

Dementia together

June/July 2020
Alzheimer's Society's magazine

Now more than ever

We're still here for you

Wild for nature

Random acts of wildness



Platform for change

Stand up for what's right

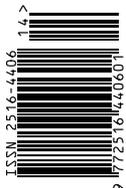
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Emergency appeal
Champions step up
Busy at home



You're not alone

You have a voice





Welcome

We open this issue of the magazine with an offer of support to those who need it, and an appeal for help from anyone who can give it.

As I write this, we still don't know when the lockdown will be lifted for everyone. Coronavirus has upturned so many lives, especially those of people affected by dementia, but Alzheimer's Society is here for you – see alzheimers.org.uk/coronavirus or **p33** for our Dementia Connect contacts.

If we had a pound for every time someone used the word 'unprecedented' in the past few weeks, we'd be doing very well. But of course we don't, and that brings me to the appeal.

As demand for our online and phone support has increased massively, the pandemic has had a devastating impact on donations. Fundraising events have been cancelled and every other income source has fallen dramatically.

We need your help to allow us to carry on being there for everyone who needs us – please use the form on the **inside-back cover** or call **0330 333 0804** to donate.

However you're able to support our work, and now more than ever, thank you.

Danny Ratnaik
Magazine Editor

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

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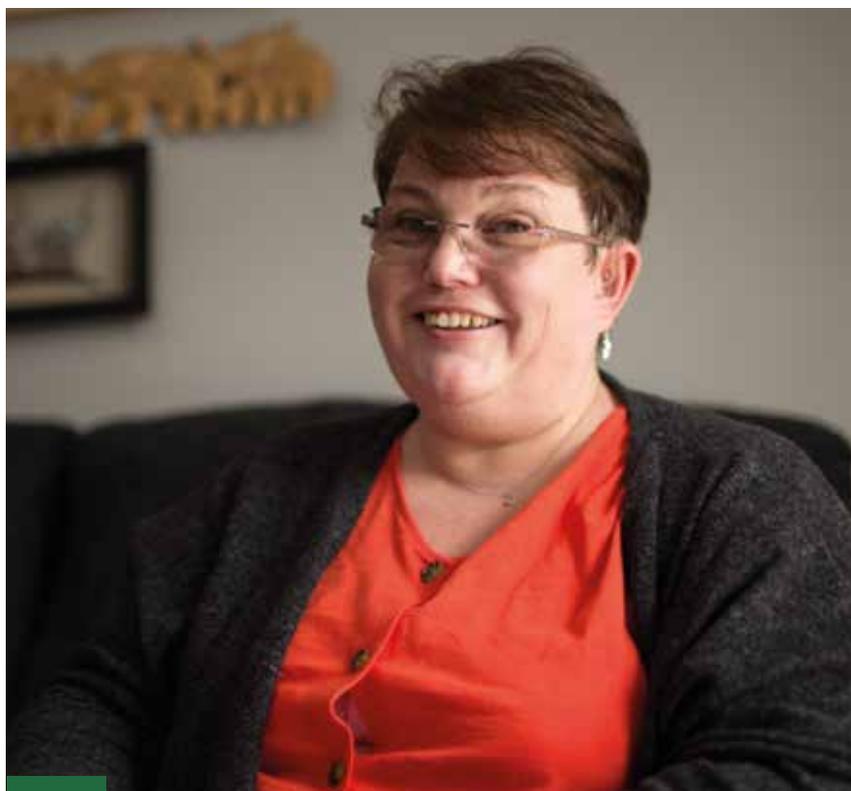
A gift of £50 can pay for 300 phone calls to support people affected by dementia. Please give what you can – turn to the inside-back cover or call 0330 333 0804.

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Coronavirus support

We know this can be an especially difficult time if you are affected by dementia. Alzheimer's Society is here for you. We can help with any questions you have about dementia and coronavirus and connect you with the support you need.

If you need advice, please call our Dementia Connect support line on 0333 150 3456 (open every day). Or if you speak Welsh, please call 03300 947 400.

GLOWing success

GLOW, our night-time Memory Walk events, have raised an outstanding £1 million and counting. Back in March, over 10,000 walkers and volunteers in fancy dress with fairy lights and face paint took to the streets across nine cities to shine a light on dementia.

We'd like to say a massive thank you to everyone who helped to create a fun and friendly atmosphere. The events that went ahead before lockdown raised a tremendous amount to support pioneering research into life-changing dementia prevention, cure and care.

Emergency appeal

Our emergency appeal in response to coronavirus is asking the public to help fund vital support for people affected by dementia. The pandemic has meant more demand for our telephone and online support at the same time as severely reducing our income.

Kate Lee, CEO of Alzheimer's Society said, 'People affected by dementia need our support more than ever, but the coronavirus pandemic is hitting us hard. We estimate losing £45 million in income over the next 12 months. Our emergency appeal will ensure we can continue to be there for everyone with dementia and that no one has to face it alone.'

A host of Society Ambassadors and celebrity supporters are backing the appeal, including football star David Beckham, actors Suranne Jones and Jonathan Pryce, and veteran newscaster John Suchet and his wife, author Nula Suchet.

To donate, use the form on the inside-back cover or call 0330 333 0804.

Stand together

The government agreed to publish daily coronavirus-related deaths in care homes thanks to the thousands of you who responded to our call to email your MP. This essential step to help protect people in care homes came after weeks of campaigning.

We're continuing to hold the government to account on important issues that we know people are facing at this difficult time, such as not being able to visit loved ones in care homes or struggling to access priority services. Your support makes all the difference.

Stand with us alongside everyone affected by dementia – visit alzheimers.org.uk/campaign

Bake a difference for Cupcake Day

While Cupcake Day might look a little different this year, we're still calling all bakers to rise to the occasion – where there's a whisk there's a way! You can host your Cupcake Day whenever and wherever you can, at home or online.

Get your free Cupcake Day kit today at alzheimers.org.uk/cupcakeday





Coronavirus volunteers' dementia guide

Our guide for people volunteering in their community as part of the response to coronavirus is helping them to support people affected by dementia effectively.

The coronavirus volunteer toolkit contains five top tips, including advice on communication.

There are also postcards with details of our

Dementia Connect support line to print, cut out and share.

Find out more at alzheimers.org.uk/covid-community-support

Online directory updates

Our online dementia directory has been updated to reflect the fact that so many face-to-face services have been suspended or replaced by online or phone contact due to coronavirus.

You can find support near you for people affected by dementia in Wales, Northern Ireland or England through a simple postcode or place name search. Each listing includes clear, essential information about what's on offer.

Visit alzheimers.org.uk/dementiadirctory to find support near you.

To list your service, see alzheimers.org.uk/dementiadirctorybusiness

Looking forward to Memory Walk



With so much distancing and isolation at the moment, we're especially looking forward to the return of our much-loved sponsored walks across England, Northern Ireland and Wales, though they may look a little different this year.

Taking part in your very own Memory Walk is guaranteed to be an uplifting and unmissable experience, suitable for the whole family. It's a fun, flexible and fantastic way to make a real difference for people affected by dementia at a time and place of your choice.

It's up to you where you walk, from lapping your garden or local park to revisiting somewhere special, and you can do it on your own, with your household or with four-legged friends.

Every pound raised is one step closer towards life-changing breakthroughs.

Find out more at memorywalk.org.uk or call 0300 330 5452.

Well, what a first couple of months I've had at Alzheimer's Society! It wasn't the start I expected as CEO, as coronavirus has thrown up challenges at every turn.

We're doing everything we can to support people through this incredibly difficult time, and we continue to speak to the government about what people affected by dementia need.

So many people have called our Dementia Connect support line and we've made thousands of calls to check how the people we'd usually see are doing. There has also been a huge increase in people using Talking Point, our online community, showing what a valuable resource this is for people feeling ever more isolated.

We can't do all this vital work without our incredible supporters, and we are so pleased that our emergency appeal continues to receive donations. The response from the nation to the 2.6 Challenge, replacing the London Marathon in April, was amazing. During times like this, it's wonderful to see how people pull together to do everything we can to help each other.

