

Dementia together

December 2019/January 2020
Alzheimer's Society's magazine

Always involved

Real-life research

Pride in Care

Inclusive as standard

Rise above

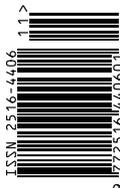
Facing criticism and stigma

Also in this issue

Demanding action
Dementia Connect
Gift ideas

The best of today

Sense of perspective





Welcome



From never mentioned to rarely out of the headlines, the 40 years since Alzheimer's Society was founded have seen a sea-change in how dementia is spoken about and perceived. This is in no small part thanks to our supporters – you – along with the many people who've been so open in sharing their experiences of dementia.

With so much still to do, the magazine is here to help you play your part in changing minds and changing lives. If you have dementia or are caring for someone who does, we're also here to make sure you know that you're not alone. We want everyone who can benefit from our real-life stories and ideas to know how they can get the magazine, so please make sure your family, friends and colleagues know how to subscribe (see below).

Regular readers will notice some changes with this issue of the magazine! Apart from a new-look contents page, we have two new articles – one on p13 about what you can do to stay well and How we can help on p32 – plus some other improvements. As ever, we're keen to hear your feedback and suggestions.

Danny Ratnaik
Magazine Editor

Questions about dementia? See p33.

Dementia together is the magazine for all Alzheimer's Society supporters and people affected by dementia.

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

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Thank you, Memory Walk – now it's time to GLOW

Millions for research

Dementia Revolution, the 2019 Virgin Money London Marathon charity of the year, raised over £4 million for the UK Dementia Research Institute, and our ambassadors and celebrity supporters are raising even more.

Radio DJ Chris Evans auctioned 50 VIP race packages for the TCS Amsterdam Marathon on his Virgin Radio breakfast show, raising over £400,000. The winning bidders joined Chris on a chartered jet to Amsterdam and ran the marathon with him in support of dementia research. Our Ambassador Scott Mitchell – whose wife, Dame Barbara Windsor, is living with dementia – and EastEnders actress Tanya Franks ran the city's Mizuno Half Marathon on the same day.

'We booked the plane, waited for the bids and the big-hearted listeners stepped up to the plate,' said Chris.

A massive thank you to everyone who got involved with Memory Walk this autumn!

Tens of thousands of you came together to walk in celebration of loved ones, and towards a world without dementia, at events in Wales, Northern Ireland and England. And an army of volunteers helped to create a fun and friendly atmosphere.

Nearly 2,000 walkers completed Memory Walk Plus, our new longer 15–21km events, including our first ever Memory Walk marathon in London.

We're now inviting you to join GLOW, our new night-time Memory Walks in March, suitable for all ages and abilities. Registration is open now, and magazine readers can claim 25% off the entry fee using the code GLOW25 before 31 January.

Use the GLOW25 code to sign up for your nearest night-time memory walk at memorywalk.org.uk/glow or call 0300 330 5452 (local rate).

Demanding action

We're putting dementia care high on the agenda for politicians before and after the general election on 12 December.

Ahead of the vote, we're making sure they see our manifesto, Demanding action on dementia, which spells out how the next government can improve people's lives. It covers social care, research and dementia in the community.

Our commitment card provides three key questions that you can ask candidates and activists during the election campaign.

See alzheimers.org.uk/generalelection for the commitment card and more.

40 years
2019

Alzheimer's
Society
United Kingdom



Gala success

Our first ever Forget Me Not Gala raised an incredible £279,200 to fund vital support.

Hosted by comedian Hugh Dennis, new and existing Alzheimer's Society supporters enjoyed a series of speakers and special performances. These included a Singing for the Brain group of people affected by dementia and volunteers from Croydon, south London.

Society at 40: Changing the conversation

Two Alzheimer's Society founders, Morella Kayman and Gordon Wilcock, joined people affected by dementia, volunteers and staff in November to mark our 40th anniversary.

Our 40th anniversary has been a great opportunity to thank all of you for your support over the years. The time given and money donated has enabled us to challenge perceptions, fund research and provide vital support.

'I'm pleased and proud of all the work Alzheimer's Society has done to challenge and change the conversation on dementia,' said Morella.

'I know that if we unite against dementia, a cure could be just around the corner. That means a better future for us all – ourselves, our families and our children for years to come.'

To join the fight against dementia, visit alzheimers.org.uk/getinvolved

NHS continuing healthcare: Updated booklet

Our updated When does the NHS pay for care? (813) booklet includes how to apply for NHS continuing healthcare funding in England, and how to appeal if it's not awarded.

Other updated booklets include Managing your money (1501), Keeping active and involved (1506) and Planning ahead (1510).

To order any of our publications, visit alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Ask the big questions

Alzheimer's Society Annual Conference 2020, themed 'Innovation and impact', will address the big questions in dementia. Discussion topics at the event, in London on 18–19 May 2020, will include brain health, dementia care, dementia-friendly societies and technology.

The input of people affected by dementia is vital to make sure your views are heard by the many attendees who work in health and social care, research, policy and local or national government.

Register your interest at alzheimers.org.uk/conference

Northern Ireland safeguards

A new process in Northern Ireland aims to protect the rights of a person whose liberty may be restricted while they aren't able to make decisions about their own care.

The Deprivation of Liberty Safeguards (DoLS) system means that such actions must be checked to ensure they are the right thing to do. DoLS are one of the first parts of the Mental Capacity Act (Northern Ireland) 2016 to come into force.

See www.lawcentreni.org or call 028 9024 4401 for free legal help.

Festive get-togethers should be joyful occasions, but Alzheimer's Society is here when worries about dementia make them more challenging.

If you haven't seen someone for a while, changes in their behaviour or memory can be more evident. This is especially worrying if they don't seem interested in seeing their GP or getting other help. Our support is for anyone with questions about dementia – call 0333 150 3456 or visit alzheimers.org.uk/getsupport

Some people with dementia won't have anyone to celebrate with. If they do, it could be a rare break from being alone. Our Side by Side volunteers help people with dementia to do the things they enjoy throughout the year – see the difference you can make as a volunteer on p14.

Jeremy Hughes
Chief Executive Officer



Don't miss...

Carol in Llanelli says that Dementia Connect means, 'At last I've got somebody on my side.' See p12.

Walking can help you stay well, whether choosing stairs instead of the lift or full-on hiking. See p13.

GLOW night-time walks will raise vital funds in March. See p17.

People affected by dementia are shaping a major research programme. See p22.

You can use our online directory to find support near you. See p32.



Insurance Day of Giving

The insurance industry has been raising vital funds for dementia research through its Insurance Day of Giving. More than 60 companies took part in the event's second year, with bake sales and fancy-dress competitions. One firm even brought in a smoothie bike (pictured) for health-conscious employees!

The day was also an opportunity to raise awareness about dementia. A Stanmore Insurance event in Bolton included a session with Alzheimer's Society staff and, in Norwich, Aviva hosted information stands and assistive technology demonstrations.

The wider Insurance United Against Dementia campaign, led by passionate individuals from across the sector, has raised an incredible £2 million since its launch in 2017.



Amazing Scouts

Our amazing four-year partnership with the Scouts came to an end this summer, having created over 23,000 Dementia Friends among its young people and volunteers.

Chosen by Scouts themselves as one focus of their A Million Hands programme, we developed resources with them to help young people make a difference for people affected by dementia.

Scout groups can continue to request Dementia Friends sessions or use these resources to learn more about dementia.

For all of our resources for young people, including for Scout groups, visit alzheimers.org.uk/youngpeople

Warmer welcomes: Heritage and tourism

We're joining forces with the National Trust to make all of its 500 sites in Northern Ireland, England and Wales dementia friendly.

The new three-year partnership will give the 74,000 people who work and volunteer for the National Trust the opportunity to become Dementia Friends and learn more about how their sites can be more welcoming to people affected by dementia.

Heritage sites are popular among many people with dementia and carers. Historic spaces, collections and stories can prompt conversation and outdoor exploration.

In a separate partnership, we've also recently launched a guide with VisitEngland and VisitScotland for tourism businesses of all sizes to better serve people affected by dementia.

Hospital inquiry in Wales

People affected by dementia are having their say on the state of hospital care in Wales.

Alzheimer's Society Cymru has been visiting hospitals across Wales to record the experiences of people with dementia, and their carers and family members.

The findings will be turned into a series of recommendations to improve dementia care in hospitals, which will be presented to an inquiry held by politicians from different parties. The inquiry will present its findings to the Welsh Government in Spring 2020.

Alzheimer's Society Cymru has also been using the hospital visits to meet with local Assembly Members.

New treatment seeks approval

Although it will take time to become available, a potential new drug to slow the progress of Alzheimer's has been described as 'hugely exciting news'.

Earlier in 2019, pharmaceutical company Biogen abandoned trials of its drug aducanumab because it looked like it wasn't helping people with Alzheimer's.

However, further analysis of data from the trials suggests that the drug could benefit some people in the earliest stages of dementia. The drug is now being taken to US regulators for approval.

'This is hugely exciting news,' said James Pickett, Head of Research at the Society. 'We're waiting for further data, but this could be the first new treatment for Alzheimer's in over 15 years.'

'Alzheimer's Society has a proud history of funding dementia research, including critical discoveries that have made today's news possible.'

'We will work alongside the company, regulators and people affected by dementia to understand the difference this could make and, if appropriate, to ensure people can benefit from this breakthrough in the future.'

Dementia Friendly Awards

Winners of our Dementia Friendly Awards were announced at two ceremonies in November. The awards celebrate the people, organisations and communities that make a real difference to the lives of people with dementia.

In England and Wales, the Outstanding Contribution award went to Ian Sherriff, who has created and championed projects in all areas of the community, locally and globally.

Dementia Friendly West Rainton and Leamside, set up by residents in County Durham, was named Dementia Friendly Community of the Year for its work with schools, churches, care homes and local businesses.

Lena Chauhan was recognised as Dementia Friends Champion of the Year. She delivers sessions to predominantly Asian communities alongside translators and medical professionals, challenging stigma and changing attitudes.

In Northern Ireland, the 40th Anniversary – Lifetime Achievement Award went to Liz Cunningham, who has raised awareness through media campaigns and interviews as a person living with dementia.

The Championing Diversity award was won by a group of adults with learning disabilities who have become dementia champions, and Tracy Smyth, the Dementia Support Worker who has been working with them.

