

Dementia together

December 2020/January 2021
Alzheimer's Society's magazine

Language skills

Companion Calls

Caring culture

Museums connect



Precious moments

Enduring heartbreak

Also in this issue

Care home visits

Virtual Carols at Christmas

Book group: Slow puncture



Strength in acceptance
Keen to share





Welcome

It's probably fair to say that 2020 has been the year none of us saw coming. For many, our end-of-year thoughts will include reflections about a lot more challenge, change and loss than we'd ever have expected.

We need to acknowledge and honour this, though it's important to also remember the incredibly inspiring ways that we have found to support each other through this time. The number of volunteers who've stepped up has been heartening, from helping neighbours with food shopping to keeping in touch with people through Companion Calls.

At Alzheimer's Society, we've been embracing a great deal of change and innovation to make sure that we're here for even more people affected by dementia in 2021 and beyond. Of course, it's you, our supporters, who make any of this possible in the first place – thank you.

Whether you carry on getting the magazine by post or choose to switch to our new email version (see p31), we'll still be sharing the real-life stories, news and ideas that make a difference.

Danny Ratnaike
Magazine Editor

Questions about dementia? See p18.

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

Contact us
magazine@alzheimers.org.uk
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Contents

December 2020/January 2021



8

Accepting the truth of a dementia diagnosis.



22

Heartbreaking times.



28

Museums reach out.

News

- | | |
|------------------|----------|
| Care home visits | 4 |
|------------------|----------|

Strength in acceptance

- | | |
|---------------|----------|
| Keen to share | 8 |
|---------------|----------|

Hard lessons	12
Every step of the way	13
Try something new	13
Network for support	14
Meet the researcher: Sarah Ryan	15
How I do my bit	16
Q&A: Myrtle Brown	17
Sharing knowledge	19
In your area	20
Spotlight: Alex Hyde-Smith	21

Precious moments

- | | |
|---------------------|-----------|
| Enduring heartbreak | 22 |
|---------------------|-----------|

Language skills

- | | |
|-----------------|-----------|
| Companion Calls | 26 |
|-----------------|-----------|

Caring culture

Museums connect	28
Letters	30
Photo scanning and other apps	32
Calendars for 2021	33
Book group: Slow puncture	34
Talking to a therapist	36
Choosing activities	37
In person again	38
Competitions	39

News

On the agenda

Our September report – Worst Hit: Dementia during coronavirus – shows how people with dementia have been disproportionately affected by the pandemic. This includes those who have lost their life or deteriorated significantly due to isolation. It also highlights how family carers are taking on many hours of additional care with little prospect of respite.

Your support has helped us to keep the report's recommendations firmly on the government's agenda during the pandemic. We received nearly 1,000 powerful accounts of people's experiences during lockdown that we sent to MPs. This helped us secure a debate in parliament which, thanks to our campaigners, MPs were asked more than 9,248 times to attend.

The debate, in November, was well attended and moving. MPs shared constituents' stories and raised concerns about falling diagnosis rates and the need for dementia research funding.

With confirmation of a pilot scheme of the keyworker status for family members to allow for safe care home visits, we'll continue campaigning for the rights and needs of people affected by dementia to be prioritised.

Care home visits: Disappointment

We've been calling on the government to ensure that people can safely visit family and friends with dementia in care homes.

Following pressure from the Society and other dementia charities through One Dementia Voice, the government announced a pilot scheme for England in October where a designated family member or friend would be given 'key worker' status. This would give them the PPE equipment and access to rapid testing necessary to visit safely. Not only had this not happened by the national lockdown in November, but the government also issued disappointing new guidance for care home visits. This suggested contact through floor-to-ceiling screens and more online and window visits.

'We're disappointed on behalf of people affected by dementia that the government is yet to give family carers key worker status,' says Kate Lee, our Chief Executive Officer. 'It's essential for meaningful human contact, which you just can't get through a piece of glass, to provide care safely and to limit the spread of the virus – anything less is completely unacceptable.'

In Northern Ireland, care homes are being encouraged by the government to allow certain key visitors to become 'care partners', so that the person with dementia can continue to benefit from their support. Having called for such action, the Society is now helping to shape this new approach, which needs to be implemented urgently.

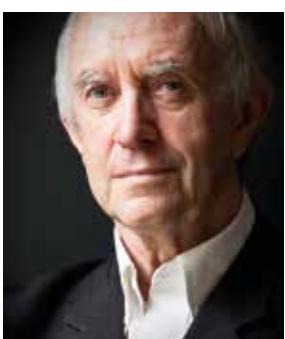
Add your voice to our campaigns at alzheimers.org.uk/campaign

Memory Walk: Making a difference

Although this year's events looked a little different due to social distancing, Memory Walk 2020 still saw over 17,200 of you unite with us against dementia. So far, over £1.7 million has been raised – thank you to everyone who helped make this year such a success! Watch this space if you're interested in putting a spring in your step in March 2021...



Virtual Carols at Christmas



Enjoy a wonderful evening of festivities with us online at this year's Carols at Christmas. We're bringing the sounds of joyful choirs, your favourite carols and readings from very special guests into the comfort of your own home.

The evening will be hosted by BAFTA award-winning actor and Society Ambassador Carey Mulligan, featuring Sir Trevor McDonald OBE, Jonathan Pryce CBE, Lesley Manville OBE and the band Scouting for Girls. We'll also have a special performance by Paul Harvey, who is living with dementia and recently had his work premiered by the BBC Philharmonic.

Carols at Christmas, at 6.30pm on 17 December, will be a festive celebration suitable for all ages, so sing along, share messages on screen and vote for your favourite carol. Tickets are free, though any donation you make will directly support people affected by dementia. You only need one ticket for a link that your whole household can use to join in.

For information and tickets, visit alzheimers.org.uk/carols

Directions

Another hectic few months for Alzheimer's Society have seen a few very special highs, including the return of most of our staff who'd been on furlough at the start of November. There were also wonderfully generous gifts from HSBC and other supporters, plus the incredible Paul Harvey's beautiful single, Four notes.

Sadly, the lows have been devastating – particularly the continued challenges for people wanting to visit loved ones in residential care. I experienced this for myself in late October when I travelled to my mum's care home on the west coast of Scotland. Braving a howling gale coming in across the Atlantic, I was able to see her through a window for a few minutes.

As this crisis rages on, the profound sadness felt by many of us not able to visit family and friends has motivated us to come together to lobby government for change. I applaud the efforts not only of the Alzheimer's Society team but also organisations like John's Campaign and Rights for Residents who we've worked with to push for a more humane solution to keeping loved ones safe.

Following all of this year's hardship and turmoil, we are certainly all ready for Christmas here at team Alzheimer's Society. I would like to wish every single one of you a safe and merry Christmas, a huge, heartfelt thank you for all your support over these strange times, and a much happier and joy filled 2021!

Kate Lee, Chief Executive Officer

@KateLeeCEO

In the press: Need for stronger evidence

The drug aducanumab hit the headlines in 2019 when its developer Biogen suggested it may be able to slow the progression of Alzheimer's disease for some people in its early stages. Regulators must now review the evidence of its effectiveness, and in November Biogen faced a setback while applying to the US Food and Drug Administration (FDA) for its approval.

A final FDA decision isn't due until March, but an independent advisory committee has voted against recommending its approval. The committee felt there wasn't enough evidence for its effectiveness – concerns shared by some in the dementia research community. FDA approval is still possible, but now less likely.

Biogen has also applied for European Medicines Agency approval and we await their decision, but they may also call for further evidence. If they did approve it, UK regulators would also need to consider the evidence.

In the 1990s, the Society was part of the pivotal discovery of the first gene known to increase a person's risk of developing Alzheimer's. This paved the way for drugs like aducanumab that target amyloid – a protein that builds up in the brains of people with Alzheimer's.

Whether or not aducanumab is approved in 2021, we believe that other new treatments will make the journey through clinical trials in the coming years.

Risk reduction: Worth every penny

A new study has underlined how investing in reducing people's risk of developing dementia may not only be effective but also financially worthwhile.

Researchers at UCL and London School of Economics say that money spent targeting smoking, high blood pressure and hearing loss could save £1.86 billion a year in England by, in theory, reducing the amount of people who develop dementia by 8.5%.

Fiona Carragher, our Director of Research and Influencing, said, 'We look to the government to act on these findings by making sure everyone knows what steps they can take to reduce their risk of dementia, and at the same time honour its commitment to double dementia research funding so we can continue this life-changing work.'

For more on reducing your risk of developing dementia, see alzheimers.org.uk/reducemyrisk

Learning for Living



A new Carers UK online programme, Learning for Living, helps people recognise the skills they've gained while being someone's carer and how these could be applied to paid work or volunteering. Carers Wales has also made it available in Welsh. Visit www.learning4living.org for the course in English, and for Welsh see www.dysguargyferbyw.org



The way forward

A new Alzheimer's Society report outlines what needs to be done to improve dementia care in England, from before diagnosis to the end of a person's life.

The report – From diagnosis to end of life: The lived experiences of dementia care and support – was informed by focus groups and interviews with people affected by dementia. Although these took place before the pandemic, the report also highlights its impact.

It makes national and local recommendations to government and NHS so that people can get care and support that is proactive, consistent, integrated and culturally appropriate.

For the report, please visit alzheimers.org.uk/diagnosis-end-of-life

One Stop's festive support

Convenience store chain One Stop has planned some fantastic festive fundraising throughout its 900 shops across England and Wales in December. Staff, many of whom are Dementia Friends, will don jingly bells and pointy ears around Elf Day. They'll also be selling Society Christmas cards and elf hats.

'We know that 2020 has been a challenging year for our customers. By raising funds for Alzheimer's Society, we can do our bit to ensure they have access to dementia support when they need it,' said Jack Taylor, Community Advisor at One Stop.

Better care, better homes

We've submitted evidence to an inquiry by the Northern Ireland (NI) Assembly's health committee, which is looking at what went wrong in care homes during the earlier stages of the pandemic and how mistakes can be avoided in future.

With another of the NI Assembly's committees, on communities, we've been highlighting the importance of designing new homes to help people who develop dementia to continue living independently in them for longer. This committee is also considering how to ensure that current public sector housing is safe for people with dementia.

Hospitals charter updated

National Dementia Action Alliance has updated its Dementia-Friendly Hospital Charter to cover the impact of coronavirus on hospitals in England.

For more about National Dementia Action Alliance, please see www.nationaldementiaaction.org.uk

Elf Day is here!

Final call for all elves – don't miss your chance! Elf Day is on 4 December, but you can hold yours whenever and however you like.

Get your free Elf Day fundraising kit at alzheimers.org.uk/elfday or call 0300 222 5770.



