

Dementia together

October/November 2018
Alzheimer's Society's magazine

Legal matters

Training lawyers

Enhanced care

Dedicated ward



Nothing to hide

Finding support

Also in this issue

Memory Walk

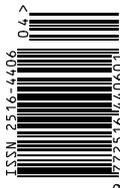
Side by Side

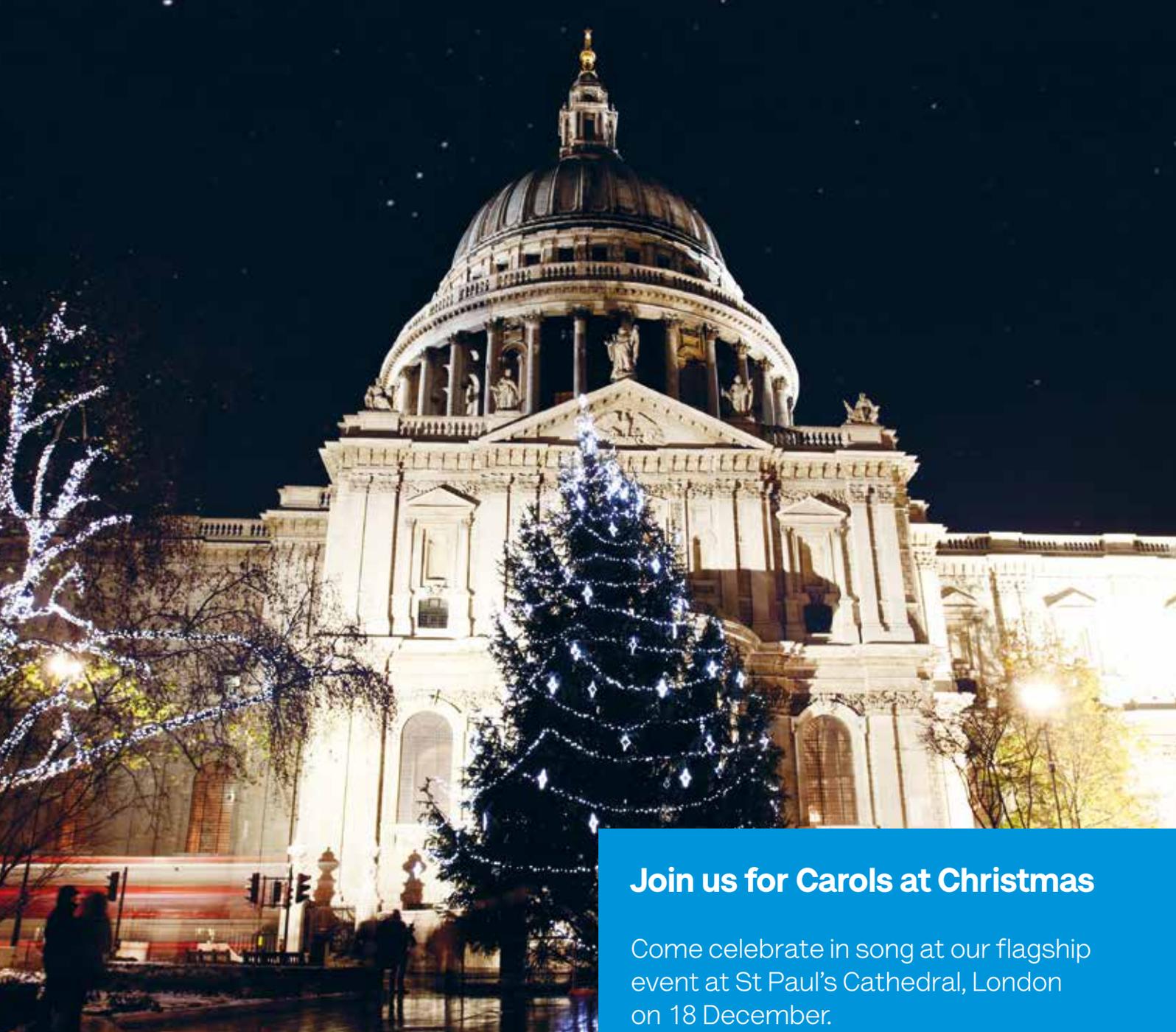
Elf Day



Better to share

Facing your fears





Join us for Carols at Christmas

Come celebrate in song at our flagship event at St Paul's Cathedral, London on 18 December.

Alternatively, there are a host of other concerts across the country.

Find your nearest concert and buy your tickets at alzheimers.org.uk/carolsatchristmas

For further enquiries please contact carols@alzheimers.org.uk or call us on **0330 333 0804**.



Carols at Christmas



Registered with
**FUNDRAISING
REGULATOR**

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

18201SO

40 years
2019





Welcome

It can be hard to comprehend just how much has changed since Alzheimer's Society was founded in 1979, though it's clear there's still so much more for us to do.

As we mark our 40th anniversary in the coming year, this magazine will continue to be here to inspire and inform everyone in the dementia movement and anyone affected by the condition.

Can you help us spread the word? We want all Dementia Friends, people with dementia, carers, former carers, fundraisers, campaigners and volunteers to benefit from our real-life stories and ideas, so please make sure your friends, family and colleagues know how to subscribe (see below).

Danny Ratnaike, Magazine Editor

Questions about dementia? See p38

This is the October/November 2018 issue of Dementia together, the magazine for all Alzheimer's Society supporters and people affected by dementia.

Subscribe or update your details

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

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

Read or listen online

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

Contact us

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

Copyright ©2018 Alzheimer's Society – please ask us if you'd like to copy our content or use it elsewhere.

News

Research hub 4



Nothing to hide
 Finding support 8

Society

Expert input 12
 Being yourself 13
 Try something new 13
 Express your elf 14
 New beginnings 15
 In your area 16

Better to share

Facing your fears 18

Legal matters

Training lawyers 22

Enhanced care

Dedicated ward 24

Letters 26
 Q&A: Veronica Williams 28
 Life with Ma 28
 Games and gadgets 30
 Voice control 32
 You're not alone 33
 Activity book 34
 Health appointments 36
 Autumn festivals 37
 Competitions 39

St Paul's: 40th anniversary launch

Alzheimer's Society is launching the celebrations for our 40th anniversary in 2019 with a carol concert at St Paul's Cathedral this Christmas.

We've been fighting to improve the lives of people affected by dementia since a small group of passionate and determined activists formed the 'Alzheimer's Disease Society' in 1979. Thanks to your continued support, we will continue to fund vital research and campaign tirelessly to end the inequalities faced by people affected by dementia.

Come and mark 40 years with us in the magical setting of St Paul's Cathedral with an evening hosted by actor and Society Ambassador Carey Mulligan.

For St Paul's tickets, ranging from £35–£100 with a 50% discount for people with dementia (under 16s go free), see alzheimers.org.uk/carolslondon or call 0330 333 0804.

(See the inside-front cover for more about our carol concerts around the UK).

Cupcake Day whips up £1.3 million

A huge thank you to all who baked and bought cupcakes for this year's Cupcake Day. Together, we raised over £1.3 million for the fight against dementia.

Cupcake Day is back on 13 June 2019 – sign up for your fundraising kit at cupcakeday.org.uk or call 0300 222 5770 (local rate).



Photograph: UCL Digital Media

UCL research hub launch

The UK Dementia Research Institute has officially opened its hub at University College London (UCL).

As well as hosting research, the UCL hub will house the institute's operational headquarters, with other research centres located at five leading UK universities.

Bart de Strooper, Director of the institute, said, 'We have a huge knowledge gap in dementia – our mission is to fill that gap.'

The Dementia Research Institute is a £290 million partnership between Alzheimer's Society, Alzheimer's Research UK and the Medical Research Council. Our role in it forms a key part of our New Deal on Research – the aspect of our five-year strategy focusing on how we will improve care today and unlock the answers for a cure tomorrow.

Read more about the New Deal on Dementia, our 2017–2022 strategy, at alzheimers.org.uk/strategy

Getting MPs on board

We were at Conservative and Labour party conferences this year to highlight unfair costs for people affected by dementia, as well as the inadequate quality and availability of care.

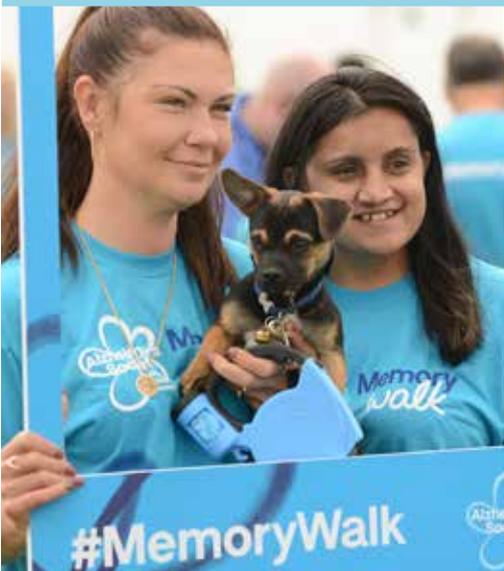
Our exhibition stand showed MPs how people with dementia are charged more than other people who need care, and that good quality dementia care is simply not available in some areas, regardless of the cost.

People affected by dementia also spoke with MPs about their experiences, while Society staff sat on panels and took part in events to press the message home.

Our Fix Dementia Care campaign calls on the government to stop failing people with dementia and to plan for a care system that works, once and for all.

Putting ever more pressure on government for real change is a core element of our New Deal on Society, part of our ambitious five-year strategy.

Unite with us to fix dementia care at alzheimers.org.uk/fixdementiacare



Memory Walk: Thousands unite

This year's Memory Walk got off to a fantastic start over its opening weekends.

From Plymouth to York and Belfast to Birmingham, thousands of walkers came together to celebrate loved ones and support the dementia movement.

They included Mo White, diagnosed with dementia at the age of 50, who cut the ribbon to start the Plymouth Memory Walk. At her side was Immy, the volunteer who supports her as part of the Society's Side by Side service. Mo said, 'I'm amazed to be with 1,200 people united against dementia. It's brilliant that people are raising awareness, as well as funds for a great cause.'

Actor Vicky McClure joined 3,000 supporters in Nottingham for her eighth consecutive Memory Walk.