For more about the winners, see alzheimers.org.uk/dementiafriendlyawards

In the press

Football: Don't be put off



Recent research into a possible link between football and the risk of developing dementia has attracted a lot of attention. This is understandable in a nation where the game is so popular, but the findings don't mean you should stop playing it.

In the largest study of its kind, University of Glasgow researchers compared over 7,000 professional footballers to 23,000 people from the general population. The professional players were more likely to develop a neurodegenerative disease, such as dementia, than other people.

Some have assumed that heading balls over a long football career is the culprit. However, this study didn't investigate why professional players may be at greater risk, and the difference might be caused by something else.

James Pickett, our Head of Research, said, 'This research doesn't say anything about the risk of a Saturday kickabout in the park.'

'There have been changes in the game over the decades. For instance, heavy leather balls have been replaced with lighter latex and plastic ones, and the risks for the modern-day professional footballer may be different.'

'If you love kicking a ball around with friends or family after work, don't feel put off – what's good for the heart is good for the head.'

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



The best of today

Celine Quinn faces up to dementia with the support of her faith, family and Alzheimer's Society. **Gareth Bracken** meets a woman accepting who she is.

Celine Quinn, now 75, recalls just what it was like growing up as the oldest of 14 siblings in County Derry, Northern Ireland.

'You were always looking after children, you spent your life rearing children,' she says. 'You just made the best of it – there was always plenty of company.'

This attitude of acceptance and picking out the positives has stayed with Celine following her dementia diagnosis in 2018. With the professional and personal support of those around her, she has been staying positive, keeping active and maintaining a sense of perspective.

Really worthwhile

A busy household grew even further when Celine's gran came to live with them. Later, when Celine married Pauric and had a child of her own, they all moved in too.

'It's just the way things were in those days,' says Celine. 'When you got married, not everybody had a home.'

Celine has held a variety of jobs over the years, and chuckles as she reels off the list.

'I've been on a market stall, run a pub, sold Tupperware, beauty products and insurance, and my last one was as a lollipop woman!'

Celine, who lives with Pauric, a retired joiner, in the village of Rasharkin in County Antrim, has always had a varied and active life. She used to play golf and still enjoys yoga, dancing, bingo, a craft club and a luncheon club. She has five children, 11 grandchildren and two

great-grandchildren and describes herself as very family orientated.

'You just thank God every day that you have great-grandchildren and the fun you have with them,' she says. 'Although when they leave, you're ready to lie down! But the fun we have is amazing, it makes life really worthwhile.'

Confusion and relief

Celine was diagnosed with Alzheimer's disease around two years ago following tests and two MRI scans. These were done after a series of confusing and distressing experiences.

'I'd been going through a terrible time,' she says. 'We were out in the car one day and I was seeing pink trees. Then after 10 minutes, I said, "I've been somewhere else."'

'Another time, everybody had crossed the road, and I'd stopped in the middle, halfway over. The

Quick read

Celine Quinn, 75, maintains a positive outlook and sense of perspective having being diagnosed with Alzheimer's in 2018.

Celine was actually relieved to receive a dementia diagnosis following a series of confusing and distressing experiences.

Celine, who lives in Country Antrim in Northern Ireland, reads to the congregation at local dementia-friendly church services.

She has found strength and acceptance with the help of support from her faith, family and Alzheimer's Society.



lights changed to green, people blew their horns but I didn't seem to be aware. That was a very frightening episode.'

Following this, her dementia diagnosis came as something of a relief.

'I then knew there was something wrong and I could do something about it, which was to face up to it and work with it,' says Celine.

'Someone locally said, "How terrible, how dreadful," but it's not like that. I said to her, "I know what I've got, I'm being looked after, and I'm learning to live with it."'

Sense of perspective

Celine sometimes gets names and times wrong, and problems with her sense of direction mean she doesn't go out much on her own. She's keen to keep a sense of perspective despite this.

'It doesn't matter if I call people by different names – some people who have Alzheimer's don't even know their own grandchildren,' she says.

'I'm not special. I've got an illness but big deal, I can work with that. I've got my family, who have adapted to my way of life. I've got everything I could possibly need.'

Celine has several other conditions, including diabetes, arthritis, lupus and a heart complaint.

'You don't take life for granted – you make the best of today,' she says.

Celine doesn't particularly worry about her own future, but does admit to concerns over her ability to support her family in years to come.

'I like to be needed and to be able to help when I am needed, that's always been me,' she says. 'My biggest fear is not being able to help my family in future, even down to Pauric.'

As well as finding the right kind of help and advice at the right time through Alzheimer's Society, Celine has also provided support to the other people with dementia who she's met through this.

'When you're a housewife and a mother you do become invisible, I suppose,' she says. 'But this makes me feel important. I appreciate it.'

Way of life

Celine also plays a key role in cross-community dementia-friendly church services in the Causeway area. Set up by volunteers in April, these services support people with dementia to continue practising their religion with fellow worshippers.

'The church is a way of life for me,' says Celine. 'It's the way you were brought up, you love your church. You also rely on your

Celine with husband Pauric and granddaughter Róise.



Photographs: Mark McCormick



church. Four of my siblings have died but I had somebody to talk to, I wasn't on my own.

'Life is surrounded by your faith. There's no way you can describe it to anybody.'

The fact that the services bring people from different communities together is a bonus.

'I don't question anyone's beliefs – you accept people for who they are, they're just people,' says Celine.

The services were established by church members after they attended a specialist dementia workshop arranged by Alzheimer's Society. Prayers at the service usually relate to dementia, and the gatherings are relaxed so that attendees feel comfortable and can be themselves.

'For the hymn the minister says, "You can sit, stand or get up and walk about," it's whatever you feel like doing,' explains Celine.

Part of the service sees Celine read a psalm or other passage to the congregation, which has been very well received.

'You see people's faces, happy and smiling,' she says. 'It makes me feel very important.'

'You're reading to people with dementia or very poor hearing, so you have to speak properly and let them understand. Afterwards

they'll say to me, "I understood every word you said there."'

Comfort and acceptance

Celine's involvement in the dementia-friendly church services has been supported by Adrian Friel and Aoife McMaster, Services Manager and Dementia Support Worker at the local Alzheimer's Society.

'When I arrive, Aoife gives me a hug at the door and I get a hug from Adrian – it's just comforting,' she says.

Celine advises other people affected by dementia to accept support from organisations such as Alzheimer's Society.

'Don't shrug people off, they're here to help you,' she says.

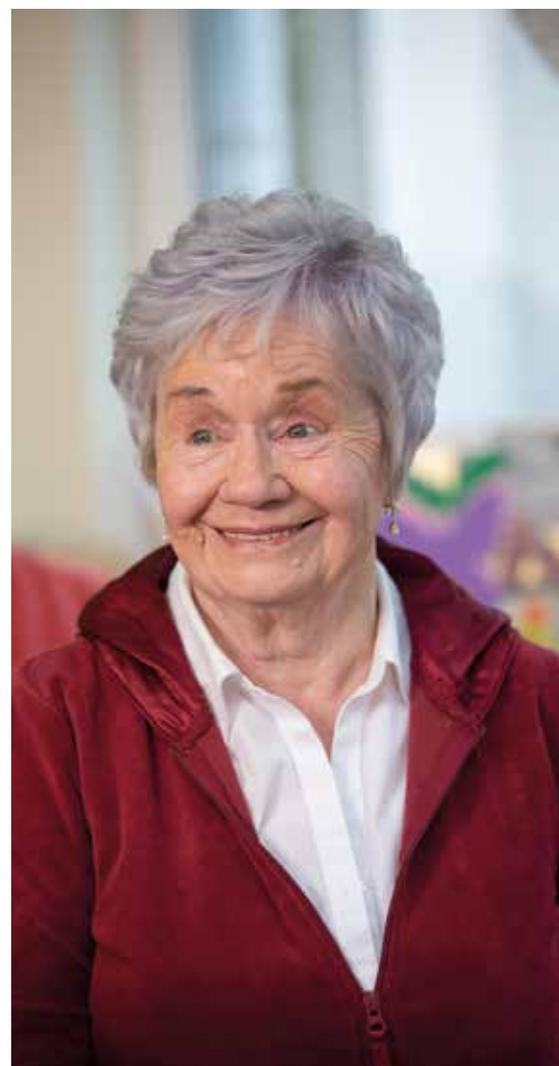
Earlier this year, Celine appeared with Adrian on BBC Radio Ulster and BBC Radio Foyle to discuss the church services and her role within them. As ever, she takes positives from these public appearances.

'Doing the reading or the radio helps me to realise that if I make a mistake or do something wrong it doesn't matter, it's not important,' she says.

Celine draws on her faith and the strength and understanding of her family to live as well as possible with dementia.

'I thank God every day for how lucky I am to be diagnosed, take the medication and just get on with it,' she says.

'I've accepted who I am, and people accept me for who I am.'



Your donations mean we can help more people live well with dementia – see alzheimers.org.uk/give or call **0330 333 0804** (local rate).

Connect with others affected by dementia through our online community, Dementia Talking Point – visit alzheimers.org.uk/talkingpoint

Use our dementia directory to find dementia services near you – see alzheimers.org.uk/dementiadirctory

Someone on my side

A woman with dementia in south Wales tells us how our Dementia Connect service is making a huge difference to her.

Dementia Connect, Alzheimer's Society's new personalised support service, means people affected by dementia are only one click or call away from the support they need. We want to reach everyone affected by dementia, and Dementia Connect links people to the right support, at the right time, in the right way.

'Dementia Connect is a more effective way of working where we can reach more people,' says Sue Nye, a Dementia Support Worker in Ammanford.

'We're making sure that people get the support they need – whether that's from Alzheimer's Society or externally.

'We'll give people advice and information, but also emotional support. We're someone to talk to who isn't a doctor or a psychologist, but who understands dementia and how it affects people.'

Becoming isolated

When Sue visited Carol, who is living with dementia in nearby Llanelli, it became clear that she could benefit from regular contact and support.

'She's a very sociable lady but was becoming isolated, so we talked about Side by Side,' says Sue.

A central element of Dementia Connect, Side by Side helps people with dementia to lead fulfilling lives with the support of a like-minded volunteer.

Carol was paired with volunteer Christine Wheeler-Jones, and they've been meeting weekly since early 2019.

'We go for lunch or a bit of shopping. We go to places I haven't been for years,' says Carol. 'I remember little things from childhood that I'd forgotten about.'