Bring Dementia Out training

Bring Dementia Out is training housing and care organisations in how to best support LGBT+ (lesbian, gay, bisexual and trans) people with dementia to live well. The interactive training webinar includes information, advice and case studies.

If you know a housing or care provider who could benefit, ask them to contact claire.days@lgbt.foundation

Updated factsheets

We've updated a number of our factsheets recently, including Hospital care (477), How the GP can support a person with dementia (425), What is alcohol-related brain damage (ARBD)? (438), Advance decisions and advance statements (463), Eating and drinking (511) and Sex, intimacy and dementia (514). Visit alzheimers.org.uk/publications or call 0300 303 5933 to order.

LGBTQ+ online

A new online peer support group, Speak out with dementia, has started for LGBTQ+ (lesbian, gay, bisexual, trans, queer) people with a dementia diagnosis. Meeting weekly over Zoom, members have the chance to express themselves and support each other in an affirming environment. The group is supported by AD Advocacy and affiliated to the DEEP network.

To find out more, contact Lucy Whitman or Aimee Day at speakoutwithdementia@gmail.com

COVID-19 and dementia: Decision aid

A guide to help carers of people with dementia who develop COVID-19 when they're facing difficult decisions is available to download.

Find out more and download the decision aid at www.ucl.ac.uk/psychiatry/decision-aid

DCAN: Making care personal

Visit the new Dementia Change Action Network (DCAN) website and get involved in implementing a more personalised approach to care in England.

Find out more at www.dcan.org.uk



Don't miss...

Andy says we should never be ashamed of how difficult things can be at times. [See p12](#).

Community Makers has helped Cherry to continue supporting people affected by dementia online. [See p14](#).

Meet Addy, Writer/Editor, and Alex, Director of Fundraising. [See p19 and p21](#).

Companion Calls are also helping people whose preferred language isn't English. [See p26](#).

Museums are finding ways to stay engaged with people who have dementia. [See p28](#).

Strength in acceptance

Having initially struggled to accept his dementia diagnosis, Musharraff Ali is now sharing his story to benefit others. **Gareth Bracken** speaks to a man who wants more people to understand dementia.

With the pandemic ongoing, our magazine interviews continue to take place by video call. This time we spoke to Musharraff Ali, who has Alzheimer's and vascular dementia, to hear about his experiencing of living with the condition.

Musharraff, who's 81, lives in South Woodford in East London with his wife Selina and daughter Nadia. Nadia joined her father on the call to offer support when needed, in both English and Bengali.

The fact that Musharraff was prepared to discuss his dementia so openly shows just how far he has come since his diagnosis in 2014.

'In the beginning, I didn't accept dementia. But if it helps others, I'm all for sharing my story,' he says.

Hunting trips

Musharraff was born in Sunamganj, which at the time was in India but later became part of Bangladesh. One of 11 children, he remembers playing tennis on his family's grass court when he was small, and later going on trips to hunt crane with his brothers, cousins and friends.

'Some of the places took a day to get there, so we went at 5.30 in the morning, with dry food and fruit,' he says. 'We also had a big fishery – an artificial lake – for angling. I used to like it.'

Musharraff's father was a political minister, who at different times had responsibility for revenue, forests, prisons and education.

'He was very active on giving women the right to vote,' says Musharraff, who would sometimes join him on political tours.

'He was also a religious man – he translated the first part of the Quran into Bengali.'

Musharraff came to England in 1961 to study chemical engineering at the University of Bradford, having turned down a place at Imperial College London. Remarkably, he didn't think he was good enough to go there.

He spent most of his career in the petrochemical industry, including designing plants for refining oil and gas. His work took him to London, Germany, Qatar and Aberdeen.

Shocking news

Musharraff was diagnosed with Alzheimer's disease and vascular dementia in April 2014, having had quadruple bypass surgery in February 2012.

'I was forgetting things, so my wife and daughter decided to send me to the doctor,' he says.

Nadia recalls she and her mother pushing the GP to refer Musharraff to a specialist, which led to him having an MRI scan followed by cognitive tests at home. The results were used by a local memory service to make their diagnosis.

Nadia remembers her father falling quiet after being told he had dementia. 'The doctor asked him what was on his mind, and he responded by asking something like,

"How long have I got?" He felt it was some kind of sentence,' she says.

Musharraff was shocked to receive the news.

'I first of all thought that I didn't have dementia. I didn't believe the diagnosis, I resisted it,' he says. 'But then I compared that I don't remember everything sometimes, so maybe the doctors were right. Eventually, I accepted the truth.'

Lighter side

The doctor went through the different aspects of home life that Musharraff might need support with, but it turned out that almost all the tasks were already being done by his wife or daughter, much to the family's amusement.

'Taking the bins out, that's my duty!' Musharraff jokes.

Although dementia has presented challenges with his memory, Musharraff still finds humour in aspects of his situation.

'Sometimes when I go out and my wife asks me to buy something, I forget about it, or I go to the shop and bring back something else!' he says.

Nadia tells the story of her mother sending Musharraff out to get five large peaches, but him instead coming back with five huge potatoes.

'I remembered "five"!' laughs Musharraff, who notes that he's generally a very even-tempered person.

'There's no point in getting angry or something like that. You don't achieve anything,' he says.

Quick read

Although he struggled to accept his dementia diagnosis at first, Musharraf Ali is now keen to share his experiences.

Musharraf, who is 81 and lives in East London, was diagnosed with Alzheimer's and vascular dementia in April 2014.

He receives strong support from his family, including daughter Nadia, who herself has received welcome advice from the Society.

Musharraf hopes his story will help people have a better understanding of what dementia actually is.



Hear our stories

Listen to people with dementia speak in their own words at alzheimers.org.uk/podcast

Lockdown life

Like so many others, Musharraff has found the pandemic and lockdown a particularly challenging period.

'It's very bad, uncomfortable. I'm bored sometimes,' he says. 'I used to go to the mosque three or four times a day. I miss the exercise, making friends and having discussions there – there's a good atmosphere.'

'I speak to my daughter, son and wife, but it can get boring talking about the same subjects, and having the same shopping list!'

Musharraff's son, daughter-in-law and grandchildren live very near to him, and he appreciates the support he receives from his family.

'Nadia is helpful all the time,' he says. 'If I forget something, she will understand. She doesn't make a problem or make a hue and cry.'

Nadia is keen to point out that their relationship continues to work both ways.

'He still supports me too, nothing has changed in that dynamic,' she says.

'He might not remember our discussions, but at the time he's lucid and gives me his honest reaction.'

'His advice doesn't lose its power just because he's elderly and has dementia.'

New experience

For Nadia, supporting her father has been something of a learning curve.

'I can only speak for the community that I come from, but I think we are the first generation to have the experience of seeing our parents live to these advanced ages,' she says.

'There's nothing that my parents could have passed on to me about dementia within the culture, so it's a very new experience, working it all out.'

The family has been receiving strong support from Alzheimer's Society, in particular from Shuhala Abbas, a Dementia Support Worker.

'I think she should be cloned!' says Nadia. 'She has a huge amount of common sense and humanity. I can see that she's thinking about steps ahead and how to make those easier.'

'She's suggested bringing somebody else into my father's life who he can develop a relationship with and get used to. Someone who could take him to yoga classes, to help with his breathing. I thought that was a really good idea.'

Strong signal

Musharraff hopes that sharing his story will raise awareness of dementia while providing

support to those who are also living with the condition.

'Many people know about dementia superficially, but they don't actually know what it is,' he says. 'Unless it happened to me, I wouldn't have known what it is. I would like people to know about it.'

Nadia says this represents a big change in her father's outlook.

'After his diagnosis, he was very reticent about letting people know,' she says. 'When an interview was first mentioned, I thought he might want to keep everything private, but his first reaction was to say yes. It's a strong signal of his acceptance, and a huge indicator of how far he has come.'

Having initially not wanted to tell friends about his dementia, Musharraff says he now adopts an attitude of, 'What's the harm in them knowing?'

Although he does wonder how dementia might affect him in future, Musharraff knows that he'll receive 'all sorts of help' from his family. And as things stand right now, he's very content.

'I'm alright, my life is good,' he says. 'I have a wonderful family who are up to the mark, and whatever I've wanted to do, I've done it, more or less.'

'I'm satisfied with what Allah has given me. There's no logic in asking for something else.'

Musharraff and his wife Selina.



What can you do to help?

Your donation helps us improve people's understanding of what it's like to live with a dementia diagnosis. [Make a donation today.](#)



For our publications in a range of languages and formats, see [alzheimers.org.uk/accessibleresources](https://www.alzheimers.org.uk/accessibleresources) or call 0300 303 5933.

For coronavirus advice and support for people affected by dementia visit [alzheimers.org.uk/coronavirus](https://www.alzheimers.org.uk/coronavirus)

Hard lessons

Andy Woodhead in the Vale of Glamorgan, who has vascular and Lewy body dementia, tells us about his life in lockdown.



Andy (right) with Bernard.

I'm 64 but I behave like I'm still in my early 20s, according to my 28-year old son Daniel, who I have frequently embarrassed with my 'Peter Pan' attitude to life.

I'm very lucky to live on the Glamorgan Heritage Coast with my husband Bernard, Daniel and his fiancé Chloe, and my mother Della, who has her own 'granny annexe'.

I was told I needed to be shielding during the long 15-week lockdown, and here in Wales we are currently under a 17-day 'firebreak' lockdown, which I doubt will be our last.

Sudden stop

I'm a very social person and, prior to the lockdown, if I wasn't out volunteering, public speaking or

teaching for Alzheimer's Society, Marie Curie, Age Cymru and others, I would be mixing with friends locally.

The lockdown came upon us very suddenly and everything stopped. I've learned a very hard lesson. I needed all of those activities, they were a distraction from the realities of my illness and made me feel useful again. As a consequence, I fell into a deep depression. In all honesty, this depression has dogged me most of my adult life, another stigma I once carried in addition to the fact that I had to come to terms with the guilt I felt about being gay.

So life was hell under lockdown. Then along came Alzheimer's Society with Zoom meetings

and phone calls, which helped enormously in opening up the outside world again, but – and there is a big but – it's not the same as getting out and being with people.

Major challenge

I know that, in addition to repeated short episodes of depression, I've lost many of my social skills and a huge degree of self-confidence. Most worryingly, I feel my dementia journey has been 'speeded up'.

I have had four very close friends who have died during the pandemic, two with COVID-19. It has been upsetting of course, but exacerbated by not being allowed to go to their funeral services.

I have tried so hard not to watch 24-hour news coverage, allowing myself only the early evening TV news. But on some days I've failed miserably, and genuinely that has not helped.

It was a major challenge trying to socialise with people outside the 'family household bubble' again after the first lockdown, which was surprising to me and my family, given the amount I loved being with people.

