

Dementia together

February/March 2021
Alzheimer's Society's magazine

No stone unturned
Research and the pandemic

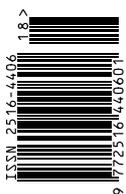
Meaningful visits
Care home campaigning

Keeping it all together
Staying strong for family

Also in this issue
COVID-19 vaccinations
Sport United Against Dementia
Book group: Remember me?



Life as it comes
Adjusting to a different lane



Welcome



No one could be blamed for struggling to feel hopeful at the start of 2021. For some of us, a return to tighter restrictions felt like going backwards. For others, an isolation that never really eased was extended.

But we have thousands upon thousands of reasons to be hopeful – you. Whether you're donating, fundraising, adding your voice to our campaigns, making Companion Calls, helping family, friends and neighbours, or sharing your experiences with others in similar situations on Talking Point, you are making a very real difference to people's lives. COVID-19 vaccinations offer another reason for optimism, even though everyone who needs them the most hasn't yet had them.

We won't shy away from the challenges that people are facing, but we also want to share our reasons for hope with all of you through this magazine. You are not alone, and we want you to be as inspired as we are by the people whose stories and voices feature in these pages.

Do carry on letting us know what you think of the magazine, as we will continue to shape what we do to be as relevant, interesting and useful as possible.

Danny Ratnaik
Magazine Editor

Need support? We're here for you – see p18.

Dementia together is the magazine for all Alzheimer's Society supporters and people affected by dementia. Contact us on magazine@alzheimers.org.uk, 020 7264 2667 or 020 7423 3676.

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

£50 can go towards our Companion Calls, where volunteers phone people affected by dementia to chat and check on their wellbeing. Please [give what you can today](#)

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Who's your Dementia Hero?

Dementia Hero Awards 2021
Nominate now

A new set of awards will showcase the people doing outstanding things for those affected by dementia during the pandemic.

The Dementia Hero Awards 2021 will recognise achievements of individuals, groups and organisations in Wales, Northern Ireland and England.

The award categories include Care and Compassion, Professional Excellence, Campaigning, Research, Innovation, Dementia Friendly Business, Fundraising, Print/ Online Journalism, Broadcast Journalism and Dementia Voice.

An Outstanding Achievement award celebrates those who have gone above and beyond during this pandemic to improve the lives and champion the rights of people affected by dementia.

The awards, sponsored by Tunstall Healthcare, will take place during Dementia Action Week, which is 17–23 May (see p6).

Make your nominations before 5 March – visit alzheimers.org.uk/dementiaheroawards

COVID-19 vaccinations

Many people with dementia have been among the first to receive a COVID-19 vaccine. The NHS aims to vaccinate everyone living in a care home by the end of January 2021, and everyone aged over 70 or clinically extremely vulnerable by mid-February.

People who receive a carer's allowance, or those who are the main carer of an older or disabled person whose welfare may be at risk if the carer falls ill, are also considered a priority group for later in the year.

The NHS is inviting people for vaccination when it is their turn. Some people will get a letter inviting them to book an appointment. If you are not currently registered with a GP, you should register now to avoid missing out on a vaccine. You will get a second dose of the vaccine within 12 weeks of your first.

We're calling for more to be done to protect people affected by dementia, including vaccinations for family carers.

There have been reports of people being contacted and asked to pay for the vaccine – these are scams and should be ignored.

For more about the vaccine and other coronavirus support visit alzheimers.org.uk/coronavirus

Do your own Memory Walk

There's another great chance to unite with us for Memory Walk this spring – take part in your own Memory Walk on 20 March, and help make a difference for people affected by dementia during the pandemic.

We hope to safely welcome you back at organised events in the autumn, but you don't need to wait until then to walk for a world without dementia.

Taking part in March is easy – you decide where to walk, how far to go and whether you walk alone, with your household or with pets in tow (all in line with the latest guidance, of course).

Sign up today at memorywalk.org.uk



Sport United Against Dementia



Sport United Against Dementia is our new campaign harnessing the positive power of sport to spearhead change for people living with dementia. The campaign will raise awareness of our support services and ensure thousands of current and former professionals, managers and sports fans can receive the support they need.

The campaign launched in November with backing from 1966 World Cup hero Sir Geoff Hurst, and our Ambassador and former footballer Robbie Savage, who lost his dad Colin to frontotemporal dementia.

In January, a live Q&A event raised funds by featuring legendary football figures Sir Alex Ferguson and Sir Kenny Dalglish, alongside England manager Gareth Southgate OBE and Liverpool manager Jürgen Klopp.



Directions

What a busy start to the New Year! Adapting to COVID-19 has meant we've learnt so much about supporting people in new ways.

Companion Calls have been a roaring success. Many people tell us they've found online groups more accessible, and they love that we've been able to offer more specialised groups for more people. During 2021, we're keen to look at how we can blend these permanently alongside our face to face, telephone and online support.

We're also relaunching Dementia Action Week in May, and we will be running a very critical eye over all our activities to check they are suitable, accessible and welcoming to all communities. Dementia does not discriminate, so it is vital we don't.

We hope to finish the financial year in sound shape due to your fantastic ongoing support, but also due to radical changes we have made to some of our expenditure. For the first time in many years, we want to invest in our IT systems so that people using our services and supporting us have a seamless experience, which has been so vital over the pandemic. We will sadly continue to close many of our offices around the country, but don't worry – your local staff will still be there for you.

Most importantly, I hope I'll be able to actually get out and meet many more of you in person for that cuppa and cake I've been promised!

Kate Lee, Chief Executive Officer
@KateLeeCEO

In the press: Apathy and FTD

Recent media reports about a University of Cambridge study suggested that apathy – a lack of interest or motivation – may be an early sign of someone developing frontotemporal dementia (FTD), years before diagnosis.

The study involved 304 healthy people who have a mutated gene that causes FTD, along with 296 of their relatives who don't have this version of the gene.

People with the mutation experienced more apathy than their family members without it, and this increased much more for them over two years. Experiencing apathy was linked to more problems with thinking over time. This was more so as people approached the age when developing FTD would mean they'd be expected to start having symptoms.

Richard Oakley, our Head of Research, said, 'There are no treatments at all for FTD, so it's exciting to see this adding a new piece of the FTD puzzle.'

'As this just looked at the third of people who get FTD genetically, we don't yet know if apathy could also be an early indicator or predict progression in the other two-thirds who develop FTD out of the blue.'

'We don't currently have an accurate way to identify someone at risk of FTD, so we're hoping this can work with our own research on spotting early brain changes occurring in genetic FTD to take us a step closer. We need more dementia research funding to get us there faster and give hope to people at risk.'

Read about our research at
alzheimers.org.uk/research

Dementia Action Week: Take a stand

This year's Dementia Action Week, 17–23 May, we're asking people to take a stand and urge governments to transform the social care system for the hundreds of thousands of families facing dementia.

After decades of unfairness and underinvestment, coronavirus has exposed just how much people have been failed by a system that is inadequate, hard to access, costly and unfair.

We're calling on governments to rebuild social care so that every person affected by dementia can get the support they need to stay happy, healthy and independent for as long as possible.

Whether you'd like to sign up to the campaign or help spread the word among your friends, workplace or community, we will have tailored resources full of ideas and advice on the simple ways you can take part.

Sign up for updates at
alzheimers.org.uk/DAW

Take on Trek26

Join an epic 13 or 26-mile trek this summer in one of five spectacular locations across the UK. You'll trek with others who know how tough dementia can be and together you'll get us closer to a cure.

All our treks are COVID-19 secure and include all the latest social distancing measures. Each has a fully supported route with regular rest stops, refreshments and toilets. You'll also get a medal and glass of bubbly on finishing the route!

Sign up today at
alzheimers.org.uk/trek26

Record donation

The insurance industry has donated £2.43 million to help us fight the challenges that COVID-19 has brought people with dementia.

The grant – our biggest ever – came from the Association of British Insurers' COVID-19 Support Fund, thanks to the Insurance United Against Dementia (IUAD) campaign.

It will fund Companion Calls for the next three years and enable us to recruit an additional 20 dementia advisers, including two who speak South Asian languages.

Since the launch of IUAD in 2017, the insurance industry has committed an incredible £5.5 million to the fight against dementia, with an overall target of £10 million.

Making ideas a reality

Our Accelerator Programme helps to get bold and innovative ideas off the ground, to deal with the challenges of dementia, including the damaging effects of lockdown. It offers up to £100,000 investment and business support.

Projects we're currently supporting include a playful, interactive comforter called HUG, a secure, prepaid debit card called Sibstar and a simple system for making video calls through a television called Kraydel.

COVID-19 has had a big impact on our ability to support amazing projects like these in the future, so we urgently need donations to keep up this vital work.
Please give what you can today.



Open webinars: Join in

The 3 Nations Dementia Working Group (3NDWG) has been successfully delivering webinars throughout the pandemic every other Tuesday, and these continue for anyone affected by dementia or interested in the condition.

The 3NDWG is made up of people living with dementia in Northern Ireland, England and Wales. The webinars are organised and hosted by people with dementia, with professionals also included on panels.

Topics covered by previous webinars – which are also available online – include COVID-19, leaving lockdown, dementia activism in Black, Asian and minority ethnic communities, and social prescribing. For webinars and more about the 3NDWG, visit www.3ndwg.org

Wales care homes campaign

People affected by dementia have been sharing their stories with the Welsh Parliament to urge action over care home visits during the pandemic.