Christine spends time listening to Carol, who feels comfortable enough to be herself. Carol has been hurt when some people who have met her refused to believe that she has dementia, but she's found Christine to be very empathetic.

'I can talk to her, she's such a nice lady,' says Carol. 'It's nice to talk to someone who doesn't judge. She understands and is very caring.'

'I enjoy her company – we have a good laugh'

Feeling better

Christine volunteers for the 'wonderful' Side by Side service because she feels that she can continue to contribute after her retirement.

'I'm lucky to have the health I've got. I feel if I've got something to offer, I should do it,' she says.

'It's Carol's choice where we go, which makes her feel important in what we're doing, and I always introduce her as my friend.'

Christine says that Side by Side has given Carol a 'certain edge on life', and Carol agrees that she's regaining her confidence.

'I was getting into a deep depression for the last couple of years, but having something to do and somewhere to go has been very helpful – I feel better,' she says. 'A lot more people need help like this.'

Making a difference

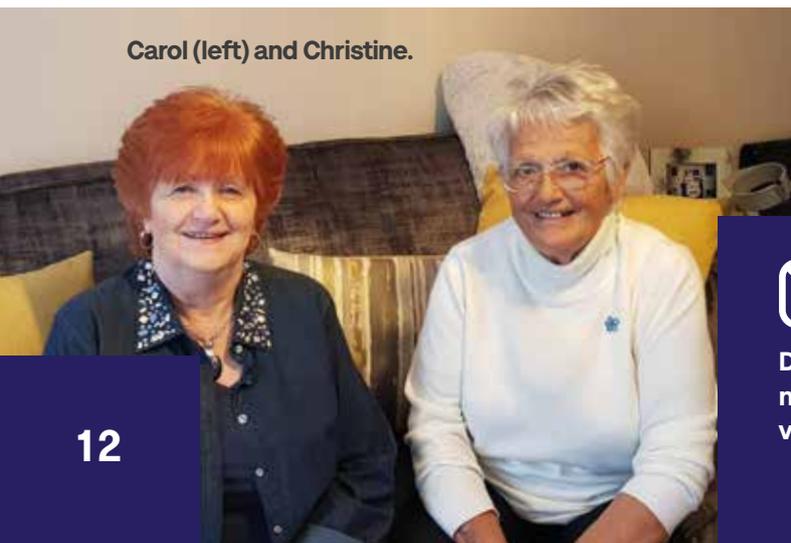
Susan Morgan, the Side by Side Co-ordinator who matched Carol and Christine, has found it rewarding to see the close connection that's developed between them.

'The impact that having a volunteer has on people's lives is fantastic,' she says.

Carol greatly appreciates the support of people like Susan, who embody what Dementia Connect can do for someone with dementia.

'Just knowing she's there makes a difference,' says Carol. 'At last I've got somebody on my side.'

Carol (left) and Christine.



Dementia Connect is new, and parts of the service may not be available in your area yet. Call 0333 150 3456 or visit alzheimers.org.uk/getsupport

Why I go walking

We ask about the different ways you keep healthy and well, whether you have dementia or not. This issue, we hear how walking helps five readers.



Roisin Hughes, 50, Belfast

I walk every day and thoroughly enjoy treks etc to keep fit. I have lost weight and feel better in myself.

Peter Jones, 66, Carlisle, with vascular dementia

I live near a cemetery and walk around it regularly most days, weather permitting, and watch the wildlife. The fresh air is good for me and it keeps my brain active. It keeps me fit.



Peter Middleton, 65, Northamptonshire, with Alzheimer's disease

I always try to walk rather than ride to a destination. I am a member of a walking organisation, and I plan my own circular walks in the local area with the aid of GPS mapping software.

I try to get out at least two or three times a week, rain or shine. I began long distance walking while in the RAF in the 1980s and have continued ever since. My motivation is the peace of mind I obtain through solitude and the wonderful sights I see – the fitness aspect is a bonus.

Jan Tarrant, West Sussex

I always take the stairs as opposed to the lift, except when with my husband. We walk around garden centres and National Trust and English Heritage sites, depending on his ability on the day.

At times I miss coastal walks, but the paths are often uneven which is not good for him. I do it for the enjoyment, building new memories for my husband, and both physical and mental wellbeing. We purchased a wheelchair for my husband because he tires easily.



William Payne, 64, Cardiff

I walk daily, thinking gently about things, distilling worries into manageable portions, recollecting good times and talking with whoever is wandering by my side.

A means of getting from one place to another has become an end in itself. I have better physical health and sense of self, the company of friends and casual acquaintances, and a more balanced perspective.

Your turn

Tell us how any of these activities help your wellbeing – singing, playing puzzles or games, learning or brushing up on a language, sleeping better and relaxation, enjoying good food, or dancing.

Email magazine@alzheimers.org.uk or write to the address on p2.

Stay well

Some things, like your age and genes, affect your chance of developing dementia but you can't change them. Things you can change? Keep your mind and body active, enjoy healthier food, don't smoke, drink less alcohol, stay in touch with people, and deal with any health problems.

If you already have dementia, the same things can help you to stay healthy and well – see alzheimers.org.uk/active for inspiration and tips to get active in ways that suit you.

Visit www.nhs.uk/livewell for health and wellbeing advice for everyone.

Not rocket science

A Side by Side volunteer in Warwickshire says there's 'nothing clever' about the role – just bring yourself to it and you can make a big difference.

John Teeling has been volunteering with Side by Side for over two years. He's seen the huge value this service brings for the people with dementia who he's met through it.

John, in Binley Woods near Coventry, also has no doubt that many other people could make great Side by Side volunteers.

'Treat the person as you would do a friend and you can't go wrong,' he says. 'It's not rocket science!'

'All they're asking you to do is befriend someone, there's nothing clever about it. You don't need a degree, just a personality that allows you to do it.'

Everyone has something different to bring to the role, and one of the things that John brings is his own experience since being diagnosed with Alzheimer's five years ago.

'I wanted to do something – I like helping people. Also, from a selfish point of view, if I do it for them then people might do it for me in future.'

Rugby and pub grub

Through Side by Side in Warwickshire, John has supported several people to carry on doing the things they enjoy. For the last year or so, this has been with Terry, who also has Alzheimer's disease.

'I see Terry every Tuesday,' says John, 'and we go to see Coventry play rugby every other Saturday. He enjoys rugby.'

'I like to get into a routine. I take him out to the park for a walk, we get a cup of tea, then go for a pub meal. Then a café in the gardens, then I bring him home. It's

about four to four-and-a-half hours. I do the driving, that's no problem.'

John says the people with dementia he supports 'know that I'm travelling the same journey as them', including Terry.

'We treat each other as confidants, almost. We just have a bit of lad talk, mickey-taking and a moan about our missuses!' laughs John.

Regular boost

John is fortunate in the responses he's had when people find out he has dementia.

'If I tell people I've got Alzheimer's, I see their attitude change. They become more forgiving. I haven't felt that anybody has rejected me because of my dementia.'

John has given talks about Side by Side at legacy events, where Society supporters learn about leaving gifts in their wills and the difference this can make. He's also involved in our Focus on Dementia Network – groups of people with dementia who come together to influence what we and other organisations do.

'I've been on the panel for an employment interview too,' he says. 'That turned out to be very interesting, I felt very included.'

However, it's volunteering with Side by Side that gives John his most regular boost from knowing he's having a direct and meaningful impact on someone else's life.

'I'm retired – I've got my family, but no hobbies apart from the rugby. It's a bit of self-help for me. I also hope the help I give will be returned.'



Terry (left) and John.



Find volunteering opportunities in your area, see alzheimers.org.uk/volunteer or call 0300 222 5706 (local rate).

More than ready

A Dementia Friends Champion in Cambridgeshire is inspired by her own experience of dementia.

When Heather Hooper's mother died in 2015, at first she wanted nothing more to do with dementia – the condition that had caused her family so much sadness. However, months later she began to feel ready to help others.

'I walked the path with Mum on her dementia journey,' says Heather, whose mother had mixed dementia. 'I was so deeply affected by the whole experience that I had to turn it into something positive.'

'Five months after her passing, I found myself knocking on the door of Peterborough's Dementia Resource Centre, asking, "How can I help?"'

'I had witnessed families and carers struggling to understand what was happening to their loved ones. I recognised that, with a little knowledge, they may be better equipped to understand and cope.'

Reaching out

Heather has drawn on her experience to volunteer in different ways, though a key area has been raising awareness of dementia.

As a Dementia Friends Champion, she runs information sessions with all kinds of local organisations to help people understand what they can do to help people with dementia.

'Through Dementia Friends, I reach out to people of all ages, particularly our younger generation. They are our future carers and will have heard about and even experienced dementia within their families, schools and communities.'

'I love witnessing the "penny dropping" moment in people of all ages when I present an information session. It's so rewarding.'

As well as creating over 840 Dementia Friends in schools, businesses and community groups, Heather gives monthly talks to student healthcare assistants and supports a regular walk in a local park for people affected by dementia. She also helped a local supermarket set up 'quiet hour' shopping, and recently ran a session with her local football team.

'Volunteering is good for the soul,' says Heather (pictured with local care home staff). 'The voluntary work I do is in Mum's memory.'

Volunteer as a Dementia Friends Champion – please visit dementiafriends.org.uk to find out more.

Dress up for Elf Day

Express your inner elf this Christmas – Elf Day is on 6 December but you can hold yours whenever you like! For Elf Day ideas, see alzheimers.org.uk/elfday



Listen up!



It's been two years since we launched our new-style audio interviews, where you can hear the stories of people with dementia in their own words.

Thank you to our thousands of listeners – if you're not one of them, maybe it's time to join us? Visit alzheimers.org.uk/podcast to listen online or download to play later, or search for us on your podcast app.





A certain someone

A supporter from Manchester cycled over 1,570km from Land's End to John O'Groats this autumn, raising more than £10,000 for Alzheimer's Society on the way.

Andrew Mossford took on the nine-day Deloitte Ride Across Britain in memory of his dad Alan, who had dementia and died in July, aged 80.

'Carers are being abused by the system,' said Andrew, thinking especially of his mum. 'Research into dementia does not receive the financial support it warrants. I want to support research into finding a cure.'

Met by his wife, daughter and dog at John O'Groats, Andrew said, 'What a feeling to see Jen, Annie and Prince on the finishing line.'