'We need to defeat dementia,' she said. 'People live with it so well but the more widespread it becomes the more we need to support people with dementia to live fulfilling lives. That's what we're here for'

Jill Moss, whose late mum Peggy was diagnosed with Alzheimer's and vascular dementia in 2010, walked in the Peterborough event.

'I'm doing this walk for my mum, and also for the thousands of people who have not yet been diagnosed,' she said.

Supporters have also been organising their own walks as part of Your Walk Your Way. Every pound raised will help provide vital information and support, improve care, fund research and create lasting change.

Unite with us to walk or volunteer – visit memorywalk.org.uk or call 0300 330 5452 (local rate).

We're launching our 40th anniversary at a special carol concert at St Paul's Cathedral on 18 December (see inside-front cover) and I hope many of you will be able to come.

We'll have much to celebrate – thanks to our lead, more people are talking about dementia and eroding the stigma around it. Many more people are getting a timely diagnosis and support from our helpline, information and online community, as well as expert help from local services (see p38).

Yet for so many, little seems to have changed. We've had no research breakthrough – the latest drugs are now 15 years old. But we are getting closer to understanding the various forms of dementia, and how we might prevent and treat them.

The travesty remains that, if you have dementia, you are denied the free support you'd be entitled to with other health conditions. People affected by dementia typically pay £100,000 of their own money for care they'd otherwise get on the NHS. Encouragingly, when I speak to politicians of all parties, they recognise that they'll lose votes at the next election if this 'dementia tax' remains.

Thanks to your support, and with hundreds more Dementia Friends every day and more research funding each year, we know we can create real change when we unite against dementia.

Let's celebrate our successes in our coming 40th year, and let's join together to make even greater progress in the years ahead.

Jeremy Hughes
Chief Executive Officer



In the press

An eye test for Alzheimer's?

Could an eye test, using a sophisticated scanning machine, detect and diagnose the early signs of Alzheimer's?

An Alzheimer's disease diagnosis can involve a number of tests and scans, often after symptoms have begun to progress. In the search for a way to diagnose the condition that is accurate, affordable and not invasive, eye tests have emerged as a possible contender.

One study, reported on widely over the summer, examined the eyes of 30 people who didn't have Alzheimer's, but 14 of them had other test results that suggested they were more likely to develop the condition.

Researchers found changes in the inner surfaces – the retinas – of eyeballs in people at risk of developing Alzheimer's. Other changes to the retina have previously been reported in some people with Parkinson's and frontotemporal dementia. However, researchers in the latest study believe they found changes unique to Alzheimer's.

This research is at its earliest stages – the study involved a tiny number of participants, and we can't be sure the researchers would be able to predict Alzheimer's from changes in retinas where they didn't know the person's medical history. We also can't be certain that the 14 people who appeared at risk would actually go on to develop Alzheimer's.

That said, if backed by further research, eye tests for dementia would be a true step forward in the detection and early treatment of the condition.

Dementia-friendly Senedd

The Society is supporting the Welsh Assembly to become dementia friendly. Of its 60 members, 38 AMs have become Dementia Friends so far. Earlier this year, a group of people with dementia suggested improvements to signage, flooring, stairs and security at the Senedd building, and we're helping to implement these. We're also supporting the development of a dementia-friendly guide for visitors.

Sector by sector

We continue to make sure that different sectors understand what they can do to make communities more dementia friendly.

Our recent Dementia-friendly media and broadcast guide encourages this industry to rethink how it represents and portrays dementia.

Following our Faith, Culture and Dementia conference, we are working on leaflets to help specific faith communities to support people affected by the condition.

Early next year, look out for our Emergency services guide, which will highlight how services can improve and will also include practical safety information.

These add to our growing number of practical guides for sectors ranging from arts venues to retailers.

Visit alzheimers.org.uk/dementiafriendlycommunities

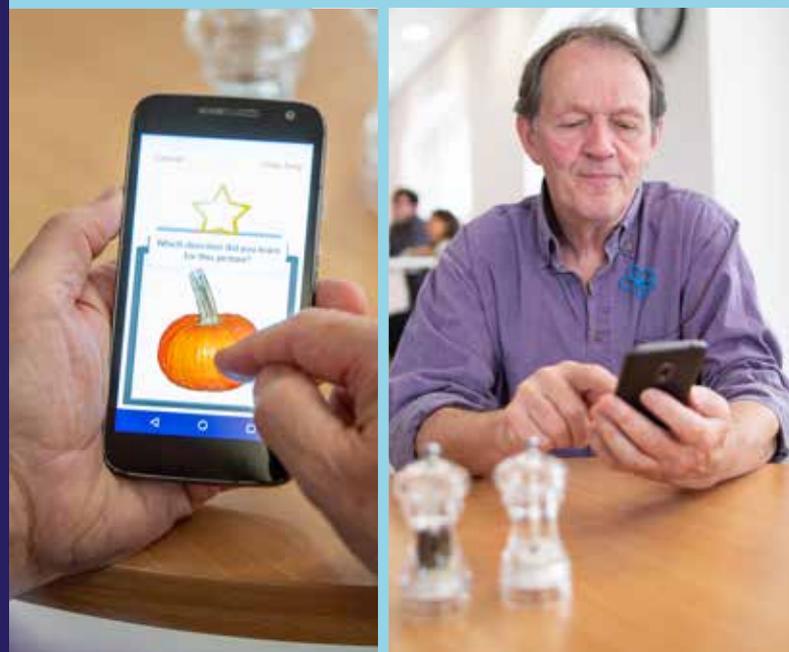
Play GameChanger to support research

Actor Kevin Whately is supporting our campaign for people to help dementia research by playing free games for people on their smartphones for five minutes a day.

Kevin, whose mother had Alzheimer's, is calling on anyone aged over 18 who doesn't have dementia to boost our understanding of how the brain works by playing GameChanger for a month. The findings will inform research into preventing, slowing down or even stopping the progression of dementia.

'It's fun, it's easy, you can do it at home and you're helping research enormously,' said Kevin. 'If we can recruit a huge number of people, it will speed up the whole process of understanding what causes this awful disease and hopefully eventually find a cure.'

GameChanger is a research project led by the University of Oxford and supported by Alzheimer's Society. To take part, visit alzheimers.org.uk/gamechanger





We are everywhere

The Alzheimer's Society Roadshow has promoted awareness and information to nearly 9,000 people at a variety of events this summer. From country shows and music festivals to Pride events and melas, our team has been there to offer support and advice on dementia, including to over 750 people at Southport Flower Show alone.

The summer started with a trip to the Devon County Show, while the Clacton Airshow saw us meet with over 1,000 visitors. Birmingham kicked off the first of many Pride events for us, including Manchester, Belfast (pictured), Cardiff, Newcastle and Southend before ending with 32 of us taking part in the London parade.

We also attended Camp Bestival, where we had a great weekend building support for our Fix Dementia Care campaign.

Blue Badges to be extended

The Department for Transport has agreed that the Blue Badge parking scheme – which many people with dementia have been denied access to – should be available for people with hidden disabilities, including dementia.

Alzheimer's Society contributed to the consultation on extending the scheme, which enables people to park closer to their destination than other drivers. The changes need to go through parliament before they come into force, hopefully in 2019.

Sally Copley, our Director of Policy, Partnerships and Campaigns, said, 'People with dementia have the right to maintain their independence and continue doing the things they enjoy. Making these badges accessible helps them to do this.'

Join Dementia Research: 10,000 plus

Over 10,000 people have now taken part in vital dementia research studies through Join Dementia Research, both people with the condition and others.

Launched in February 2015, Join Dementia Research makes it easy for members of the public to be matched to studies that they could participate in. These can include anything from drug trials to surveys trying to understand how to improve quality of life for people with dementia and their loved ones.

Join Dementia Research is run by the National Institute for Health Research and supported by Alzheimer's Society, Alzheimer's Research UK and Alzheimer Scotland.

Sign up at joindementiaresearch.org.uk or call our National Dementia Helpline on 0300 222 1122 (local rate) for more information.

In briefs

Argos and Wilko collections



Two of our newest high street partners, Argos and Wilko, are hosting bucket collections at the end of October, and we're looking for volunteers to raise awareness and funds at local stores. Sign up for collections in your nearest Argos or Wilko on 27 or 28 October – visit alzheimers.org.uk/bucket-collection

24,000 friends in Northern Ireland

There are now over 24,000 Dementia Friends in Northern Ireland. Dementia Friends is the biggest ever initiative to change people's perceptions of dementia, transforming the way people think, act and talk about the condition.

Contact dementiafriendlyni@alzheimers.org.uk

Incontinence report

Alzheimer's Society is calling for better support for people with dementia affected by incontinence. We held a workshop involving nine other organisations, people with personal experience of incontinence and professionals to discuss common problems and potential solutions. The resulting report recommends tackling stigma, more dedicated services for people affected, better training for health and social care professionals, and investment in research.

Nothing to hide

Amid some difficult days since his dementia diagnosis, Elmar has found support in a place where he knows he's not being judged. Gareth Bracken meets a man benefitting from a welcoming group.



Hear Elmar's story

Listen to this and previous stories at alzheimers.co.uk/podcast

Elmar, who has Alzheimer's, has experienced some very dark and difficult days, and some of what he has to say about the future is hard for his partner, David, and others to hear.

Dementia affects everybody differently, and some services might not meet everyone's specific needs.

A specialist memory café is providing a safe space and much-needed support for both Elmar and David.

Global travel

Having worked as a TV and radio engineer in his native Austria, Elmar came to England in the mid-1960s, aged 22, getting a job as a waiter in south-west London.

'At that time the only way I could get entrance was to work in a hotel or restaurant, so I had no other choice,' he says.

'I thought my English was pretty good but the customer would start talking and I couldn't answer, so they always had to call somebody else!'

This career path turned out to be a good one for Elmar, now 74. He worked his way up,

eventually becoming sales and marketing director for a number of international hotel companies.

'I travelled worldwide, going to meetings and giving presentations,' he says. 'I spent more time away and on planes than actually being in London.'

By the time Elmar retired aged 62 in the mid-2000s, he had met David, a businessman and consultant. They had a civil partnership a couple of years later and live in Putney, in south-west London.

Stressful time

Elmar, a big fan of skiing, was in an induced coma for a week after a serious accident around 10 years ago. After Elmar came out of hospital, David noticed a change in his mental abilities.

He says Elmar became slower at recalling information, and he believes the accident or medication probably played a part.