The Senedd's Cross-Party Group on Dementia, chaired by MS Lynne Neagle and managed by Alzheimer's Society Cymru, heard stories from three supporters with family members in care homes. They included Kevin Jones in Wrexham, who featured in [December/January's magazine](#). He spoke of the difficulties of not being able to visit his partner Jean.

Two Welsh Government ministers, with responsibility for dementia and social care, commented on how moving the stories were. They have committed to working with greater urgency to enable meaningful visits for people with dementia in care homes.

Create change with DCAN

Join the Dementia Change Action Network (DCAN) and help address challenges facing people affected by dementia, including COVID-19.

The network is supported by the Society and the NHS in England. It involves people affected by dementia and others to help understand how NHS plans to personalise care and support can improve people's lives.

Membership is free and there's a role for everyone. You can feed back on plans, join focus groups or take part in more in-depth enquiries.

To join DCAN or find out more visit www.dcan.org.uk

A festive 'thank you'

Last year's Elf Day has raised over £400,000 and counting, while our Carols at Christmas event was our most successful ever, raising nearly £64,000! A huge thank you to everyone who supported these events – we hope that taking part helped you end a challenging year on the right note.



Don't miss...

Michael, who has posterior cortical atrophy, says lockdown has changed him. [See p12.](#)

Jeanne has been running more Dementia Friends sessions online while caring for her mother-in-law. [See p14.](#)

Meet Martin, working on campaigns in Northern Ireland, and Stephen, Chair of our Board of Trustees. [See p19 and p21.](#)

Dementia researchers are doing all they can to keep their vital work going during the pandemic. [See p26.](#)

The fight continues for people in care homes to have meaningful visits from family and friends. [See p28.](#)

Life as it comes

Anne is grateful for the support she's had to adapt to living with a dementia diagnosis. **Gareth Bracken** meets a woman who's adjusting to life in a different lane.

'I've had vast experience of life, moving in the fast lane,' says Anne, a former nurse who held senior positions within hospital A&E departments for many years. 'I was multiskilled – I had to be.'

Anne, who is 80 and lives in Aberystwyth on the west coast of Wales, was diagnosed with mixed dementia in early 2020.

'Now I find if I try to do too much, I can't. I can't do the things I used to and I can't forward plan, my brain doesn't go there,' she says.

Despite facing the challenges of dementia, her other health

problems and the coronavirus pandemic, Anne is more than happy to share her experiences.

'Dementia does get me down sometimes, but I've got nothing to hide – just like I've never hidden any of my other disabilities,' she says.

Open-air life

Anne grew up in Wolverhampton in the West Midlands as the oldest of three children. Her father died when she was nine.

'My early upbringing wasn't without its problems,' she says. 'My mother had a pretty rough time. It was a hell of a job to bring three children up.'

Anne applied for student nursing and worked in hospitals all her life before retiring in 2000. She has two sons who both live in England.

Anne enjoyed the 'open-air life', going on camping holidays with friends in a touring caravan. She also travelled internationally and recalls trips to Russia and countries in Africa. She is very fond of Wales, where she eventually settled with her late husband.

'I love Wales – the Welsh are lovely people,' she says.

Medical problems

Following a car accident in 2019 in which she was hit on the head, Anne had an MRI scan. This led to a diagnosis of mixed dementia, of Alzheimer's disease and vascular dementia, by a memory assessment service early last year.

'I was getting depressed I suppose, because my short-term memory wasn't so good. But not

for one minute did I think I might have dementia, because I was coping with life. I thought they'd got it wrong,' she says.

Anne was diagnosed as being in the early stages of dementia, and memory problems continue to present challenges in her daily life.

'I'll go upstairs for something and think, "What the hell have I come up here for?"' she says.

'I have to write down more than I used to. I never needed to make a shopping list, because I knew exactly what I wanted, but now I do. Dates I put down on a big calendar.

'I also put my disabled driving permit somewhere safe and haven't seen it since!'

Anne has diabetes, had her colon removed several years ago and uses a mobility scooter to get around. She doesn't walk well following surgery for a torn tendon in her knee.

'I wasn't a well person before dementia, I've got several medical problems,' she says. 'Dementia is now affecting me physically as well as mentally.'

Biggest drawback

Anne is a very independent person and was badly affected by the news that she is no longer allowed to drive.

'That hurt me more than anything, and still does,' she says. 'I used to be a keen birdwatcher in the countryside and could have driven to the most beautiful woodlands, but I need a bus or train to get out of town now.'

Quick read

Anne, who lives in Aberystwyth in west Wales, has received excellent support from Alzheimer's Society since her mixed dementia diagnosis.

Anne, 80, faces challenges with her short-term memory, and coronavirus restrictions have also affected her mental wellbeing.

Anne is full of praise for the Society staff and volunteers who call her to provide advice, support and conversation.

Anne says that dementia is nothing to be ashamed of and should be accepted the same as other medical conditions.



Hear our stories

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

'I still do my own shopping – I manage it in several trips on my scooter. Or my dog sits on the platform and we go to the park. So it keeps me mobile, but losing the car is the biggest drawback.'

Aside from a lodger in the top floor of her house, Anne lives alone. She had been keen to move into a flat in supported accommodation, but it turned out that the building couldn't accommodate her mobility scooter, much to her frustration.

Very careful

Anne feels that her moods have got worse as a result of dementia, while her mental wellbeing has also been affected by lockdown restrictions. She has been limiting her time spent outside and around other people, including friends and family.

'I only go into town when I think it's going to be quiet, and I'm very careful,' she says.

'I haven't got the company I used to, and I can't get out or function as I'd want to. The isolation frightens me more than dementia, because I know what it can do.

'It's not been very good – I can't wait to get back out.'

As of early January, Anne was still waiting for news about having the coronavirus vaccine.

'I'm as aware as anybody about the virus, because of my nursing background,' she says. 'I want the vaccine and I've phoned my surgery, but I don't know when it will happen.'

Always there

Anne receives good support from friends and her sons, who have continued to be there for her since her dementia diagnosis.

She's also grateful for Alzheimer's Society, with regular phone calls from Dementia Support Worker Rhiannon Smith. As well as providing information and advice about dementia, Rhiannon also referred

Anne to Care and Repair Cymru, who helped make her home safer. She also supported Anne in getting a lifeline alarm, which Anne used after a fall in her garden.

'Rhiannon has helped me with my physical and mental condition, she's been very good,' says Anne. 'She always knows the answers and the right thing to say. She shows empathy and always reacts if I need anything.'

'I know she is always there if I want her. My son has rung her too, when he's been concerned.'

Anne has also benefited from regular phone contact from our volunteers, including Companion Calls, which have been supporting people during the pandemic.

'The calls have been excellent, they really have, particularly with what's going on at the moment,' says Anne. 'They listen to me and always seem to know the right thing to say. They're good at conversation and understand where I'm coming from.'

'We talk about all sorts of things – the volunteers are very worldly and you can hold a discussion with them. They're very interesting to talk to and I haven't been bored with their company at all! They're a big help.'

Unfair stigma

Anne feels that there is unfair and unnecessary stigma around conditions like dementia.

'Dementia is an illness. I think people try to hide it, but it's nothing to be ashamed of,' she says. 'It should be accepted the same way as cancer or diabetes or heart failure. What's the difference?'

And although things aren't easy right now, Anne continues to maintain her independence with the support of those around her.

'I'm getting forgetful but I'm still functioning, I can cope,' she says. 'I just live life as it comes.'



What can you do to help?

You can help ensure that all people with dementia receive the same support from Alzheimer's Society that Anne's had. Please [give what you can.](#)



Rhiannon and Anne.



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

Use our Dementia Directory to find dementia services near you – see [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory)

Lockdown: 'I've changed'

Michael Andrews in Bradford, originally from Northern Ireland, is 61. He tells us about life with posterior cortical atrophy (PCA), a type of dementia, during lockdown.



It's hard to describe PCA. People think I'm daft when I try to explain that I can see something but at the same time I can't see it.

Things all join together if there's a clutter of stuff. On supermarket shelves, all the tins merge together and it looks like one big blob. I've basically got to come out, give it 10 or 15 minutes, then go back in and try it again. I also have issues with black holes – a rubber mat or a puddle looks like a hole as I get up to it.

Couldn't cope

I was one of those people who couldn't stay indoors, I always had to be out. But at the start of the pandemic, I was sent a letter saying that I had to shield. They later told me that I could go out to the shops,

but it's impossible for me to work out two metres distance, I just can't. If somebody is on the same pavement as me, I've got to cross the road – that way I know I've got my two metres.

I live on my own and, before the pandemic, I would meet a few people in town for tea and coffee. And I had hospital appointments, the occupational therapist coming out, and face-to-face groups for people with dementia.

Once we went into the first lockdown, they were all took off me. I'll be honest, at the very start I didn't think I was going to get through it. I just couldn't cope. It was actually affecting my speech – I was forgetting how to talk.

I knew the only way to get through it was to start making routines for in the house. Pick a room, totally clean the whole room. One day I'll do downstairs, the next day I'll do upstairs.

Switch away

When I started to get busier again, although it was all through Zoom, it was bringing my speech back. I enjoy the Face it Together support group, but doing it virtually isn't the same as actually meeting the people.