'Every day has been an epic adventure of its own. As for Days 7 and 8 in Scotland, well I can only assume that a certain someone upstairs was helping push me up those mountains, and drive me through those winds.'



Crickhowell welcome

A new group in Crickhowell, Powys is planning how to better support local people affected by dementia, following their community's recent recognition as becoming dementia friendly.

The Crickhowell Area Dementia Friendly Community steering group met for the first time in October, attended by local Assembly Member Kirsty Williams and MP Jane Dodds. At this special event, a local organisation founded by our volunteer Suzan Alderton and her husband Mike, the Living with Dementia Society, also presented cheques totalling £8,000 to Alzheimer's Society and other charities.

Ian Thomas, Dementia Friendly Community Co-ordinator, said, 'Crickhowell has done a lot so far, with almost everyone in the town getting involved in raising awareness of dementia and supporting people affected by it, including starting a monthly pop-up café, Caffi Croeso. The group is building on this by looking at everything from faith groups and carers groups to work with schools and local woodland volunteers.'



An autumn of best days

Over 30 people affected by dementia have enjoyed an autumn of weekly guided walks at Hyde Hall in Chelmsford, a Royal Horticultural Society public garden. Alzheimer's Society in Essex organised the group as part of a wider programme helping people to stay active.

Nicola Lambert, Group Co-ordinator, said, 'When dementia begins to make everyday tasks a trickier proposition than they used to be, the opportunity to do something without pressure or expectation is invaluable.'

'Caring for a person with dementia isn't always easy either, so participating in an activity without the trials and tribulations of daily life can be a chance to recharge the batteries and just enjoy time together.'

'Hearing a carer say that it was "the best day I've had with Mum in three years" proves how important these experiences are.'

Glowsticks at the ready

Katharine Evans, Fundraising Business Manager, is looking forward to our GLOW walks in March – will you join her?



Every year I wait excitedly for the opportunity to volunteer at Memory Walk, and now at GLOW too – our new sponsored night-time walks.

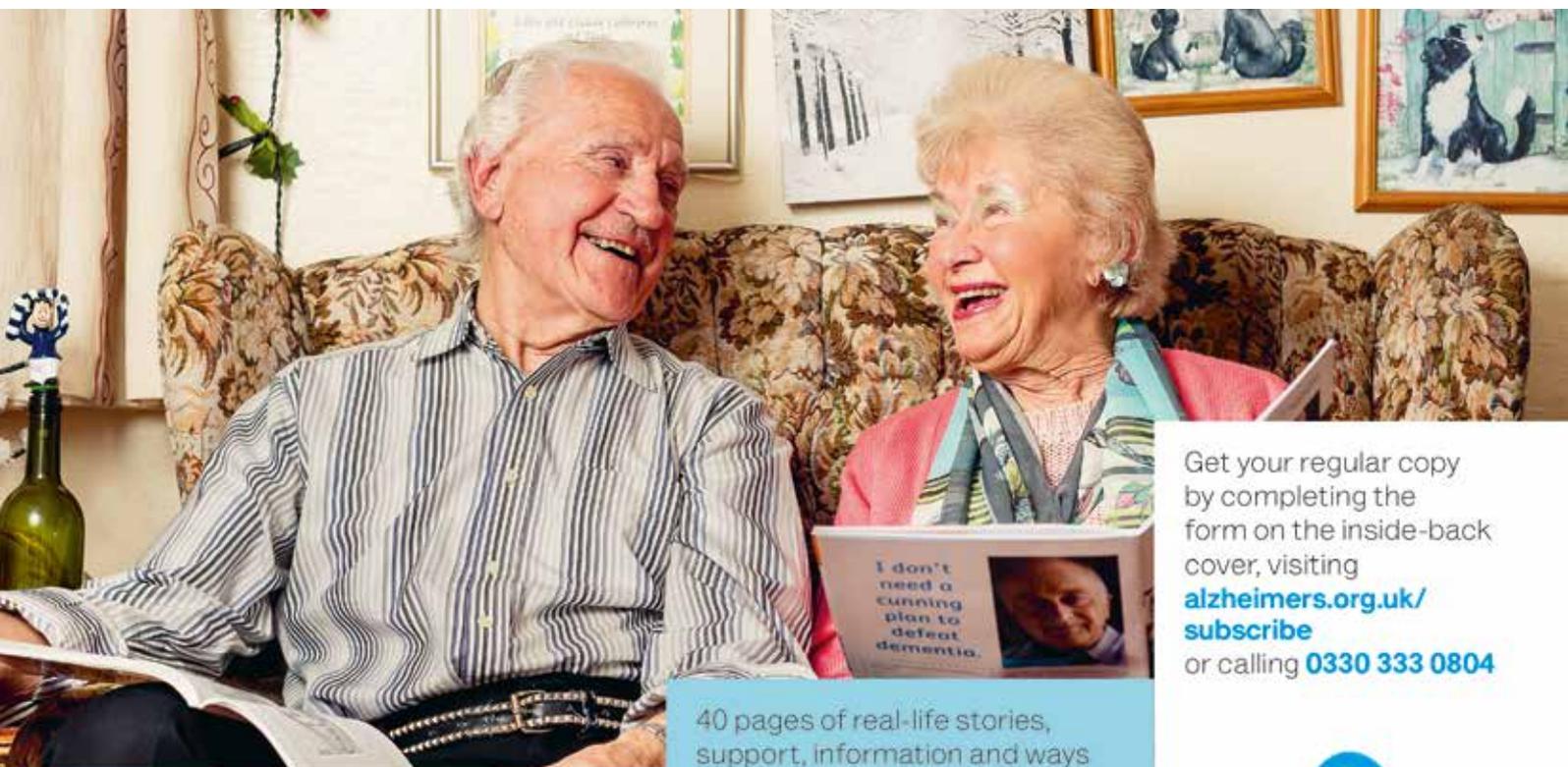
Volunteering at these events is a lot of fun and you meet so many inspirational people, both volunteers and walkers. I'm always reminded of why I do my day job. The personal stories I hear, and the joy and heartache shared openly in every conversation, mean that I go back to work with a renewed sense of purpose. In March 2020, our new GLOW walks will be taking to the streets in locations from Belfast to London, and from Tyneside to Bristol.

Like our regular Memory Walks, they're 2–10km long. People of all ages and abilities take part, and they have so many different reasons for doing it. However, everyone there shares a passion for wanting to celebrate loved ones and to unite against dementia.

The fact that GLOW walks are after dark adds a magical twist. A beautiful atmosphere is created by the colours of so many glowsticks, and the spirit of coming together for a single cause.

I hope you can join us at your nearest GLOW walk – it's a wonderful way to help make a difference.

Use your special reader's code – GLOW25 – before 31 January for 25% off the sign-up fee at memorywalk.org.uk/glow or call 0300 330 5452 (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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Rise above

Versha Patel knows what it's like to face criticism, stigma and a lack of understanding about dementia. **Gareth Bracken** meets a former carer who now helps others.



When her mum Sitaben was diagnosed with vascular dementia, Versha Patel dedicated herself to finding and providing the best support she could. However, some of her actions were misinterpreted by other people – including members of her own family – leaving her exposed to rumours and judgement.

With the support of her husband and others, Versha found the strength to not only ignore the criticism, but also offer to help others in a similar situation.

First family

Born in Kenya in 1943, Sitaben Patel lived in India before getting married in her early 20s. She came to England with her husband Mohanbhai in 1964 and the couple later ran an off-licence in Bolton until his retirement in 1999.

Quick read

Versha Patel wants there to be greater understanding about dementia and its impact, especially among Indian communities.

Her mother, Sitaben, was diagnosed with vascular dementia in 2011 and she died in 2018.

Versha says she felt bullied by some in her community, who misunderstood some of her decisions.

Versha now feels able to give support and advice to other carers facing similar challenges.

‘They were the first Indian family in the area where they had the shop and it was quite difficult culturally,’ says Versha, a security manager who lives in Bolton.

‘There were a few racist attacks on the business.’

Sitaben, who also worked as a machinist, was always a supportive and very independent person.

‘She helped her siblings settle when they first moved to Bolton and cared for her mum and dad,’ says Versha.

‘Apparently Mum was the first Indian woman in the community to pass her driving test. She did the cash and carry while my dad stayed in the shop.’

Mohanbhai died not long after his retirement, and this had a huge impact on Sitaben. She turned her attention to helping raise Versha’s young daughter, Hannah.

‘Mum adored Hannah,’ says Versha. ‘I think looking after her granddaughter brought her back to life after Dad passed away.’

Taking action

Sitaben would visit India almost every year, and it was on a trip in 2011 that Versha first noticed changes in her mother’s behaviour.

‘I stayed with her for two weeks and she was getting confused and experiencing some incontinence,’ says Versha. ‘She told me to take Hannah to visit a relative, but it was someone who had died years ago.’

Versha visited her GP back in England, who put together a plan of action for when Sitaben returned. This led to tests and a diagnosis of vascular dementia in May 2011.

Versha immediately sought to discover more about the condition.

‘I did a lot of research – I was on the internet every night,’ she says. ‘I had to think long term, so I was looking at social care, assessments and carers.’

Versha, her brother Yash and Hannah all cared for Sitaben around their existing work and school commitments. The family also received good support from Sitaben’s younger brother and his wife.

Fight for care

Versha found it difficult to secure appropriate and good quality professional care for her mum.

‘I had an approved carer from the council but that was diabolical. They would turn up late and forget to give the medication,’ says Versha.

Sitaben was initially granted only half an hour of care a day to help take her medication, but Versha battled to get her more. She arranged for Sitaben to have replacement care, which highlighted just how much support her mum now required.

‘I had various meetings with social workers. My auntie and I eventually went to the head of social care,’ she says. ‘We had to fight to get 37 hours of care a week – something I felt Mum was entitled to because she’d worked really hard when she came to this country.’

Versha was fully prepared to take action if she felt that acceptable standards weren’t being met.

‘I’d complain about anything – some of the carers were probably quite shocked, but I wanted to make sure Mum got the best care.’

Versha eventually found a ‘fantastic’ domiciliary care agency that provided Gujarati-speaking carers to support Sitaben at home. Sitaben also began visiting a day centre three times a week.

Feeling bullied

Sitaben's health was deteriorating and she was losing mobility, prompting Versha to request that family members phone ahead before visiting. However, some relatives took this as a sign that they were no longer welcome.