Honesty helps

My family have been a great support to me, but they have had the challenge of dealing with my mood swings. They've had no respite!

We should never be afraid to talk about our feelings or ashamed of how difficult things can be at times. It is our willingness to be honest about how we really feel that helps others.

Every step of the way

Jules Walton, in Stratford-upon-Avon, tells us about her Step Up for Dementia challenge.

My mum was diagnosed with dementia over two years ago. She's a beautiful lady with a fantastic heart and, like everybody out there, she doesn't deserve this.

Mum's care home went into lockdown two weeks before the whole of the UK. I felt lost. I'd been seeing Mum every day and I hated the thought that she would think she had been abandoned.

I had the awful call to say that Mum had suffered a seizure. I panicked because I couldn't go to her. I wanted to hold her and tell her that we were there for her, but I had all of that stripped away.

And it was just like fate, that in a matter of hours an email popped up from the Society about Step Up for Dementia. So I just said yes, I'm doing it – I needed to feel like I was doing something for my mum.

Mum in my heart

I did a million steps rather than the suggested 850,000 because it sounded better when I was begging people to sponsor me!

I walked every single day, minimum 14 miles. I always had Mum in my heart to keep me going, always talking to her when I was down and fed up with not being able to go to her.

I finished at the grounds of Mum's care home. They'd got banners, balloons, pans they were banging, whistles, everything. And as I walked down the drive, there in the doorway was Mum. I wanted to run to her. Well I did, and they shouted, 'No Jules, you can't, come back!' So I stopped, and she just looked – the look on her face, she knew it was me.

Immense support

Dementia takes away somebody who you love so much, but COVID has made that 10 times worse. Step Up for Dementia was a big positive to me, because it distracted me from my reality and enabled me to do something which was good for my own sanity and health.

I've now done 2.5 million steps for Mum and raised nearly £5,000. And this isn't the end for me – it's the beginning of something I'll continue to do. I'll keep shouting from the rooftops for Alzheimer's Society, every step of the way.

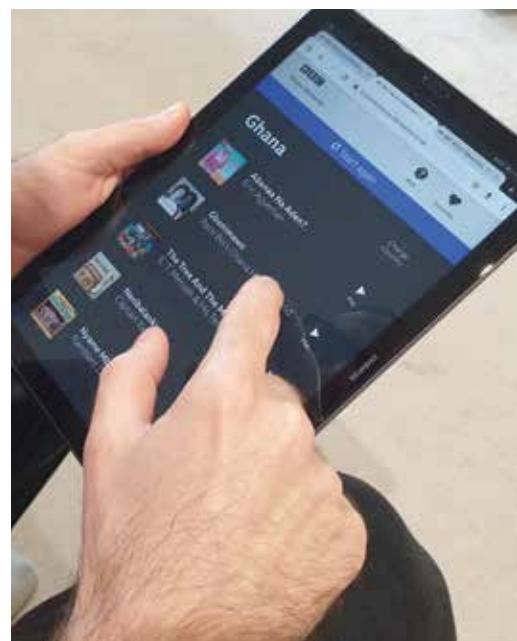
Visit alzheimers.org.uk/events or call 0330 333 0804 for Step Up for Dementia and other ideas to challenge yourself.



BBC Music and Dementia

Take an international journey through music with BBC Music and Dementia. Teaming up with BBC World Service and listeners across the world, BBC Music Memories has expanded its archive of clips (with links to full tracks) and its range of Memory Radio episodes to span more decades, cultures and life experiences.

Listen, explore and find out more at www.bbc.co.uk/musicanddementia



Become a Dementia Friend

Dementia Friends learn about dementia so they can help their community. You can become a Dementia Friend by taking part in an online session, and also by watching our online videos.

Visit dementiafriends.org.uk to get involved.

Network for support

Cherry Evans shares how the Community Makers network has helped her to continue supporting people affected by dementia since the first lockdown.



I previously had the privilege of working for Alzheimer's Society, but since July 2019 I have been employed by Pembrokeshire Association of Voluntary Services as Dementia Supportive Community Connector. My role is to develop and facilitate activities that enable people affected by dementia to achieve the best quality of life.

I was looking for inspiration to develop activities in a new way, owing to the lockdown. The Community Makers network has been an opportunity to learn from others and share information and advice, which has helped us run our successful online Tea and Natter group.

Not forgotten

Prior to the lockdown, we had eight memory cafes around the county. These provided an opportunity for

people affected by dementia to socialise in an informal setting, with old friendships rekindled and new friendships made. The cafes were a source of peer support and sharing of information.

Overnight these were lost, and with no end date for the lockdown there was no sign of when they could be resumed. We created the Tea and Natter group as a way for people living with dementia to socialise and to ensure that they did not feel forgotten.

The online group has been meeting every week since late May. The sessions are very relaxed. Some weeks we have a quiz, one week we spoke about our favourite songs and the next we sang along to songs via YouTube. By linking YouTube to Zoom, we have watched and discussed our favourite children's TV programmes, such as Andy Pandy and The Woodentops.

We have had guest speakers including our local Society dementia adviser, and one week a Trading Standards officer spoke about scams.

Knowledge and tools

When face-to-face groups were suspended, I had no idea how to provide an opportunity for people to interact.

Community Makers gave me the knowledge and tools to continue providing opportunities for people living with dementia to feel part of something. I learnt about Zoom – I had never heard about it, let alone used it, but I gained the confidence to set up weekly Tea and Natter meetings over Zoom.

Community Makers meetings have been very helpful for sharing ideas, and the website is a great resource. It is very easy to use and very informative, especially the templates and guides. I would recommend anyone considering setting up a virtual group to take a look.



Community Makers is an initiative between the Society, the Association for Dementia Studies at University of Worcester and the UK DRI Care Research & Technology Centre. It's supporting groups for people affected by dementia to get online – visit www.communitymakers.co for details.

Meet the researcher: Sarah Ryan

Alzheimer's Society Junior Fellow at the University of Manchester.



Favourite things?

- Book – Can I cheat and count the whole of Terry Pratchett's Discworld series as one?
- Way to spend time – Hiking in the Peak District.
- Memory – Family holidays in Cornwall when I was little.

Why dementia research?

I remember learning how brain cells talk to each other when I was a young teen. I realised then that everything that makes us who we are – our thoughts, feelings, memories, personalities and language – is all the result of electrical and chemical activity inside our brains, and this completely blew my mind.

I decided to study neuroscience at university so I could learn more about these processes, and was particularly interested in what happens when they go wrong.

That led me to study dementia, where these all-important aspects of our identities are affected because of a disease that physically damages the brain.

How has Alzheimer's Society supported your work?

I'm incredibly grateful to Alzheimer's Society for investing in me as a Research Fellow. This means the charity funds my work, paying my salary and costs associated with laboratory-based research, for a three-year period. It would not be possible for me to carry out my research without this support.

What are you currently working on?

I work on a type of dementia called frontotemporal dementia, or FTD for short. FTD is one of the most common causes of dementia in younger people, and typically

affects people in their 50s. In many cases, the disease is caused by a genetic error which can either happen spontaneously or be passed down in families.

I use cells grown in a dish to mimic what happens inside the brain of someone with FTD, and try to understand how a faulty gene stops brain cells from working properly.

What difference do you hope this will make?

My aim is to really understand what's going wrong inside the brain cells of someone with FTD at the level of specific proteins and other molecules. If we understand disease processes at this level, we can design new treatments to intervene and stop the disease from progressing. I hope my research will one day lead to new treatments that will help people affected by frontotemporal dementia.

In what direction would you like to take your research in future?

I'm interested in looking at the role of the immune system in frontotemporal dementia. We can see clear signs of inflammation (a type of immune response) in the brains of people with FTD, which could contribute to the disease process. If so, it is possible that anti-inflammatory medicines might be useful to treat FTD – but more research is needed to investigate this.

How I do my bit

We ask people about how they keep active and well, whether they have dementia or not. This issue, we hear about making the world a better place.

Josie Gale, 37 in Greater London

I volunteer for a small charity in the borough that I work in. They support elderly and vulnerable people with a number of schemes, but I specifically volunteer for their befriending one.

In normal times, I visit a lady in her 70s who lives on her own and is largely housebound because of a stroke. At the moment, all I can do is call her, but the charity is continuing to support her by doing shopping for her.

I used to work for a charity but when I moved to a more corporate job, I wanted to do something which would give back to my local community, so that I'd still feel like I was doing my bit. A benefit for me has been making several friends – with the lady I have befriended and with the people that work and volunteer at the charity.



Josie Gale.

Patrick Hawkins, 78 in Kent

Having cared for my wife at home for the past nearly nine years, it has been a difficult and demanding time. We were declared eligible for NHS Continuing Health Care funding in October 2019 after an over two-year battle. Whilst my priority is caring for my wife, now with adequate care funding, I have some time to help others living with dementia.

I have contacts through being a member of my GP's Patient Participation Group, churches, local community care and retired health professionals. Through these introductions, I have been able to help others at the beginning of their journey living with dementia.

I've had great satisfaction in being able to help others based on my experiences of living and studying dementia.

Kerry Allan, 39 in East Yorkshire

As a youth worker, I am part of a coalition that works with all the youth services in my area to get the very best for children. This summer, I was part of a project that provides lunches for families in Goole who needed them to stop holiday hunger.

We opened this up to everyone, and after eight weeks of daily lunches we had served 2,000 to the children and their families in my area.

I see there is a real need for this service and a couple of hours a day is not a lot to change people's lives in a small way.

Chyanne Hooks, 24 in Essex

I volunteer for two charities on a regular basis, while helping with fundraising activities for others.

Volunteering was something we were encouraged to do by the school. I was a child member of Girlguiding, so it was a natural progression to become part of the leadership team. I started volunteering for my local theatre because I'm passionate about the industry and want to work in it but need experience.

I get to learn new skills, meet fascinating people and generally have a good time. My volunteering shifts tend to be in the evening, so I can fit it around working and caring for my nan, who has dementia.



Chyanne Hooks.



Stay well

Some things you can't change, like your age and genes, affect your chance of developing dementia. Things you could change include keeping your mind and body active, enjoying healthier food, not smoking, drinking less alcohol, staying in touch with people, and dealing with any health problems.

If you already have dementia, the same things can help you to stay healthy and well.

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

Q&A: Myrtle Brown

Myrtle Brown in Newtownards, aged 73 with Alzheimer's disease.

What's changed most since your diagnosis?

It is difficult to judge properly because of the virus lockdown etc. I had to stay at home for 12 weeks. Luckily it was good weather, so I could potter about in the garden with my plants. The worst part was not being able to take my dog out and chat with the other dog owners. Before then, I was able to go on with most of my life as normal.

What would you take to your desert island?

I would take my Kindle loaded with my Bible and lots of books. However, as in an island without electric, I would take my Bible.