'It was difficult for us because we didn't know what the problem was, so I used to think it was just Elmar being a bit lazy – asking me for the answer without having to think about it,' says David. 'It was

quite stressful at times for both of us.'

Elmar had tests over a number of years before being diagnosed with Alzheimer's disease in May 2016.

'It started off very lightly – I possibly couldn't think of something immediately but it didn't take me that long,' says Elmar. 'Now I'm really bad, particularly with names, even my dearest friends.'

'I've got a little book and I write down names and what connection they are. If I'm really desperate, I have a look.

'If you asked me what I ate yesterday for lunch or what I did, it takes a while, if I remember it at all. I just don't have that. It's irritating.'

Elmar has also become less outgoing, which he puts down to difficulties with word finding and language.

'Sometimes I'm not as fluent when I speak to strangers,' he says.

'I have times when I just cannot think of a word in English. Sometimes it comes up in German but I can't use it because nobody else knows what it is!'

Quick read

Elmar, a former sales and marketing director in the hotel industry, was diagnosed with Alzheimer's disease in May 2016.

He struggles with 'depressive days' and is resolute about wanting to avoid the kind of end of life experiences that his mother and sister had.

Elmar attends Rainbow Memory Café, set up to cater specifically for lesbian, gay, bisexual and trans (LGBT+) people.

Elmar and his partner David both speak very highly of the café, which provides support in a welcoming environment.



Depressive days

Elmar has chosen to be open about his dementia with friends.

‘I decided that there’s no point pretending that everything is fine and hunky dory, so I’ve always told everybody what the situation is – there’s nothing to hide,’ he says.

He is also candid about his difficulties coping with the condition.

‘I have downers, depressive days,’ he says. ‘There doesn’t necessarily have to be a reason and it’s not predictable.’

‘My mother and sister, who both had dementia, were in a terrible condition when they finally left,’ he adds.

Grappling with what the future may hold, Elmar shares a distinctly personal decision that he is prepared to end his own life at some point, which David understandably finds difficult. Although anyone’s views may change over time, Elmar speaks unequivocally.

‘I have decided that I will not let myself get to the stage where I’m totally out of my personality, can’t talk to anybody, don’t recognise anybody,’ he says.

‘I will do something to go before then, I’m absolutely firm about it.’

‘I used to worry about the whole thing, but I recently came to the conclusion that I’ve had a good time and had a good life, so it’s not an issue.’

David says, ‘I understand what Elmar is saying and the reasons why. At the end of the day, it’s going to be down to him to decide really, when

the time is right. But it’s hard – it’s very hard to take at times.’

Suitable support

After seeking out additional support last year, Elmar and David began attending a local group for people with dementia and carers. However, they didn’t feel they had much in common with the other members, many of whom had more advanced dementia.

Elmar also says that he didn’t always feel welcome as a gay man with his partner.

‘We went twice and I felt very uncomfortable because of something I heard,’ he says. ‘I’m not saying everyone there was anti, but there were definitely people who were probably not too happy.’

The men now attend the Rainbow Memory Café, run by Opening Doors London, a charity offering information and support specifically for older lesbian, gay, bisexual and trans (LGBT+) people in the UK.

Launched last October, the café offers dementia advice and

support in an environment where LGBT+ people know they will be welcomed and included.

‘The first time we went, I was impressed with the whole thing,’ says Elmar. ‘It’s well organised and they bring in guest speakers to present on different subjects, which is very interesting.’

‘I see a variety of people there with similar problems that I have, although there are big variations.’

‘For me it quickly became very important, as it’s of great value and gives a lot of help.’

The group also means a lot to David.

‘We can talk about anything we want, it’s very open,’ he says. ‘You can be yourself and there’s no issue about your sexuality.’

Best thing

Elmar hopes the group will expand, as he feels it could benefit many others.

David, who is running a half-marathon to raise money for the café, believes that having appropriate services are crucial in encouraging gay people affected by dementia to seek support.

‘There’s a massive population of LGBT+ people out there and I think a lot of the services that are already set up don’t specifically cater for them,’ he says.

‘As the population gets older, there are going to be more gay people going into homes, more gay people needing carers. Staff need to be trained correctly in how to deal with them and the issues they have.’

Although Elmar continues to have difficult days, the café remains a standout source of support. ‘I’d always go there rather than do anything else,’ he says. ‘I think it’s actually one of the best things I can do.’

Thoughts about dying

Alzheimer’s Society campaigns for everyone with dementia to have good quality care, up to and including at the very end of life. People should be able to plan ahead, and their care should respond to their needs and wishes.

We do not call for changes in the law on assisted dying or euthanasia, and we monitor legal developments to ensure that people with dementia are safeguarded appropriately.

Anyone who wants to talk about things that are getting to them, whether they are feeling suicidal or not, can talk to Samaritans – call 116 123 (free) at any time or email jo@samaritans.org



Next steps

- 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 online directory to find services near you – visit alzheimers.org.uk/getsupport
- For more about Opening Doors London, which has members across the UK, see www.openingdoorslondon.org.uk or call 020 7239 0400.

Expert input

People with dementia in Hereford are helping to make their local cathedral dementia friendly.

Keen to become more accessible to people with dementia, Hereford Cathedral decided to call on the experts.

The Usurpers – part of our network of people affected by dementia who have their say on local and national topics – were happy to step up.

The Hereford group chose their tongue-in-cheek name because of our original description of these groups as service user review panels, or ‘SURPs’.

Free rein

The Usurpers were given a private tour of the cathedral, which dates from the 11th century, so they could identify any potential issues. This included an area where the cathedral hopes to create a quiet space for people with dementia and others.

‘Essentially, we were given free rein to wander around and poke our noses in all areas,’ says Dave Daniel, 51, who has Alzheimer’s.

‘We were actively encouraged to be curious and ask questions.’

The tour was followed by an in-depth session where the Usurpers put their suggestions to cathedral staff.

Ideas included having a sign at the entrance to say the venue is accessible for people with dementia, as well as generally larger signage throughout.

They discussed how people with dementia could benefit from more clearly defined outdoor pathways and different colour schemes for the café, toilets and exhibition space.

The Usurpers thought that cathedral staff and volunteers should become Dementia Friends to better understand the difference they could make. Seeing staff wearing Dementia Friends badges would also give people with the condition more confidence to approach them.

Taken seriously

Within a month of the group’s visit, cathedral volunteers had begun attending Dementia Friends information sessions and the sign at the front of the building was in place. The cathedral had also introduced special quiet hours at specific times.

‘Some projects can take three to five months before we receive feedback, so that was very positive,’ says Lorna Gregg, a Dementia Adviser who supports the Usurpers.

Her Society colleague Sarah Goodger feels the cathedral already had quite a good understanding of dementia.

‘I think the group helped give them more direction and focus towards becoming a dementia-friendly setting,’ she says.

The cathedral’s response has been welcomed by group members.

‘It is rewarding to know that those in charge are not only dementia aware but are being proactive in the way they tackle the issue,’ says Dave.

‘It is sadly not the norm to be taken seriously as soon as someone knows you have dementia, so to find such a forward-thinking organisation was fantastic.’

Another Usurper, Andy, was diagnosed with dementia with Lewy bodies six years ago.

He says, ‘It’s good to feel that organisations in Herefordshire are interested in raising staff awareness of dementia and improving access. It is vitally important that local communities ensure everywhere is accessible and inclusive to people with dementia.’

Dave says that organisations need to recognise the realities of dementia.

‘Dementia still carries an element of stigma, but the more big businesses embrace and normalise it in their world, the quicker wider opinion will change.’

For opportunities to use your experience of dementia, see alzheimers.org.uk/yoursay



Being yourself

A Side by Side volunteer in Wales has found that helping someone else still feel part of the world has given her a new place in it too.



When she first volunteered for Side by Side, Lucy Swannell was apprehensive about meeting Bill, the person with dementia she'd been paired with. However, that didn't last long.

'When all you know about somebody is some details on a form, it's hard to know if you'll get on,' says Lucy.

'I needn't have worried, as Bill put me at ease quickly. I soon realised I could be myself – as daft as two brushes – and Bill would tolerate my bad jokes with a withering, "I'm worried about you," and occasionally even laugh.'

View of the sea

Side by Side links people with dementia to volunteers who help them carry on doing the things they love. For Bill, in Aberystwyth, a connection to the sea made it the obvious place for him and Lucy to spend time.

'He enjoys going to somewhere on the coast where, depending on the wind chill factor, we'll either sit outside or stay in the car,' says Lucy. 'I bring a flask of coffee and some sugar, and that – along with a view of the sea – is all we need.'

'The sea brings back memories of trips to faraway places, though we talk about so much else too. Once we've put the world to rights, we might move on to books, films, music and family.'

'There are not many people I can imagine talking to for over an hour, in fact I don't think I talk to anyone like I talk to Bill. You'd think after more than three years we might run out of things to talk about, but the phrase "we can talk about that next week" comes up a lot.'

'Instead of crawling out of town with the rest of the cars after work on a Thursday and thinking about what to have for tea, I get to go to the beach with Bill, drink rapidly cooling coffee and talk about everything and anything under the sun – the stars if it's winter.'

'The pace of life nowadays often feels too fast, but I never think I should be doing anything else when I am with Bill.'

So much more

Lucy is glad of the support she's had as a volunteer, and has no qualms about encouraging other people to get involved with Side by Side.

'You'll get to know someone you wouldn't have met otherwise, and somebody who is so much more than their diagnosis of dementia.'

'It makes me happy to see Bill in full flow holding forth on a subject that he is passionate about, because then I know Bill is winning. Bill still has a lot to offer the world and I want to help him always feel part of it.'



Be a GameChanger

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

Sign up at alzheimers.org.uk/gamechanger

Read Care and cure



The latest Care and cure, our quarterly research magazine, includes news about research to improve support for carers, GPS insoles, the importance of star-shaped brain cells and much more. Visit alzheimers.org.uk/careandcure

Become a champion



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

Find out more at dementiafriends.org.uk



See if Side by Side is available near you at alzheimers.org.uk/sidebyside
Call 0300 222 5706 (local rate) or email volunteers@alzheimers.org.uk to find out more about volunteering.

Express your elf

A Dementia Friend in Lancashire is embracing Elf Day to raise vital funds.

On and around this year's Elf Day, on 7 December, Society supporters across the nation will unleash their inner elves at work, school and home to raise money and awareness.