'I had to tell people to ring before coming round, otherwise Mum would have seen them through the window, get up and risk hurting herself. But some family members didn't understand,' says Versha.

A few relatives also reacted badly to Sitaben having replacement care.

'People started spreading rumours that I wasn't looking after Mum properly and that I was going to steal her money and house,' says Versha.

'I felt bullied by family and community members. I'd take Mum to festivals and weddings, to try and have a normal life, but it was very difficult. I felt I was being watched.'

Versha married Manish in 2013, and he immediately became a great source of support, along with her brother Yash and Hannah.

'Some people wouldn't want to come into a marriage knowing their mother-in-law was ill, but he was very committed to looking after Mum,' she says.

'He gave me the strength to not listen to others.'

Difficult time

Sitaben enjoyed being at home, watching Indian TV channels and EastEnders. The family also held religious ceremonies and

birthday celebrations in the house. However, as time went by she became even less mobile and began losing her speech.

'We'd take her out as much as we could, but she was deteriorating,' says Versha. 'I started accepting that Mum was going to die.'

'I made a big fuss of her 75th birthday in April, because I felt something was going to happen.'

Sitaben died in July 2018, aged 75.

'We had a 13-day mourning period, with the funeral in between,' says Versha. 'It was a very peaceful send-off but also a very difficult time.'

Best life

Versha wants there to be greater understanding about dementia and its impact on



people's lives, especially among Indian communities.

'There needs to be more awareness of this,' she says. 'People need to understand exactly what this is about.'

'I think Mum felt isolated but people didn't visit and the community didn't really help. Local community figures need to come and see exactly what it's like.'

Versha has started to support other carers who are facing similar challenges.

'I think I am now ready to give myself to others who are going through what I've been through,' she says. 'I've got advice on how to keep on at social services, and how to hold your head up and deal with people gossiping.'

'I also feel it's very important to accept when someone is in their final stages – that helped me become stronger.'

Now able to look beyond what others may say or think, Versha takes comfort from knowing that she did everything possible for her Mum, including at the end.

'We gave her the best life we could,' she says.



Versha with daughters, Hannah and Arya, and Manish (centre), and Yash (right) with his fiancé Vanessa.

Photographs: Mike Frisbee

For our booklet *Caring for a person with dementia: A practical guide* (600), see alzheimers.org.uk/publications or call **0300 303 5933** (local rate).

Connect with others affected by dementia through our online community, Dementia Talking Point – visit alzheimers.org.uk/talkingpoint

Dementia Friends is changing people's perceptions of dementia in all communities – get involved at dementiafriends.org.uk

Always involved

People affected by dementia are helping to ensure that research into the condition is the best it can be. **Gareth Bracken** meets a group that's supporting a major long-term study.

Since 2014, the IDEAL research programme has been looking at people's real-life experiences of dementia, to see what helps them to live as well as possible.

IDEAL, which stands for 'Improving the experience of dementia and enhancing active life', involves over 2,500 people with dementia and family members or friends who provide support.

Based at the University of Exeter, with Alzheimer's Society funding and involvement from other organisations and universities, IDEAL follows people's lives over several years. The researchers do this using face-to-face interviews and questionnaires.

The study looks at what things influence how people affected by dementia are able to live well, and the impact of changes over time.

A group of people affected by dementia has been advising on different aspects of IDEAL.

Called ALWAYSs – short for 'Action on living well: Asking you' – the group's members draw on their personal experiences, skills and expertise to do this.

'The group is the first port of call for researchers to sense-test ideas and ways of working,' says Rachael Litherland from Innovations in Dementia, who supports and facilitates the group.

'It brings in a perspective that the researchers don't have.'

Big discussion

Group members, who come from across the country, have different reasons for wanting to be involved.

'I like the idea of being at the forefront of research,' says Julia, who cared for her late mother. 'We're helping researchers from an early stage with our experiences.'

Keith, who was diagnosed with Alzheimer's disease in 2010, feels that the IDEAL study can help change how professionals approach dementia.

'Medication is tried and tested, so sometimes they play safe with that and stay away from the support side,' he says. 'I don't think there's anything quite like IDEAL anywhere, so it can really make a difference.'

The ALWAYSs group has influenced the various ideas that the study is based upon, as well as its themes and ambitions.

Quick read

People with personal experience of dementia are helping to shape research into living well with the condition.

Members of the ALWAYSs group have been sharing their advice and opinions with researchers working on a study known as IDEAL.

Their input has covered everything from the concepts behind the project to how researchers should speak when interviewing people.

Julia, an ALWAYSs member, says her role within the group gives her a real sense of involvement.



Photographs: Thousand Word Media



'We had a big discussion about that and found things that were far more important than what was already there,' says Monica, a former carer.

The group also had the idea to create a questionnaire to help people with dementia outline what living well means to them, which will then be incorporated into the research.

'There are smaller things too,' says Julia. 'We discussed what researchers should wear when visiting people in their homes. How should they act? Speaking slowly. All things we know about.'

Positive message

Rachel says that the IDEAL researchers value the ALWAYSs group and its input, which group members appreciate.

'Researchers say they're learning from us,' says Keith. 'Some can be protective of projects, but this team are very open and considerate.'

The IDEAL study is identifying what changes could be made by individuals, families and

communities to enable people to live well with dementia. At the end of the programme, researchers will produce recommendations and an action plan for people who provide health and social care.

'We're hoping it brings a better understanding of the experience of dementia – how do you make it so that everyone is at the more positive end?' says Jane, a former carer. 'This group understands how bad dementia can be, but we're about looking for solutions.'

David, who cared for his late wife and mother-in-law, says the IDEAL project provides 'a positive message in the open arena' that he can pass on to anyone diagnosed with dementia.

Asking you

Members have also benefited personally from their involvement with ALWAYSs.

'You're not alone in your experiences – other people experience the same things,' says Rosemary, who is married to Keith.

Lesley, who has dementia, says she's learned something from every ALWAYSs meeting she's attended. 'I can share things with my daughters and neighbours,' she adds.

Maureen, who attends meetings with her husband Tom, who has dementia, has also gained a lot from being involved.

'This is the only group I can share my thoughts and feelings with. I can be honest and I get answers,' she says.

Tom adds that he enjoys spending time with the different people in the group.

Monica says the members have all become friends, while Jane speaks of a sense of 'trust and respect'.

Reflecting on her time with the group, Julia highlights the part of the ALWAYSs name that refers to 'asking you'.

'That's what it's all about,' she says. 'It's getting the questions and answers that are important to people.'

'I have a real sense of involvement.'

Your support means we can fund a range of cutting-edge research – visit alzheimers.org.uk/give or call **0330 333 0804** (local rate) to donate.

To take part in vital dementia research, visit www.joindementiaresearch.org.uk or call **0300 222 1122**.

Find out more about our research into the cause, cure, care and prevention of dementia – see alzheimers.org.uk/research

Pride in Care

Older LGBT+ people may feel especially vulnerable when they need care. **Gareth Bracken** reports on a scheme promoting inclusivity and understanding among care providers.



Quick read

A quality mark is recognising organisations that provide quality care and support to older LGBT+ (lesbian, gay, bisexual and transgender) people.

Developed and overseen by the charity Opening Doors London, the Pride in Care standard involves surveys, assessments and visits for care providers.

The first place to receive the standard is home care provider Right at Home Central London, which has focused on its staff culture.

Landermeads care home in Nottingham is going through the accreditation process, introducing changes to be more inclusive.

Organisations providing care for over-50s, including people with dementia, can now work towards a quality standard to show how they support LGBT+ (lesbian, gay, bisexual and transgender) people.

'It was clear that there was a need for the Pride in Care standard,' says Jim Glennon, Training and Consultancy Manager at Opening Doors London, a charity that supports older LGBT+ people.

'I looked at existing research into the attitudes of health and social care staff to LGBT+ clients and patients. There was some prejudice, but more a lack of confidence and people saying they didn't feel they'd had sufficient training.

'I also used our own knowledge from the 2,000 older LGBT+ people we work with. Older LGBT+ people going into care tend to be single, often have no children and can be estranged from their family.

'So often, when they're contemplating care, it's going to be care on their own and they may

be feeling vulnerable. They may go back into the closet because of fear of how they'll be treated.'

Opening Doors London oversees the process for Pride in Care accreditation. This looks at staff attitudes and training, policies, procedures and publicity, and the experiences of people using services, as well as Opening Doors London ambassadors assessing the organisation.

The Pride in Care standard lasts for three years, after which it can be renewed. Opening Doors London keeps in touch with accredited organisations, sharing news and supporting how staff are recruited and managed, where needed.

'Pride in Care can be powerful in creating lasting cultural change,' says Jim.

Better culture

At the moment, 12 organisations are at different stages of the Pride in Care assessment process. The first to be awarded the standard was Right at Home Central



Photographs: Mark Harvey

London, which offers live-in care and home care, including to people living with dementia.

'We've had some LGBT+ clients and felt there must be more we can be doing for them,' says Bryan McMorrine, Managing Director and Owner.

'We want clients to feel more comfortable discussing their sexual orientation or gender identity. If they're holding something back, then it's harder for us to build a relationship with them.'

An initial survey revealed that some of Bryan's staff didn't understand why the Pride in Care standard was necessary.

'That was a big negative, but it showed exactly why we needed it,' he says.

As part of the process, Right at Home Central London introduced changes to benefit both its staff and clients.

'Our policies and procedures weren't wrong, but they weren't fully inclusive,' says Bryan. 'I wrote a new policy and procedure for if an employee was transitioning.

'All of our job adverts now say that applicants must be prepared to work with LGBT+ people in a non-discriminatory way. We want to make sure the LGBT+ community know they won't be discriminated against.'

Ezra Akar, a Care Manager for Right at Home Central London, says the Pride in Care standard has generated a better culture among staff, which can only be good for clients.

'Our support workers feel more comfortable and confident going out to LGBT+ people, which helps make those clients feel more comfortable, protected and safe,' she says.

Having the standard has already made a notable difference to Bryan and his team's work.

'We recently had a new LGBT+ client who wasn't sure about having someone live with them, but was happier about it when they heard we had the standard,' he says.

Very proud

Landermeads care home in Nottingham – which has been recognised for its work supporting people with dementia – is going through the process for Pride in Care accreditation.

'We value people's emotions and who they are, but I felt there were things we could do to make our environment even more inclusive,' says Ros Heath, the home's Owner Manager.