I am so proud to be part of this amazing team and I'm looking forward to rising to all the challenges that we will no doubt face in future, alongside all the brilliant people who support, volunteer with and work at Alzheimer's Society.

Kate Lee
Chief Executive Officer

United
Against
Dementia



Social care: Desperate need

As coronavirus naturally dominates headlines, one particularly important issue has been the dire situation in care homes, where residents have desperately needed better protection against the virus.

It's incredibly important for these challenges to be highlighted in the media, though many of them are extensions of problems that existed prior to the pandemic. Our campaigning is now even more vital.

We continue to hear from thousands of people affected by dementia about the issues they experience with social care. Based on this, we're campaigning for testing and protective equipment to be available in all care homes, for social care standards to be protected, and to uphold the rights of paid and unpaid carers.

Until the coronavirus outbreak, Philip – who lives in London – regularly visited his mum Sylvia, who has dementia, in her Lancaster care home. He feels frustrated that social care has not been a government priority.

'It was only when care homes and deaths in them were flagged up by the media and organisations like Alzheimer's Society that the government started to acknowledge issues relating to the sector,' he says.

'I am pleased the pace has now changed and I hope this highlights to the government that they absolutely must start to address the state of the social care system and its value to the wider community when this is all over.'

Help us campaign for people affected by dementia to get the care they deserve at alzheimers.org.uk/campaign

Santander support

Our corporate partner Santander UK has been working with Alzheimer's Society and Age UK to support older people and those affected by dementia during the coronavirus pandemic.

Branch staff have been checking in on the wellbeing of local older customers with telephone calls and supporting them to manage their finances during lockdown, also helping to combat loneliness.

Responding to its employees' desire to support vulnerable people throughout the crisis, Santander UK has doubled the amount of time they can spend doing voluntary work alongside their roles, from 35 to 70 hours a year.

The Santander Foundation also donated £500,000 to our emergency appeal to help us provide the support that people affected by dementia need at this time.

Coronavirus response: Across sectors

We've been championing the rights of people affected by dementia across industries and sectors during the coronavirus pandemic.

Alongside our work with retail firms (see p 12), we called on the NHS for pharmacies to offer and advertise free prescription delivery services.

We've helped the efforts of National Trading Standards, Financial Conduct Authority, Ofgem and Ofcom to make sure that fewer people fall victim to scams.

We've influenced many companies to reach out to potentially vulnerable customers to tell them about available support.

We're also making national housing associations and services that run independent living facilities aware of our coronavirus guidance on activities and scams, so that they can better support their residents.

Dementia Friends: Live online sessions

As people living with dementia face social isolation now more than ever, we've created new ways for people to become a Dementia Friend .

Dementia Friends learn about dementia so they can use this understanding to support people in their community.

In response to the coronavirus pandemic, you can now become a Dementia Friend by taking part in a live online session as well as by watching online videos.

Become a Dementia Friend – see dementiafriends.org.uk



Innovations: Community makers

Thanks to people sharing their experiences through our Innovation Hub website, we've been exploring ways to help dementia groups go online.

In March, we asked how coronavirus is affecting people with dementia and carers. Based on this, we're looking at how 'Community makers' could help bring people together to fight isolation in the current crisis and beyond.

We're working with the Helix Centre – part of the UK Dementia Research Institute at Imperial College London – people affected by dementia and others to see what help facilitators would need to run support, activity and discussion groups virtually.

Keep up with the latest developments on the Innovation Hub – visit innovationhub.alzheimers.org.uk

Online Singing for the Brain



Thousands of you joined people affected by dementia for our live virtual singalong at the end of April – an hour of fun, laughs and connection hosted by Alzheimer's Society on Facebook.

We enjoyed singing some old classics in the company of actor and Society Ambassador Vicky McClure, whose grandmother had dementia.

With our usual Singing for the Brain groups currently unable to meet in person, many of these have also taken place online so that people affected by dementia can continue to enjoy music and interaction.

For one carer in Wales whose mother has dementia, the virtual Singing for the Brain session was just what they both needed.

'That was amazing!' she said. 'Mam said she really enjoyed it, and it was lovely to see her smiling, laughing and singing again.'

The 2.6 Challenge

Although the London Marathon was, like so many events, postponed due to coronavirus, a new challenge took its place so that people could still raise funds for charities relying on their efforts.

The marathon, planned for 26 April, raises millions every year, so organisations joined forces to hold the 2.6 Challenge instead. Supporters have chosen themed challenges that suit them, from running 2.6 miles to holding an online workout with 26 friends.

Thank you to all of the amazing heroes who have taken part for Alzheimer's Society – we'd love more of you to dream up your own challenges too!

See alzheimers.org.uk/homegrown or call 0330 333 0804 for inspiring fundraising ideas that you can do at home.



News

Thanks to our volunteers

Alzheimer's Society is saying a huge thank you to all our volunteers this Volunteers' Week.

Volunteers' Week, in the first week of June, is a special time for us to celebrate our amazing volunteers and everything they do for people affected by dementia.

Volunteers are an essential part of our team – every minute you give makes a huge difference. Whether you're able to volunteer for us at the moment or not, your patience and support during this time is invaluable and we're incredibly grateful.

Find volunteering opportunities near you at alzheimers.org.uk/volunteering

Don't miss...

We're helping retailers meet the needs of people affected by dementia and coronavirus. See p12.

Finding ways to relax and focus could help you to stay well. See p13.

Dementia Friends Champions have stepped up for their communities during the pandemic. See p14.

We've continued supporting people despite social distancing and isolation. See p22.

More people than ever are there for each other on Talking Point, our online community. See p32.

You're not alone

Diagnosed with dementia while still in her 40s, Amanda Quinn wants others to know they have a voice. **Gareth Bracken** speaks to a woman calling for more understanding.

‘It’s daunting as to what’s going to happen,’ says Amanda Quinn of the coronavirus lockdown. ‘Even the thought of going back out once this is lifted is quite frightening.’

When we spoke in May, Amanda hadn’t left her home for weeks. This is because, as well as living with dementia and diabetes, she doesn’t have a spleen. Being without the organ – an important

part of most people’s immune system – means Amanda is at greater risk of severe illness from coronavirus.

‘It leaves you feeling very insecure,’ says Amanda, 51, who lives with her husband and two of her children in Rhondda Cynon Taf, south Wales.

She is finding media and social media coverage of the virus particularly unhelpful.

‘I think the way they are going on about it is beginning to make people paranoid about what’s going to happen,’ she says. ‘They need to start focusing on something more positive that’s going to come out of this, because something has to.’

Amanda is trying to pass the time and switch off from the world around her by reading and doing adult colouring. She is also receiving regular calls from friends, family and Alzheimer’s Society to check on her wellbeing.

Amanda would usually attend monthly meetings of Memoria – a theatrical group of people with dementia and carers, facilitated by the charity Re-Live. As this isn’t possible right now, the group is keeping in touch through weekly video calls instead.

Naturally, Amanda is still finding things very difficult.

‘It’s kind of claustrophobic in a way,’ she says. ‘I’m not seeing the people I used to see. I miss my two older boys.’

‘I don’t even know what day it is – I’ve lost track of everything.’

Don’t leave me

Amanda is from the Scottish town of Helensburgh, about 30 miles north-east of Glasgow. She moved to Wales with her four children around 17 years ago to escape a violent marriage.

She married her second husband Steve – a long-distance lorry driver – four years ago, and they live with her son George and daughter Bethany. Amanda previously worked as a nursery nurse and a chef.

Amanda was diagnosed with young-onset Alzheimer’s disease in early 2018, age 49. Her son has Asperger’s and it was his social worker who first noticed that something wasn’t right.

‘She kept saying that I should really see a doctor, but I thought, “I’m not bothering, there’s nothing wrong with me,”’ says Amanda.

Amanda did visit the doctor about an ear problem, though at the start of the appointment she couldn’t remember why she was there. She was referred for memory tests, which she thought would be a waste of time.