How has Alzheimer's Society helped you?

All the staff have been very helpful, especially the phone calls just checking in.

What song or tune sums up your life so far?

I do love the hymn Amazing grace.

What single thing would improve your quality of life?

I would want the monthly groups to reopen and other new gatherings arranged.

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

Perhaps I could go back to my teenager years and get more self-confidence.

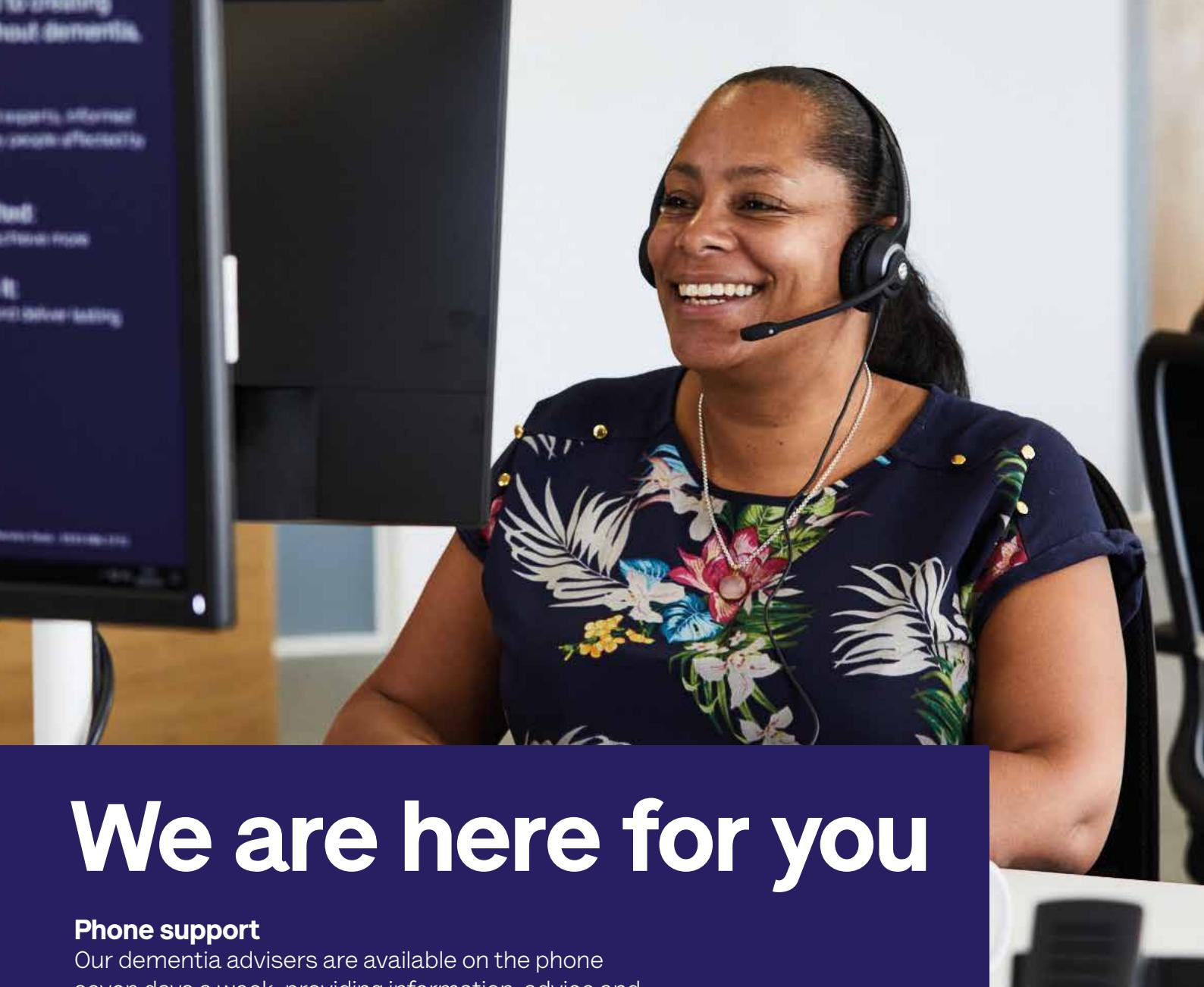
What is your most treasured possession?

I suppose my sewing machine as I was able to make some of my own clothes, including my wedding dress.



Myrtle with her dog Charlie.

If you have dementia and would like to answer our questions for a future column, email magazine@alzheimers.org.uk



We are here for you

Phone support

Our dementia advisers are available on the phone seven days a week, providing information, advice and emotional support to anyone affected by dementia.

Online support

Find a wide range of information on our website to help you understand and live with dementia. Visit our online community Talking Point to connect with others in a similar situation and search for local support services on our dementia directory.

Face to face support

Face to face support services are not currently running due to coronavirus. When it's safe, our dementia advisers will connect you to the relevant support in your area, from one-to-one services to local support groups.

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

Person living with dementia

Contact us today

0333 150 3456

alzheimers.org.uk/getsupport

Sharing knowledge

Writer/Editor **Addy Olutunmogun** on how we update our dementia information, which helps thousands of people every day.



I'm very proud to be part of the team that's dedicated to always improving our information for people affected by dementia. This includes over 100 publications in print, online and in audio, and it's a core part of how we support people.

Upcoming additions include a new activities handbook for carers and a new factsheet about denial and lack of insight. We've also updated our factsheets on communicating and hospital care. These topics are particularly relevant at a time when many people are coping with increased isolation and worsening symptoms of dementia.

Updating

With so much changing so often, this year has really highlighted the importance of up-to-date information.

Even without the pandemic, we review and update all our publications every three years. We do this based on the latest evidence, and on what people affected by dementia and other experts think of them.

This keeps our information accurate and relevant so that it can help people to make decisions, face challenges and get the right support.

Always more

Involving people with dementia and their carers, family and friends is especially important. It ensures that this information is as representative and accessible as possible.

Getting feedback from people affected by dementia is certainly the most rewarding part of my job. It reminds me of the impact of my work, and that no experience of dementia is the same.

There is always more to understand and more we can do to improve the support we offer.

Humbling

Earlier this year, I led some feedback sessions about new designs of The dementia guide, which is for people with a recent diagnosis. It was humbling to hear people's individual stories and to learn how the guide could better reflect their experiences.

These discussions took place over Zoom due to lockdown, after weeks of isolation. This gave them an extra special feeling of collaboration and togetherness. I can't wait for the updated version of The dementia guide to come out so that I can share the results with everyone who contributed!

We'd love to hear from you if you're interested in feeding back about our information – email publications@alzheimers.org.uk



For our factsheets and other publications, see [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications) or call 0300 303 5933.

In your area



Tractor triumph

A community in Enniskillen, County Fermanagh, raised over £5,000 for Alzheimer's Society with a tractor run in September.

Cavanacarragh Community Association, supported by local family firm Slevin Plant Hire, hosted the event, which saw everyone involved maintaining social distancing. Liam and Jimmy Slevin came up with the idea for it, in honour of their Mum.

Tractors old and new rode in convoy along a 19km route from Cavanacarragh's community hall and through Enniskillen town.

On its Facebook page, the community association said the money raised was 'a testament to the community spirit and generosity of the people of Cavanacarragh and surrounding areas'.

They added, 'To all those who brought tractors, helped with organising the hall and tractors, feeding the hungry drivers, collected or made donations and involved in any other way, many, many thanks.'

Amanda Gale, Community Fundraiser at the Society, said, 'People living with dementia have been one of the groups most affected by COVID-19 and, whilst the current situation has been difficult for fundraising, the demand for our services has increased.'

'That's why we are so grateful to the community of Cavanacarragh for their fundraising – your support really does help people affected by dementia across Northern Ireland now, when they need us most.'



Friends in Principality

One of our corporate partners Principality Building Society, headquartered in Cardiff with 53 branches across Wales and the borders, has celebrated over 450 of its staff becoming Dementia Friends.

Principality has donated over £130,000 to support our Dementia Connect service since 2019. Now because of the pandemic, staff members have also volunteered to make Companion Calls.

Julie-Ann Haines, Principality's Chief Executive Officer, said, 'It is so important that we are supporting the most vulnerable during these difficult times. The huge demand for Dementia Connect highlights the effect that little social interaction and not keeping up with daily routines has on people living with dementia.'

Stacey Hawdon, Corporate Fundraiser at Alzheimer's Society, added, 'We're incredibly grateful to Principality Building Society for its continued support. The ongoing pandemic has been particularly difficult for people living with dementia, many of whom feel isolated and alone.'



Song for Mum

A Norfolk-based singer-songwriter, known for collaborations with former Genesis guitarist Steve Hackett, is raising awareness of dementia with her latest single, Memory Lane.

Amanda Lehmann has also set up an online tribute page for her mother Ann Goodwin, who died aged 80 with vascular dementia in 2016. Memory Lane will feature on her forthcoming solo album, due out next year.

'I wanted to reach out to anyone who has been affected by this horrible disease,' says Amanda of Taverham, near Norwich.

'I remember writing the first lines after I'd visited her. I pulled over into a lay-by feeling upset and, after a bit of a weep, started scribbling down some lyrics to get my feelings on paper.'

'The song grew alongside Mum's illness and it wasn't until after she passed away that I sat down and pulled all the bits together into a complete song, with accompanying melody and chords.'

Nik Gardner, Community Fundraiser, said, 'We're so grateful to Amanda for setting up a fundraising page in her mum's memory – she has raised an incredible amount already.'

Watch the single's video at www.amandalehmann.co.uk and visit Amanda's tribute page at www.ann-goodwin.muchloved.com

For fundraising ideas, visit alzheimers.org.uk/fundraise or call 0330 333 0804.

Spotlight:

Alex Hyde-Smith, Director of Fundraising

Why dementia, why the Society?

Dementia is one of the most important issues of our time. Within a few days of my stepfather going into a care home in March, they had to go into full lockdown.

When we spoke recently, I told him I was going to get Mum and he asked me to remind him of her name. It is an ever-present reminder of the need for what we do.

How to fill an unexpected day off?

A long walk with my wife Shreya and daughter Amaya, interrupted by a nice pub lunch, and then back home for an afternoon movie (with a family box of Maltesers).

Proudest moment?

They all revolve around watching my daughter grow up into a strong, proud, confident and able

young woman. Recently, we were watching a programme about stunt pilots and she said, 'I'd love to have a go at that'. I said, 'Really? Can you fly a plane?' and she immediately replied, 'Not yet!' I loved that – she has this powerful sense that she can be anything she wants if she tries hard enough. And I agree!

Worst advice you've been given?

For another charity, I was once asked if I could cancel a Christmas appeal because it would cause too many calls at such a busy time of year. That appeal raised £2 million, so I'm glad I didn't listen!