That said, I don't think I'm going to be able to mix with people inside when lockdown lifts – I've changed. It now feels claustrophobic and I get sort of nervous. There's so much noise, too many distractions.

I'm currently having cancer treatment and I actually think it's affecting the dementia symptoms. I have the treatment on a Tuesday, and until Thursday night I'm out like a light. It's like having a really bad dose of flu. I start to get confused a lot easier and it makes me sleep a terrible lot.

An Alzheimer's Society Companion Call volunteer phones me up once a week. It's a friendly conversation, a basic chit chat, which is useful.

I've always played the flute and accordion, but I can't read music now, so another routine is to listen to CDs and see if I can play the songs. It actually switches me away from dementia, I seem to forget about it when I start playing.



Try something new

Win £10,000!



Trek26: A brilliant day

Bea McCarty, in Cardiff, shares how taking on Trek26 last year helped honour her late father-in-law's memory.

I raised just shy of £2,000 doing Trek26 Stonehenge last September. Although there had been changes because of the pandemic, people had already pledged money and I thought, 'Let's just get it done!'

I did it for my father-in-law Ken, who was amazing – a special man to me. He died in May 2017, and it's the best way to honour him and his memory, as he liked walking too.

I can't run because of dodgy knees, but I love walking. A few years ago I did the 13-mile route in the Brecon Beacons, which I enjoyed. So I thought I would make it more of a challenge and do the full 26 miles. I got a friend to do it with me, whose mum also had Alzheimer's.

Someone to call

The very day we got Ken's Alzheimer's diagnosis, we'd been negotiating to buy a house and we'd talked about him and my mother-in-law moving closer to us.

I called the Society and was on the phone for about an hour with the adviser, who talked me through everything. She was so supportive. We decided to move to Cardiff instead to be closer to them.

My mother-in-law and I did a carer's course. Without that, we could have fallen into the trap of thinking that Alzheimer's was just about forgetting people you know.

Alzheimer's Society were so supportive and caring – there was always someone to call. They helped us with things to put in place, like power of attorney. They grounded us with practical things, so we didn't panic. Without them we'd have been lost for sure.

Unexpected emotion

The day of the trek was brilliant, it was a really beautiful walk. Mile markers tell you what you're achieving and what the money raised is going towards.

It was sad that family couldn't be there to see us cross the finish line because of the pandemic. However, although I didn't expect this one to be so emotional, it still was because of what we'd achieved.

I would absolutely recommend it. The trek was well organised and felt safe. You don't need experience, and you get training plans and lots of other information.

Fundraising helps me to celebrate Ken and also to help the Society's vital work. Something needs to be done and Alzheimer's Society is doing it.

Take part in a 13 or 26-mile trek in one of five breathtaking locations – sign up today at alzheimers.org.uk/trek26

Start 2021 on a high by winning one of the 362 prizes in The Big Win New Year Super Draw, with a whopping £10,000 top prize. Our amazing players raised over £500,000 by playing last year, money that went to fund vital support services and research. Entry is only £1 per ticket – good luck!

Enter at alzheimers.org.uk/raffle

Tune into Deepness

Deepness Dementia Radio is produced by Deepness Dementia Media – a community of people affected by the condition. The schedule features everything from jazz and classical to rock and world music, as well as talk radio, storytelling and Dementia Island Discs.

Listen live and find out more at www.deepnessdementiamedia.com

Have a good laugh

Join us for Joke's on You, Dementia! – a hilarious evening on 11 March at 7pm. Society Ambassador Jo Brand will headline an online event hosted by actor and comedian Hugh Dennis, joined by a stellar comedy line up. Tickets are free with optional donation, and you only need one per household.

Book your ticket at alzheimers.org.uk/jokes-on-you-dementia

Finding a way

Jeanne Pring, a Dementia Friends Champion in north London, tells us about supporting her mother-in-law and running information sessions through lockdown.

My mother-in-law Connie, who I call Mum, is 83 and has mixed dementia – vascular dementia, Alzheimer’s disease and frontotemporal dementia. She was officially diagnosed early 2018, but had been living with the symptoms for several years prior. I have been caring for her since 2015.

I started off knowing very little of this condition and discovered that the people around me were not any wiser. I was very lost until I discovered Alzheimer’s Society. Whether I need information, support, training or a place to vent, the Society is there for me.

I’m now a Dementia Friends Champion, an active member of the Islington Dementia Friendly Communities steering group and I volunteer in many other ways. I want to help create a more supportive community for Mum and others living with dementia as well as their carers.

Change and responsibility

Prior to the pandemic, I would regularly take Mum out for cognitive stimulation, light exercise and social interaction. COVID-19 put a stop to this, which has not been of benefit to Mum. Her dementia has certainly progressed significantly, and she is physically more fragile.

Looking after Mum was even more challenging at first, when there were so many unknowns – having to think of ways to keep her stimulated at home, sourcing essential supplies and of course keeping her safe.

Thankfully, we have been able to participate in a number of virtual activities, which have been useful. Of course, these do not compare with the level of interaction and stimulation provided by an outing.

Our routine has settled down and things are now much better. However, supporting Mum also means being shielded with her,

which has an impact on my physical, emotional and mental wellbeing. I miss being able to go out and get some respite, or to meet up with friends.

The responsibility of keeping the household safe and running smoothly is stressful, especially having to play different roles – the happy face for Mum and the concerned face for when she is not looking.

Change for others

I became a Dementia Friends Champion in October 2019. I was only able to arrange four in-person sessions, but since last May I have delivered about 40 online sessions and made nearly 400 Dementia Friends.

I have limited available time, especially while caring full time, but online sessions are easy to organise and allow me to reach a wider demographic.

I hope to help people who otherwise may be lost as I was, especially with the pandemic where family members may find themselves having to care for their loved ones with little or no physical outside assistance.



Jeanne and Connie.



Become a Dementia Friend by taking part in an online session or by watching our online videos. Visit dementiafriends.org.uk to get involved.

Meet the researcher: Sana Suri

Alzheimer's Society Research Fellow, Head of Heart and Brain Group at the University of Oxford.



Favourite things?

- **Book** – This is going to hurt by Adam Kay is one of my favourites, especially in the current times.
- **Way to spend time** – Board games, puzzles or countryside walks.
- **Memory** – Any large family gathering, they're always a source of laughter, dramatics and happy chaos!

Why dementia research?

During my postgraduate studies, I learned that a lot of biomedical research has focused on extending our lifespan without an equal emphasis on maintaining quality of life in older ages.

In our ageing society, one of the biggest challenges will be to understand why some people go on to lead relatively long and healthy lives, while others are vulnerable to

age-related disorders. This is what first drew me towards dementia research, and it has since fuelled my decade-long passion for dementia outreach, policy and public engagement.

How has Alzheimer's Society supported your work?

The Society has given me an invaluable stepping stone to becoming an independent dementia research leader. It's through my fellowship that I have been able to lead a large-scale dementia neuroimaging study and establish my own research group.

What are you currently working on?

We know that 'what's good for the heart is good for the brain', but we still don't fully understand why. My research examines this heart-brain link, investigating how the health

of our heart and our body's large blood vessels affect the brain and memory as we grow older.

I combine different kinds of scans to obtain a complete picture of how our lifestyle can influence changes in the brain's volume, connectivity and blood supply. The long-term goal is to help pinpoint how and when in our lifespan we can modify our lifestyle, and especially our heart health, in order to delay dementia.

What difference do you hope this will make?

Dementia can have a lasting societal impact, and it is particularly meaningful to be leading research into how to prevent or delay its onset. In 2020, I had the exciting opportunity to present expert testimony at the House of Lords inquiry into the government's healthy ageing policy. It was especially fulfilling to draw on my own research to help develop evidence-based policies, and I hope to keep engaging with policymakers on that front.

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

My long-term vision is for our work to guide clinical and policy decisions on dementia prevention. I am interested in the prospect of lifestyle-based preventative interventions that are personalised and involve a range of approaches – for example, exercise as well as diet and mental stimulation – and I hope to build towards a large clinical trial in that field.

How I enjoy the outdoors

We ask people about how they keep active and well, whether they have dementia or not. This issue, we hear about getting in touch with nature.

George Gallimore, 62 in Greater Manchester

Walking in rural settings and rediscovering my old hobby of birdwatching. Usually out for three to four hours enjoying the sights and sounds of nature, and the odd egg butty. The exercise element cannot be understated for us both – me to provide a diversion from the anticipatory grief I find myself encountering, and my wife to keep her in the best of health for as long as possible. Couch potato expertise is no good for anyone, particularly in the dementia world.



Steven Litchfield, 69 with Alzheimer's in Nottingham (facilitator of Friends for Life DEEP 'Ay'e-Up Mi Duck')

We did virtual walks on video for those who were still in isolation and delivered bedding plants to improve their gardens. We are also involved with In at the DEEP end, a dementia group for swimmers – they switched to weekly short walks due to unavailability of pools. We try to share the load with others, who are willing but not always able, as we know dementia means change without warnings.



June Lim Bhatti, 59 in Leicester

Walking more, exploring the wonderful countryside and stately homes. I have taken up running too. I surprised myself with achieving 5km – my first in 40 years after leaving school. I was influenced by a story I read about a group of ladies with cancer doing a sponsored run around a park. My family are super active, and my youngest is my personal trainer with my running!