Many will dress up on the day itself but, as Ann Duckworth proved last year, elf-themed fundraising can take any form at any time.

Fierce passion

Ann, from Oswaldtwistle in Lancashire, was born and raised on the family farm. Her mum Kathleen worked there until well into her 70s before retiring.

Ann first noticed changes in her mum's mood and behaviour back in 2015, and the following year Kathleen was diagnosed with vascular dementia.

The changes in Kathleen's behaviour in the evenings – often called 'sundowning' – were particularly challenging.

'We tried to look after her as a family and took it in turns to stay with her at night, but her sundowners exhausted us all and we realised that we needed professional help,' says Ann.

Kathleen moved into a care home in 2017, which Ann and the family found heart-breaking.

'It was frustrating to see our matriarch, who watched over us with fierce passion, struggle to remember who we were or even her own name,' says Ann.

Kathleen died in January at the age of 87.

Beyond expectations

Ann had already taken part in Cupcake Day at work and become a Dementia Friend, but spending time in

Kathleen's care home around so many people with dementia spurred her on to sign up for Elf Day.

'Armed with a car full of ingredients, I set off to my daughter's in Scotland and, with the help of my eight-year old granddaughter Grace, made and decorated over 100 elf hat biscuits,' she says.

Ann took the biscuits to the dental practice where she worked, dressing as an elf not just for Elf Day but the entire working week. Her colleagues wore elf hats and ears to join in the fun.

To her astonishment, the biscuits sold out within the first few hours and she had raised over £470 by the end of the week – well beyond her expectations.

Brilliant work

'Involving colleagues and patients helped to raise awareness of the brilliant work Alzheimer's Society does,' says Ann.

'People were happy to help in any small way, as this dreadful condition affects more families than we realise.

'They also shared their own stories about the difficult journey that is dementia.'

Ann encourages others to join her in taking part in this year's Elf Day.

'It's a fun way to raise money and awareness,' she says. 'Every little helps and can go a long way to finding a cure for this cruel, devastating condition.'

Register your interest to take part in Elf Day on 7 December – visit alzheimers.org.uk/elfday





New beginnings

Helen Pitt shares her experience of supporting more people through our new Dementia Connect service, which we've introduced in two areas so far.

In March, Birmingham and Solihull became the second area where Alzheimer's Society is adopting our new service, Dementia Connect. This cuts through all of the confusion and delay to offer people support that's tailored to their needs.

It's been an exciting time as our specialist dementia advisers settle into two roles – one supporting people over the phone, the other able to visit people at home as well.

These two roles allow us to give people the support they need, when they need it. We know a home visit can be really helpful, but it isn't always necessary. Our telephone advisers are very good at giving people the information and advice they need – and identifying when someone could benefit from more. We also make regular 'keeping in touch' calls to see how people are doing and deal with any new issues.

I've been supporting people in person since starting at the Society in April 2017. I began the new telephone role with some trepidation, and there's naturally been a settling in period for all of our team.

However, the work has been really fulfilling – not least because we're able to support significantly more people than before. I'm looking forward to helping make sure that everyone affected by dementia gets the support they need.

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



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

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

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

Subscribe to Dementia together magazine today



In your area



Brigade on board

Alzheimer's Society launched a new partnership with Girls' Brigade Northern Ireland (GBNI) in September to raise awareness of dementia among their 21,000-strong membership of girls and young women.

We helped them to produce three packs containing Dementia Friends and intergenerational activities for different age groups. GBNI members will use these towards their Service badge, which requires three hours of activities.

Georgina Mauger, our Senior Youth Engagement Officer, said, 'We've supplied every GBNI company with resources, and we're encouraging leaders to become Dementia Friends Champions and to get involved with Dementia Action Week next May.'

Pamela Frazer, Dementia Friendly Community Support Manager, added, 'There has already been a great response from leaders – we're delighted that the resources are being so well received.'



All in a day's ride

Two cyclists in north-east Wales raised over £1,000 for the Society by completing a 24-hour bike ride on what turned out to be the hottest day in June.

Rob Dawson, whose mother had dementia and died in February, and Debbie Ellson cycled 209 miles from Shotton in Flintshire to the Anglican Shrine in Little Walsingham, Norfolk.

Given the unusually hot day and a cold night, they were especially grateful for the help they got from Debbie's husband and Rob's wife.

'We could not have done the challenge without the support of Garry and Pam, who provided back-up through the ride with food, water, extra layers, a spare bicycle, and emotional support and encouragement,' said Rob.

Big friends

The north-east London borough of Hackney hosted a special Dementia Friends information session on 18 September to round off a day of awareness raising.

People from across the borough took part in the BIG Dementia Friends information session at the Hackney Empire in the lead-up to World Alzheimer's Day on 21 September. Our roadshow was also outside Hackney Town Hall during the day, answering people's questions about dementia and promoting the benefits of a timely diagnosis.

The borough previously ran a Dementia Festival during May's Dementia Awareness Week, hosting public art, music, dance, gardening and leisure activities for over 300 people.



The greatest mow on earth

A prison officer who raised almost £10,000 for us is now also an official record-breaker for his lawn tractor ride from John O'Groats to Land's End last summer.

Andy Maxfield's 874-mile journey, taking five days, eight hours and 36 minutes, was recently recognised as a Guinness World Record. He was inspired to fundraise by his father James, who lived with Alzheimer's for 13 years and died on New Year's Day, aged 78.

Andy's initial aim was to raise £1,000 through a charity ball in Preston, Lancashire, when the idea of trying for the record came up while seeking a raffle prize from lawnmower manufacturers John Deere.

He said, 'I never set out to go on an epic journey, never mind end up with a world record. It poured with rain every day, however surprisingly the time went very quick, meeting loads of interesting people along the way.'



**Dementia has no cure,
but you can change this.**

**Join our epic 13 or 26
mile treks in summer
2019 and choose from
five breath-taking
locations.**

**Every step you take will
bring us closer to a cure.**

**Sign up now
alzheimers.org.uk/trek26**



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

**Challenge
yourself.
Take on
dementia.**



Better to share

With her husband becoming ever more dependent as a result of his dementia, Anima Bhuiya is doing her best to cope. **Gareth Bracken** meets a carer who is facing her fears.

It's difficult to take in, difficult to accept. But what can you do? You have to accept it, there is no other way.'

Anima Bhuiya is finding it increasingly challenging to care for Sudhir, her husband of over 50 years, who has Parkinson's disease and Alzheimer's.

Anima, who lives in Leeds, finds some comfort in sharing stories and support with other local carers. However, away from

this occasional respite, she continues to have deep concerns about what the future may hold.

Gentle and honest

Sudhir, now 87, came to England when he was 18 to study for a degree in mechanical engineering. After a few years working back in India, he returned to England where his job involved research into agricultural engineering.

Anima, who grew up in Kolkata (then Calcutta), came to England after finishing university, working in accounts for the Post Office.

Her marriage to Sudhir in 1965 was an arranged one. They spent only an hour in each other's company before getting married a few weeks later.

'Our bond is very strong,' says Anima. 'We've been married and living together for nearly 55 years, with no grievance against one another.'

Quick read

Anima Bhuiya, whose husband Sudhir has Parkinson's disease and Alzheimer's, is finding it extremely difficult to see his health deteriorate so badly.

A former mechanical engineer who was always very independent, Sudhir is now totally reliant on his wife and visiting carers.

Anima takes some comfort from attending a dementia café in Leeds, where she can speak with other carers.

She worries constantly about how both she and Sudhir will cope as his health worsens.



‘He’s a very gentle person who is also very honest – he never lied or cheated anybody.’

The couple have one daughter and two granddaughters, and many of Anima’s wider family live in India.

‘We used to visit every year, but now my husband can’t because of his illness,’ she says.

‘I went last year on my own for a short time and I still hope to go this year, but I’m not sure – it depends on his condition.’

Totally dependent

Sudhir was diagnosed with Parkinson’s disease seven or eight years ago. During a medical appointment a few years back, a specialist concluded that he was also in the early stages of dementia.

‘When I was told he had dementia, I couldn’t believe it because he hadn’t been showing it,’ says Anima.

‘He’d been talking to himself in his sleep, saying things that didn’t make sense, but I just thought it was a habit of his.’

The reality of the situation hit Anima during a flight home from India.

‘We were coming back on the plane and Sudhir didn’t recognise me,’ she says. ‘That’s when I came to know that he really does have dementia.’

Sudhir now has trouble recognising people other than close family or the carers he sees regularly.

He has become less polite and more impatient, sometimes even shouting, which is very

out of character. He can also find everyday tasks difficult to comprehend.

‘Sometimes I give him food and he’ll ask me what he should do, whether he should eat it,’ says Anima.

‘He was always a very independent person – he wouldn’t depend on somebody if he could do it himself. But now he’s totally dependent on others.’

Daily challenges

Sudhir, who is partially blind and uses a hearing aid, also receives support from two homecare providers, which provide different levels of personal care. He needs help with eating, drinking, medication and going to the toilet, and sometimes with standing and walking.

Anima finds it extremely difficult to see her husband in this condition.

‘He’s deteriorating rapidly,’ she says. ‘He’s lost weight, his strength, his mind – he’s lost everything. It’s painful to me.’

Anima faces daily challenges as she does her best to support her husband.

‘I was recently up at 6.30am helping the carer to try and get him to sit on the toilet, which he couldn’t do,’ she says.

‘It makes me think about how he and I will cope in the future. I worry every moment.’

‘The GP has spoken about a nursing home but I don’t want Sudhir to go away from me, not for as long as I can bear it.’

Open-minded

A welcome source of support has come from a dementia café run by mental health and wellbeing charity Touchstone. Hamari Yaadain, which means ‘our memories’



in more than one South Asian language, meets twice monthly in Harehills, Leeds.

The group brings South Asian people with dementia, carers and relatives together for conversation and activities.

Anima previously attended the group with Sudhir, but with his health worsening she now goes on her own. She has got to know other members and they chat, play games and exchange experiences.

'I'm looking after my husband all the time, so it's a break from that,' she says.

'When you're mostly staying in one room in your house, it's important to go and share your difficulties. It might even help you forget them temporarily, otherwise you're worrying all the time.'

'Although you can't forget it, you can at least overlook it for a few hours. It's an opportunity for the recreation of your mind.'

Anima praises the way the group is run, and says its members offer welcome emotional support.