‘I got a bit agitated,’ she recalls. ‘I said, “These stupid tests are making me look thick.”’

Those tests, along with scans and blood tests, led to a dementia diagnosis.

‘They told me I could have had it for a few years,’ says Amanda. ‘The first thing I said to my husband was, “Please don’t leave me.”’

To make matters worse, the medical consultation was concluded in front of a full waiting room.

Quick read

Amanda Quinn, 51, was diagnosed with young-onset Alzheimer’s in 2018 and wants greater awareness about who dementia affects.

Amanda, who lives in Rhondda Cynon Taf in south Wales, was diagnosed aged only 49 in a manner she describes as appalling.

Amanda, who isn’t leaving her house during the coronavirus pandemic, wants others to realise that dementia doesn’t only affect older people.

She wants everyone with dementia to know that they still have rights and a voice to be heard.



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

'I felt so belittled,' says Amanda. 'I got into the car and burst out crying. I felt humiliated and had just been given this death sentence that wasn't going to go away.'

'The way I was treated when I had my diagnosis was appalling. I was sent away with a prescription and nobody contacted me for nearly six months. You can't do that to people, it's cruel. You need a bit of compassion and understanding.'

'I kicked up such a fuss that now when you get diagnosed, you come out from the doctor and see a member of the memory team for information and Alzheimer's Society contacts.'

Taboo topic

Amanda's lifestyle and personality have changed as a result of her dementia.

'I can't remember what I'm meant to do on a day-to-day basis,' she says. 'I used to be very house proud, everything was in its place, but now I can't remember how to do it all. I can't remember how to cook. My sense of humour is not the same, it's gone.'

Amanda also has incontinence, a topic that she feels deserves greater discussion.

'It's quite a big issue in my life,' she says. 'I can't leave the house without a changing bag of wipes and clean clothing.'

'It's such a taboo subject. I was one of the ignorant ones who thought dementia only happened to old folk. And even when it happened to me, I thought it was only memory loss. People need to be made aware of what challenges can come with dementia, and unfortunately incontinence is one of them.'

Amanda's husband Steve is often away working for long periods and phones home several times a day. Her older boys would visit under normal circumstances, but daughter Bethany is her main carer.

'Bethany does everything really,' says Amanda. 'She takes me to appointments and does all the cooking and bill paying, and now she's doing all the shopping.'

'She wants to go to university and become a midwife, but at the moment she's put that on the back burner to be there for me.'

Any age

Amanda has developed good relationships with several Alzheimer's Society staff.

'They're always there to give me that bit of help and support which sometimes I might need,'

Amanda and her daughter Bethany



EMERGENCY APPEAL

Help us raise awareness and campaign for change – to donate now, turn to the inside-back cover or call **0330 333 0804**.

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

she says. 'It's everything really – practical advice, emotional support. They're reassuring. If I ever need to talk, I can pick up the phone.'

'It's my family, friends and Alzheimer's Society that pick me up if I'm feeling down.'

Amanda takes part in one of our Focus on Dementia Network groups, where people affected by dementia share their experiences to influence the work of the Society and other organisations. She also speaks at conferences and has shared her story through the Society and national media.

'It's important for people to be aware that dementia can affect any age. It's not only an old person's disease,' she says. 'It could happen to them.'

'People also need to realise that you don't have to suffer with

dementia, you can live with it. You still have a voice to be heard, you still have rights. You're still that person who brought them up as children or befriended them. Things have changed you, but you haven't changed.'

Amanda feels that dementia awareness is sadly lacking among some sections of the public. She recalls one incident where two men were sat in her and Bethany's reserved seats on a train.

'Bethany said that I had dementia and I got a mouthful of abuse,' she says. 'The man was screaming, "People like you need to be locked away, you're a danger to society." When we got back, I just cried.'

Hopes and dreams

As she considers how her dementia might progress,

Amanda is more concerned with her children's future than her own.

'I still have hopes and dreams, although whether they'll happen, I don't know,' she says.

'But it worries me, how it will affect my children. I'm fortunate, I suppose, that I'm not going to know.'

'I say I don't want to go into a care home but that's not fair on them – they still have their lives to lead.'

Looking ahead, Amanda shares Alzheimer's Society's desire to defeat dementia through research.

'We need to find a cure,' she says. 'It won't be in my lifetime, but there needs to be a cure for future generations.'



Visit [alzheimers.org.uk/share](https://www.alzheimers.org.uk/share) to tell us about your experiences of dementia.

Quick response

As lockdown creates difficulties for people affected by dementia to get food and supplies, we are using our influence to remove barriers.

Since the coronavirus outbreak, Alzheimer's Society has been working across industries and sectors to make sure people affected by dementia are included in planning.

We knew early on that many people with dementia and carers were having difficulties shopping for essentials and getting priority deliveries. We quickly began using our connections in retail to help address these problems.

Left behind

Mike Parish lives in Somerset with his husband Tom, who has dementia along with other health conditions. Tom received an official letter identifying him as extremely vulnerable and advising him to stay shielded indoors for three months.

Tom's symptoms mean that Mike can't leave him at home alone, but Mike struggled to have Tom recognised as being vulnerable by supermarkets. This made it extremely difficult to get shopping and supplies, and for three weeks they had no access to fresh food or essential groceries.

'I can't imagine how many more people there are in my predicament, who are having to put their dependants at risk by going shopping or collecting shopping,' said Mike.

'We are mostly all survivors and we make things happen, but sometimes people might not be in a position to influence the essential support needed.'

Armed with this kind of direct evidence of how people with dementia and carers were being left behind, Alzheimer's Society went straight to those in a position to make a difference.

Urgent action

We outlined the difficulties facing people affected by dementia – and how these could be overcome – to the Secretary of State for Environment, Food and Rural Affairs as well as supermarket chains and industry bodies like the British Retail Consortium and Association of Convenience Stores (ACS).

'We secured the government's agreement that people with dementia, their families and carers should get priority support from local authorities and supermarkets,' says Emma Bould, our Programme Partnership Project Manager. 'We also successfully called for all supermarkets and local authorities to have a helpline for vulnerable people to order food, and we continue to push for further urgent action.'

Providing support

Another great outcome has been how ACS responded. It's been advising its 33,500 members – local independent shops and small convenience chains – about how they can best support people affected by dementia.

This has included guidance on home deliveries, dedicated opening hours and payments made by someone else on behalf of a vulnerable customer.

ACS developed a checklist so that shops can easily let us and their local authority know how they can help people – information we pass on to those who could benefit.

We're also working with ACS to help convenience retailers better understand and support customers living with dementia by creating 25,000 Dementia Friends.

'This is an uncertain and difficult time for us all and it's important that we play our part in providing support for those who need it,' says James Lowman, ACS Chief Executive.

Mike and Tom



If you're struggling to access food or medication, contact our Dementia Connect support line on 0333 150 3456 or get in touch with your local authority.

How I relax and focus

We ask people about how they keep healthy and well, whether they have dementia or not. This issue, we hear about ways to unwind and get perspective.



Pam Dixon, 76, Essex

I like reading daily for relaxation – it's been a lifelong activity.

My favourite author is Alexander McCall Smith, in particular his books on the No 1 Ladies' Detective Agency. It's set in Botswana and I'm from Bulawayo in Zimbabwe, so it's my

part of the world.

As it is not possible to go to the library at the moment, I'm just reading anything I can get hold of!



Paul Harvey, 49, Essex, with Lewy body dementia

I like to go fishing at the weekend – spending time on the bank, I can shut my brain down, take in my surroundings and enjoy nature. The friends I go with know my diagnosis, and the fishing lake people know as

well, so they come and check on me.

When I gave up alcohol I got back into my fishing, and I try to go every weekend. After fishing, my memory is good at the start of the week, then by the end of the week I just need to go fishing again. I tried to find ways to relax after the lockdown started but found it hard as I used to look forward to the weekend.