There were many positive responses to an initial staff survey, but it also showed room for improvement.

'It showed that we have lots of very good practice and are very inclusive – staff agreed that the standard fits with what we do,' says Ros.

'But it did also highlight some elements of banter that some non-care staff thought was acceptable, but which isn't.'

Landermeads has rewritten policies and procedures to make them more inclusive. They have also made more subtle changes, such as adding rainbow butterflies to its building and literature – imagery they hope LGBT+ people will recognise.

'We're hoping that things like that will give a message of inclusivity if LGBT+ people come to us,' says Ros.

Landermeads is soon to be assessed and potentially awarded the Pride in Care standard.

'I'd be very proud to receive it,' says Ros. 'This is important – it's something to be taken seriously.'



For our booklet LGBT: Living with dementia (1511) and factsheet Supporting a lesbian, gay, bisexual or trans person with dementia (480), see 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/dementiadirectory

For more about Pride in Care, email prideincare@openingdoorslondon.org.uk or call 020 7239 0400.

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

Letter of the month

Which Jean?

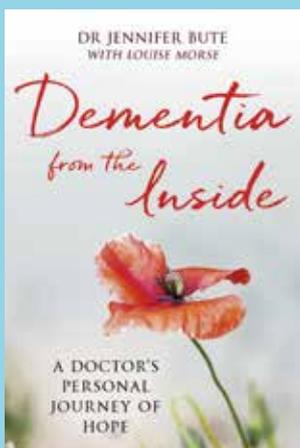
I thoroughly enjoyed reading Dr Jennifer Bute's book *Dementia from the inside*, as featured in a previous issue of the magazine, not least for its wealth of detail and sound, practical advice.

One small observation from my own experience, which may be of use here – when sending a birthday, or perhaps more pertinently, a Christmas card to someone living with dementia, it seems wise to include a more full identifier than might be the norm, be that a small photograph, a surname or the context in which you know the person to whom you are writing.

I think of the distress, some years ago, of an elderly friend, living with vascular dementia, on receiving no less than three Christmas cards all signed simply 'Jean'. She knew from the list she had prepared with one of her daughters that she had sent cards to two Jeans but, whether this card was from one of them or whether from an entirely different person, she couldn't tell and no one could help her.

Heather M NicMillan, Cheshire

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



Heather refers to *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.

This is me

My husband was in hospital recently and a copy of your 'This is me' leaflet was made available as soon as staff knew he had dementia.

When completed, this was at the front of his medical notes. Every person who helped to care for him was aware of his dementia and his needs and preferences.

Thanks are due to both the enlightened hospital – Royal United Hospital Bath – and to the Society.

Merrilyn Richardson, Wiltshire

Society response

We're always delighted to hear how a resource like This is me has helped to improve a person's care, and it sounds like this hospital was making great use of it.

'This is me' can help anyone receiving professional care who has dementia, delirium or communication difficulties, whether they're at home, in a care home or in hospital.

Visit alzheimers.org.uk/thisisme to download or order English language or bilingual Welsh/English versions, 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 February/March issue to arrive by 6 January. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Seen elsewhere...



Andrew Tinley, a Dementia Friends Champion, shared a picture on Twitter after signing up new Dementia Friends at his theatre in Derby:

It was lovely to be in the @DerbyTheatre rehearsal room for our festive production of A Christmas Carol and deliver a @DementiaFriends info session to the cast ahead of our #DementiaFriendly performance!



When we shared a video on Facebook of Dame Barbara Windsor and other celebrity supporters on our 40th anniversary in November, many of you joined in their good wishes, including Joanne Hartley in Hull:

Happy birthday to Alzheimer's Society. You have helped to make our journey with my mum so much happier and stronger. She's doing amazing and it's all thanks to your amazing staff and volunteers in Hull – shout out to Julie Ibbertson, she's our angel.



When someone shared his conflicted feelings about his mother's imminent move into a care home on Dementia Talking Point, many members rallied around, including DesperateofDevon:

We on Talking Point will be there with you in thought, and here for you as and when you need us (((((((((((((((big hugs)))))))))))))) Hope all goes well.

OPG deputyship fee refunds

The Office of the Public Guardian (OPG) says that people charged deputyship fees between 1 April 2008 and 31 March 2015 may be due a partial refund. Deputies are authorised by the Court of Protection in Wales and England to make decisions on behalf of someone who doesn't have capacity to do this themselves.

If you're currently acting as someone's deputy, then you should automatically be offered a refund if you're due one. However, if your deputyship has ended or the person you were a deputy for has died, you will need to apply for the refund.

To find out more, visit www.gov.uk/deputyship-refund or call 0300 456 0300 (local rate) and select option 6.

Power of print

Epson is celebrating the power of print to support people affected by dementia in its partnership with Alzheimer's Society.

In a 'save or share' promotion across its range of EcoTank printers, customers can either reclaim some cash back or donate it directly to us. Epson is also sharing examples of how printing can help in some of the day-to-day challenges of dementia.

Find out more at www.epson.co.uk/saveorshare



‘My mum has dementia and pays for her own care, but her care home has asked her to find somewhere new to live. What rights does she have?’

Evicted from a care home

Apart from being upsetting and stressful, it can be tricky to know how to respond if a care home wants to evict someone. Much will depend on the home’s reasons for asking your mum to leave.

Reasons

There are situations where a care home can ask a resident to leave.

The home should do whatever it reasonably can to meet a resident’s care needs. However, if it can’t provide the right care, then the person might be asked to move somewhere that can.

The same is true if the person is violent and there’s a real risk of serious harm to staff, other residents or themselves if they remain.

Someone could also be evicted if they have repeatedly failed to pay their fees and now owe a significant amount of money.

Rights

Even if the care home has reason to ask your mum to leave, she still has rights that must be respected.

She should be given the reasons why she’s being evicted, and the opportunity to appeal the decision.

She should also have a notice period of 28 days, or longer if this is stated in the care home contract.

Responding

Look through your mum’s contract with the care home – clauses about ‘termination of contract’ should say how the arrangement can end and what the notice period should be. The contract may also give her additional rights, such as stating that there should be a meeting with management or a mediation process.

If the care home hasn’t given its reasons for asking your mum to leave, then ask for these. If you disagree with the reasons, ask to discuss them and explain why you disagree. If this doesn’t resolve the situation and you still don’t agree, then the care home should be able to tell you how to appeal its decision.

If the care home doesn’t have an appeals process, then you can raise a complaint to it about this. If you’re not satisfied with its response, you could ask the relevant ombudsman to look into your complaint independently. This would be the Local Government and Social Care Ombudsman in England, the Public Services Ombudsman for Wales, or the Northern Ireland Public Services Ombudsman.

You could also speak to local social services for further advice, and for help in finding a new care home.



More information and advice

The Relatives and Residents Association – www.relres.org or call 020 7359 8136. See www.shelter.org.uk for links to Shelter, Shelter Cymru and Housing Rights, or call 0808 800 4444 in England, 0345 075 5005 in Wales or 028 9024 5640 in Northern Ireland.



John Udraufski, Bridgend, aged 68 with Alzheimer's

What's changed most since your diagnosis?

I had to surrender my driving licence, that really affected my day-to-day life. I've been driving since 1971 and I've always loved motor vehicles, so it was a big wrench when I lost my ability to drive. I understand why though – when I had the assessment they immediately told me I had to stop, as my mind wanders. I've got a bus pass but it only works in Wales, so I can't use it when we travel down to Devon.

What would you take to your desert island?

I'd take the internet, so I could keep up with what's going on in the world.

How has Alzheimer's Society helped you?

Alzheimer's Society has been brilliant. They signpost us to other help, like getting an Admiral nurse out to see us. I'm also involved in a Focus on Dementia Network group, where we look at things and say what we think about them.

What song or tune sums up your life so far?

Always look on the bright side of life, from Monty Python's Life of Brian. I don't like being depressed – I was becoming a bit of a recluse before we went on holiday to Mallorca recently, but I'm making an effort to go out at least a couple of times a week now.

What single thing would improve your quality of life?

More public awareness of dementia. People are scared of it – when they find out you have dementia, they talk to you as if you don't have a brain. There's been improvement, but not enough.

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

If I could still know what I know now, then 1971 when I joined the army. I was so naive! I don't think my life would change a lot, but I think it would change a bit.

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 p2.

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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volunteers@alzheimers.org.uk

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





People affected by dementia in Bristol try out a selection of gift ideas.

Gift ideas

It was a bumper session in Bristol as three Focus on Dementia Network groups came together for a special gathering in the city centre. Facilitated by Alzheimer's Society staff, these groups ask people affected by dementia for their thoughts and feedback about a range of topics.

We were visiting to get their opinions on games and gift ideas designed with people with dementia in mind, all of which are available from our online shop.

Precious Petzzz

Precious Petzzz are lifelike pets made with synthetic fur, which appear as if they are breathing. The group was shown a dog and a cat that are designed to be therapeutic and provide a sense of security.

People noted how real the dog looked, though there were also some reservations.

'I think it's a good idea, but a bit spooky,' said Iris. Mary felt it was 'quite pleasant once you get past the "creepy" stage'.

Some group members found the cat comforting and soothing. They thought it could be an especially good gift for someone who used to have pets but isn't now able to have a real one.

Snakes and Ladders/Ludo

An all-in-one board game set includes simplified versions of two classic board games, with Ludo on one side of the board and Snakes and Ladders on the other.

The Snakes and Ladders design appealed to Desmond, while Valerie thought that having numbered cards instead of dice was a good idea. 'Dice are fiddly and you're not so likely to drop cards on the floor,' she said.

A few of the group felt that the Ludo was too simple and more suited to children. However, it was acknowledged that different games will appeal to people whose dementia is at a different stage.

Although Mary thought the price seemed rather a lot, Desmond felt it was worth it once you see it laid out and start playing it.

Link and Think

Link and Think is a conversation game where players begin by rolling a dice to receive an instruction, for example, 'Pick two tiles. Which do you dislike?' They then select the tiles and talk about their choices.

The transport version of the game contains tiles such as 'ferry' and 'steam train', while the hobbies edition includes 'fishing' and 'knitting'.

Group members noted that the game stimulated conversation and got people engaged. It was also felt to be reasonably priced and nicely produced, with clear instructions.

The game offered many possibilities, even if the conversation went off topic. 'It could be good for getting to know people, or yourself,' said Chris.

