElysium**

'The best way to deal with cruel angry behaviour, is with the humblest sincerest kindness that you can muster. None of the cruel words being uttered are truths just the wrangling of a mind corrupted by a cruel disease.' **BLONDY**

'My wife's anger usually dissipates as quickly as it boils up so it is often best just to look at her and say nothing until it does. Hugs sometimes work but not when she isn't sure who I am. Saying anything at all so long as it is completely irrelevant to her anger can be a good defence.' **northumbrian_k**

'I have found if I can distract him by putting music on or taking him into the garden he seems to calm down, other times I just go out of the room.' **Nabroc**

'When it happens I keep repeating to myself, "It's the dementia, don't argue, don't reason," but it's easier said than done. When I'm coping well, I often say sorry for upsetting her (even if I haven't) try and find out if she's in pain, thirsty etc, and comfort and reassure her depending on what might have caused the anger and vile comments. I've read that distraction helps but not in our case.' **Just me**

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

Next issue

What advice would you give about helping someone with dementia to manage their money? Email magazine@alzheimers.org.uk or write to the address on p3.

Holiday memories



Whether days at the seaside, package trips, family reunions or far-flung adventures, the moments and sensations we experience on holiday often stay with us as particularly happy. They can prompt valuable conversation, reminiscence and activities as dementia progresses.

Looking at, handling and discussing holiday souvenirs, postcards and photos can be absorbing and pleasurable in itself. It can also help carers to understand a person with dementia more fully – their preferences and perhaps some formative experiences.

The internet is a good source of images, videos and music that could enrich this. In addition to using the usual search

engines, you can find and watch archive films at player.bfi.org.uk/free, www.yorkshirefilmarchive.com and www.britishpathe.com

Doing a jigsaw of a seaside or other travel scene could stimulate conversation and holiday-themed reminiscence cards are also available, including in the Daily living aids section of our online shop (see below).

Holidaying is a great theme for many different activities. Would someone enjoy being involved in planning, preparing and enjoying food they've had on holiday? Could painting, drawing and making salt dough or papier-mâché versions of the sights they've seen be fun? Are there any songs or styles of music that a person associates with holidaymaking or specific travels?

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 – visit shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

Your relationships

This booklet will help you understand how your relationships might change when you have dementia.

It provides information on preparing for and living with these changes as well as how other people can support you.

Check out the other booklets in our Living with dementia series at alzheimers.org.uk/publications

To order your free copy call **0300 303 5933** or email orders@alzheimers.org.uk quoting code 1507.



We're here to help

Contact us with all your questions or concerns about dementia.

Online

Visit our website for information and advice or to find local support services on our Dementia Directory. You can also talk to others with our online community, Dementia Talking Point.

alzheimers.org.uk/get-support

Phone

Our specialist dementia advisers are here to listen, offer tailored information and provide you with the right support.

Call us now on **0300 222 1122** or email helpline@alzheimers.org.uk

Information and publications

We produce a wide range of resources covering all aspects of dementia and dementia care. Order or download for free.

alzheimers.org.uk/publications

'Was able to find out about a local activity group which my Mum and I attended for the first time this week.'

'No matter what you're going through, there is someone who understands. I don't feel alone now.'

'The information provided has been very helpful, interesting and easy to understand. I have a friend who has just been diagnosed with vascular dementia and what I've read will, I hope, enable me to be more empathetic to her situation. Thank you.'

alzheimers.org.uk

 [@alzheimerssocietyuk](https://www.facebook.com/alzheimerssocietyuk)

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Simple MP3 Music Player



We have a Simple MP3 Music Player for one lucky winner drawn from correct entries received by 2 September.

Q: The UK number one single that topped the charts for the longest time during 1975 was:

- A. Sandie Shaw's 'Long live love'.**
- B. 'The power of love' from Jennifer Rush.**
- C. Queen's 'Bohemian rhapsody'.**

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.

Memory Walk T-shirt



We have a Memory Walk T-shirt for one lucky winner drawn from correct entries received by 9 September.

Q: If you visit memorywalk.org.uk or call 0300 330 5452 (local rate), the types of walks that you'll be able to find are:

- A. Memory Walk (2–10km), Memory Walk Plus (over 15km), GLOW (2–10km at night).**
- B. Memory Hop (1m), Memory Skip (2m), Memory Jump (3m).**
- C. Cakewalk (for as long as you want to), sleepwalk (for as little as possible), ministry of silly walks (for as long as you can).**

Amplidect Combi Photo phone competition

S Povah in Cheshire won an Amplidect Combi Photo phone. Answer: Calling the telephone the 'blower' comes from voice pipes on naval ships, which you had to blow into to attract the attention of the person at the other end.

Bird Watcher Bundle competition

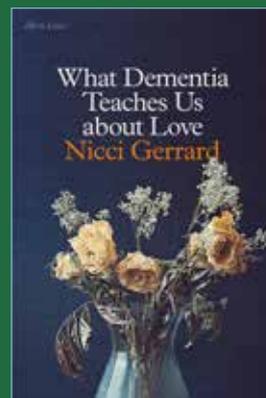
ME Dunthorne in Lincolnshire won a Bird Watcher Bundle. Answer: Birds often seen in British and Irish gardens during summer include house sparrow, blue tit and swift.

Married to Alzheimer's giveaway

The five readers who each won a copy of Married to Alzheimer's by Steph Booth, were AM Bird in West Midlands, R Mehta in Greater London, L Madden and G Gregory in Lancashire, and K Good in Suffolk.

Book giveaway

See p35 for a chance to win a copy of What dementia teaches us about love, by Nicci Gerrard.





Walk for a world without dementia

Share stories and create memories at **Memory Walk** this autumn.

Gather your friends and family and join thousands of others walking for their loved ones.

Who will you walk for?

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

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 Registered with **FUNDRAISING REGULATOR**

Sign up today

memorywalk.org.uk

or call **0300 330 5452**



Memory
walk