Rebecca Agsakal, Derby

I joined a twice-weekly yoga class and I practise at home at least three times a week. I use the mindfulness element from the end of each session to help me sleep and relax.

I wanted to strengthen my core as I run and train regularly. I am more flexible. My sleep is of a better quality. I feel calmer in myself and more positive.



Susie Woodman, 53, Hampshire (pictured with her dad)

I do a daily meditation, usually in the morning and around 20 minutes long.

I will do it every day, regardless of how long I can commit to it. So even if it's five minutes, it's every day. I use an app called

InsightTimer – you can set it to 'ping' or 'bong' at whatever time you want.

Being present is essentially what life is about, so practising this is fundamental to a life that flows. I make sure my husband understands that I need the time and space to do it.

I feel more relaxed, with less stress and more perspective. I feel more in the flow of the universe – synchronicities happen more often when you're present.

Susan Burns, England

I craft daily at home. It's a release and distraction from the stresses of the day – I needed an outlet from my job, something that was not related to nursing. I also raise money for charities by selling my crafted items.

Stay well

You can reduce your chance of developing dementia by keeping your mind and body active, enjoying healthier food, not smoking, drinking less alcohol, staying in touch with people, and dealing with any health problems.

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

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

Champions step up

A Dementia Friends Champion in Somerset has been helping people in her community isolated by coronavirus to get vital support.

As measures against coronavirus came into place, some were surprised by how many, strangers and friends alike, stepped up for people in their community who risked being cut off from essential support.

However, as this included millions of you already involved in Dementia Friends, dementia action alliances and dementia-friendly communities, we weren't surprised at all.

Margaret Tatham – a Dementia Friends Champion in Watchet, Somerset, who set up her local dementia action alliance and dementia café – was one of those who saw how they could make a difference.

Crucial contact

When it became clear how many people needed to isolate themselves, Margaret knew that maintaining contact and sharing information were going to be crucial.

'I've been trying to keep in touch, really,' she says. 'Any useful information I find out, I send by email to those from our Forget-me-not café and others.'

'I'm so aware of people who haven't got email too, so I write letters to send by post or put through their door.'

Margaret stressed how Alzheimer's Society is still here for people affected by dementia, linking them to our Dementia Connect support line and online community, Talking Point.

Basic needs

Even the simplest information is vital when people are worried about basic needs.

'At first we had a list from the church about which shops were delivering,' says Margaret. 'We added as far as we could – pubs, local deli, Indian takeaway – and we made sure everybody knows about the coronavirus community help group in town.'

Local dementia-friendly businesses also came through for people isolated by the pandemic. For example, the Star Inn, a member of Watchet and the Quantocks Dementia Action Alliance, and Richard Little Family Butchers, which recently earned a dementia-friendly certificate, were among those introducing home deliveries.

Make it personal

Margaret (pictured below) understood the particular impact of isolation on people affected by dementia.

'It's difficult for all of us,' she says, 'but if you have dementia or are a carer, it's much more difficult.'

'Everybody has routines, things they do – our café, Singing for the Brain, bowls – but now can't. It's harder for people with dementia to find things to do, and I'm not sure people realise how difficult it is for carers to be stuck inside.'

Amid so much uncertainty, it's even more important for people to know that others appreciate and relate to them.

'I phone everybody at least once a week. People particularly like it when I phone, they say, "It's lovely to hear your voice," "It's so nice to talk to you."

'I even wave at one couple from the bottom of the cliffs! They absolutely love that. It's trying to make it personal.'



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

Every step counts

A supporter in Nottingham is taking part in Memory Walk again this year having seen the impact of dementia on her own family.



Estelle Clarke in Nottingham is taking part in Memory Walk this autumn to support people affected by dementia, now and in the future.

Estelle's father Philip, who lives in Derbyshire, was diagnosed with frontotemporal dementia in May 2016, aged 56. His brother also had the condition, which is sometimes called Pick's disease.

'Even though we'd been through the same with my uncle, it was still a complete shock to all the family,' says Estelle, who was only 24 at the time.

'We've had to support each other through all the difficult times.'

Incredibly tough

Philip's condition can cause him to get frustrated or lose patience very easily. On one occasion after a medical appointment, he pushed his wife into their car in a burst of anger.

'That was incredibly tough to witness,' says Estelle. 'Mum is an incredibly patient woman and has been unbelievable in caring for Dad. We try and support him and make sure he is happy, but it's not been easy.'

Philip, now 60, is very protective of his finances, which Estelle has to take a lead on now.

'I had to mature very quickly for my Mum and Dad,' says Estelle, who received advice from the Society's support line about power of attorney.

Great help

Wanting to raise vital funds for Alzheimer's Society, Estelle first joined Memory Walk in 2016 with her parents, brother and fiancé. She's taken part with a friend twice since then and plans to walk again this year.

Every pound raised helps us get one step closer to a world without dementia, and you can even complete your own Memory Walk by doing laps of your garden, local park or revisiting somewhere special.

For Estelle, Memory Walk is a great opportunity to support families like hers.

'We had known so little about dementia, so it was a chance to share our experiences and help others who were going through the same difficulties,' she says.

'I know that it would have been such a great help for me to have read about someone my age whose family was going through this.'

Estelle hopes more research will mean that she or anybody else who might develop dementia in future can have the best chance of living well with the condition.

'The more money and awareness we can raise now, the greater chance of help at a later stage,' she says.

Defeating dementia starts with a single step – register for Memory Walk at memorywalk.org.uk or call 0300 330 5452.

Send an eCard



We have a great new range of eCards on our online shop. Our 'Thinking of you' and 'Stay safe' eCards are a lovely way of keeping in touch with family and friends, and you can choose to add a donation.

See shop.alzheimers.org.uk/alzheimers-society-ecards

Shop with AmazonSmile

smile.amazon.co.uk

Your Amazon orders can raise vital funds. Choose Alzheimer's Society at www.smile.amazon.co.uk and use this URL when ordering from now on – Amazon will donate 0.5% of the net price to us. If using their app, switch to AmazonSmile by tapping through Menu/Settings/AmazonSmile.

Choose us at www.smile.amazon.co.uk

Create a Tribute Fund

A Tribute Fund is a wonderful way to celebrate the life of a loved one while supporting our work, and you can set one up online. It provides a focus to honour the person with memories, photos and videos, creating a link to share with others.

Visit alzheimers.org.uk/inmemory or call 0330 333 0804 to find out more.

In your area



Beautiful feeling

A singer in Belfast has been holding live music sessions on Facebook to raise money for Alzheimer's Society.

Lydia Chambers used her one-hour slots on news and entertainment page Northern Ireland Craic two nights in a row to ask people to donate via her JustGiving.com page.

Taking the requests of viewers from as far afield as Canada and the US, Lydia sang hits of artists ranging from Amy Winehouse and Lewis Capaldi to Fleetwood Mac and Van Morrison.

'The response to my livestreams has been fantastic,' she said, 'and I'm doing more of them on RetroSoundz Music, The Virtual Lounge and Singers Paradise Lounge pages.'

'Friday night was dedicated to my Auntie Helen and Saturday night was dedicated to my granny, Mammy Chambers.

'I get this strange feeling that my Mammy Chambers and my Auntie Helen are looking down on me to help and I won't lie, it's a beautiful feeling!'

Find out more and support Lydia at www.justgiving.com/lydia-chambers1914



Influence at any distance

Despite the lockdown, people affected by dementia continue to influence the Society's work using video calls and email.

Our Dementia Voice team has held regular Join the Conversation group calls on the Zoom video app, providing technical support where needed. They discuss different topics each week to inform our services and campaigns. Through the Virtual Reference Group Network, even more people have answered weekly emails asking about the impact of coronavirus on their lives.

Ronald Amanze, taking part in video calls, said, 'They help me to appreciate that other people are going through the same things as me, and I take strength from listening to the honesty of other people's opinions.'

Ben Storrah, one of many Society staff to benefit from their insights, said, 'I gained a whole new perspective on the guidance I was preparing to write – it was invaluable.'