Rebecca Morris, 34 in Conwy

I like to go for a really long walk with my husband and two dogs, at least two hours to tire the dogs and ourselves out. I like smelling the different flowers, picking wild garlic and blackberries and trying to spot birds and different animals.

I've lost weight with all the extra walking. Any tensions or stresses I feel before the walk are aired. If I'm feeling under the weather or tired, then the fresh air makes me feel better and the endorphins released keep me smiling for a long time after.



Alison Anyon, 61 in Shropshire

I love gardening and walking. We have redesigned our garden to make it more manageable. We have two raised beds so that I don't have to kneel down as much. I am trying to put in lots of perennial and herbaceous plants with lots of colour, so we can enjoy the garden all year round.

I can't do as much walking as a few years ago due to my fibromyalgia, but I still like to get out and about, even if it's only into town and back. However, I do need to have a stop and sit down in town before coming back.

Relaxation, fresh air, sunshine, listening to the birds sing, watching our cat in the garden, collecting leaves in the autumn, berry picking – these are all benefits from being outdoors.



Stay well

Your age and genes affect your risk of developing dementia, but you can't change them. Things you can 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 well. Visit www.nhs.uk/livewell for health and wellbeing advice for everyone.

Q&A: Jitendra Kaumar Gupta

Jitendra Kaumar Gupta in Bradford, aged 73 with dementia.



What's changed most since your diagnosis?

Some people are very friendly, very good, but some have been very different – their attitude has been completely different, they see me in a very different way. Probably they don't understand what I'm going through, and sometimes I feel more depressed. People should be more friendly.

What would you take to your desert island?

I wouldn't take a CD or book at all. I'd rather take a good friend with me. I'm not interested in CDs or books – if my wife or a friend is with me then I'll be alright.

How has Alzheimer's Society helped you?

The Society has helped in giving me confidence. I meet other

people in the same scenario and then I find I'm not the only person suffering with this. We can talk to each other about what we're doing and how we're feeling.

Judith from Alzheimer's Society keeps calling me every week to ask about my welfare and see if I need help with anything. She's very sympathetic. It gives me more confidence that somebody is behind me and with me if I need to deal with something.

What song or tune sums up your life so far?

I usually like Indian music, old Indian music. Classical music and film music from the 70s, 80s and 90s. I can't pick one song though!

What single thing would improve your quality of life?

When you have dementia, you need a good, close friend with you, whether it's a wife or someone else. You need somebody to talk to and share your feelings with, someone you have a good relationship with. I'm lucky I already have that – I can only think of the life that I have.

What is your most treasured possession?

My confidence. If you have got confidence in yourself then you can achieve anything, you can talk with people, meet with people. I've seen people in the same age group, they've done so much in life, but they still don't have confidence. Confidence is the most treasured possession, that's what I feel.

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.

Contact us today

0333 150 3456

[alzheimers.org.uk/getsupport](https://www.alzheimers.org.uk/getsupport)

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

Person living with dementia



Beyond stalemate and crisis

Martin Reilly, Public Affairs and Campaigning Officer, looks back on a pivotal year in Northern Ireland.



The restoration of devolution to the Northern Ireland Assembly back in January 2020 marked an end to three years of political stalemate. I, along with so many others, looked forward to finally seeing our MLAs getting back to work. My role had just commenced and it was an opportune time to be pressing MLAs, who were keen to show that devolution mattered.

However, within a few short weeks, Northern Ireland's new ministers found themselves amid a global pandemic. Our health and social care system had struggled without a government, and it was now under intense, creaking pressure.

Unfortunately, just as people living with dementia bore the worst of the coronavirus pandemic in England and Wales, Northern Ireland was no different.

Inspiring action

I heard from families who couldn't visit a parent in their care home on a milestone birthday, saw people in tears as they recalled losing a loved one without having the chance to say goodbye, and signposted families to much needed emotional and wellbeing support.

We drew on these hugely emotional stories to inspire action, so that the government would fully implement the 'care partners' model in care homes. This means using testing and PPE so that designated visitors can continue to help support a relative or friend living in a care home.

Sharing real-life stories is the best way to effect change, and I know from personal experience that people who have an illness often want to shape things in a more positive way for those who come next.

Significant change

It's clear that the ongoing reform of adult social care across Northern Ireland needs to produce a significant change for the most vulnerable people. Their rights and wishes on how social care is delivered must be put at the centre and the voices of people living with dementia need to be listened to.

While our current focus is to ensure government does all it can to help keep people safe, we're also working to make dementia a standalone priority for the health service as it 'builds back better' from the pandemic.



Add your voice to our campaigns in Northern Ireland, Wales and England – visit alzheimers.org.uk/campaign to find out more.

In your area



Alderman Fielding and his wife Phyllis showing their support.

Mayor's choice

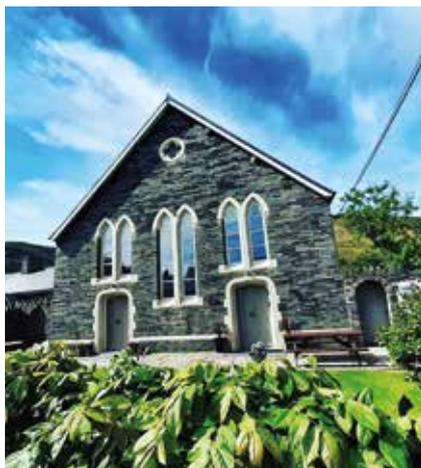
Alzheimer's Society has been chosen as the official charity of the Mayor of Causeway Coast and Glens Borough Council in Northern Ireland.

Alderman Mark Fielding decided to support us in this way after seeing how dementia affected his father in later life.

He said, 'I saw at first-hand how someone close to me was affected by the condition as my father had dementia in the last two years of his life. For most of that time he was cared for in a very professional manner in a nursing home.'

'I am thankful he had a long life and developed dementia at a later stage. However, there are some families whose loved ones live with dementia for a considerably longer time and often they are cared for in their own home by husbands, wives, partners or children which brings its own challenges and difficulties for everyone.'

Aoife McMaster, Dementia Support Worker, said, 'We're so grateful to the Mayor for choosing us as his charity of the year. The pandemic has had a significant impact on our fundraising, so this support will make a huge difference.'



Two homes for just £3

You still have a chance to win a stunning property in Snowdonia while raising funds for the Society by entering a prize draw by Valentine's Day. Tickets are only £3 each or four for £10.

Capel Jerusalem, near Tywyn on Cardigan Bay, is a chapel that's been lovingly converted into two luxury homes by Martin and Sue Stephenson, with seven en-suite bedrooms and a sauna, hot tub and baby grand piano. After living in one home and letting the other out, the couple are moving back to Yorkshire and wanted to help fight dementia.

'We have sadly lost two relatives to this terrible disease,' said Martin, 'and my dad was diagnosed with dementia a couple of years ago.'

'The aim is to sell enough tickets to be able to donate £100,000 to Alzheimer's Society, to help them in the important research and support services that they offer.'

Tickets are on sale until 14 February and the winner, who'll get the keys to the property if enough tickets are sold and a cash prize if not, will be drawn on 1 March.

Visit www.winadreamproperty.co.uk to buy tickets before 14 February.



Knitting champs

A north London knitting group is providing vital stimulation for people with dementia by donating twiddle muffs to Alzheimer's Society and others.

The Hornsey Charity Knitting Group, started by Ching Smith, is affiliated to the Alexandra Women's Institute. Members knit twiddle muffs along with cannula sleeves, lap blankets and shawls, gifting them for local hospitals and care homes as well as people supported by the Society. Twiddle muffs come with beads, buttons and contrasting textures to help keep a person's hands busy with interesting sensations.

The group was determined to continue despite not being able to meet up due to coronavirus restrictions.

One member, Kathleen, said, 'When I'm knitting and embellishing the twiddle muffs, I think of my mum and how much she would have enjoyed them. And wish I had known about them when she needed one.'

Siobhan Cronin, Dementia Navigator at the Society, said, 'They have been doing such good supportive work for years, and they really do make a difference. We have many isolated, low income families really struggling with advanced dementia needs. These items are so useful, bringing comfort and stimulation to people in the later stages of the condition.'

Stephen Hill, Chair of our Board of Trustees

Why dementia, why the Society?

Several family members have had dementia, including my grandmother and more recently my late father. It seems to me that dementia still lives in the shadows and although much progress has been made, it is still an 'underdog' when set against, say, cancer.

How to fill an unexpected day off?

My triathlon coach would like me to get out and do extra training, but I'd be tempted to settle in and watch Netflix, especially on a winter's day!

Proudest moment?

The best part of being a leader of an organisation is when you see people flourish and go on to do great things and know that you played some small part in that. I've been fortunate enough to see that

on several occasions and it is a powerful motivator.

Worst advice you've been given?

One of my tutors at university (a long, long time ago) advised me to give up his subject and called me a moron, which I thought was pretty harsh. Fortunately, I ignored him and ended up doing OK!

Biggest priority for coming months?

Definitely helping and encouraging the senior leadership team to develop the Society's strategy. The current health crisis has shown that we are all going to have to work in different ways and has highlighted real problems with social care – the Society's role has never been more important. Our strategy needs to answer how best to deliver what is really needed.

Most important thing learned from a person with dementia?