Biggest priority for coming months?

The same as ever for me – creating the best team and the right fundraising programme, and empowering people to do their best work.

Most important thing learned from a person with dementia?

That an often forgotten cruelty of this disease is that people are aware enough, certainly in the beginning, to feel an overwhelming sense of guilt for the loved ones who need to look after them.

Most looking forward to?

I believe we will all look back on 2020 as a defining moment in our careers, and one we should be extremely proud of – especially as all that hard work leads to better outcomes for people affected by dementia.





Quick read

Kevin Jones has been unable to be with his partner Jean, who has dementia with Lewy bodies, since March.

Jean, 80, lives in a care home, with Kevin only able to visit looking through her bedroom window.

Kevin, in Wrexham, north Wales, is grateful for the regular phone contact he's had from our Companion Calls.

He's sharing his and Jean's story so that others in a similar situation may feel less alone.



Precious moments

Lockdown has prevented Kevin Jones from being with his partner in her care home. **Gareth Bracken** speaks to a man who is enduring a heartbreak separation.

When this horrible, horrible condition started, our lives changed basically overnight,' says Kevin Jones, whose partner Jean has dementia with Lewy bodies.

Jean now lives in a care home that has been locked down during the pandemic, with Kevin only able to see her through a bedroom window.

'I'd give anything to be able to sit by her side, hold her hand and give her a kiss,' he says.

Kevin, who lives in Wrexham, north Wales, says, 'This is not just my story, this is Jean and I – she was my rock.'

Loyal and genuine

Jean, now 80, grew up in Newport and was an office manager for various companies. She met Kevin in 1990, while she – by then divorced – was holidaying with her daughter Julie.

'We met purely by chance and it was love at first sight,' says 71-year old Kevin, a former police officer.

Jean was excellent at crosswords and sudoku, and she loved opera. Having both retired in 2000, she and Kevin enjoyed winter sun holidays and cruises.

'She was always loyal, supportive and 100% genuine,' says Kevin. 'My only regret is that I had not met Jean 50 years ago instead of only 30.'

Very anxious

In December 2016, Jean fell as

she was leaving the couple's flat. They pushed ahead with a planned holiday, but it was soon clear that something wasn't right.

'Jean became very anxious at the airport and wouldn't let go of my hand,' says Kevin. 'At the hotel, she wouldn't come down for breakfast and didn't want to be around crowds or interact with people. She also lost all interest in our usual walks.'

Jean had numerous medical appointments over the following months. Despite support from Kevin and others, she began to have spasms and had to spend time in hospital. She was diagnosed with Parkinson's, and a consultant confirmed that she also had dementia with Lewy bodies.

People who have dementia with Lewy bodies can have problems with attention and alertness that vary over time, and difficulties judging distances. They may see or hear things that aren't there, have persistent false beliefs or experience disturbed sleep. Difficulties with movement, which increase the risk of falling, affect many people with the condition.

As with other types of dementia, symptoms increase and get worse over time. As it progresses, day-to-day challenges become more similar to other types of dementia.

Jean would say, "What are those birds doing on the ceiling? Why are there cats and dogs walking on

the walls?" recalls Kevin. 'She also started shouting and screaming at night, which was very distressing.'

With Kevin struggling to cope, Jean moved to a nursing home for around six months, where her health improved. But after returning home she soon deteriorated and moved back into a care home, this time on a permanent basis, in June 2018.

'We were very lucky that we found a home which could support Jean with dementia, epilepsy and Parkinson's,' says Kevin. 'It was excellent – I went every single day and was made part of the family.'

Heartbreaking visits

One Sunday in mid-March, Kevin was with Jean when the home's manager said the building was going into lockdown.

'Jean didn't really understand what was happening,' says Kevin. 'I said to her, "I don't know when I'll be able to come back here and be physically with you, my love. I love you lots and I'll see you as soon as humanly possible."

'I was utterly distraught, because I knew I might never again be with the woman I love.'

The home encouraged socially distanced outside visits, but because of Jean's frailty and health, Kevin wanted her to stay in her warmer room. He sees Jean through her ground floor window every Sunday.

'The staff wheel her chair to the window. We can't have a conversation, but at least I can see her. Some residents are on the first floor and their loved ones haven't been able to see them since March.'

'It's heartbreaking and I'm devastated when I come home to an empty flat. I just sit on a chair and cry. I'm in utter shreds. Then as the week progresses, I get stronger.'

Kevin was shocked when Jean developed COVID-19 in July, though thankfully she recovered.

Dementia with Lewy bodies

Around 10–15% of people with dementia are thought to have dementia with Lewy bodies. Often mistaken for Alzheimer's disease, it also shares symptoms with Parkinson's disease.



Photograph: Keith Freeburn

'At the time I was very upset,' he says. 'I've since taken stock and understand the difficulties they have in these care homes. If you have a flood, some water might get in.'

Listening ear

Kevin gets weekly Companion Calls over the phone from Society volunteer Rachel.

'Rachel was my only light at the end of the tunnel when I was self-isolating,' says Kevin. 'It was all I had from March to August – some weeks she was the only person I spoke to.'

'She has been a listening ear, and very supportive. I can say how I feel, how I miss Jean. She never judges me or criticises, she just listens.'

'I would like to sincerely express my gratitude to her and Alzheimer's Society. If I wasn't able to talk to somebody, I think I'd have serious mental issues. I'm truly thankful for those calls.'

Kevin welcomed the recent announcement of a pilot scheme for family carers to be treated as key workers.

'Whatever model they use, if something was offered to me, I'd jump at it,' he says.

Strongest bond

Recent months have been agonising for Kevin, but he's keen to share his and Jean's story.

'For anyone out there with nowhere to turn, like I was in March, they may think, "I'm not alone."

And, as difficult as he finds them, Kevin continues his weekly visits to see Jean, no matter what.

'On occasion, up until very recently, she could look at me with recognition in her eyes,' he says. 'I know, when we have that moment, the bond between us is stronger now than it has ever been.'

'Those moments are so precious to me, I just can't explain. That keeps me going.'



What can you do to help?

You can help us to support people who are caring for a loved one with dementia.
[Make a donation today.](#)

Stand up for people affected by dementia during the pandemic by joining our campaign at alzheimers.org.uk/campaign

For our What is dementia with Lewy bodies (DLB)? (403) factsheet, go to alzheimers.org.uk/publications or call 0300 303 5933.

Language skills

Alzheimer's Society is keeping connected with people through a range of languages during the pandemic. **Gareth Bracken** looks at how volunteers, staff and interpreters are helping.

For people with dementia, the pandemic has meant less social contact with their friends, family and community. We introduced Companion Calls to help fight the negative impact that this greater isolation has on a person's health and wellbeing.

Trained Companion Call volunteers make regular phone calls to check in and have a friendly chat, to help people feel more connected and less lonely.

Quick read

During the pandemic, Alzheimer's Society is supporting people with dementia in a range of languages.

So far, our Companion Call volunteers speak 29 different languages between them, and these calls are very well received.

Some of our staff can support people in their preferred language, also bringing an understanding of their particular culture.

With the help of an interpreting service, we can speak with people calling our support line in the language that's best for them.

To make sure that these calls are supporting people from a range of communities, we've so far signed up volunteers who speak 29 different languages between them.

'Companion Calls have been a tremendous help to people with dementia throughout the pandemic, but even more so for those whose first or preferred language isn't English,' says Bridget Thompson, Volunteering Development Co-ordinator.

'They can have a relaxed and friendly conversation, and making a cultural connection with a volunteer can be great for reminiscence.'

All things Welsh

Eiry Thomas in Carmarthenshire, south-west Wales, is a longstanding Society volunteer who has been making Companion Calls in Welsh since June.

'I've felt for a long time that people with dementia are often forgotten,' says Eiry, who phones five women every week.

'Four of the ladies live in south-west Wales, so I know the area. We chat about lots of things – the weather, how they feel, COVID restrictions, radio and TV programmes, sport (especially when Wales is involved). I just hope it brings a bit of happiness to them.'

Although the women can all speak English, they requested a volunteer who could talk to them in Welsh. Eiry asked them about the importance of having the calls in Welsh and translated their responses.

'It's important to use the language of my country,' says one.

Another adds, 'I was brought up to speak, write and read Welsh. Welsh was everything to my parents.'

One of the women said that all her friends and carers speak Welsh, while another said that she had an interest in 'all things Welsh'.

'It's important to give a service in people's first language,' said the son of one of the women.

Quality time

For some people, receiving support in their first language is not only about making the experience more comfortable and effective for them, but to make communication possible.

Diana Reisgies Baez found out about Companion Calls through her employer Santander, one of our corporate partners. She makes regular calls in Spanish to a woman with dementia who speaks very little English.



What can you do to help?

You can help train Companion Call volunteers to support more people affected by dementia from all communities. [Make a donation today.](#)

'We talk about Spanish food, her family history, music – I found a Spanish song for her,' says Diana.

'She tells me that the calls make her happy and help her forget about her worries and pain.'

Diana's mother has Alzheimer's and lives by herself in Spain.

'I know how hard it's been for Mum during lockdown, so when I had the opportunity to help someone here, I didn't think twice,' says Diana. 'I'm injecting some energy and kindness into their day.'

Diana translated a message she received from the daughter of the woman she phones. It reads, 'Thank you so much for the quality time you give to Mum. Because of your voice and the way you talk to her, she can tell you're a wonderful person with a heart full of love. We're really grateful.'

Cultural understanding

It's not only our volunteers who provide culturally appropriate support in different languages. Anuja Jalota is a Dementia Support Worker in Wolverhampton who has been keeping in phone contact with people affected by dementia who speak Punjabi.

'It's particularly hard for a carer looking after their spouse, as they have no outlet during lockdown,' she says.

'Talking to someone who understands what they are going through is comforting for them. My understanding of the culture and

being able to have a conversation in their first language also goes a long way.'

Anuja has received many appreciative comments in Punjabi. 'You have cheered me up,' said one person. Another said, 'I feel lighter having spoken to you.'

Full access

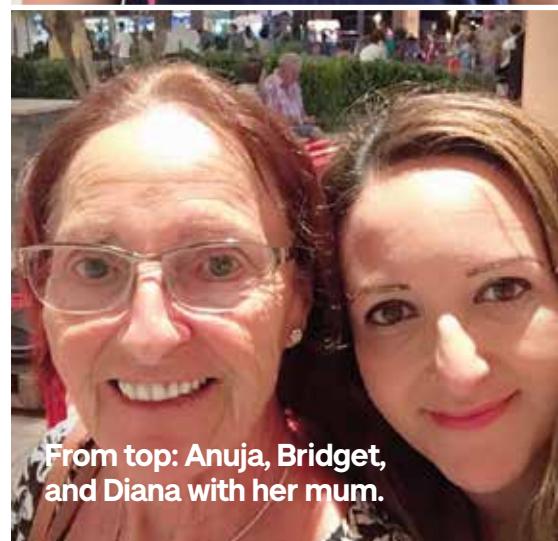
For people calling our Dementia Connect support line, we can use a service called The Big Word to interpret conversations into the language that's best for them.