The 3 Nations Dementia Working Group is also working harder than ever to keep in touch with others affected by dementia through video calls, webinars and social media.

Find out how to help shape our and others' work at alzheimers.org.uk/dementiavoice or email yoursay@alzheimers.org.uk



Outrunning coronavirus

A determined supporter in Yorkshire is doing a string of virtual fundraising challenges to replace events postponed due to coronavirus.

Inspired by her late grandad's dementia, Hazel Kerrison, in Sutton upon Derwent, was set to run the Manchester Marathon, Endure24 near Leeds and the Yorkshire Three Peaks challenge.

'I was going to put it all on hold,' said Hazel, 32, 'but given what's happening now, a lot of charities have lost an awful lot of income.'

After running a full marathon in 970 laps around her garden, she decided to complete a virtual ascent of Everest in two five-day stretches by climbing her stairs over 2,000 times. She also simulated the Yorkshire Three Peaks elevation and distance with 765 stair climbs and a 38km garden run over two days.

Nicki Nalton, Community Fundraiser at Alzheimer's Society, said, 'The support of Hazel and people like her is vital. Thank you to everyone donating and raising funds for us, particularly in these uncertain times.'
Support Hazel at www.justgiving.com/runningforalzheimerssociety2020

Visit alzheimers.org.uk/fundraise or call 0330 333 0804 for fundraising ideas and to see how we could help.

Taking your calls

Denh Pham, Dementia Adviser, shares how our Dementia Connect support line is helping callers during the coronavirus outbreak.



Being there at the end of a phone line is something our dementia advisers have always done. However, coronavirus has made phone support even more vital for people affected by dementia.

Many callers have felt confused or conflicted over how to follow government guidance, or worried about someone continuing to get essential support.

I've been asked about whether a person might not be given lifesaving treatment for coronavirus when they also have dementia, concern about carers whose partners can be verbally aggressive and threatening, and struggles with not being able to say a 'proper goodbye' when a loved one is dying.

Responding to these isn't easy, but I'm thankful for all our training and the fact that our team is always there for each other.

We really listen to callers to help them identify their options. We can email or post additional information or put them in touch with local support where appropriate.

Often, it's more about working through difficult emotions to see where these have come from. Coming to terms with how they're feeling can mean it's easier to identify next steps – and to have the confidence to take them.

There's something really uplifting about the way communities have pulled together at this time. I hope that awareness of the importance of these connections remains when we come out the other side.

**If you need support or advice, call our Dementia Connect support line on 0333 150 3456.
If you're a Welsh speaker, call 03300 947 400.**

Urgent appeal for help

Coronavirus means people living with dementia need us more than ever before

Can you help us provide a lifeline at this time of crisis?

Please donate what
you can at
alzheimers.org.uk/give
or return the donation form
at the back of the magazine



Platform for change

Inspired by her father, Nimisha Sharma has been sharing her family's story to raise the profile of dementia. **Gareth Bracken** meets a daughter standing up for what's right.

At the time of our conversation in mid-April, Nimisha Sharma hasn't seen her father Sharad, who has dementia, since the UK went into lockdown because of the coronavirus pandemic.

Nimisha, who lives in Rugby in the West Midlands, won't be able to visit her parents' home in Leicester until the current social distancing and isolation measures are relaxed.

'They're having to be careful, so Mum is only going out for essentials,' says Nimisha, who would usually visit a few times a week. 'Dad isn't classified as high priority, so they haven't been given access to priority shopping hours. It makes me anxious because he's so vulnerable.'

Sharad, 66, is no longer able to speak and Nimisha would normally use touch to show affection. However, she is currently limited to daily video calls.

'It's really hard,' she says. 'One minute I think I'm OK as the video chats cheer me up, but I also can't hold his hand or be there beside him.'

'In the last couple of months, Dad hasn't been smiling as much and is sleeping quite a bit during the day. He's changing every day but I can't see him, which panics me. I feel I'm missing out on precious time with him.'

'I don't think he understands the coronavirus situation, but maybe ignorance is bliss.'

Nimisha is also unable to support her mother with Sharad's care as she usually would.

'Not being able to help is hard,' she says. 'I'm struggling because I feel a bit useless.'

Passion for life

Born in Kenya and of Indian descent, Sharad came to the UK in the 1970s, working as an IT consultant for many years. He was always very active and loved doing exercise and socialising.

'Dad was someone who made the effort to visit or call people,' says Nimisha, who works in PR and communications. 'He was bubbly and had a passion for life.'

Sharad is the oldest of six siblings and others would come to him for guidance or advice.

'He was really the backbone of his family,' says Nimisha.

Sharad was diagnosed with young-onset Alzheimer's disease in 2016, in his early 60s. The family had first noticed changes in his behaviour up to seven or eight years previously.

'He would say things that were out of character and make decisions he wouldn't usually make,' says Nimisha. 'He would also forget things, like the names of food.'

'Dad was never one to complain about feeling ill or being

hurt, so I think he didn't want to let on to us that something was wrong, but I think he knew.'

Although she isn't sure if Sharad was able to comprehend his diagnosis, Nimisha remembers everything vividly.

'It was horrible,' she says. 'It felt like being told, "Your dad is going to die and there's nothing you can do about it." For the next two weeks I was just crying – it felt like I was grieving. You're overwhelmed to the point of shock.'

Quick read

Nimisha Sharma, in Rugby in the West Midlands, is sharing her family's story to bring more attention to dementia.

Nimisha's father, Sharad, was diagnosed with young-onset Alzheimer's disease in 2016, in his early 60s.

Nimisha, currently unable to visit Sharad due to coronavirus, took our Fix Dementia Care campaign to Downing Street last year.

She hopes that by highlighting the impact of dementia, she is supporting her father's legacy.



Nimisha shares updates about her father's dementia on social media to raise awareness and get people talking about the condition.

She and Namrata joined Sally Copley, our Director of Policy Campaigns and Partnerships, in presenting a Fix Dementia Care petition to the Prime Minister.





Up and down

Sharad was still able to communicate and drive for the first year or two after his diagnosis. But as his dementia progressed, the family struggled to get the support they needed.

‘GPs aren’t specialists and social services have a financial threshold, so we didn’t get much help back then,’ says Nimisha.

Finding it difficult to get straight answers to their many questions, the family turned to Alzheimer’s Society.

‘The Society has been super helpful,’ says Nimisha. ‘They were able to break down the diagnosis for us and give advice on how to deal with certain things that Dad was doing. They’ve also given a lot of emotional support.’

Nimisha and her mum Usha also attended an Alzheimer’s Society Carer Information and Support Programme (CrISP), where they received information and advice on supporting a person with dementia.

Usha continues to be Sharad’s main carer.

‘Mum stopped working a year after he was diagnosed

and her life revolves around him 24/7,’ says Nimisha. ‘She has up and down days, but she’ll keep going with a smile on her face. She’s very strong and very inspiring to me.’

‘People say that Dad looks so well, but they only see end results, not the process and the turmoil for Mum.’

Grief and anguish

Nimisha is frustrated that dementia doesn’t receive the attention it deserves.

‘It’s a terminal illness that’s overlooked. You’re watching a person waste away in front of you, which causes constant grief and anguish,’ she says.

‘It’s so sad that dementia isn’t up there with cancer. There’s not the same level of support.’

She also believes there is a particular lack of awareness among South Asian communities, which isn’t helped by some languages not even having a word for dementia that people recognise and use.

‘People are seen as either sane or insane, healthy or unhealthy, but this is a grey area,’ she says.

‘It’s such a difficult condition because you can’t see it. In a photo, Dad looks fine. But there needs to be more awareness of how destructive dementia is.’

‘There’s an element of ignorance among the South Asian community. With an increase in dementia, there needs to be a platform for the Asian community to have an honest discussion about this.’

Spread the message

Nimisha started a blog about her experiences of dementia. After sharing it with Alzheimer’s Society, she and her sister Namrata took on a public role in our Fix Dementia Care campaign.