'We share the pain we're all going through,' says Anima. 'We talk about everything – everybody is open-minded.'

'If someone is in difficulty we'll know about it and support them. You also see that you aren't the only one who is suffering.'

'When you're mostly staying in one room in your house, it's important to go and share your difficulties. It might even help you forget them temporarily.'

Facing struggles

Anima chooses to be open about both her husband's condition and the struggles that she faces in caring for him.

'I think it's better to share, there's nothing to hide. You can then talk about it with others,' she says.

'I also see no harm in sharing my story publicly – it might help someone else.'

Anima extends this approach to her 13-year old granddaughter, Sanjana, who is fully aware of her grandfather's health conditions.

'She knows about Sudhir's dementia and is very kind to him, very helpful,' says Anima.

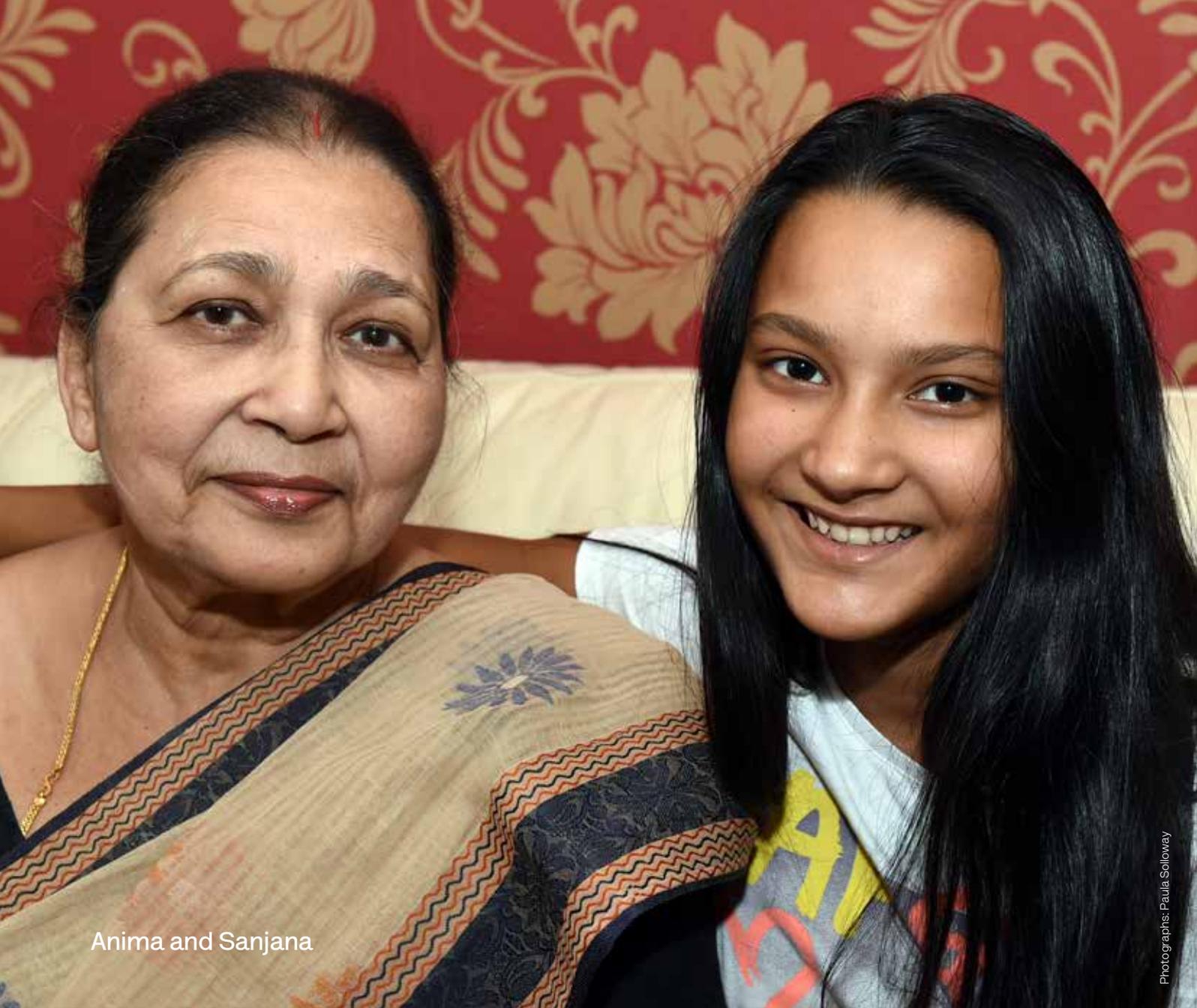
With her husband's health worsening and the challenges of being a carer growing ever greater, Anima is frank about her situation.

'There is nothing to look forward to, no improvement to be expected,' she says. 'Life now is very painful.'

However, Anima contrasts awareness of dementia in England with India, where she feels the condition is less well understood.

'Family in India aren't always familiar with it, but in this country people have a good understanding – they sympathise. It's such a common disease,' she says.





Anima and Sanjana

Photographs: Paula Solloway

Next steps

- For our publications in a range of languages and formats, see alzheimers.org.uk/accessibleresources or call 0300 303 5933 (local rate).
- Use our online directory to find dementia services near you – go to alzheimers.org.uk/getsupport
- For more about dementia-friendly communities, visit alzheimers.org.uk/dementiafriendlycommunities

Legal matters

Will to Remember makes it easier for people to make or update their will. **Gareth Bracken** reports on training to help solicitors provide the best service.

Many of the people who make or change their will with support from our Will to Remember initiative are affected by dementia in their day-to-day lives. To help solicitors offer the best service for them, Alzheimer's Society provides a specialist dementia awareness training course for lawyers.

Quick read

Will to Remember is an Alzheimer's Society initiative that supports people to make or change their will with trusted solicitors.

Our specialist training helps solicitors feel more confident in supporting people with dementia, their families and friends.

Elizabeth Oakland, a solicitor in Manchester, gained a much better understanding of how dementia might affect a client.

Julie Lee used Will to Remember and chose to support our work by leaving a gift in her will.

'Making or updating a will is highly important, but people may put it off or feel daunted by it, especially if they're facing a dementia diagnosis,' says Anna Ward, Will to Remember Manager.

'I feel we have a duty of care to remove the barriers that are maybe stopping people.'

Will to Remember

Will to Remember is an Alzheimer's Society initiative to help you make or update your will. It offers a network of trusted solicitors to choose from, a free will guide and a £150 discount that costs the charity nothing.

There's no obligation for you to leave a gift for the Society in your will, though this is something we encourage everyone to consider!

From the heart

Will to Remember solicitors are encouraged to complete a Dementia Friends session at the very least, and ideally to complete our specially designed training.

This course is designed to help those in the legal profession feel more confident in supporting people with dementia, their families and friends.

The half-day workshop examines how dementia affects the brain and how to recognise the need to use alternative approaches when working with someone affected by the condition.

Most of the courses are delivered by Sue Brewin, an Associate Trainer with the Society.

'Seeing a solicitor can be complicated at the best of times before you add dementia on top,' she says. 'I get them thinking about how they can slow down, use simpler language – perhaps find another way of giving information.'



'It's about getting them to really understand the effect of dementia on everyday life and what they can do differently so that someone can be more involved in decision making.'

Sue wrote the course four years ago with the help of her godmother, who had dementia.

'She was really involved, right up until the later stages of her life,' says Sue. 'When something comes from the heart of someone with dementia, it gives it that credibility.'

Better understanding

The training has been very well received by solicitors across the country.

'I found the course really informative and came away feeling I had a much better understanding of dementia and the effect it has on those people living with it,' says Elizabeth Oakland of Touch Solicitors in Manchester.

Attendees have also gained knowledge of how to make their environments more welcoming for clients.

'I now view the office differently and consider how this may appear to someone living with dementia,' says Jennifer Turnbull of EMG Solicitors in Newcastle.

She adds, 'The level of understanding I now have is impacting nearly every aspect

of my working life as well as day-to-day life.'

After ensuring that all staff became Dementia Friends, Birchall Blackburn Law made changes to their speech, instructions, signage and even seating position when meeting with clients with dementia.

The firm's Catherine MacCracken says the training has seen her develop a different mindset.

'It helped me look from the inside out, rather than the outside in, which we lawyers do so much of the time,' she says.

Leaving a legacy

Will to Remember provides clients with a straightforward service while generating vital funds for Alzheimer's Society's work.

One client in Leicester updated her will through Josiah Hincks Solicitors, a firm whose staff have completed our specialist dementia awareness course. She was impressed with both the solicitors and Will to Remember.

'They were very professional and efficient – it was simple and I couldn't fault it,' she says.

'My mother had Alzheimer's for many years. You want to support an organisation that supports people who experience that illness.'

Another Will to Remember client, Julie Lee, was only too

happy to leave a gift to the Society after both she and her mother made wills with Roche Legal near York. The firm's founder, Rachel Roche, has volunteered for Memory Walk and maintains close connections with the Society.

'I wanted to support the charity with a percentage of my will,' says Julie. 'It might be a lot, it might not, but something is better than nothing. It was easy, convenient and worked really well.'

'If the Society doesn't keep getting income, we won't be able to find a cure or support people living with dementia today.'



Next steps

- See alzheimers.org.uk/willtoremember or call 0370 011 0290 to find out more about Will to Remember.
- Visit alzheimers.org.uk/training or call 01904 567909 for more about Alzheimer's Society's training and consultancy.
- For more about dementia-friendly communities, go to alzheimers.org.uk/dementiafriendlycommunities



Enhanced care

Hospital patients who have dementia experience a better recovery when they're in the right environment. **Gareth Bracken** visited a ward in Southampton with a specialist approach.

A specialist ward at Southampton General Hospital is giving their patients with dementia a better chance of returning to their own homes once discharged.

G7 is an enhanced dementia care ward that's smaller and calmer than a typical ward. This allows patients who have dementia or delirium to receive treatment somewhere that feels more relaxed and less clinical.

Quality time

Patients are free to walk around and can enjoy stimulating activities such as arts and music.

'The environment enables them to feel less confused and more at home,' says Jeni Bell, a Clinical Specialist Admiral Nurse.

There is one staff member for every three patients, a higher than usual ratio.

'In an acute ward you can't really switch your approach from patient to patient, but here you can spend quality time with them,' says Luca Frosini, a Staff Nurse.