Jane Kinnaird, a Dementia Connect Adviser, received a call from a man who was struggling to communicate in English, asking if there was anyone there who could speak Mandarin. Using The Big Word, within 10 minutes she was speaking to him through an interpreter about his memory concerns.

'I feel that if he needed support from us again, he would be comfortable to call and know he could easily communicate his needs and have full access to our service,' says Jane.

For us to use this service, a caller needs to say the name of their preferred language – in English – and leave their own name and a number to call back on.

'It's good to know that those who might be able to express themselves better in another language are able to come to us for support and advice,' says Jane.



From top: Anuja, Bridget, and Diana with her mum.

Call our Dementia Connect support line on **0333 150 3456**. For a language other than English or Welsh, say which language (in English) and leave your name and number. For our Welsh-speaking support line, call **03300 947 400**.

For our publications in a range of languages and formats, see alzheimers.org.uk/accessibleresources or call **0300 303 5933**.

Caring culture

Museums are finding creative new ways to stay engaged with people who have dementia during the pandemic. **Gareth Bracken** explores projects reaching out despite lockdown restrictions.

Over the past few years, many museums have been finding new ways to help people affected by dementia benefit from their collections and other resources. Although the pandemic has affected so many aspects of life, we look at innovations that continue to make a real difference by connecting with and involving people.

Quick read

Many museums are finding ways to keep connected with people with dementia, in care homes and the wider community.

Since the first lockdown, Northern Ireland War Memorial has helped deliver online exercise and reminiscence sessions for care home residents.

Bristol Museum & Art Gallery has been sending care homes origami gifts and a series of postcards suggesting movement and dance activities.

Brunel's SS Great Britain, in Bristol, hopes to extend virtual tours to care homes, after they were enjoyed by memory café attendees.

Just when needed

The Northern Ireland Museums Council (NIMC) has been supporting a range of museums to undertake dementia-friendly activities, before and during the pandemic. This includes the Northern Ireland War Memorial in Belfast, which tells the story of the home front in Northern Ireland during the Second World War.

After the first lockdown in March, the museum created a free singalong CD of 1940s songs, based on its dementia-friendly singing and reminiscence workshops. An accompanying songbook offered suggested exercises taken from Love to Move, the British Gymnastics Foundation seated exercise programme for older people. These resources were sent to care homes across Northern Ireland to raise people's spirits.

The museum has also partnered with Sport Northern Ireland for two pilot schemes – funded by NIMC – that provided online Love to Move sessions for residents of Kirk House care home in Belfast, including those with dementia. The second of the schemes, which combine reminiscence, activities and exercise, was called Memories, Movement & Museums.

'This time we've provided the care home with a COVID-secure loan box of objects and

photographs, which makes it a more multisensory experience for the participants,' says Michael Fryer, Outreach Officer at the Northern Ireland War Memorial.

Feedback from care homes shows how these sorts of activity can bring enjoyment to people with dementia at a challenging time. In thanking the museum for hosting Love to Move sessions, one care home staff member said, 'They came just when needed – with the isolation of lockdown, the residents really needed something else to think and talk about.'

Finding solutions

Before lockdown, Bristol Museum & Art Gallery hosted pop-up Creative Cafés for people affected by dementia. These aimed to improve the health and wellbeing of participants through creative activities and by exploring the wealth of objects and paintings at the museum.

With the support of Alive Activities, a charity working in care homes, residents were invited to the cafés, though not all of them were able to attend. In response, the museum launched ArtBox, a scheme that takes activity boxes of sensory and tactile objects directly to people with dementia in hospitals and care homes.

When the first lockdown began, the museum held online workshops to show its staff and

For our dementia-friendly guidance for arts, heritage and cultural organisations, see alzheimers.org.uk/arts

artists how to make origami window hangings, which were sent as gifts to care homes.

Working with carers, activity co-ordinators, hospital staff, artists and a local dance practitioner, the museum then created Being Human Moves, a series of seven postcards suggesting movement and dance activities. Based on sculptures and collections at the museum, the postcards are being sent to contacts including care homes. The museum also hopes to produce packs containing word and poetry activities and games.

'We are keeping in contact and supporting people living with dementia and carers as best we can, and using our creativity to find solutions to this end,' says Ailsa Richardson, Engagement Officer for Older People at Bristol Museum & Art Gallery.

Lots to offer

Also in Bristol is Brunel's SS Great Britain, a museum ship originally designed by legendary engineer Isambard Kingdom Brunel.

Since 2018, over 130 staff and volunteers at the attraction have become Dementia Friends. The museum also worked with Alive Activities to engage care homes, and it built relationships with other organisations that support people living with dementia.

Prior to the pandemic, the museum organised activities at a memory café and a day centre, as well as a special guided visit for care home residents.

After lockdown restrictions came into place, the museum held online sessions for people who'd normally attend Alzheimer's Society memory cafés. This included a virtual tour of the ship using video footage.

One person got in touch afterwards to say, 'I would like to thank you all for a lovely session, it actually kept my husband engaged with what he was watching and the discussion afterwards, where normally he might switch off.'

The museum now hopes to trial similar sessions for other groups, including care home residents.

'The benefits of engagement with heritage for people living with dementia are widely recognised, so I think we have a lot to offer care home residents,' says Leila Nicholas, Communities Officer at Brunel's SS Great Britain Trust and a Dementia Friends Champion.

'The museum can engage people with a range of interests, from engineering and ships, to stories and social history, or simply through having a fun and surprising experience.'



Visit alzheimers.org.uk/covid-activities for activity ideas for people with dementia at home or online.

Find out more about Dementia Friends and how to become a champion at dementiafriends.org.uk

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

I was diagnosed with vascular dementia four years ago and it was only because I pushed for answers why. I decided it was not going to ruin what time I had left and to keep busy and my brain working. I also wanted to help people with their diagnosis and learning to live with it. My idea is don't sit back and think the end is coming. My advice is to keep busy, start with new hobbies and make new friends who understand what you are going through.

I also have epilepsy, angina, lumbar stenosis and dry macular degeneration, which can be controlled. It was a shock when my health deteriorated so fast, stopping my horse-riding, going to the gym, martial arts, swimming, walking and lots more. I have always missed this a lot, and now we have COVID it is worse.

Being locked up most days is causing problems with depression.

Since my licence was taken off me, I felt more trapped in and it's hard to go anywhere. You have got to accept this and just get on with your life. I am lucky because I have a wife who looks after me, some people don't see anyone from day to day and just want company.

I have a friend whose husband has advanced Alzheimer's and has always been a gentleman in every way. He liked to shake your hand, have a chat and laugh. I met him in the supermarket – he came over to shake hands and I had to stop him, but he did not understand why. He has got worse and does not understand why he doesn't go singing each week. He has gone inside himself and not getting into any conversations, which leaves his wife feeling lonely.

It's alright being locked down but many people with dementia don't understand, and that is not good for them or their carers. I

would like to be free and not be shielded. I would like to make my own mind up about what to do. I hope that this virus will be over soon.

John Holt, Lancashire

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

Your turn

Tell us what you think – email magazine@alzheimers.org.uk

Letters for the February/March issue to arrive by 4 January. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Prepared for winter? Priority service registers

People affected by dementia can register to get extra support in case something goes wrong with energy or water supplies, or if they need help with using appliances safely.

For information about extra support you may be entitled to, contact your electricity, gas and water companies and ask about their priority service register (in Northern Ireland, these are sometimes called customer care schemes). If you're not eligible for their register or scheme, still ask what other support they could give you.

Seen elsewhere...



On Twitter, Aylesbury Town Council shared a picture from a successful online Dementia Friends session and looked forward to more next year.

‘A big thank you to everyone who joined our @DementiaFriends Champion, Benedicta Lasoye, for an engaging session about dementia in your community. Want join in next time? Our next free online session will be Mon 17 Jan 2021 so save the date! #Aylesbury @dfaylesbury’



After we announced on Facebook that Paul Harvey will play at our virtual Carols at Christmas, along with a video of him playing his ‘Four notes’ composition, Anne Sara Burrell was one of many to comment:

‘I’ve performed at previous Carols at Christmas concerts for Alzheimer’s Society and they have been a really uplifting celebration of Christmas. This year’s virtual event is a great way to donate to Alzheimer’s Society and help them to support people living with dementia and their families in such a difficult year.’



As it became clear there’d be a second lockdown across England, Talking Point member Whisperer shared a challenge on our online community for politicians:

‘I would simply challenge MPs of all political colours to read this forum, then look me in the eye and say they are content with the current situation in adult social care? Carers and their loved ones deserve better. Remember MPs, dementia makes no distinction for rank, privilege or wealth. In a dreadful way it is truly a leveller.’

Switch to email

Thank you to the over 1,400 readers who have switched to the email version of the magazine so far, getting links to the latest online articles, PDFs and audio interviews.

This means we can focus our printing and mailing on people who especially benefit from getting the magazine in the post – we know just how valuable this is too!

If an emailed magazine would work for you, you only need to enter your name, postcode and email into our online form. To switch today, visit alzheimers.org.uk/switch

You shop, they donate

Turn your Amazon order into support for people with dementia – when you shop through AmazonSmile, Amazon donates 0.5% of the net purchase price to your chosen charity. We’ve raised over £138,000 thanks to everyone who’s switched to AmazonSmile so far! Choose Alzheimer’s Society at

www.smile.amazon.co.uk





People affected by dementia try out an app that scans photos and tell us about other apps they've used.

Photo scanning and other apps

People with dementia and carers in West Sussex joined us over Zoom for another consumer panel. This time they had tested the EZYscan app and EZYrig to scan in photos, negatives and slides. We also talked about other apps that they had tried.

EZYscan and EZYrig

The EZYscan app, which is free to download, helps you to scan in photos, negatives and slides, so you can share, store and print treasured memories. It works with the EZYrig, which you'll be able to buy from our online shop soon. Once assembled, this frame lets you position a smartphone precisely when using the app.

Everyone who tried this product said they'd have liked more written instructions about downloading the app and putting the EZYrig together.

'I prefer to have a bit of paper in front of me to give me the instructions, I must admit,' said Ian. 'And putting it together was not easy at first, and then I twigged out how it worked.'

Pete Boswell from EZYscan said they'd be including written instructions based on this, alongside new clearer online videos that show you how to use it.

Once the EZYrig was assembled and the app working, it was a hit with everyone.