Many things, but perhaps among the most important is how reaching out to people (they won't always ask for help) and letting them know they are not alone is incredibly comforting. Many people can, perhaps with our help, continue to live independently for years in their own home. Knowing this can ease their fear of losing control.

Most looking forward to?

I am looking forward to getting back, probably gradually, to a normal life, and getting vaccinated. I miss not being able to travel to see my family, and more selfishly, I miss not being able to get out and race my triathlons!

Stephen at the World Championship Triathlon in Chicago in 2015.



Keeping it all together

Yvonne Ducasse is doing all she can to keep her mum safe during the pandemic. **Gareth Bracken** meets a daughter who's staying strong for her family.



Quick read

Yvonne Ducasse is striving to keep her mum Joyce, who has dementia, safe and well during the pandemic.

It has been an extremely difficult time for Yvonne, who previously moved from London to Buckinghamshire to live with Joyce.

Having cancelled Joyce's carers, Yvonne is single-handedly supporting her mum and young family, while also working.

Despite the challenges, Yvonne wouldn't want Joyce to be supported by anyone other than her family.

It's been a really tough time all round and I'm feeling the pressure, but I can't crack and go down as everything would fall apart,' says Yvonne Ducasse. She's been working four days a week while single-handedly supporting her mother and young family through the pandemic.

'I can't tell you how stressful it is to balance work, my children's wellbeing and Mum's safety. I feel like a hamster on a wheel as I try to be everything to everybody,' she says. 'But if Mum died of the virus I'd feel like I'd failed her, I'd never forgive myself.'

Core values

Yvonne lives in Buckinghamshire with her two children, age four and 12, and mum Joyce, who's 80.

Joyce was diagnosed with Alzheimer's disease in 2017, while still living alone, after Yvonne became concerned about changes in her Mum's behaviour.

'Her washing was piling up, she wasn't cooking properly and she was slowly going downhill. I took her to the GP who referred her to the memory clinic,' she says.

Joyce is a former nurse who has always been a very caring person.

'She was quite dynamic, good at forward planning, very kind and generous, shrewd, smart and well put together,' says Yvonne. 'The dementia hasn't affected her core values – she still asks if there is anything she can do for the children.'

Following her diagnosis, Joyce's memory problems continued to present challenges.

'She was frequently losing her keys and wasn't doing her shopping as she used to. She'd forget how to turn the TV on and would just sit in front of it,' says Yvonne.

'The thing that really stood out for me was when she disappeared from home one Sunday and I

couldn't get hold of her. Eventually, I went into town and found her sitting on a bench. She said she was waiting for a taxi, but I checked her phone and she hadn't called one.'

Daily battles

Deciding that something had to change, Yvonne moved from London to Buckinghamshire, to a house that was also suitable for Joyce.

With Yvonne working in London to support her family, in a demanding human resources role for a financial company, carers would come in to support Joyce. Although things were far from easy, the arrangement provided consistency and security for Joyce. However, everything changed with the arrival of COVID-19.

'I was wary of the virus very early on, so I stopped Mum's carers and our cleaners, to minimise the



risk,' says Yvonne, who also took her children out of school.

'I was home schooling, working, cooking and cleaning, and having battles with Mum every single day about her hygiene or getting out of bed. I've taken away all the support systems that were there to make my life easier, to my own detriment. It's been very tough, as the responsibility has been 10-fold since COVID, but if anything happened to Mum, I'd have to live with that.'

Even more alone

Yvonne found the early months of the virus difficult, but life became even worse later in the year.

Although her employer is very understanding and provides flexible working arrangements, Yvonne still finds herself working until midnight on some occasions. She's even taken over the care of Joyce's African grey parrot, without which she worries her mum might decline even further.

'At least the adrenalin kept you going the first time round, but this time I'm just tired,' she says. 'The struggles have morphed into daily life for me. I don't see family or colleagues and life has almost been on hold. It's really isolating.'

'People say they understand, but I don't think they really do. But I also don't want to complain about things too much, because it just becomes diluted.'

Joyce's memory problems can also be challenging.

'Mum gets fixated on stuff that she hasn't got control over anymore, always asking me the same questions over again,' says Yvonne, who feels that Joyce has deteriorated slightly during the pandemic. 'I don't want to appear rude or ignore her, but how do you deal with that every five seconds?

'She'll also swear blind she's done things that she hasn't. I have to have a conversation with myself, to let her be.'

Best place

Joyce has chronic obstructive pulmonary disease and bronchitis, and has been shielding throughout the pandemic. She only leaves the house for medical appointments.

'If I tell her about the virus, she'll understand it in the moment, but she doesn't understand the dangers and risks, so I can't be complacent about it,' says Yvonne, who has been encouraging Joyce to do chair exercises to stay active.

Yvonne strongly believes that Joyce is better off living at home.

'I know there are some great care homes out there, but God knows if Mum would have survived,' she says. 'I feel like Mum is in the best place here.'

To make matters worse, Yvonne is also in an ongoing battle with the council over social care support for Joyce.

'When Mum was living on her own and having to pay rent, she got free social care. But when we moved here they started charging her, because even though she's contributing to the mortgage, she isn't legally liable to do so. I'm challenging it, because I think it's awful and really unfair,' says Yvonne.

Very precious

Yvonne says that Joyce's appreciation helps to keep her going.

'Sometimes I feel like I don't have the capacity or energy, but when Mum says, "You're a really good daughter to me," that resets me,' she says.

Yvonne also doesn't want anyone to feel sorry for her.

'The responsibility is on my shoulders and I've got to keep the plates spinning, but it's my choice and I'm not unhappy,' she says.

She also considers whether others in a similar situation might relate to her experiences.

'I've got nothing to be ashamed of, and it may help people to know that they aren't alone, and that it's OK to feel how they feel,' she says.

And despite the major challenges she faces, Yvonne wouldn't have things any other way.

'Mum feels secure with her family and is around people who love her. She is very precious, and we know what she has done for us in our lives,' she says.

“

I know there are some great care homes out there, but God knows if Mum would have survived,' she says. 'I feel like Mum is in the best place here.

”



Connect with other people affected by dementia through our online community, Talking Point – see [alzheimers.org.uk/talkingpoint](https://www.alzheimers.org.uk/talkingpoint)

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



What can you do to help?

You can help support people who are caring for a relative or friend with dementia. Please give what you can today.



No stone unturned

Dementia research has been badly affected by the pandemic. **Gareth Bracken** hears how Society-funded researchers are doing everything they can to keep their vital work going.

As with so much else, coronavirus has had a significant impact on dementia research. Many projects were delayed or put on hold as researchers found themselves locked out of labs or their participants unable to travel to study sites. Some researchers had to drop everything and help the NHS's response to COVID-19.

Researchers have been adjusting and readjusting to each change, picking up the pieces, restarting experiments and making up for lost time. However, strict social distancing has meant less time in labs and new daily challenges. The consequences of recently announced lockdowns across the UK remain unclear.

Reopening sites

Before the pandemic, participants in the PREVENT dementia programme visited universities in London, Oxford, Cambridge, Edinburgh and Dublin for memory and thinking tests, brain scans and to give samples.

PREVENT, part-funded by Alzheimer's Society, is finding out what increases the risk of dementia for people decades before any symptoms start.

The visits were all suspended from mid-March until October, and even then only two of the five sites reopened. Recruitment for the study is likely to be completed nearly a year later than planned.

'Unfortunately, PREVENT has been significantly impacted by the pandemic,' says Katie Wells, the programme's National Research Co-ordinator.

'During the first lockdown, we were unable to continue with in-person research and there was very little of the assessments that we could complete remotely. Our researchers used this time to analyse data already collected.

'It was then a slow but thorough process to restart the study visits safely in person.'

The reopened centres have social distancing measures in place, with staff using PPE and participants wearing face masks. During England's second lockdown, the research was classed as essential and so the study was able to continue.

One participant said, 'I was proud to volunteer for such a worthy programme and delighted that it was up and running again after the first lockdown. I had every faith that the PREVENT team would have all the necessary precautions in place to keep me safe.'

Professor Craig Ritchie, who leads PREVENT from the University of Edinburgh, remains excited about the programme's prospects.

'The energy and determination around PREVENT has never diminished, and we are very well

Quick read

Dementia research, including work funded by Alzheimer's Society, has been badly affected by the coronavirus pandemic.

The PREVENT programme, which studies dementia risk, lost months following the first national lockdown, and still hasn't fully returned.

Another study, Continuing Compassion in Care, is facing severe delays because COVID-19 studies have been prioritised for approval.

The pandemic has also hit dementia research funding, and we've joined with others to call for urgent support from the government.

set to generate the knowledge and deliver the impact for improving brain health and dementia prevention,' he says.

Maintaining compassion

Continuing Compassion in Care is another Society-funded study that has had to adapt. The research is developing a way to measure how people provide or experience compassion when caring for a relative with dementia. It's also exploring how to help carers manage their emotions during difficult or stressful times.

Initial face-to-face interviews with carers in south-east England were delayed by the pandemic, though they were eventually completed.

A large survey, which will be used to test the new measurement tool, has been severely delayed as it requires approval from an ethics committee that's currently prioritising COVID-related studies.

To make use of the additional time, Nuriye Kupeli, a Senior Research Fellow at UCL (University College London), has added questions to the survey that relate to carers' experiences during the pandemic.