Last autumn, they joined Society Ambassadors at 10 Downing Street to present an open letter, signed by more than 100,000 people, calling on the Prime Minister to fix the social care crisis.

Later that day, the sisters appeared live on Channel 5 news to discuss the campaign and their family’s story.

‘It was a surreal day, but it shows that one voice can make such a difference,’ says Nimisha. ‘I felt grateful and blessed to be that voice and speak up for those who need support, and hopefully make a change.’

‘I think if Dad knew, he’d be so proud.’

Indeed, much of Nimisha’s inspiration for sharing her story publicly comes from her father. ‘Dad always encouraged us to stand up for what’s right – that’s the kind of person he was,’ she says. ‘I think it’s important to come forward to broadcast and amplify the message, because dementia hasn’t had that platform.’

‘I just hope that we’re doing something right by my father and his legacy.’



EMERGENCY APPEAL

Help us offer people like Nimisha the support they deserve – your gift can make every difference. Turn to the inside-back cover or call **0330 333 0804** to donate.

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

Join our campaign for better dementia care at [alzheimers.org.uk/campaign](https://www.alzheimers.org.uk/campaign)

Now more than ever

Coronavirus means that people affected by dementia need Alzheimer's Society even more than before. **Gareth Bracken** looks at how we've made sure we're still here for people.

Quick read

Coronavirus has been changing everyone's day-to-day lives, but Alzheimer's Society has made sure we're still supporting people.

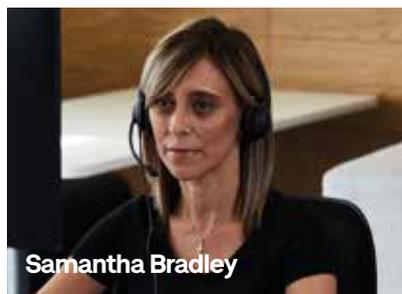
We've found ways to stay in touch with people we'd usually see in person, making tens of thousands of calls.

The online and phone aspects of our Dementia Connect service have been even more important for people needing information, advice and support.

Serena Snoad, our Online Community Manager, says, 'We're not going to let a pandemic get in the way of people getting the support and connection that they need.'

The coronavirus pandemic means people with dementia and carers have been isolated and cut off from usual sources of support. Thanks to the continued support of our donors, fundraisers and volunteers, we've been adapting our services as the situation has changed.

When the lockdown made face-to-face support impossible, we found other ways to stay in touch with the people who need us. We've also made sure people know about the aspects of our Dementia Connect service that they can access over the phone or online.



Samantha Bradley

Still here

We've been making tens of thousands of calls to people we'd usually see in person. This means we're still here for them and can check how they're doing, provide advice and information, and see what ongoing help they need.

Samantha Bradley, a Dementia Adviser in the West Midlands, told us about just one of the people she's supporting through these calls.

'She has dementia and is living alone, and she misses her family as well as going to regular groups,' says Samantha. 'I've given her information and reassurance, and made sure she's having shopping delivered to her home regularly and eating well.'

'We discussed how scary things are at the moment, and I explained that it's normal to feel this way and that we're here to support her whenever she needs us. She said it's so lovely to know that people care about her.'

Ann, who lives in Aberdare in south Wales, cares for her 95-year-old mum, Iris, who has Alzheimer's and lives separately.

'It can be really hard work with Mum – there's a lot of pressure,' says Ann, who hasn't been able to enter Iris's home.

However, calls from Dementia Adviser Lindsey Whatley have made a world of difference to Ann.

'Lindsey phones me regularly to see if I've got anything she can help with and answers my questions,' she says.

'I might be feeling really down but she gives me a bit of hope. Listening to that outside voice is a big help. Her calls make me feel more relaxed. She tells me that, if I ever feel vulnerable, I can just give her a ring.'

Many regular groups have also been keeping in touch through video calls, online events and email.

‘It’s fantastic to see our staff and volunteers finding different ways to make sure we’re still supporting people affected by dementia,’ says Lindsey, ‘even though we cannot be there in person right now.’



Chances to chat

Before coronavirus, Hugh Black in County Antrim was supporting two people with dementia through our Side by Side service. Unable to see them in person anymore, he says he jumped at the chance of calling them for a chat instead.

Hugh’s calls cover everything from family and friends to music, food and pets.

‘If my partners get as much from the calls as I get from making them, then they will truly prove to be helpful during this dreadful period,’ he says.

Hugh’s taken on extra calls with a carer and another person with dementia – 77-year old Danny Brown, who has vascular dementia and lives alone.

‘I’ve never met Hugh, but I’ve got to know him,’ says Danny. ‘We never know what the conversation is going to be, but we just float along and laugh – 10 minutes becomes an hour. Hugh gives me space and I go right back in time.’

Because of the support he’s received from us over the years, Danny describes the Society as ‘an extension of my family’.

He says of Hugh’s calls, ‘I’ve got something now that I didn’t have in my life eight to 10 weeks ago. It’s become part of my day.’



Relying even more

The lockdown has meant people have been relying even more on some aspects of our Dementia Connect service, such as our online information, support line and online community, Talking Point.

The support line has had a surge in calls from people needing coronavirus advice, and we’ve updated our website and social media as the situation has changed.

There has also been a huge increase in Talking Point members, as people share advice and experiences with others in similar positions.

One new member, with the username Zebra 123, was especially thankful after sharing their upset at not being able to visit their 98-year old mother, who has Alzheimer’s and lives in a care home.

‘I am totally overwhelmed with the kindness and understanding you have shown me,’ they said. ‘Your empathy, tips for handling the situation, and the love and care you have given me is so heart-warming and comforting.’

Another member, Sunshine2*, described Talking Point as ‘one big family with lots of knowledge to share’, adding, ‘I truly don’t know what I would do without it.’

Serena Snoad, our Online Community Manager, says, ‘We’re here for everyone and we’re not going to let a pandemic get in the way of people getting the support and connection that they need. Online and phone support is more important now than ever before.’

EMERGENCY APPEAL

Help us to support everyone affected by dementia during the pandemic and beyond. Turn to the inside-back cover or call **0330 333 0804** to donate.

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

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



Photograph: Resis Hoddott/2020vision

Wild for nature

A nature challenge is encouraging ‘random acts of wildness’, even adapting to coronavirus restrictions. **Gareth Bracken** finds out how people affected by dementia can get involved.

30 Days Wild is an annual challenge created by The Wildlife Trusts, a charity bringing people together across the UK to connect with the natural world.

Now in its sixth year, 30 Days Wild inspires people to do something nature-related – a ‘random act of wildness’ – every day in June. This could be anything from birdwatching or collecting outdoor items on a nature table to simply eating al fresco.

This year, activities have been adapted to restrictions in place due to coronavirus, since connecting to nature is even more valuable for people in isolation.

Free online packs – some specially tailored – are available for anyone to download.

Resources include a wallchart to track and plan activities, a nature table template and a bingo game. People are also encouraged to invent their own ‘wild acts’, whether to feel closer to wildlife or to help protect it.

Positive effects

Last year, a specific 30 Days Wild activity pack was produced for care homes for the first time. This came after Your Health care homes reported that their residents felt calmer, happier and had fewer falls after enjoying nature as part of the challenge.

The pack was based on the sort of activities that had worked well for the homes. The best ideas are simple, can be done at any time and help people to reminisce or simply just talk to each other.

‘It introduced opportunities for residents to engage with nature in interesting ways,’ says Louise Baker, Marketing Assistant at Your Health. ‘These included nature journals, wild artwork and picnics in the sun, as well as plant potting, butterfly gardening and feeding the birds.’

Whether they had dementia or not, the residents also enjoyed eating strawberries, creating miniature ‘fairy gardens’, dipping their toes into cool paddling pool water, bee counting and even water fights.

One person living in a Your Health home, Gail, particularly appreciated the opportunity to create a daisy chain.

‘I feel like I did when I was young, sat in the grass making them all those years ago,’ she said.

Another resident, Baz, was equally engaged after spotting some fish in a lake.