'We have had great success with it,' says John. 'We managed to do some photographs and some old negatives.'

John and Joyce scanned negatives of a friend's pictures of her as a baby with her grandmother, sharing them with her via WhatsApp.

'Getting that negative onto the phone and seeing that on the camera phone was marvellous,' said John.

Joyce said, 'Bearing in mind we all have 6 million photographs in boxes somewhere, that will be a good project!'

Although Gerard hadn't been able to download the app, he had constructed the rig without any problems and would also have plenty to scan.

'I've got a collection of 4,300 35mm slides upstairs which were my father's and a lot of my own material, which I would like to be able to transfer,' he said.

'It's something that you could sit and do, and look back on your history,' said Jan, 'which is something that helps people with dementia, doesn't it?'

Asked whether they'd be using it regularly, John said, 'We will do, it's a good tool. It keeps you thinking, it's a good exercise.'

Ian said, 'I've got so many photos and slides, I'll probably spend the next three or four years going through them all and looking at them all properly!'

When people said a rig that could hold a tablet, such as an iPad, would be useful, since you'd see a larger image, Pete said he was already working on a prototype for this.

Other apps

Gordon, Alison, Mick and Chris had tried other kinds of apps, including Flower Garden, which lets you grow and send 'virtual flowers'. They weren't impressed by the few things you could do with it before needing to make in-app purchases.

Another, Memory Tracks, links music to daily tasks to help support people with dementia or other cognitive impairments. Alison was put off from downloading it because of all the terms and conditions you had to agree to beforehand, and Chris thought it would be easier to simply play music using an app like Spotify.

'We've made our own playlists and a couple of friends have done them for us as well, so that if Mick wants to relax we just play those,' said Chris.

John also recommended a free wordsearch app that he uses, with endless themed puzzles.



Win an EZYrig

See p39 for a chance to win an EZYrig to use with the free EZYscan app.

Calendars for 2021

Memory Calendar

A page-per-day calendar showing today's date, with space for simple reminders or notes. Designed by Keith Horncastle and his late wife Val, who found it helpful in day-to-day life with dementia.

The Memory Calendar is £10 from our online shop.



Large type wall calendar

Easy to read and spacious, this wall calendar has plenty of room for your daily notes.

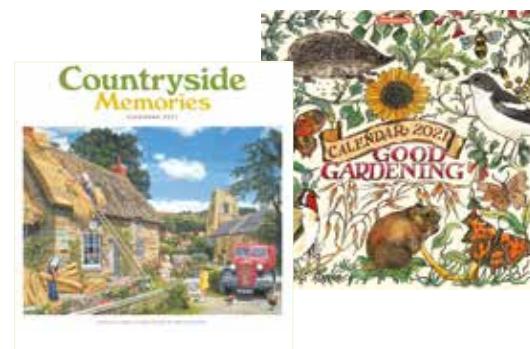
The Large type wall calendar is £9.99 from our online shop.



Garden and countryside

Good gardening calendar features Emma Bridgewater's animal and plant illustrations, and you can enjoy Trevor Mitchell's rural scenes in Countryside memories and Days gone by calendars.

The Good gardening calendar is £11.99, Countryside memories calendar is £8.99 and Days gone by slim calendar is £5.99, all from our online shop.



Album covers reimagined

Sydmor Lodge Care Home residents became social media stars in Robert Speker's photos of them recreating classic album covers – you can now enjoy these year-round with the Care home album covers calendar!

The Care home album covers calendar is £6.99 from our online shop.



Shining a light on dementia

Exeter Dementia Action Alliance has produced another calendar, heart-warmingly illustrated by cartoonist Tony Husband to raise a smile as well as awareness.

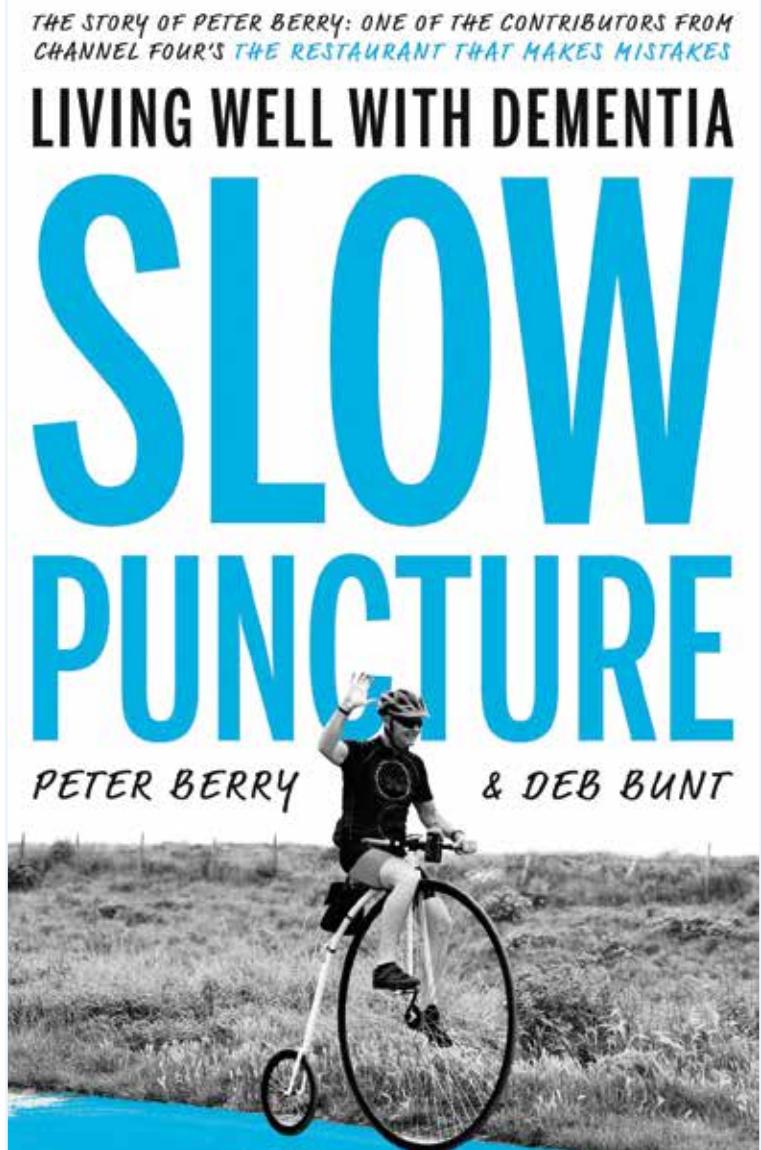
The Shining a light on dementia calendar is £7 plus postage and packing – email exeterdaa@outlook.com



Our online shop offers fantastic gifts and many products designed to help people affected by dementia to live well at home – visit shop.alzheimers.org.uk

We hear about an account of a year in the life of a keen cyclist diagnosed with young-onset dementia.

Slow puncture



Slow puncture follows a friendship grown out of unique circumstances. Chapters alternate between Peter, who has young-onset dementia, and Deb, recently retired to Suffolk from a tough job in London.

'He is funny, up for a challenge, a showman,' says Izabela Karasinska-

Stanley, in our Publishing team. 'She is cynical and has lost faith in humanity. They are joined by a love of cycling and embark on a series of fundraising challenges.'

'The main event is the Four Counties Cycle Challenge, where Peter leads Deb and a crew of supporters through Suffolk,

Norfolk, Cambridgeshire and Lincolnshire on a penny-farthing.'

Jane Buckels in Wales, who lives with dementia, says, 'Books on dementia often dwell on the later stages, when the main character is dependent on others and has little obvious awareness of the world around them.'

'It was refreshing to read a book which celebrated what someone with dementia can achieve and that a diagnosis is not the end.'

Clever and inspiring

'It is cleverly written and very easy to read – each co-author picking up the thread of the story from the other and moving it along,' says Izabela. 'Peter has a very visual way of describing the world, using analogies and metaphors to explain the way he feels.'

Joe Williams, a former carer in north Wales, says, 'It is a truly inspirational story, which everybody should read.'

Peter Middleton in Northamptonshire, agrees. 'This is a story about living with dementia, and Peter's determination to continue to squeeze every drop of happiness out of the time remaining to him.'

'It should be read by all of us who have a diagnosis of dementia. We see ourselves mirrored in Peter's thoughts and experiences. We recognise and share his fears and ambitions.'

Clare Crowther, a carer in Cornwall, didn't think it avoided the progressive nature of dementia either.

'I didn't expect it to evoke such poignant feelings in me – it's quite an emotional journey!' she says. 'I am partly left with a sense of foreboding of what is yet to come for my husband, for me and for our wider family.'

Anne Marie Bird, a reader in the West Midlands, says, 'I have not been able to put this book down, and it has given me a better understanding of what people go through.'

Informative and emotional

Izabela found the way that each person tells their story to be revealing.

'Deb is self-effacing but grows in confidence and hope,' she says. 'Peter becomes more afraid and loses progressively more memories – his chapters get shorter as the book goes on.'

Jane says, 'The book has some very good descriptions of the condition, which those with a diagnosis of young-onset dementia will recognise, although not all have such an aggressive type as Peter.'

'I found it witty, emotional and sometimes spiritual,' says Sue Last, a carer in north Wales. 'It graphically portrays the very different ways in which dementia can manifest itself.'

Andrew Rodwell, in London, says, 'It really struck me that Peter was only 50 when he found out he had this terrible illness.'

'Something else also resonated – the cruelty of insurance policies with banks for people with Peter's condition and a fleeting mention of difficulty with HMRC.'

This struck a note with Clare too, 'The bank's terminal illness policy would not pay out because dementia was not classed as a terminal illness, but they couldn't remortgage the house or take out a loan because he has a terminal illness!'

Escaping the 'monster'

'There is never a time in the story when Peter's dementia is not present,' says Izabela. 'He cycles to escape his "dementia monster" and is never weighed down by it for long, but the mounting sense of loss that both Peter and Deb feel is not something that the book tries to hide.'

A Sturges, in Cumbria, says. 'Some dementia-related books are informative but can be depressing to read. Whilst Slow puncture is totally realistic about Peter's decreasing short-term memory, his enthralling cycling adventures make it a book that is hard to put down.'

'I like the fact that it comes from the perspective of both the person with dementia as well as the observer or friend,' says Sue.

Peter Middleton agrees, 'This is a well-written commentary on the descent into dementia, as seen

from the perspectives of both the subject and a close friend. It is funny, poignant and profound.'

Dedication and joy

'The aspect of this book that I've found sits with me the most is Peter's dedication to living, and to living well,' says Izabela. 'It is Deb's dedication to Peter, and their joy at cycling together. It is the effect that one person can have on another's life, regardless of circumstances.'