Throw and Tell Ball

Each panel of the Throw and Tell Ball features a different preference or experience. When a person catches the ball, they choose one of the panels under their thumbs and talk about that topic.



A few of the group agreed that the ball would suit people of all ages and could be enjoyed by the whole family. 'Everyone loves talking about themselves, so this is a great game,' said Ron.

Karen thought the game might not be for everyone. She'd previously played it with attendees at a Memory Café who had felt 'put on the spot'.

However, Chris said the ball covered subjects that people wouldn't necessarily think to ask otherwise. 'It brought out interesting things from around the table,' he said.

Curious Cat jigsaw

The 13-piece jigsaw, called Curious Cat, sparked memories for Wendy, who discussed the ginger cat that she used to have as a pet.

The puzzle is the easiest in its range, and was a bit too simple for some. 'We want a better challenge,' said Sarah, who attends the group with her wife Millie. 'Something in between this and a 1,000-piece jigsaw.'

The jigsaw comes with a printed backing board that's designed to assist and encourage a person to complete the puzzle, which people found helpful.

Chris thought the jigsaw was good quality, while another member felt the pieces were a good size for people in the later stages of dementia.

'It's lovely, isn't it?,' said Millie, once she'd finished the jigsaw.



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

Without VAT, the Snakes and Ladders/Ludo set is £17.36, Link and Think is £9.99 per pack, and the Curious Cat jigsaw is £12.49 (you don't have to pay VAT if it's bought to be used by a person with dementia or other condition). The Precious Petzzz are £26.99 each, while the Throw and Tell Ball is £14.34.



Win a Precious Petzzz
See p39 for a chance to win.



'I have vascular dementia and I live alone in Liverpool. I'm keen to meet people and find out what support I can get, but I don't know what's going on locally.'

Having a good support network is really helpful when you have dementia and live on your own. Meeting other people who can relate to your situation also makes a big difference.

You can get help through us in many ways (see opposite), and our online dementia directory can help you find services and activities for people affected by dementia that are available in your area. These could include anything from social groups to care homes.

Your options

If you enter your location and the kind of support you're looking for, the directory will give you a list of results to look through.

For the location, you can type in an area, part of an address or a postcode – the more specific you can be, the better.

You're then asked to select types of support, and you can choose as many as you like. There's a tick box in case you only want to search for Alzheimer's Society services, plus a link to a category guide to explain more about each type of support.

You can change these later if you'd like to search using a different location or combination of types of support.

Your results

When you get the results, you can choose between local, regional and national listings. Local services will be within a certain distance of your location, and you can adjust this distance. They'll mostly take place at local venues like community centres or care homes. Regional listings include services for people living in your community, sometimes provided through home visits.

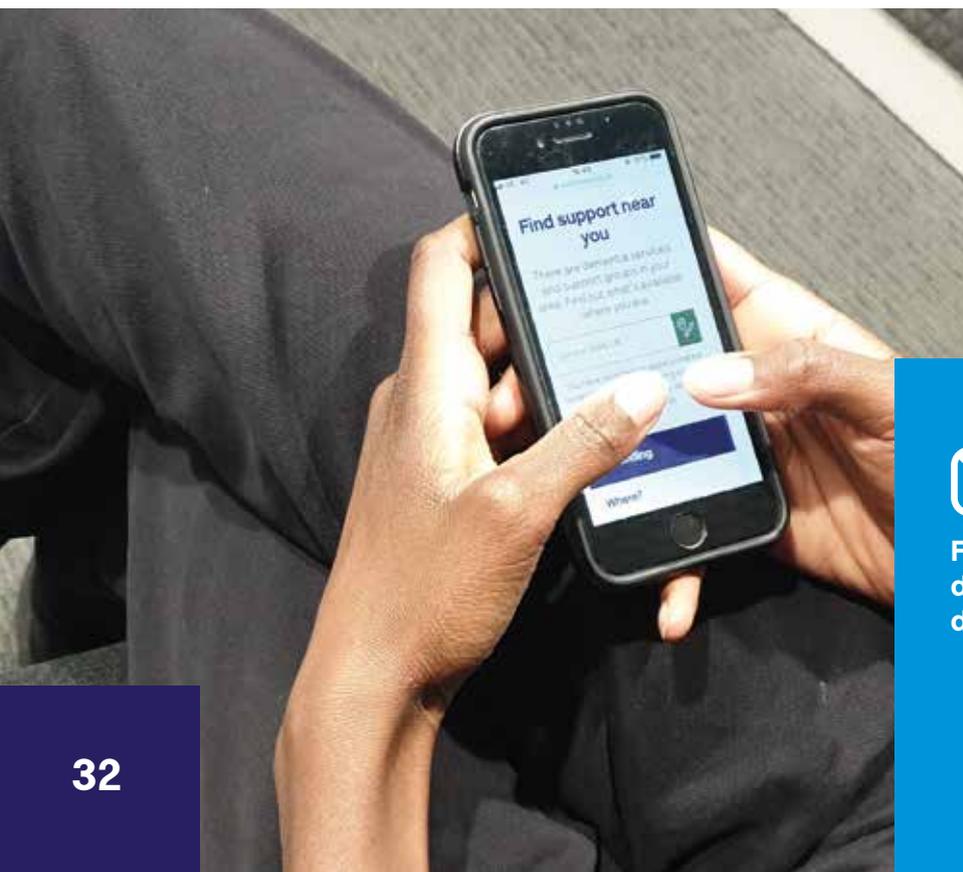
The listings say where each service is and who it's for, alongside a short description of what it offers. If you scroll down to the bottom of the page and there are still more results, you'll be able to click 'load more' to see them.

Each service has its own page with more information about who runs it, practical information and contacts so you can get further details, such as opening times. You'll also see a map of where to find it, and you can click through to directions too.

What else?

The directory could bring up a wide range of options in some parts of the country, and fewer local results in other parts. Either way, you should see regional and national services that could also help.

Remember that you might be able to get what you're looking for from local groups and organisations that aren't listed. Your local library, community centre, local authority or GP practice may be able to help you to find these as well.



Find support near you using our directory at alzheimers.org.uk/dementiadirectory

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.'

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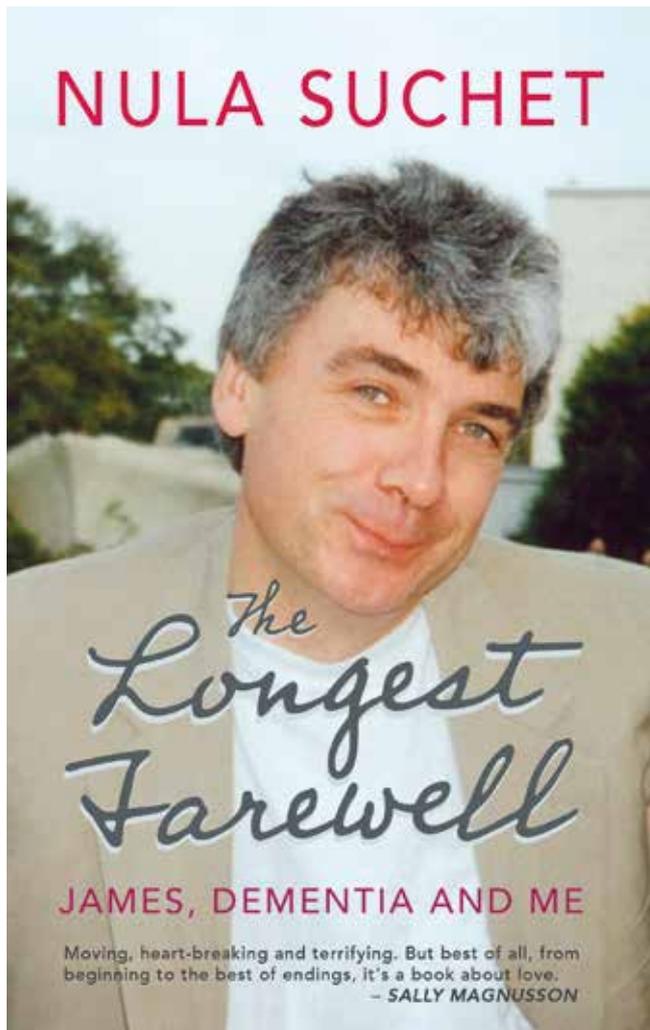




Readers share their views about a real-life story of losing a partner to dementia, but also of finding unexpected love through the experience.

The longest farewell

Our book this issue tells the incredible story of how its author – then Nula Black – not only cared for her late husband James, who had frontotemporal dementia, but also how she met John Suchet, who she would eventually marry. They met because John’s wife Bonnie, who also had dementia, lived in the same care home as James.



Caroline Branney, who manages our Dementia Knowledge Centre, says, ‘This is a moving, poignant description of James’s mental and physical deterioration, and the effect it has on their lives and those around them. Fortunately, the ending of this true story is unexpectedly bittersweet, though overall I found the book very heart-rending.’

Joanne Gaskell in South Yorkshire agrees, ‘I must say, it brought back some sad memories for me. My mum was diagnosed aged 52 and passed away at 57. I can 100% understand what Nula and John both went through for many years – such a cruel disease, with no treatment or cure.

‘It is so frustrating for the families, you all become the victim of dementia. I’m glad Nula and John both found happiness again. An excellent but sad book.’

Gillian Andrew, a reader in Greater London, says, ‘Despite its stark frankness about her late husband’s dementia, I found it compulsive reading.

‘I imagine people with no experience of dementia would be shocked by some episodes. Those of us who have had our own experience – in my case with my mother – can relate all too well to many of them.

‘The saddest comment I heard my father make was that my mother was no longer the person he married, so one particularly poignant passage for me was, “it has taken away my life... and so it can claim another victim – two for the price of one.”’

Difficult diagnosis

While there is much about the story that may be challenging to read, it’s familiarity could also be a source of comfort to some.

‘Nula started writing about their experience when, after five years of caring for him at home, James went to live in a care home,’ says Caroline. ‘She says she was later able to organise her account and temper it with the benefit of hindsight.

'I was particularly struck by the length of time it took for James to receive a dementia diagnosis – explained in the book by a combination of denial and also lack of awareness, even in the medical profession, of younger people with dementia.'

Gail Digby, another reader in South Yorkshire, says, 'I read the book with great interest, as my husband had frontotemporal dementia. This is rarely written about, and indeed is less well known and given much less attention than other types of dementia.'