‘Wow, they look like trout – they’re just like when I fished here as a boy. That’s amazing to see!’ he said.

Zoe Searston, manager of Langwith Lodge Residential Home in Nottinghamshire, noticed that many residents who had dementia became less agitated after spending time outdoors focused on wildlife, which helped reduce their risk of falling.

‘Certain activities during 30 Days Wild calmed and engaged them,’ she says. ‘Mental wellbeing affects our residents’ physical health, and we have witnessed the positive effects of nature on both.’

Quick read

30 Days Wild is an annual challenge from the The Wildlife Trusts that encourages people to connect with nature.

The challenge inspires people to do something nature-related every day in June, though activities can be done any time of year.

Care homes have found that their residents – including people with dementia – enjoy and benefit from engaging with nature.

Alzheimer’s Society is working with The Wildlife Trusts to ensure that activities in 30 Days Wild are dementia friendly.



Photograph: Peter Cairns/2020Vision

Adapting activities

Although centred on June, 30 Days Wild can be enjoyed at any time. After taking part last year, staff and residents at Redmount Residential Home in Devon were inspired to continue with nature-themed activities.

‘Residents love to spend time looking at items brought in by one of our volunteers,’ says Tara Williams, the home’s manager.

‘She frequently brings in cuttings from her garden or the home’s garden, so the residents can talk about things and discuss their wild childhoods and the times they enjoyed outdoors as adults too.’

With the coronavirus pandemic restricting people’s movement, 30 Days Wild is focusing on things that can be done within current rules on social distancing and travel.

‘This year’s pack includes activities that have been adapted so that they can be done closer to home, like keeping a nature journal, watching a wildlife webcam or feeding the birds,’

says Dom Higgins, Head of Health and Education at The Wildlife Trusts.

‘Many care homes have gorgeous grounds and appreciated the ideas to help them make more of these spaces and the nature on their doorstep.’

Get wild

Alzheimer’s Society has been working with The Wildlife Trusts to ensure that suggested activities are dementia friendly or can be adapted. We’ve also been sharing information about 30 Days Wild and the benefits of engaging with nature.

‘30 Days Wild offers a great range of inclusive ideas, with many that are suitable for people affected by dementia,’ says Steve McFadyen, our Programme Partnerships Officer for Sport and Leisure.

‘It’s really important that more people affected by dementia who are socially isolating at home or in care homes know that ideas and activities like this are available to help add some joy to their days.’



Photograph: Nick Upton/2020Vision



‘With the coronavirus pandemic, taking part in meaningful, engaging and fun activities is more important than ever before. We hope people across the country, whether in a flat, caravan, house or care home, can get wild with nature!’

Sign up for 30 Days Wild at www.wildlifetrusts.org/30DaysWild

Be inspired by ways you can raise vital funds to beat dementia while at home – see alzheimers.org.uk/homegrown or call 0330 333 0804.

For activity ideas for people with dementia while isolating, visit alzheimers.org.uk/covid-activities

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

A letter addressed to Alzheimer's

Letter of the month

Dear Alzheimer's,

This letter has taken me several weeks to plan and many days to write, due in part to you obstructing my thinking and writing. Could it be that you are scared of what I may say to you? I feel well today, and through the glint of the bright sun I see you smirking that false smile you unveil when you sense your ascendancy over people like me.

Did you realise that it is almost a year to the day that my book *Dear Alzheimer's* – a series of letters to you – was launched at a fabulous event at Waterstones, Canterbury? A night when, try as you might, you were banished and the 'sold out' signs kept you firmly in the street.

You do make me frustrated, but never angry. Anger is like drinking poison and expecting the other person to die, and I will not do this.

It is now many weeks since we left the sanctuary of our house and garden. I have faced many challenges being confined to our home. While this is hard to contend with, it has also presented opportunities.

You encouraged me at first not to dress as I would normally, in order that you slide me into apathy. Your efforts here floundered, and I quickly decided that dressing as if I was going out was going to help me considerably.

Establishing a routine is always important and even more so at this time. I have tried strenuously to remain connected to old and new friends, and our garden is looking more colourful by the day. From our property we are blessed with a lovely vista and outlook and that also influences my outlook on life.

Our cupboards are the tidiest they have been since you came to stay. I am both throwing away things we no longer want or need and reconnecting to memories and valuing treasures from our past, some of which you have sought to rob me of.

Maybe if I write to you again it will be in sunnier times. I am growing a beard, so you are less likely to recognise me in a crowd once mingling among people again becomes a part of my life. I am also worried you will exploit my poorer memory, so I will wear a face mask to remind me about the importance of physical distancing. I hope this will not impede social connections too much.

Yours safely in lockdown,

Keith Oliver, Alzheimer's Society Ambassador, Kent

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

This is me: Read it, use it

I was pleased to see your April/May article about Norfolk and Norwich University Hospital, and a nurse taking the time to read the 'This is me' leaflet and talking to her colleagues about it. Revitalise holidays also uses this leaflet for its Alzheimer's breaks.

However, this good news is not the situation in some other hospitals. And I'm referring to a time before the coronavirus crisis – which now has, most likely, made matters worse.

My mother was hospitalised and ended up in a non-dementia friendly ward. Seeing her experience, put bluntly, was horrendous. She was supposed to be there for rehabilitation but sadly that environment had a significant detrimental effect, both on her physical and mental condition.

Her copy of 'This is me' didn't get looked at. When it was displayed on the board above her bed, it got covered by other stuff.

P Bladon, Worcestershire

See alzheimers.org.uk/thisisme or call 0300 303 5933 for a free copy of 'This is me' – available in English and in bilingual Welsh/English versions.



Your turn

Tell us what you think – email magazine@alzheimers.org.uk Letters for the August/September issue to arrive by 6 July.

Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Seen elsewhere...



Sandra Barker, a Research Network volunteer in Lincolnshire, joined a weekly lockdown fundraiser by sharing a picture and link to donate on Twitter:



“ Any excuse but it is officially #DressingGownFriday! @alzheimerssoc is here for everyone affected by dementia particularly when many are isolated at home. Help us by texting UNITE £5 to 70660 to donate to a great cause. ”



When we shared a video on Facebook of 11-year old Martha and her mum Sarah singing a song written for grandmother Jane, who they haven't seen since lockdown, many people responded including Danielle Dingle:

“ Absolutely beautiful song!! Brought tears to my eyes. My Dad has vascular dementia and what I wouldn't give to be able to visit him and hug him right now. Thoughts with everyone in this same situation at the moment. ”



A new member thanked others on Talking Point for all their helpful advice:

“ I don't feel quite so alone now. And it's good to know that what we are experiencing is similar to others' experiences. I admire you all for what you have coped with in the past and may still be dealing with. This thing doesn't come with an instruction manual, does it? ”

Our LPA service is still open

Alzheimer's Society continues to help people with dementia in England and Wales to set up Lasting powers of attorney (LPAs) – something that many may find reassuring and timely to do during lockdown.

Through an LPA, you can appoint people to make decisions on your behalf if you're unable to later on. Planning ahead can make it much easier for the people you'd like to do this when it's needed.

People can set up LPAs through the Office of the Public Guardian (OPG) website, but the Society's free digital assistance service can help if you don't have internet access or can't complete the forms online. Our trained volunteers can't offer legal advice, but they can complete online LPA forms for you.

Social distancing restrictions may make it more difficult to get the required signatures, but the OPG has produced some useful guidance on ways around this.

Call 0333 150 3456 for more details about our LPA digital assistance service.

For our Lasting power of attorney (472) factsheet and NI factsheet: Enduring Power of Attorney and controllership (NI472), see alzheimers.org.uk/publications or call 0300 303 5933.

Dementia and driving

Researchers are looking for people's views and experiences of driving after being diagnosed with dementia.

If you have dementia and either used to drive or still do, take part in the short survey at www.bit.ly/drivinganddementia



‘My brother is 82, has Alzheimer’s and lives alone. He hasn’t left his house for weeks because of coronavirus and I’m worried about him.’