As Lucy Ward, G7's Manager, puts it, 'Nurses on other wards don't have the time to unpick what's going on, whereas we do.'

Psychiatrist Vicki Osman-Hicks is the Older Person's Mental Health Consultant for G7. She says it's unusual for a hospital to offer mental health and geriatric care in this way within the same unit.

'Typically a psychiatrist is outsourced and comes in, but I'm here on the ward to support the team,' she says.

There has been a great improvement in the health and wellbeing of many people.

'Some were biting and hitting people on other wards, but they come here and a fog lifts,' says Lucy.

The impact can be almost immediate.

'On another ward a patient won't wash or take tablets, but within even a day here they're more willing, more engaged,' says student nurse Joe Eddy.

Quick read

A specialist ward at Southampton General Hospital is giving patients with dementia a better chance of returning to their own homes.

The G7 ward is smaller and calmer than other wards, and provides a higher staff-to-patient ratio.

Patients who move to G7 from other wards often experience an improvement in their health and wellbeing.

Rox Carare, whose father Octavian stayed on G7, says the care and support provided to the whole family was extraordinary.



This is me

Staff get to know patients by using This is me, a simple form from Alzheimer's Society that details a person's preferences and background (see alzheimers.org.uk/thisisme).

'I live my life by it – it's the best thing', says Kirsty Baker, a Health Care Assistant. 'If a patient is upset, I can talk about the topics and build up trust.'

G7 staff, many of whom are Dementia Friends Champions, are always looking for ways to help patients feel comfortable on the ward.

'One man was used to having a drink in front of the TV, so his family bought in non-alcoholic beer to make it more like home,' says Becca Darbon, a Therapy Tech. 'We tried to replicate it as much as we could.'

Families appreciate the opportunity to be involved in their relative's care and discharge.

'A patient's son said it was the first time that people had actually heard what they had to say and helped them,' says Jeni.

'Families have to make life-changing decisions under pressure, but if they feel supported then they feel stronger to make a decision that's right.'

Returning home

G7 is staffed by those who have put themselves forward for the role, such as Stephen Dore, a Senior Healthcare Assistant.

'My mum had vascular dementia and passed away in a different hospital, rather than at home where she wanted to be, because they fuffed around too much,' he says.

'I felt the need to join G7 partly because of her bad experience.'

Mel Smith, a Sister on G7, asked to move there after hearing of its great work.

'I used to be scared of people with dementia but now that I've heard their stories and seen what they have to offer me, I wouldn't work with anyone else,' she says.

Vicki says the ward has helped reduce the length of time patients spend in hospital.

'We're able to optimise care and recovery so that many patients can return home, which is so important,' she says. 'We didn't want the ward to always be a step to institutional care.'

Some patients do have to move into care, which is why G7 continues to build relationships with local homes so they can best decide which are the most suitable.

Extraordinary care

Rox Carare is full of praise for G7 after her father was admitted there in March.

Octavian, who has Alzheimer's, entered the ward after a fall at home, which also had a great impact on his 88-year old wife.

'G7 was extraordinary, as they not only cared for my father and his medical needs but also engaged my mother in his care and allowed my parents to be together constantly,' says Rox, a dementia researcher.

Rox's mother was able to stay at the hospital overnight when daily trips became too tiring, while Rox herself was grateful to the ward staff, who took her calls at 4am while she was working abroad.

'My father benefitted from the highest calibre of medical care and the rest of us were warmly treated,' she says.

'That's a unique feature of a busy NHS ward, but also key to the successful care of patients.'

Next steps

- The updated Dementia-friendly hospital charter gives advice on how hospitals can become dementia friendly – see www.dementiaaction.org.uk/dementiafriendlyhospitalscharter
- For our Hospital care (477) factsheet, go to alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Visit dementiafriends.org.uk to become a Dementia Friend or Dementia Friends Champion.



A question about antibiotics, plus some highs and lows shared on social media and through our online community.

Antibiotics: A question of effect

My father has had Alzheimer's disease for eight years. Since December 2016, he has been living in residential care. During this time, despite the excellent care my father has received, he has acquired several minor infections of either the respiratory or the urinary tract. Each time, he has recovered with the help of antibiotics. My father currently has a chest infection and is again receiving antibiotics.

My sister was first to notice something extraordinary – when my dad is on antibiotics, he seems more alert and his cognition seems to improve. The other day, my mother was feeding my dad when he suddenly said, 'This is nice.' He later called out my mum's name and later again said, 'I hope...', and some other random words. He also nodded in the affirmative when asked whether he wanted some more drink.

This might not sound very impressive, but my father has been unable to communicate at all for over a year. Our experience in the past has been that any apparent improvement in my dad's condition disappears when he comes off antibiotics.

I wonder whether anybody else has noticed a similar effect when their relative has been prescribed antibiotics, and whether any medics out there have any thoughts on the matter.

Peter Bailey, Greater London

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

Society response

Seeing improvements in a person's condition when they have advanced dementia can have a big emotional impact, even if these changes are fleeting.

It's extremely difficult to know that a specific thing, such as antibiotics, has caused improvements in an individual case when there could be many other factors. Of course, it's perfectly natural to look for causes, and other people have assigned an opposite effect to antibiotics from their own experiences. It might be worth remembering that overuse of antibiotics is also a concern, as it contributes to their ineffectiveness. Your experience appears to be unusual, and so it would be interesting to hear if it has been shared by other people.

There's so much we've yet to learn about what causes dementia and affects its development – including questions about the role of infections and antibiotics – and this is why more research is so vital.

In the meantime, it's heartening to know that your father's infections are being treated effectively, since this clearly makes an important difference to his wellbeing.



Your turn

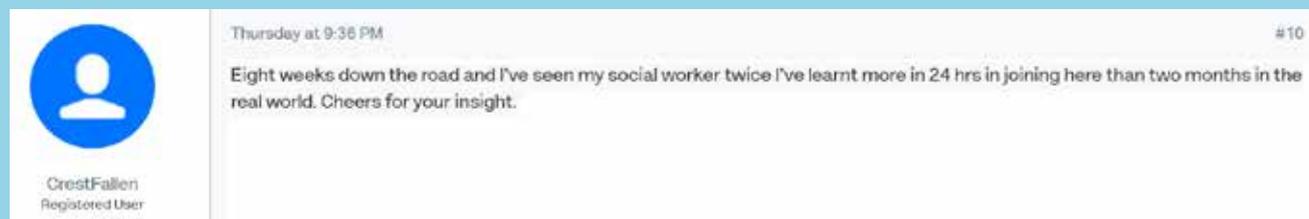
Tell us what you think – write to Magazine Editor, Alzheimer's Society, 43–44 Crutched Friars, London EC3N 2AE or email magazine@alzheimers.org.uk

Letters for the December/January issue to arrive by 7 November. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.



Seen elsewhere...

On Talking Point, our online community, CrestFallen asked for advice about a form they signed while the local authority was assessing their mum's finances. They really appreciated the rapid, supportive and informative replies that they got from fellow community members.



Linda Johnson at Dove House Hospice in Hull was delighted when Society Ambassador Wendy Mitchell shared our August/September article about their work with mental health unit Maister Lodge on Twitter.



Alison Rust related to an article shared on our Facebook page about Dementia Friends Champion Denise Wilton and her dad Allen, and let people know about her husband's fundraising.



Reminder: OPG refunds

You may be due some money back if you paid an application fee to register a Lasting power of attorney or Enduring power of attorney in England or Wales with the Office of the Public Guardian (OPG) between 1 April 2013 and 31 March 2017.

For more details or to make a claim, visit www.gov.uk/power-of-attorney-refund or call OPG on 0300 456 0300 and select option 6.

Air travel research

Are you a person with dementia or their travel companion who has travelled by air since 2016? An occupational therapy researcher wants to interview people in England and Wales to help develop aviation guidelines, so that people living with dementia can keep travelling by air for as long as possible.

For information, please email katherine.turner@plymouth.ac.uk or call 07745 389926.

Learning disability and dementia

An Alzheimer's Society learning disability and dementia project has created over 200 new Dementia Friends. As well as supporting people with a learning disability and dementia, their relatives and carers, the work enabled 16 people with a learning disability to become Dementia Friends.

Veronica Williams
London, aged 73
with dementia



Photograph: Benjamin Gilbert/Wellcome Collection

What would you take to your desert island?

All I want is my gospel music CD and Bible. Music relaxes me, I listen to the words. They wake up the 'inner man' in me. Although I won't be remembering what I'm reading, when I read the Bible I'm reading the word of God.

What single thing would improve your quality of life?

I've got something – I have a partner now, he knows about my dementia. We're the same age. He takes me places, we go out for a meal twice a week. He took me to Jamaica and we're going to Venice. We've been friends for nearly two years. He's the best thing that's ever happened to me, and he'd say the same thing.

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

I'd like to go back to age 17, just leaving school. I was heading for my career, and by age 20 I had my own hairdressing business.

What is your most treasured possession?

My four children, 12 grandchildren and six great-grandchildren are my treasure. We're close, it comes from the way your parents bring you up. My mum was the queen. Mum and Dad had it hard when they first came to this country in the 1950s, there weren't many black people around. The house was always full of people – they always made sure there was room.

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

Ma recently left her northern home to stay with us for a summer party, held to celebrate various birthdays and meet her three-week old great-grandson. She remembered some of the house from living here a few years back, enjoying the familiar faces and her old room, which we've kept the same.

Ma was delighted to hold the baby and chatter away to him – a surprise, as when our daughter was born she was reluctant to hold her, saying, 'I prefer them when they're older.'

After settling in well, she was confused and tearful in the morning, trying to make sense of where she was and, I suspect, worrying that this was a permanent move. Her granddaughter cheered her up and reassured her, fortunately also finding spare Alzheimer's medication to replace the pills that had not arrived with her!

Back in her northern home, another visit by the baby has affected the whole family. Holding her great grandson clearly brought back Ma's memories of having twins and 'a very absent husband', as she put it.

Seeing her talking to the baby and reciting This little piggy (with some unusual words), her other son said it felt very special having Ma around, as it made him appreciate what a great mum she was.

Once again, we are grateful that she continues to live so well.

Dilly, a daughter-in-law

(continued next issue)



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



Over 2.5 million
people have become
Dementia Friends.
Will you join them?