Joe says, 'Having to live with dementia, Peter still shows empathy and understanding of the effect it has on his loved ones, and yet Peter continues to move forward to the best of his ability.'

'I've never been a cyclist, I prefer my two feet!' says Jane. 'But the adventures are well told and entertaining and were a good read.'

Anne Marie adds, 'What a wonderful moving achievement by Peter and his family – wishing them some more happy memories!'

Slow puncture: Living well with dementia by Peter Berry and Deb Bunt (Book Guild 2020), 200 pages, £9.99, ISBN: 9781913208936.

Also available as an ebook.



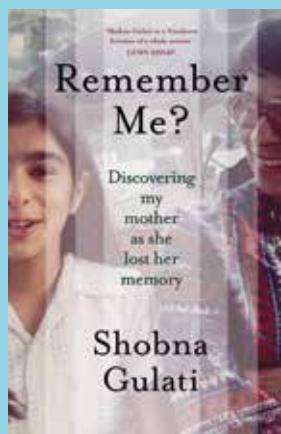
Your turn

For the next issue, we invite you to read **Remember me?: Discovering my mother as she lost her memory** by Shobna Gulati (Octopus 2020),

256 pages, £16.99,
ISBN: 9781788402477.

Also available as an ebook.

Tell us what you think about this memoir of caring for a parent who has dementia. Email magazine@alzheimers.org.uk by 4 January so we can share it in our next issue.



Book giveaway

We have five copies of **Remember me?** to give away – email magazine@alzheimers.org.uk by 15 December quoting 'Remember' for a chance to win one (see p39 for terms and conditions).



‘My uncle’s GP told him that he may be depressed – could counselling help him, even though he was diagnosed with dementia earlier this year?’

Talking to a therapist

Your uncle may benefit from counselling or one of the many other types of ‘talking therapy’. Which type depends on what your uncle wants to get out of it, and how his dementia affects his ability to take part in it.

Talking therapy could give your uncle the chance to speak openly about his thoughts and emotions, and it could help him adjust to living with dementia.

These therapies are generally more effective for a person in the early or middle stages of dementia. In the later stages, more problems with communication, attention and memory can make it harder to benefit from them.

Types of talking therapy

There are many types of counselling. They all aim to help a person to better understand their problems and explore how to manage them. Counselling is often used to help someone cope with difficult events, and it can help them to feel less depressed.

Another range of talking therapies – psychotherapy – can help a person understand how their personality and beliefs influence their thoughts, feelings, relationships and behaviour. This can then change how they think, feel and behave.

Cognitive behavioural therapy (CBT) is a popular type of psychotherapy that many people with dementia have found helpful.

Making therapy work

Different types of talking therapy ask the person to think about and discuss ideas and feelings in different ways.

Dementia can affect how well your uncle’s able to do this, but there may be ways to make it easier for him, such as by making the sessions shorter. For CBT sessions, using memory aids such as cue cards could help.

If your uncle was happy for you or another relative or friend to attend sessions with him, you could help him practise strategies or approaches that he’s agreed to try afterwards.

How to get therapy

Your uncle’s GP should be able to give him details about therapists in his area, and some GP surgeries have talking therapy services based onsite.

Talking therapies are usually free of charge through the NHS, though there can be a long waiting list. Some local charities and faith groups may also offer talking therapies or informal support services.

Another option may be to find a private therapist, who’ll charge a fee. The British Association for Counselling and Psychotherapy can help you find a qualified therapist who’s registered with them – see www.bacp.co.uk or call 01455 883300.



Further information

For our Supporting a person with dementia who has depression, anxiety or apathy (444) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933.

Choosing activities

Having meaningful things to do is important for all of us, but it can be a challenge to find the best activities for a person as their dementia progresses.

When thinking of ideas, keep the person's individual likes, preferences and interests at the forefront of your mind. Get their involvement in choosing and preparing for activities where possible. When suggesting ideas, remember that some people may feel overwhelmed by too many options.

What are the person's strengths and abilities? An activity based on these will be far more enjoyable than one that highlights what they can't do.

An activity that was great to do one afternoon might not work so well the next morning, or even another afternoon. It helps to have a flexible approach as a person's abilities and moods change.

Give the person the support they need to do an activity, but be careful not to take over. Be prepared to finish or do something else if it looks like they're losing interest.

Over time, what we think of as an 'activity' often needs to adapt and change. In the later stages of dementia, this could be things that stimulate the person's senses and help them to interact with others, such as handling familiar objects, listening to their favourite music or using aromatherapy.

Visit alzheimers.org.uk/publications or call 0300 303 5933 for our new publication, *The activities handbook: Supporting someone with dementia to stay active and involved* (77AC).



Understanding denial and lack of insight

When a person is diagnosed with dementia, they may not understand or accept their diagnosis.

This factsheet for carers, family and friends offers advice on how to manage this situation.

To order your free copy, call **0300 303 5933** or email orders@alzheimers.org.uk quoting code 533.





Talking Point members' advice on seeing someone with dementia in person for the first time in months.

In person again

'Don't worry if the person doesn't seem to know who you are – just be aware that the emotional tie is still likely to be there and the feeling of "closeness" is likely to be intact.'

'Just a few weeks ago, my wife looked at me and asked, "Who are you?" The important thing was that she wasn't afraid and readily accepted my answer. This afternoon we were driving home from the day centre and my wife later told me that at that time she didn't know who I was, but thought that I was a nice man (thank goodness for the last part of that!)'

karaokePete

'Seeing them will no doubt be an emotional moment for you. It might be for them as well, or perhaps the illness has advanced too far for that to be the case. Perhaps they no longer show emotion, or in their memory they saw you last week not many months ago, so why would it be emotional for them? Expect the unexpected.'

'Perhaps another member of the family who cares for them daily has tried to keep you up to date with how their illness is progressing. When you meet them and all the gradual changes are seen in one go then accept what presents to you. A carer does not need judgement because their reports were not "accurate" enough, perhaps sparing you pain or just living day to day with the loved one they adjust without realising. That carer has been through a lot, supporting the shared love one.'

Whisperer

'If the visit or "contact" is short, that is not a sign of failure. My mother dispatches people with unseemly haste. The point is, though, that she is happy!'

'I think we can at times, hope love can cut through dementia. It can't sadly, however large the love was at one time.'

'If you think they may not recognise you, then try calling out an upbeat greeting before they see your face. Speech takes a different pathway through the brain.'

'If things go badly remember that dementia can be tidal through the day. So, if you had seen them at 8.35am, the visit may have been very different!'

Weasell

'I think that it is better to treat the person as if you have just met them and take your lead from them. Don't try to remind them of things from their past as it will only confuse them. If you are lucky they will remember you but if not just enjoy the day.'

Jacques

'Don't mention other family members if they're not sure who you are, keep it simple. Try to chat about a really happy memory from the past or a pet – my mum forgets humans, but never ever forgets our pets!'

'If you're one of the lucky ones and get chance to hug, enjoy every single wonderful second.'

Wishing20

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



Next issue

What advice do you have for people with dementia and carers about coping with colder weather? Email magazine@alzheimers.org.uk



EZYrig for EZYscan

We have an EZYrig kit – for use with the free EZYscan app – for one lucky winner drawn from correct entries received by 14 January.

Q: You can use EZYscan with the EZYrig to scan:

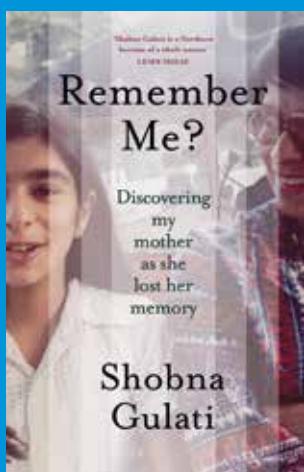
- A. The horizon for early signs of trouble.
- B. Photos, negatives and 35mm slides of treasured memories.
- C. For lifeforms when you approach a new planet.

Send us your answers with your name and address – email magazine@alzheimers.org.uk

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.

Book giveaway

See p35 for a chance to win a copy of *Remember me?: Discovering my mother as she lost her memory* by Shobna Gulati.



Memory Calendar

We have Memory Calendars for three winners and Cotswolds playing cards for three runners-up drawn from correct entries received by 7 January.

Q: The year 2021 will be:

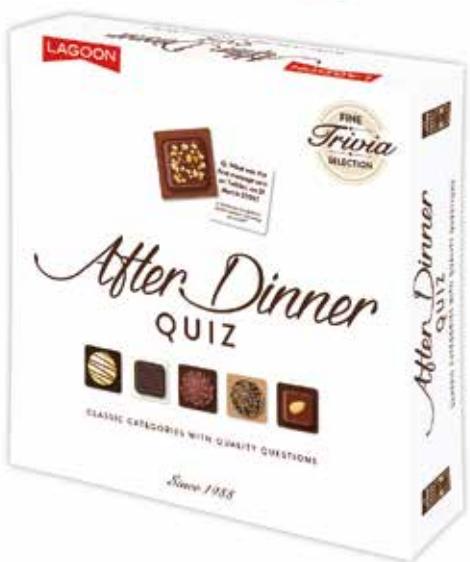
- A. A common year with 365 days.
- B. A leap year with 366 days.
- C. An uncommon year with 367 days.

Christmas cards competition

J Williams in West Midlands, D Jones in Staffordshire and P Edwards in Lincolnshire each won three packs of 10 Christmas Wreath cards. Answer: The first modern Christmas card was designed by English illustrator John Callcott Horsley in 1843.

Book giveaway

The five readers who each won a copy of *Slow puncture: Living well with dementia* by Peter Berry and Deb Bunt, were A Rodwell in Greater London, A Sturges and P Kenley in Cumbria, A Waspe in Suffolk and A Bird in West Midlands.



Visit our online shop

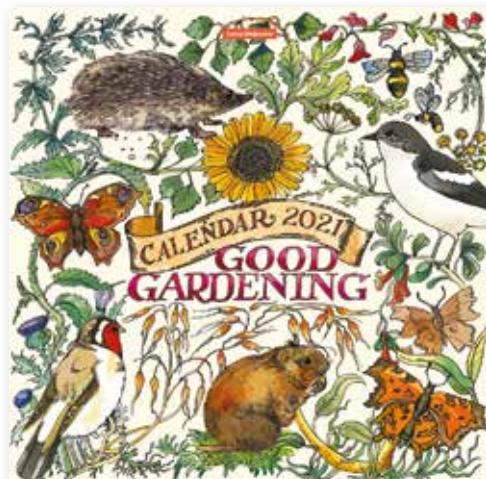
This Christmas buy a gift that makes a difference from our online shop, shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

Our last day for standard UK delivery is **Wednesday 16 December** and for express delivery is **Monday 21 December**.

PS Don't forget if you're shopping on Amazon you can still support us through **Amazon Smile**.



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



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