'Although I developed a tool to measure compassion before COVID, I will now be assessing compassion following a pandemic,' she says. 'It will provide an insight into how compassion was experienced and how carers managed their emotions during a particularly difficult time.'

Nuriye also used knowledge gained from earlier phases of her study to help colleagues develop a guide to support carers in making difficult decisions during the pandemic.

Urgent funding

The pandemic has also hit dementia research funding. Alzheimer's Society is currently funding 183 projects with a combined value of £37 million. To protect our investment in them, we couldn't award any new research grants in 2020.

Earlier this year, we joined forces with Alzheimer's Research UK and the dementia research community to call on the government to urgently support dementia research.

'Before the pandemic, dementia researchers were making a discovery a day. Momentum was building and decades of hard work was beginning to pay off,' says Hannah Churchill, Research Communications Manager at the Society. 'Without urgent additional funding, the trail of discoveries will go cold and the prospect of a dementia-free future will slip further away.'

'Research is the only way to beat dementia and it must not be an afterthought as we emerge from the pandemic.'

For more about our research programme, visit [alzheimers.org.uk/research](https://www.alzheimers.org.uk/research)

Our Research Network members use their experiences of dementia to drive our research – find out more at [alzheimers.org.uk/researchnetwork](https://www.alzheimers.org.uk/researchnetwork)



What can you do to help?

You can help get vital research back up and running to improve the lives of people with dementia, now and in the future. Please give what you can today.

Meaningful visits



Quick read

Our supporters have helped call for safe care home visits for people with dementia, though the latest lockdowns have meant more restrictions.

Having just seen her mum for the first time in nine months, Sarah-Jane Whitfield was devastated when visits were stopped again.

Talking Point member Stefan expressed his devastation at being kept away from his partner for the past 10 months.

With other organisations in One Dementia Voice, we're continuing to campaign for meaningful visits for people with dementia in care homes.

We've been campaigning for people with dementia in care homes to be able to see family and friends safely. **Gareth Bracken** hears from relatives desperate for close contact.

Since last April, Alzheimer's Society has campaigned for people with dementia in care homes to have meaningful visits from relatives or friends who provide vital support. Window visits, excessive use of PPE and perspex screens aren't practical for so many people living with dementia, who need to hug and hold hands with visitors.

We joined other organisations as One Dementia Voice to call for family carers to get key worker status, with COVID-19 testing and visiting rights. Our supporters – people like you – contacted your national and local elected representatives tens of thousands of times to share real-life experiences and concerns.

While guidance for safe visits in Northern Ireland and Wales had been announced, we secured a debate at Westminster in November to discuss just how important family and friends are in the care of people with dementia.

The government agreed to pilot a care visitor scheme in 20 care homes in south-west England, and we recommended how visits would work best. In early December, updated guidance set out how care home residents in England could be reunited with their loved ones.

Urge the government to do more for people affected by dementia at [alzheimers.org.uk/campaign](https://www.alzheimers.org.uk/campaign)

Grieving again

Before many people were able to take advantage of new visiting guidance, stricter measures were reintroduced, ending in a return to lockdowns across the UK by early January.

Sarah-Jane Whitfield, whose mum has Alzheimer's, managed just one close-contact visit at Crossways care home in Sutton, south London before restrictions tightened again.

'I cannot begin to tell you how emotional and amazing it was to see my mum after nine months,' she says. 'She doesn't recognise her grandchildren or friends anymore, just me. I was able to hug her and sit with her, and I have been able to paint her nails and do some colouring with her.'

'Now the government states I cannot visit even though I was having a COVID test. I have grieved the loss of my mum even though she is alive, and now I am grieving all over again. I'm devastated. My mum may forget who I am. I feel I have abandoned her.'

Risk versus actual harm

Some relatives haven't even been able to enjoy a single face-to-face visit. Sharing his experiences on our online community, Talking Point member Stefan has described his devastation at being apart from his partner of 35 years. He's only been allowed window and garden visits, which haven't been very appropriate.

'She is my best friend and we did everything together, but now we've been forcibly separated for 10 months,' he says. 'I still have no idea when I will be able to see her again properly – it's an endless nightmare.'

'The longer this endures, the more harm is being done, not just to the imprisoned care home residents but also to those who love them. Not only is there no perspective on the risk versus actual harm being done, but there is no evidence of any empathy, understanding or common sense in those who have the power to change the situation.'

'Mine is just one small story among so many about the myriad and devastating emotional impacts of this continuing, inhumane visitor lockout.'

Keeping connected

Adam Purnell is Care Lead at Kepplegate, a care home in Preesall, Lancashire. He's also an ambassador for John's Campaign – part of One Dementia Voice – and a Rights for Residents campaigner.

Kepplegate offered indoor, socially distanced visits for relatives as early as June, and has been facilitating close-contact visits since December, using COVID testing. These continued in mid-January after relatives approved the home's latest safety measures.

'Maybe we've been gutsy, but to us the risk of malnutrition, dehydration, isolation and loneliness outweighs the COVID risk,' says Adam. 'If a visit is person-centred, it can boost a resident's mental health.'

'It's been fantastic to show what's achievable and what can be done.'

Adam will keep on campaigning for people to stay connected.

'I'm proud to be championing a way back to normality in care homes,' he says. 'Visiting should be the right of every family carer, period.'

The fight continues to make sure people living with dementia in care homes have meaningful visits, and for guidance to be implemented properly.

Fiona Carragher, our Director of Research and Influencing, says, 'The government must do everything it can to keep people in care homes safe from the virus, but must act with compassion to prioritise meaningful visits continuing in a safe way, allowing residents to have the one thing that matters most.'



What can you do to help?

With your support, we can continue campaigning for people with dementia in care homes, ensuring they can have meaningful visits from relatives or friends. Please **give what you can** today.

Call our Dementia Connect support line on **0333 150 3456**, or for Welsh speakers call **03300 947 400**.

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

'Please do not bring me to shame'

My uncle Ivan is in his early 80s, living alone in Ireland. My cousin's widow, Barbara, lives nearby and she has become responsible for Ivan as his behaviour has increasingly shown him to have some kind of dementia. This has been exacerbated by the social restrictions the pandemic has brought to bear on him.

Recently, Ivan's doctor asked for him to be assessed by a specialist nurse. A very friendly lady visited Ivan and asked him similar

questions to those that my mother had to answer, here in England, when she was at the beginning of her illness.

Ivan told the nurse that a picture of a lion was a dog, the camel was a horse, a hippo was a cow and he was unable to carry out other tasks in the test. At the end of the meeting the nurse gave Ivan some paper and a pen and asked him to write her a sentence, anything he wished. Ivan wrote, 'Please do not bring me to shame.'

Barbara says that she began to cry and I was very moved, too, when she told me about it. My brother Mark and I were very lucky. Mum's 'ladies' – her carers – always treated her with so much love and respect. Ivan is able to articulate his need and he obviously thought it as well to do so.

Dawn Butler

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

Money over need?

My 92-year old mother, who had dementia, sadly passed away late last year. I believe there were serious mistakes made, based purely on money and not on my mother's health needs.

I imagine most people will not have heard of NHS continuing healthcare (CHC), and neither would I if a friend had not told me about it. The NHS has an obligation to ensure that, before anyone is asked to pay for their care home fees, they are given the chance to be assessed for CHC.

A full assessment for CHC for my mother should have been done before leaving hospital or immediately after discharge, but I firmly believe that this was not done to avoid having to pay for her care, which they would have to do if she was found to be in need of CHC.

I am not prepared to let the matter go, if only for the sake of other people going through a similar situation.

Steve Catterall, Lancashire

Society response

Getting the support you're entitled to, including CHC, is far too difficult for far too many people affected by dementia. It's horrible to be left feeling that you haven't even been offered the help you should have had.

Unfortunately, there are a number of situations where a CHC assessment isn't required. If you're assessed for CHC and refused, then there's an appeals process. In England, if there's been no assessment, you could ask the CCG (clinical commissioning group) to carry out an assessment covering the

period you believe someone was entitled to CHC. However, doing this for your late mother's care may be no easy task.

Of course, the details of each person's situation can make a big difference – call our Dementia Connect support line on **0333 150 3456** to speak to a dementia adviser.

Beacon, a social enterprise, can provide up to 90 minutes of free specialist advice on CHC issues – call **0345 548 0300** or visit www.beaconchc.co.uk

To add your name to our campaigns for better care and support for everyone affected by dementia, please see alzheimers.org.uk/campaign

Seen elsewhere...



Through her Pontio'r Cenedlaethau Twitter account, promoting intergenerational work in Gwynedd, Dementia Friends Champion Mirain Roberts celebrated another session with further education students at Coleg Meirion-Dwyfor.

“ Presenting my second online @DementiaFriends session to @meiriondwfor students this morning. It's great that we can still offer the sessions online and teach other about @AlzSocCymru @alzheimerssoc 5 main messages! ”



On Facebook, when we said how heartbroken we were to learn that Dame Barbara Windsor had died, many of you shared your own wishes and experiences of loss, including Claire Peacock in Staffordshire:

“ RIP Dame Barbara a true legend. My condolences to her family and friends. My dad passed 14 years ago from this awful disease. Fly high Dame Barbara ♥ much love to everyone who is fighting this and their families ♥ ”



After losing her husband to dementia, Talking Point member Amethyst59 shared her deep appreciation for our online community:

“ I just could not have made the long journey I did without the support I got from this forum, the friends I have made through it. What a wonderful resource it is. If you are home alone caring, there is always someone to contact. If you need advice, someone has travelled the road before you. Thanks to Talking Point, I was able to ensure that I really made the right decisions, and that we made the best of the life that we had together. ”



Your turn

Tell us what you think – email magazine@alzheimers.org.uk
Letters for the April/May issue need to arrive by 3 March. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Switching to email is easy!