Visit
dementiafriends.org.uk
to get involved





A south London activity group tries out a range of games and some gadgets that speak the time.

Games and gadgets

Daffodil Activity Group meets in a bright and well-kept community centre in south London once a week. Dementia Support Worker Sheena Ogilvie and a committed team of volunteers create a welcoming place for people with dementia to enjoy a range of activities.

It was the perfect place for people to try out a range of games and a couple of gadgets from our online shop, any of which could also be great gift ideas.

Link and Think

There are four themed Link and Think games – Careers, Celebrity, Hobbies and Transport. Each has 24 tiles with a word on one side, and a large wooden dice with instructions and a question on each face.

With the tiles all facing down, players take turns to throw the dice, giving them a different number of words to reveal before answering questions such as

‘Which is your favourite?’ and ‘What is different about them?’ Paul was delighted to draw his own former job – engineer – in the Careers game, and after drawing ‘nurse’, Maria had a lot to say about her experiences as a children’s nurse.

Stewart’s enjoyment of the game was clear, though he said, ‘The dice is quite heavy and it makes you jump when it’s rolled, as it’s so noisy!’

Shelley added, ‘This is a great conversation piece – I’ve never heard Stewart talk so much before about his hobbies and past.’

Jigsaws

Our shop has a range of jigsaw puzzles with different numbers of pieces, including a 63-piece set that features a painting of the Giant’s Steps in Cornwall.

As he began to reconstruct this picture, Nicky recalled his own painting and sketching, as well as earlier memories.

‘It reminds me of my childhood holidays to the seaside,’ he said.

Stewart appreciated the jigsaws’ design and range.

‘The pieces are easy to pick up as they are big,’ he said. ‘I like the different images the puzzles come in, I could do a different one each time.’

Aquapaints

Aquapaint sets each come with five images that start as a black outline on a white background, but which come to life in technicolour when brushed with water.

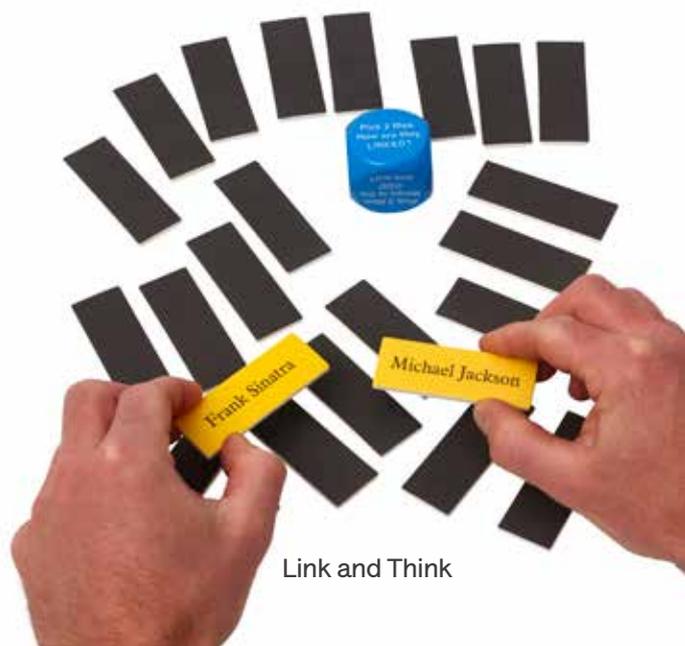
Paul liked carefully painting a tractor, ‘It makes you forget your worries, so you can relax.’

Gloria noticed the image whitening again as it dried, and said she’d like to begin painting her picture of a romantic couple on a deckchair over again. ‘I feel like I’ve achieved something,’ she added.

Shelley said, ‘These are very reasonably priced for how many you get, and you can reuse them.’



Jigsaws



Link and Think



Talking button clock

Talking watches

We showed the group two Pelham quartz watches that speak the time when you press a button, a 'women's' design with a 28mm face and a 42mm 'men's' version. Both have crocodile leather-effect straps, and gold coloured dial surround.

Shelley said it was 'a bit expensive' for a watch that didn't also light up, though Stewart thought it would be useful even without doing this.

'The watch needs a light on it,' he said, 'but the face is really big and clear for me to see. It's quite quiet, so I would have to hold it up to my ear to hear the time.'

However, the design was less to his taste, 'It looks like a women's watch more than a men's watch to me, due to the strap and how gold it is.'

Talking button clock

The Talking button clock speaks the time clearly and loudly when

you press it, and the date if you press it a second time. It can also be set as an alarm.

Maria was impressed by how easy it is to use. 'It's great!' she said.

However, Stewart thought a light on the button would be useful, so that it could be seen in the dark.

'It's very useful and loud enough to hear the time, and the date if needed too,' said Shelley.

Sheena agreed, 'It would be good to have by your bed in the morning!'

Most of these products are exempt from VAT if bought for a person with dementia or other condition – if so, then Link and Think games are £9.99, Aquapaint sets £12.49, jigsaws £9.99 and Talking watches £24.99 each. The Talking button clock is £17.25.

For these and many other useful aids and gifts, see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).



Talking watches



Aquapaints



See p39 for a chance to win a Link and Think game or Talking Time Pal.



‘My step-dad has dementia and now struggles to play CDs or use the TV. Could voice-operated technology, such as Amazon Echo and Alexa, help?’

Voice control

Developments that allow people to use technology in their home by speaking instructions or asking questions aloud are increasingly popular.

You can use your voice to operate ‘smart’ devices like Amazon Echo, Google Home and Apple HomePod. These access online ‘virtual assistants’, such as Amazon’s Alexa, Google Assistant and Apple’s Siri, so you can play music or control the TV, lights and much more. You need additional equipment, such as smart lightbulbs, to do some of these things.

This technology could help many people with dementia, though it’s important to think about whether it’s right for your step-dad’s specific situation.

Considerations

Your step-dad would need to consent to having these devices set up in his home. If he isn’t able to make this decision, and if an attorney or deputy hasn’t been appointed, then a best interests decision needs to be made on his behalf – discuss this with his care professionals.

In order to use a voice-operated device, the person needs to recall that it’s there and that they need to use a ‘wake word’ – such as ‘OK Google’ or ‘Alexa...’ – when talking to it. Written instructions beside the device could help, as could placing it where your step-dad

would use it, for example where he’d expect a CD player to be.

These devices are always on and ready to respond whenever the ‘wake word’ is used. Some people have concerns about what information they record, how long this is stored and who can access it.

Potential

An advantage of this kind of device is that you can add new functions. You could program it to remind your step-dad about appointments or when to take medication, or even to introduce itself and say how to use it.

It may also be used to make phone calls, and if your step-dad has a personal alarm service, he could use it to call them too.

If he gets a ‘smart home’ system as well, you could connect this so your step-dad can adjust heating and other systems by speaking.

When someone asks a virtual assistant repetitive questions, it responds without annoyance or stress creeping into its voice.

Although this kind of device could never be a substitute for human contact, it may provide entertainment and help while family or friends aren’t around.



For our Assistive technology – devices to help with everyday living (437) factsheet, visit alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Join our online community to learn other people’s experiences – see alzheimers.org.uk/talkingpoint



Even if your situation is unusual or unique, sharing concerns and problems with our online community can still help.

You're not alone

Facing new challenges as time goes on is something shared by everyone whose life is affected by dementia. It can be easy to feel alone in situations you're going through, especially when these are new, unusual, challenging or even unique.

You might want to talk to other people about it, but may be held back by questions in the back of your mind like, 'What if nobody understands?' or, 'How could anyone else know?'

On Talking Point, our online community, you will find a safe place where people discuss all sorts of situations. This can be about anything from how to help a loved one who keeps a secret stash of alcohol, to how to support someone who is compulsively buying things.

Common or not

It may be that you find yourself in a situation that's actually more common than you expected.

In the past, members have asked about coping with a family member's denial about their dementia, explaining where a deceased relative is and being a

'sandwich generation' carer, supporting their parents and children at the same time. Until they talked about their experiences on Talking Point, they all felt as if they were the only ones facing them.

Even if other people aren't able to relate to the specific details of what you're dealing with, they may still be able to draw suggestions from their own experiences. Either way, Talking Point is the kind of place where you'll always find a supportive and non-judgemental response.

Look around

You don't need to have signed up as a member of Talking Point to read discussions on it, so you can have a look around first to make sure it's the right place for you.

If you aren't sure about posting in a forum that anyone online can read, there is also a section called 'dealing with difficult feelings' that can only be seen by other people who've joined as members.

Whatever you're going through and however unique it might feel, Talking Point is where you can share your experiences with other people affected by dementia, ask questions and be reminded that you are not alone.



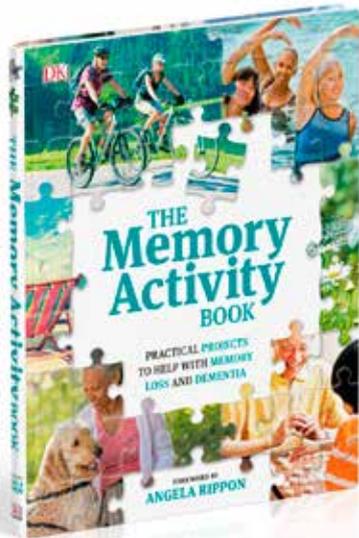
Join in

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



We hear what readers thought about a book of practical projects to help with memory loss and dementia.

Activity book



Written by an experienced occupational therapist, *The Memory Activity Book* features over 70 activity ideas, specially selected for people experiencing memory loss or dementia.

Caroline Branney, who manages our Dementia Knowledge Centre, says, 'This attractive coffee-table paperback is delightful in its layout, illustrations and photography alone.'

'Introduced by facts about memory and dementia, this book encourages you to pick and choose activities that match your interests and capabilities, with step-by-step instructions that can be shared with others.'

Margaret Butler in London agrees, 'I'm not much of a reader, but this has many useful ideas. There's a lot there, more than you would have time to do!'

Can do

Caroline is impressed by the book's affirming approach.

'I like the focus on what you can do rather than what you cannot do,' she says, 'while the author also encourages you to not discount activities that could involve a slight risk.'

'Maintaining a variety of interests helps you to reduce social isolation and remain physically active, and could help to avoid depression. The book encourages us to keep a balance between self-care, productivity and leisure that suits our own personal preferences.'

Maggie Cheshire, who works with older adults living with dementia in Bedfordshire, was also struck by the rounded nature of activities suggested in the book.