'My husband was diagnosed in 2013 and died in 2018. My experience was similar to Nula's and I found it strangely comforting that she experienced the same feelings as I did on my journey.'

'Music was of great importance to my husband, the difference being that he sang, very loudly for very long periods of time, and usually the same refrain over and over again.'

Gradual acceptance

The journey described in Nula's book takes readers through a difficult process of acceptance, and to an end of life experience that is far from ideal.

'Once James is diagnosed, Nula is completely stunned and feels guilty that she has been frustrated by her husband's behaviour and had her "head in the sand" about the changes, which she learns can never be reversed,' says Caroline.

'Gradually she comes to accept that their relationship is never going to be quite the same. Nula takes James to all his favourite places – out fishing, to Paris and the opera – but eventually they stop going out, as it is no fun anymore.'

'Nula's description of how the disease progresses is harrowing. She says she feels "utterly defeated" once she has accepted that James needs full-time professional care.'

'I strongly share Nula's views about end of life care, or lack of

it,' says Gillian, 'that, "Never in my most awful nightmares could I have imagined such a terrible ending to a human life." A fitting tribute to her courage in sharing such personal experiences and feelings would be if the medical profession found a way to address this.'

Gail says, 'The main difference I found between Nula and myself was in care at the end of life. Her experience was quite appalling, whereas the care we received was truly amazing.'

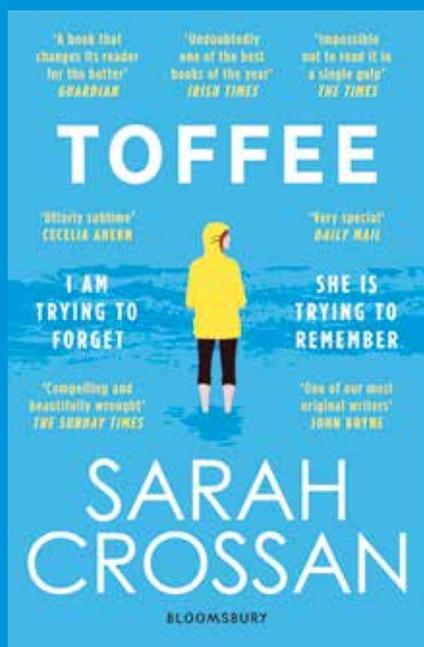
'Interestingly, I experienced the sense of my husband becoming himself again just before he died. It was as if he was "back" – his eyes were seeing me and he understood all that I had been saying to him, though he couldn't talk or communicate at all. I treasure that time.'

She adds, 'I am awaiting the film version and will recommend the book to the members of my frontotemporal dementia support group, which functions in Sheffield and whose support I have appreciated over the years.'

The last word goes to Gillian, who says, 'I wish Nula and John every happiness in the new chapter in their lives.'

The longest farewell by Nula Suchet (Seren, 2019), 280 pages, £12.99, ISBN: 9781781725184.

Your turn



For the next issue, we invite you to read **Toffee** by Sarah Crossan (Bloomsbury 2020), 416 pages, £12.99, ISBN: 9781408868126. Available in hardback, ebook and audiobook, and from February 2020 in paperback.

Let us know what you think about this story about a runaway who's mistaken for an old friend by a woman who appears to have dementia, told in accessible verse. Email magazine@alzheimers.org.uk or write to the address on p2 by 10 January so we can share it in our next issue.



Book giveaway

We have five copies of *Toffee* to give away – email magazine@alzheimers.org.uk or write to the address on p2 by 15 December quoting 'Toffee' for a chance to win one (see p39 for terms and conditions).



Members of our online community, Dementia Talking Point, share advice about dealing with other people's lack of understanding.

Lack of understanding

'My partner's daughter only seemed to realise what is happening and how hard things can get when I told her we couldn't meet for lunch on a particular day because I had to go to counselling. I have learned to ignore people and do the best I can with the mental and emotional reserves I have and if it doesn't suit other people then I am sad, but do what feels right anyway.'

'Cognitive behavioural therapy taught me to always find one good thing that happened or one thing I achieved each day, then write them down in a diary so there's always something positive to hold on to, no matter how hard the day has been. It works most days as a coping mechanism.'

nae sporran

'I have learned to ignore "helpful" remarks from people who have no experience of dementia, saying they would never have someone in their family go into a care home. How do they know?'

'Being honest with your family about the toll it takes on you is sometimes better than battling on. I don't expect my friends to understand, only those who have had a similar experience.'

Helly68

'I lived nearest to Dad, so I didn't mind checking on him most days. But I found that, as his condition worsened, my siblings became more unwilling to help. By the last year of his life I was pretty much left to deal with everything by myself, and there was a lot to deal with!'

'Three things helped keep me sane. I bought myself a pushbike – getting out in the fresh air, even if only for half an hour, and getting physically tired helped my mood, as did the exhilaration of freewheeling downhill. I learnt to expect nothing from my siblings. I got loads of support from my friends on Dementia Talking Point. Without that, I'm sure I'd have sunk.'

Bunpoots

'I had some difficulty getting my wife's sister to see the truth of our situation. She invited us to her house and spent most of the time talking tactlessly about holidays and (largely invisible) family members.'

She could not understand why I appeared to be so tired and sensitive to the things she said, as in her view my wife seemed a "little better". Maybe she was fooled by "hostess mode" or just did not want to see the plainly obvious.'

'I was so downhearted that I decided to share with her an unvarnished account of a typical day in our life, including some very unsavoury details about toilet habits. It may have been like shock therapy for her but did the trick, as afterwards she finally seemed to "get it" and began to act in a more supportive way.'

northumbrian_k

'People definitely judge and, unless they have experience of looking after someone with dementia, they do not understand as they may only see the person at "their best". It's not their fault I guess, but that judgement can be very difficult to deal with. I felt constantly criticised by Mum's neighbours and felt I couldn't win. All sorts of manipulative games were played and snide comments made. It didn't help that Mum could put on that wonderful "hostessy" front and would airily dismiss any concerns.'

'My local carers organisation has been fantastic and gave me many months of support and counselling. This has been an absolute lifesaver in giving me "permission" to have a life and to understand about self-care and getting a balance.'

leslyz

Visit alzheimers.org.uk/talkingpoint to read more and join our online community.

Next issue

What advice would you give about coping when either you or a person with dementia you care for is ill, such as with a bad cold or food poisoning?

Email magazine@alzheimers.org.uk or write to the address on p2.



Creating pictures

Many of us take great pleasure and satisfaction from creating pictures in various ways.

Someone who's already painting, drawing or taking photographs could continue enjoying this after a dementia diagnosis, though they may need to adapt how they do this at times. A person with dementia who hasn't done this for a while, or perhaps ever, might like to take it up again or try it as something new.

People might be inspired by whatever's around them or on their mind. Talking about favourite subjects or reminiscing may also spark ideas, as could seeing other artists' work when visiting a gallery, looking at books or searching online.

New materials or equipment, such as a tabletop easel, could help someone carry on creating pictures as their needs change. If you're getting these on their behalf, involve the person in decisions wherever possible – for example, they may have a preference between types of paint. Support with other aspects, such as mixing colours or changing camera settings, could also help.

Colouring books and Aquapaints – where water makes colours appear in an image – focus on specific aspects of painting and drawing, and some products are specially designed for people with dementia. Many of these are available in our online store (see below).

Visit shop.alzheimers.org.uk or call 0300 124 0900 (local rate) for many helpful products, including our guide *Taking part: activities for people with dementia* (£10 plus postage).

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

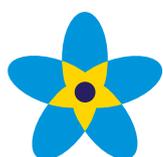




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Against
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Precious Petzzz



We have a Precious Petzzz – either a cat or a dog – for two lucky winners drawn from correct entries that we receive by 12 January.

Q: Out of all adults in the UK, according to veterinary charity PDSA:

- A. 2% own a dog and 94% own a cat.**
- B. 26% own a dog and 24% own a cat.**
- C. 86% own a dog and 14% own a cat.**

Water-free washing

We have one Nilaqua towel-off shampoo and one body wash (200ml each) for five winners drawn from correct entries received by 5 January.

Q: ‘Shampooing’ is believed to have been introduced to the UK in 1814 by:

- A. Celebrity hairstylist Vidal Sassoon.**
- B. Monsieur Champagne, coiffeur to the Queen of Poland.**
- C. Entrepreneur Sake Dean Mahomed and his wife Jane Daly.**



Send us your answers with your name and address – email magazine@alzheimers.org.uk or post to the address on p2.

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.

Fidget Widget Tool Kit competition

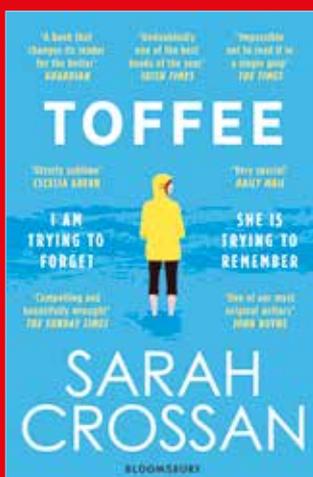
D Beavon in Bristol won a Fidget Widget Tool Kit, and individual Fidget Widget tools go to J Bell in Derbyshire, K Lilley in Essex and S Downer in Somerset. Answer: The five Fidget Widget tools support a person to use their hands and fingers to turn, slide, roll, spin and twist.

The longest farewell giveaway

The five readers who each won a copy of The longest farewell, by Nula Suchet, were AM Bird in West Midlands, PSK in Cumbria, G Andrew in Greater London, J Kenner-Lee in Hertfordshire and J Gaskell in South Yorkshire.

Book giveaway

See p35 for a chance to win a copy of Toffee, by Sarah Crossan.



Reusable coffee cup competition

Reusable coffee cups were won by L Tubby in Norfolk, AM Bird in West Midlands, P Dring in Northamptonshire, G Gregory in Lancashire, PSK in Cumbria, FE Whitham and V Poulston in Cheshire, J Samuel in Berkshire, S Clarke in Staffordshire and H King in East Sussex. Answer: The World Wide Fund for Nature expected the number of single-use drink cups and lids used in the UK last year to be 4.1 billion.

SALE

up to 50% off



Sale starts 16 December!

We've got a wide selection of Christmas cards, diaries, calendars and gifts that are up to 50% off.

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