Just enter your name, postcode and email address at alzheimers.org.uk/switch to get the magazine by email instead of in the post. The more who switch, the more we can focus on producing the print magazine for people who especially benefit from getting it through their letterbox (and if that's you, then please don't worry – you don't need to do anything to continue receiving the magazine this way). To switch today, visit alzheimers.org.uk/switch

Consumer panel

People affected by dementia try out a range of products that are designed to be helpful at home and easy to use.

Help at home

Our West Sussex consumer panel met again over Zoom to say what they thought of three lights, three remote controls and a device that speaks the time.

LED lighting

The 'Get up in the night' sensor light can be placed anywhere and shines for 30 seconds if it senses movement in the dark.

Lindy said, 'It was very easy to set up and brilliant – really, really effective.'

'We had it sitting outside the bedroom,' said Peter, 'and every time the cat walked past it came on like a light show!'

John said, 'It's a well-made product. We're using it in the hallway at the bottom of the stairs, so it comes on when I come down in the night to use the loo.'

Alison said, 'You could put it in a cupboard to come on when you open the door. We had it on a skirting board.'

Gordon added that it's 'very much five-star, impressive'.

A second product, the 3-in-1 portable daylight lamp, can be used as a torch, desk lamp or phone charger and holder.

Chris said, 'Mick really liked the lamp, he's been using it since we got it. It's got good instructions on the front, and he liked using it as a mobile phone holder as well. It's good for reading at night, especially as you can dim the light.'

Stan said, 'I was able to charge it using my mobile phone charger – that was after charging my mobile phone from the torch.'

'It's easy to hold, a nice product,' said Jim.

The Daylight touch desk lamp is adjustable to a wide range of positions and sliding your finger over a scale on its base changes its brightness.

'It worked easily and well,' said Pat, 'though it's not a style I would choose.'

Jan and Ian loved the design of this lamp, however.

'I just want to hug it, it's very tactile,' said Jan. 'I can't tell you anything bad about it.'

Ian said, 'It's nice and bright, and you can point it to where you want.'

The sensor light has been popular in our online shop for a while, and based on this feedback we'll also be stocking the 3-in-1 lamp and the desk lamp.

Remote controls

Panel members tried three remote controls that have large, clear buttons, but struggled to set them up.

The Easy TV-5 and Easy TV-10 operate your TV when linked through the existing remote control.

John and Joyce gave up after trying to link the Easy TV-5.

'I think it's the sequence of buttons,' said Joyce, 'If you don't get them right in time, then it doesn't link up.'



Roger said, 'I tried it first on my smart TV and had some success, but the buttons didn't do what they were supposed to. I tried it on an older TV and got it all working, and now it does work on the smart TV too. It is mind-bending to get right!'

The HandleEasy universal remote control is designed to work with most devices, though setting it up was again a challenge.

Lindy said, 'I gave up on the first day, but the next day I looked it up on YouTube and it was easy after that.' The only thing she hadn't been able to get it to do was turn the TV on or off.

We feed these comments back to suppliers so they can continue to improve their products.

Talking time pal

The Talking time pal announces the time and date when you press a button, and it can be carried in a pocket or attached to a key chain or lanyard.

Although Stan found it tricky to remove the battery cover and needed help setting the time and date, he said, 'Once set up, it was a doddle.'

Joan said, 'It's very easy to use and uses a very clear voice.'

Lindy said it wasn't the right product for Peter, as she kept needing to reset it after he inadvertently changed the time while fiddling with it.

John wore it around his neck, adding that it's safer giving someone the time on the street without risking your phone or watch being stolen.

Prices: 'Get up in the night' sensor light £16.62, 3-in-1 portable daylight lamp £39.99, Daylight touch desk lamp £75, Easy TV-5 and Easy TV-10 remote controls £10.99, HandleEasy universal remote control £24.98, Talking time pal £13.86.

Visit shop.alzheimers.org.uk for products to help people affected by dementia to live well at home. You don't have to pay VAT on some products if they're for use by a person with dementia or other condition – tick the box stating that you're eligible for VAT relief at checkout.



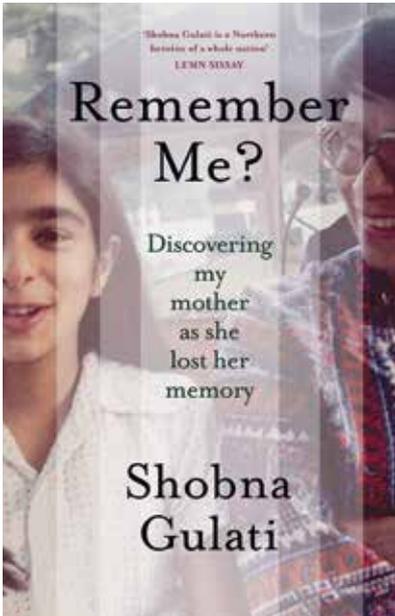
Win LED lighting

See p39 for a chance to win a sensor light, 3-in-1 lamp or desk lamp.



We read Shobna Gulati's memoir of caring for her mother, who had dementia.

Remember me?



Shobna Gulati, so familiar on TV through *Coronation Street* and *Dinnerladies*, wrote *Remember me?* in response to her mother's dementia and the experience of being a carer. However, Addy Olutunmogun, in our Publishing team, says it's about much more than this.

'It is a powerful and relatable story about the complexities of a mother-daughter relationship,' she says. 'It is a reflection on how dementia changed this relationship, bringing gains as well as causing losses. It's also an account of the history, culture and values of a British-North Indian family in Oldham, and how their cultural heritage affected their experiences of dementia.'

Tracy King in Sheffield says, 'This is a very honest, bitter-sweet account of a family held together by their mother. It's very well written and quite captivating.'

'The book touches on so many different topics apart from dementia – culture, religion, dignity, family life, psychology, racism, pride, problem-solving, emotions, and so much more.'

'Shobna has had an incredible life,' says Andrew Rodwell in London. 'From stardom in *Coronation Street* to living in her car in London.'

Addy says, 'Despite her fame, Shobna's successful career is reduced to a mere backdrop in her memoir. She takes us into her real world, in an incredibly honest, vulnerable and down-to-earth way with warmth, personality and humour. It's as though she was sitting with you on the sofa, cup of tea in hand.'

Vivid and tender

Asha, Shobna's mother, was diagnosed with mixed dementia in 2017. Addy describes Shobna's portrayal of her as 'vivid, tender yet unflinchingly honest'.

'We see how dementia takes away elements of Asha's identity in heartbreaking ways,' she says, 'but also how it reveals different aspects of who she is, "like an onion... we were peeling back a whole new layer and finding out so much more about her in the process.'"

Andrew says, 'Her relationship with her mother seemed quite love-hate, with difficult moments about broaching the subject that she must give up driving when it became erratic and dangerous.'

The impact of Asha's language and culture is a key theme, including the lack of a term for

dementia in Hindi or Punjabi that doesn't feel stigmatising, and the role of 'sharam' – shame – in her community.

'However, being able to express her cultural identity is also key to Asha living well with dementia,' says Addy. 'For example, the taste and smell of dishes that she used to cook bring positive memories and emotions for her, even in the later stages of her condition.'

Art of caring

'Another powerful message in the book is Shobna's insight into the "art of caring",' says Addy. 'She explains how she had to overcome her idea of what she thought a carer should be – "nurse-like... organised... detached.'

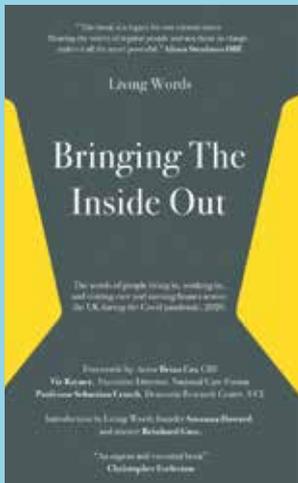
'Instead, she learned to accept that it was OK to do things your own way and "bring your own unique skills and personality" to the role. For Shobna, this meant using her natural empathy to identify her mother's needs, and using her creativity and imagination to resolve difficult situations.'

Tracy agrees, 'It portrays Shobna's own journey from empathy to creativity, how she learnt to go the extra mile and find the inner strength to cope and remain upbeat as she and her family care for their mother as dementia takes its grip on her life. I loved it.'

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.



Book giveaway



We have five copies of **Bringing the inside out** to give away – email magazine@alzheimers.org.uk by 15 February quoting 'Inside' for a chance to win one (see p39 for terms and conditions).

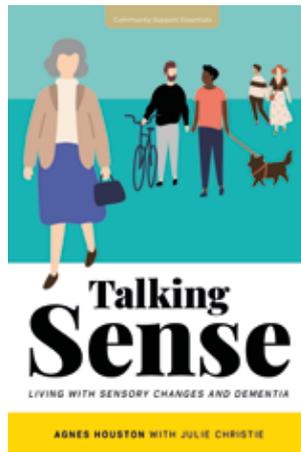


Your turn

For the next issue, we invite you to read **Bringing the inside out: The words of people living in, working in and visiting care and nursing homes across the UK during the COVID pandemic** by Living Words (Living Words 2020), 234 pages, £8.99, ISBN: 9781527280601.