She says, 'Although the title of the book focuses on memory, I like the fact that the benefits for the whole person are addressed.'

'The book emphasises the importance of social contact, which could help to address increasing concerns about loneliness in residential settings.'

'Many of the suggestions are suitable for all ages, giving the opportunity for intergenerational contact and family participation.'

Karen Lilley in Essex says, 'I think this is a brilliant book. I work in a care home with people who have dementia and I would recommend every care home to have one. It is full of ideas that

can be adapted to suit individual capabilities.'

'I used it in a one-to-one session and the resident loved looking at the large, colourful pictures, which also triggered some good reminiscence conversation.'

At a glance

Maggie appreciated how ideas were presented in the book, particularly the clarity about each activity's benefits.

'There are lots of great ideas for activities and occupations, but what I love best is the "At a glance" and "How it helps" boxes that go with each.'

Caroline thinks the ideas would be inspiring for many readers.

'The "Out and about" chapters are a reminder that simply being outdoors can lift your spirits and make you feel good about yourself. Here, there is a range of lovely ideas from going birdwatching to hanging wind chimes in a sensory garden, each with clear bullet points of explanation.'

'The puzzles and games and arts and crafts sections could be useful for anyone running an activities group, as well as for use at home. The puzzles go beyond number and word games to include sensory puzzles and how to make your own jigsaws.'

'Looking through this book may inspire you to try something new or creative that you haven't considered before. Many activities will already be hobbies or old

favourites that can be revived alongside learning new skills.

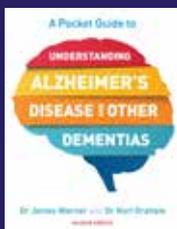
'People often neglect the simpler things in life, including activities we enjoyed as children or with our children. I am confident there will be ideas for things to do here that you and your family or friends can enjoy together.'

Maggie says, 'I think I will be referring to this book a lot and using it to encourage enjoyment of the moment for clients as well as their families and carers.'

Another carer in London says, 'The memory activity book is very useful and informative. I have already started putting some ideas into practice!'

The memory activity book,
by Helen Lambert (DK, 2018),
224 pages, £16.99,
ISBN: 9780241301982.

Your turn



For the next issue, we invite you to read A pocket guide to understanding Alzheimer's disease and other dementias, by James Warner and Nori Graham (Jessica Kingsley, 2018), 160 pages, £9.99, ISBN: 9781785924583.

Let us know what you think about this book by 8 November so we can share it in our next issue – email magazine@alzheimers.org.uk or write to the address on p3.

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

Other useful resources



Darllen yn Well/Reading Well

Reading Well Books on Prescription for dementia, which makes a selected list of titles providing information, advice and personal stories available in England's libraries, has been rolled out to libraries in Wales. Translations of listed books into Welsh have also begun.

Visit www.reading-well.org.uk/wales

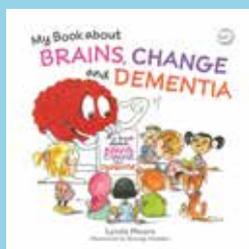


Keep smiling

This updated A5 handbook includes practical advice for when a person's dementia or disabilities make them unable or reluctant to care for their mouth and teeth.

Keep smiling: Mouth and teeth care for older people, by Janice Gardner and Emma Williams (Relatives & Residents Association 2018), 40 pages, ISBN: 9781900216111.

Free download at www.relres.org, or to order (£6) call 020 7359 8148.



Brains, change and dementia

This book breaks down misconceptions about dementia and speaks directly to younger children. It also reassures parents of the value of being open about dementia.

My book about brains, change and dementia, by Lynda Moore (Jessica Kingsley, 2018), 48 pages, £10.99, ISBN: 9781785925115.



Winston's world

Results of research into dementia homecare are portrayed through the eyes of Winston, a cartoon cat, with thought-provoking scenarios to improve care.

Winston's world, by Tony Husband and

Justine Schneider (University of Nottingham, Nottinghamshire Dementia Action Alliance, 2018), 92 pages.

Free download at www.idea.nottingham.ac.uk/resources/winstons-world, or to order (£6 plus postage) email justine.schneider@nottingham.ac.uk or call 0115 823 1294.



Talking Point members share advice about what to do when a person with dementia doesn't want to attend regular check-ups.

Health appointments

'I found that house visits (or in our case, visits while at the day centre) worked terrifically well. My other half wasn't averse to medical check-ups but he was more relaxed when they took place in familiar surroundings, plus when his mobility got worse, this saved so much hassle.

'A lot of community health services now offer house visits, but you might have to be referred. We had an optician, a dentist and a foot health person attend the day centre regularly, plus the memory clinic consultant was more than willing to come out, but only after I had asked.

'My other half knew that he was being tested by the consultant and even though he tried to co-operate, it stressed both him and me. Once the visits were shifted to his day centre, he only had to see the consultant for a few minutes each time and was then able to resume his usual activities while I had a longer chat with the consultant.

'Community health dentists are also a lot more experienced than regular dentists in knowing how to put a "difficult" patient at ease. Ours were absolutely marvellous – nothing fazed them.' **Beate**

'I never tell Dad beforehand, I just spring it on him. I have even set my phone alarm and then answer it with an, "Oh yes, we can do that." Then I tell Dad he has just been fitted in for a check-up and we can go now.' **Duggies-girl**

'I don't tell Mum anything until we are in the car and on our way, as I would probably have difficulty getting her out of the house. She usually forgets where we are going within 30 seconds and asks me continually on the hour-long drive.' **reedysue**

'My husband used to object, as he was in complete denial of his condition. I often used to say that I had a doctor's check-up and that, as we needed to do the supermarket shopping afterwards (he always enjoyed that), he could come with me to save me coming back for him. Worked a treat!' **di65**

'It is best to fit in these visits between some other errands, then it feels it is a regular part of the day. Or sometimes I book my own check-ups at the same time so they are not on their own.' **Myra_52**

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



Photograph: Freemages.com/jess.lis



Next issue

Do you have any suggestions for helping everyone, including a person with dementia, to feel involved and able to enjoy Christmas and other festivities?

Email magazine@alzheimers.org.uk or write to the address on p3.



Autumn festivals

For people who grew up celebrating them, Halloween and Guy Fawkes Night can evoke strong memories. This year, other festivals falling around this time include Navratri (10–18 October) and Diwali (6–11 November) for Hindus, and Guru Nanak Gurburab (23 November) for Sikhs.

A person with dementia could enjoy organised firework displays or community events, though noise and crowds may limit this as the condition progresses. For people who can't take part in this way, festivals can still prompt conversation about how celebrating them has changed over time and place.

You may be able to enjoy your own indoor or outdoor fireworks, with the usual safety precautions, or watch them on TV or YouTube. For an 'indoor bonfire', make a triangular frame from cardboard tubes (paint them or wrap in coloured paper) then cover with twigs and coloured strips of paper to represent flames, and eat baked potatoes or parkin cake.

As well as eating them, planning and making traditional foods can also be fun. Perhaps create new food traditions – use icing, sweets or fruit to decorate cakes, which could be readymade or from cake mix. If traditions like trick or treating could cause distress or confusion, then a polite sign on the door might help.

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

Photograph: Freemimages.com/craig.torou



Living with dementia – Driving

This booklet explains the legal issues around driving and dementia. It also considers the practical and emotional impact of stopping driving.

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

To order your free copy call **0300 303 5933** or email orders@alzheimers.org.uk quoting code 1504.



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

Talk to us

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

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

Talk to others

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

Visit alzheimers.org.uk/talkingpoint

Find the information you need

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

See alzheimers.org.uk/publications

Support near you

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

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

Carer

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



Calendars and diaries

We have our 2019 Alzheimer's Society calendar, a Memory calendar and a Stockings on the mantle advent calendar for three winners drawn from correct entries received by **24 October**, while five runners-up will receive 2019 Alzheimer's Society diaries.



Q: The 1985 TV series based on Sue Townsend's book about a teenager with a love interest called Pandora Braithwaite was:

A. The diary of a nobody. B. Mrs Dale's diary. C. The secret diary of Adrian Mole.

Elf hat and T-shirt

To help you get ready for Elf Day on 7 December, we have an Elf hat with bell and Elf T-shirt for one winner, plus Elf hats for four runners-up, drawn from correct entries received by **31 October**.



Q: In the 2003 comedy film Elf, a boy grows up believing he's an elf after inadvertently crawling into Santa's sack on:

A. Christmas Eve. B. St Patrick's Day. C. Halloween.

Games and gadgets

We have a Link and Think game and a Talking Time Pal for two lucky winners drawn from correct entries received by **7 November**.



Q: The first person to say 'At the third stroke, it will be...' for the UK's speaking clock service in 1936 was:

A. Amy Johnson, the aviator. B. Ethel Jane Cain, a telephonist. C. Agatha Christie, the author.

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

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

Activity book giveaway

The five readers who each won a copy of The memory activity book, by Helen Lambert, were K Lilley and A Mowlam-Tett in Essex, M Cheshire in Bedfordshire, M Butler and R Mehta in Greater London.

Food book giveaway

The three readers who each won a copy of Better brain food, by Ngaire Hobbins and Michelle Crawford, were D Smillie in Cumbria, J Epton in Nottinghamshire and E Cummings in Hertfordshire.

Christmas card competition

P Davis in Norfolk, J Wedlock in Surrey, J Taylor in South Yorkshire, CY Blundell in Somerset and an anonymous reader in Worcestershire each won a pack of 10 of our exclusive Returning home cards.
Answer: The line that first follows 'While shepherds watched their flocks by night' in the popular carol is 'All seated on the ground'.

Reminders competition

G Brown in West Sussex won a Rosebud reminder clock, while E Stephenson in County Durham and L Crosby in North Yorkshire won Dry-wipe reminder frames. Answer: The classic film that revolves around the meaning of a media mogul's final utterance, 'Rosebud', is Citizen Kane.



Gifts that make a difference

Our Online Shop has everything you need this Christmas. You can buy cards, wrapping and gifts for all the family. We also have a great range of products designed especially for people living with dementia, including games and activities. These can help to prompt memories, stimulate conversation and are fun for the whole family!

Every purchase you make helps fund our work, supporting all those who need our help and ultimately finding a cure for dementia.

shop.alzheimers.org.uk

FREE
delivery on
all orders
over £50