Tell us what you think about this collection of people's experiences of challenging times. Email magazine@alzheimers.org.uk by 4 March so we can share it in our next issue.

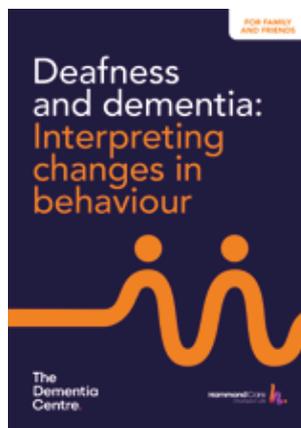
Sense and sensibility



Talking sense

A practical book about the impact of dementia on vision, hearing and other senses is now available in audio. The audiobook of **Talking sense: Living with sensory changes and dementia**, by Agnes Houston and Julie Christie, can be downloaded in full or as individual chapters. You need to provide your name and email address to access the audiobook or the PDF, but both are free.

Visit www.dementiacentre.com/resources and search 'talking sense'.



Deafness and dementia

A new resource to help in supporting a deaf friend or relative who has dementia can be downloaded for free. As above, you only need to provide your name and email to access **Deafness and dementia: An information booklet for family and friends**.

Visit www.dementiacentre.com/resources and search 'deafness and dementia'.



Falling

Viggo Mortensen directs and stars in this film about a gay man's relationship with his headstrong and homophobic father, whose dementia means he needs his children's support as his life changes. Released at the end of 2020, available to watch online on BFI Player and elsewhere – see www.modernfilms.com/falling



Update: Supernova

The release of **Supernova**, featuring Stanley Tucci as a man with dementia and Colin Firth as his partner, which we've highlighted previously, has been moved to early March.



'How can I help my ex-wife, who has dementia, ease out of coronavirus restrictions as these change?'

Easing restrictions

Masures to control the pandemic – from individual shielding and areas moving between tiers to full lockdown – have been affecting people with dementia in many different ways.

The more common effects include depression or anxiety, loss of confidence or withdrawal due to lack of social interaction, and disorientation with changes in routine.

Old routines

For many people, the process of coming out of restrictions will involve reconnecting with the world and getting back to some form of normality.

It might be helpful to look at what your ex-wife's daily routine used to be, and then slowly trying to reintroduce the things she used to do.

You may need to adapt things slightly for her too. For example, going to a day centre for short periods and building up to the length of time she is comfortable with, or going out for a walk a few times before going into any shops.

A new normal

Bear in mind that some of your ex-wife's difficulties may be due to the progression of her dementia, which sadly can't be reversed. Similarly, someone who has lost skills during the pandemic might not always be able to relearn them.

This may mean that your ex-wife isn't able to get fully back to doing the same things that she used to. However, adaptations can be made to help people to live as well as possible with the skills they do have.

Getting help

If your ex-wife is depressed or anxious, talking therapies such as counselling could allow her to talk freely about how she feels with a professional and find useful ways forward. The effectiveness of talking therapies will depend on how progressed her dementia is.

With any changes in behaviour or skills, the most effective way to support your ex-wife will depend on the type of her dementia, how far it's progressed and how it's affecting her. It will also depend on her individual personality and life history. There could be a lot of trial and error. You can discuss the specifics of the situation with an adviser on our Dementia Connect support line, and with others who've faced similar challenges on our online community, Talking Point.

Difficulties won't always need coronavirus-specific answers. For example, our online and printed information about depression and anxiety should give you enough to know more about talking therapies and how to find a counsellor.



Further information

Call our Dementia Connect support line on **0333 150 3456**, and for Welsh-speaking support call **03300 947 400**.

Talking Point, our online community, is open 24/7 – see alzheimers.org.uk/talkingpoint

Visit alzheimers.org.uk/get-support for dementia information and to find support near you.



Photo: iStockphoto.com/Peter Klindenski/Center for Ageing Better

Help with activities

Even without coronavirus restrictions, it can be a challenge to find the activities that a person with dementia will enjoy doing as their condition changes over time.

One of our latest publications is here for you – **The activities handbook: Supporting someone with dementia to stay active and involved**. This is full of information and ideas to help you do just that, including useful things to keep in mind and where to get further support. Other idea-packed books include **The memory activity book** by Helen Lambert (DK, 2018) and **Chocolate rain** by Sarah Zoutewelle-Morris (Hawker, 2011).

A wide range of websites share activity ideas and useful resources. For example, try www.arts4dementia.org.uk for artistic stimulation, www.playlistforlife.org.uk to tap into the power of personal music selections, www.britishgymnasticsfoundation.org/lovetomove for fun seated exercises or www.actodementia.com to find recommended touchscreen apps. Organisations such

as the National Trust, Park Run and Royal Horticultural Society can also provide inspiration for enjoying the outdoors as seasons change.

There are more specially designed products than ever before that provide activity and sensory stimulation for people with dementia. Many of these are available from our online shop – visit shop.alzheimers.org.uk or call **0300 124 0900**.

Of course, other people who've been in similar situations are often the best sources of information and support. Thousands of people affected by dementia share their experiences and ideas through our online community, Talking Point – alzheimers.org.uk/talkingpoint

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



Driving

When you are diagnosed with dementia, you may still be able to drive safely for some time. However, you have to contact certain organisations and tell them about your dementia.

Our booklet explains the law around dementia and driving. It has guidance on managing decisions and feelings about driving including when you have to give it up.

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



Coping with the cold

'If you don't move much you can feel cold even with blankets and the heating on so it's worth having a walk round regularly to get the old circulation going.

'I swear by hot water bottles, with a furry cover for safety. I sometimes sit with my feet on one whilst working on my computer – very cosy.' **Jaded'n'faded**

'My advice is 'just pay'! It's Bali in the bathroom here. I work out care home bill = £1,200, bill for waste £200 (however hot) = £1,000 profit for staying at home.'

Weasell

'Know what benefits you can claim and about the winter fuel allowance. See if your supplier does the money back warm home discount, which some suppliers do and others don't. Works £140 back in your electric meter, so we put it all on the gas instead of splitting it. Our house is very cold as it is made of precast concrete and we pay more as we pay in key and card meters. We keep all the doors shut so keeps heat in.' **jennifer1967**

'I'd say dementia-proof the central heating if your person with dementia lives alone. My dad was always turning his thermostat right down and then complaining his heating wasn't working.

'On one memorable occasion, my daughter and I got to his bungalow to find Dad trying to dismantle his gas boiler. After that we had a tamperproof thermostat fitted and, as he was nice and warm, he didn't feel the need to "mend" the central heating all the time.'

Bunpoots

'As a carer, rule number one is to take particular care of my own mental and physical health to help ensure I am capable, for as long as possible, to be her carer.

'For me, this means either a daily walk of about an hour and if possible a round of golf once per week, but dreading the day that further care is needed to support me in supporting Pauline, as this may not allow the flexibility needed for me to look after myself.' **Agzy**

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

Next issue

What advice do you have for someone who's helping a person with dementia prepare to move into a care home?
Email magazine@alzheimers.org.uk



LED lighting

We have a 'Get up in the night' sensor light, a 3-in-1 portable daylight lamp (pictured) or a Daylight touch desk lamp for three lucky winners, plus Talking time pals for three runners-up drawn from correct entries received by 10 March.

Q: In lighting, 'LED' stands for:

- A. Lots of electronic devices.
- B. Semiconductor light source.
- C. Light-emitting diode.



Running tops

We have Alzheimer's Society running tops for three winners drawn from correct entries received by 3 March.

Q: You can raise funds running while social distancing through Run for Dementia – see alzheimers.org.uk/run-dementia – which challenges you to:

- A. Run 50 or 100 miles in an hour.
- B. Run 50 or 100 miles in 30 days.
- C. Swim 30 miles in 50 or 100 days.

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 Bringing the inside out by Living Words.



EZYrig for EZYscan competition

J Bunnage in Hampshire won an EZYrig kit. Answer: You can use EZYscan with the EZYrig to scan photos, negatives and 35mm slides of treasured memories.

Memory Calendar competition

O Rowse in Warwickshire, A Cowan in Rutland and P Lovesey in Lincolnshire each won a Memory Calendar, while E Bernstein in Greater London, M Pinheiro in Northamptonshire and KM Curran in Lancashire each won Cotswolds playing cards. Answer: The year 2021 will be a common year with 365 days.

Book giveaway

The five readers who each won a copy of Remember me? by Shobna Gulati were L Ridgway in Buckinghamshire, A Rodwell and J Shah in Greater London, T King in South Yorkshire and F David in County Antrim.



Dementia Action Week needs you

Monday 17 – Sunday 23 May 2021

Coronavirus has exposed the fact that families facing dementia have been failed by the social care system they rely on.

The time has come for governments to set right decades of unfairness and underinvestment and to build a social care system we can all be proud of.

This Dementia Action Week, Alzheimer's Society is asking the public to urge governments to transform the social care system – for the hundreds of thousands of families facing dementia today, and for generations to come.

34.5 million of us know someone living with dementia in the UK. Together we can bring about change.

Sign up to hear more alzheimers.org.uk/DAW

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