Impact of isolation

Many people living with dementia have had to isolate themselves at this time from family, friends and others who support and care for them. This can leave people feeling unsettled and confused.

Coronavirus has also disrupted daily and weekly routines, which could otherwise help a person to feel safe and secure when so much else is disorientating.

It’s a difficult situation for you and your brother, but – apart from looking forward to things returning to normality – there are things that could make a difference.

Connections

Use whatever methods you’re both comfortable with to stay in touch, whether by phone, email, text or one of the many video calling apps, such as Zoom or Skype.

Seeing your face while hearing your voice could help your brother feel less isolated. Arranging calls at regular times may also add structure to his day. Are there other people he’d appreciate this kind of contact with?

Many people find our online community, Talking Point, a valuable way to connect with others who are affected by dementia. This may help you as well as your brother – see alzheimers.org.uk/talkingpoint

If your brother normally goes to groups or events, are there ways to keep these going online or over the phone?

Supplies

Home deliveries of food and other supplies can be arranged on your brother’s behalf, online or by phone. The GP or local pharmacist can help make sure your brother doesn’t run out of regular medications, including having them sent by post.

To pay for deliveries, you could ask your brother about getting a ‘third party mandate’ to give you temporary access to his bank account. You’d need to speak to his bank, and your brother would need to complete a form and consent to this.

Activities

Keeping active and doing things he enjoys doing may help your brother to retain his skills and independence for longer. What does he like doing? Are there activities you could suggest to him?

Doing specific things at set times, even household chores, can also provide helpful routine and structure.

Support

If your brother usually has face-to-face support from Alzheimer’s Society, we’ll phone him to check how he’s doing and offer advice. This will be done by a trained staff member or volunteer, perhaps someone he’s met.



Visit alzheimers.org.uk/coronavirus for coronavirus advice for people affected by dementia.

Call our Dementia Connect support line on **0333 150 3456**.

If you speak Welsh, you can call our Welsh-speaking support line on **03300 947 400**.



Sheila Colbeck, Hampshire, aged 90 with vascular dementia

What's changed most since your diagnosis?

I can't remember what I did last Saturday. I get cross with myself when I can't quite remember what something is. I feel like I should remember what that is.

What would you take to your desert island?

I'd probably take something like the New Testament. It's full of wonderful stories you can take to heart. There is the one where the man stopped to help the chap at the side of the road, who's been hit by robbers. I like that one.

What song or tune sums up your life so far?

'Keep right on till the end of the road, Though the road be

long, let your heart be strong. Keep right on round the bend.' (Keep right on to the end of the road, by Harry Lauder)

What single thing would improve your quality of life?

My quality of life is as good as it can be, as long as I'm not ill and my children aren't ill. I would like them to fix incontinence. I think they will one day, it just hasn't been sorted yet.

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

I had some nice holidays with my husband. We went to Japan and it was very interesting. Then later, with my partner, I went to Moscow and we went down to the Black Sea by train.

What is your most treasured possession?

I don't have one. I grew up in the war and we couldn't have anything we wanted then.

Coronavirus restrictions mean Sheila hasn't been able to leave her care home. Although she enjoys sitting in its garden, she says, 'I miss going swimming and going out with my children.'

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

Here to help

Alzheimer's Society's online shop has a great range of products to help people with dementia and their carers at home.

These include reminder clocks to keep track of time, easy to use telephones to stay in touch and a fantastic selection of simple music players, games and activities that support enjoyment, independence, communication and quality of life.

Our products are tested and reviewed by people living with dementia and their carers.



Shop helpful products
shop.alzheimers.org.uk
or call **0300 124 0900** (local rate)



Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645.
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We preview fun and engaging products from our online shop that people affected by dementia are feeding back about in our next issue.

Busy at home

A group of people with dementia and carers are trying out a range of games and activities from Active Minds at home, and we will feature what they think of them in the next magazine.

This issue, we're looking at these products. They are all available from our online shop, and they include activities that people can enjoy on their own as well as those for people to do together.

Aquapaint sets

Aquapaints allow you to reveal a colourful picture by using a brush dipped in water to fill in spaces around a black outline. Each set comes with five images, and the colours fade as the water dries so that you can 'paint' them again.

The Natural world set includes pictures of a butterfly, goldfish, cat, peacock and horse. Eight other sets can also be ordered from our online shop – Days out, At home, Everyday, Loves, Transport, Tool shed, In the garden and At the seaside. **Each is £14.58, or you can buy a bundle of five for £57.91 (all excluding VAT, which you don't have to pay if it's to be used by a person with dementia).**

Jigsaw puzzles

Active Minds jigsaw puzzles are plastic, with durable and easy

to clean pieces. The enchanting pictures have been selected to inspire conversation and reminiscence, and to be clear enough for people with some visual impairment.

The 35-piece Cat's whiskers puzzle depicts a cat and other animals lapping at milk spilt on a doorstep, while the 63-piece City dusk shows Tower Bridge in the snow against a glorious sunset. **Our online shop offers a further 14 jigsaw puzzles of 13, 24, 35 or 63 pieces, all costing £12.49 each (excluding VAT).**

Link and think

Link and think games each include 24 word tiles and one special dice. With the tiles spread out, you throw the dice and follow its instructions. Along the lines of 'Pick three tiles – which is your favourite?' or 'Pick two tiles – how are they different?', these prompt opinions, memories and discussion.

The Transport themed game includes word tiles like 'motorbike', 'bus' and 'hot air balloon', while Careers has everything from 'baker' and 'judge' to 'journalist' and 'electrician'.

These and two other themed Link and think games, Hobbies and Celebrity, are available from our online shop at £9.99 each (excluding VAT).

Snakes and ladders and Ludo

Snakes and ladders and Ludo are popular games that will be familiar to many. You can play both using this Active Minds set, which has a reversible board and large counters that are designed to be easy to pick up and handle.

Since some people can find ordinary dice fiddly to use and hard to read, this set uses numbered 'dice cards' that you draw from an envelope to see how many spaces to move.

The board designs have been simplified, with clear illustrations and high contrast colours.

The Snakes and ladders and Ludo set is £17.36 (excluding VAT) from our online shop.

Animal audio bingo

In Animal audio bingo, one bingo caller plays animal noises on a CD while up to eight players place counters on images of matching animals on their bingo card. If extra help is needed, the caller also has a flip book with a picture of each animal that they can hold up along with each sound.

The pictures are bold and colourful, and the animal sounds add a fun dimension to the traditional game – though you still get to shout 'bingo!' when you've matched all nine animals on your card.

Animal audio bingo costs £20.83 (excluding VAT) in our online shop.



‘My partner has advanced posterior cortical atrophy. I love my local small-town community, but no one I talk to really understands what I’m going through.’

If someone in your life has dementia, getting support from expert professionals and from understanding friends, relatives and neighbours makes a massive difference. However, there’s something irreplaceable about being in touch with people who know what it’s like to stand in your shoes.

Everyone’s experience of caring for someone with dementia is unique, but there’s a great deal of common ground too. It often feels like only someone with personal experience can truly relate to what you’re going through.

Alzheimer’s Society supports people affected by dementia in many ways (see opposite). This includes helping people to share their experiences and advice with each other through our online community, Talking Point.

Online community

Talking Point has been connecting people affected by dementia for years. The restrictions put in place due to coronavirus have made it essential for a great many more people.

Talking Point is open 24/7, and people can be surprised by the

responses they get from fellow members in even the small hours. Volunteer moderators and hosts nurture the community’s welcoming and supportive spirit, and the Talking Point team is on hand if you have questions about joining or taking part.

Look around

You can look around at other people’s discussions, reply to their posts or start your own threads. Most people join Talking Point using a made-up username, which can help in being open about what your experiencing and how it really feels.

The community has different forums for specific topics, but also more general areas and some even for when members want to talk about anything apart from dementia. There’s also a members-only area, which includes a forum for people who are dealing with especially difficult feelings.

Since there are so many Talking Point members, there’s a greater chance of hearing from someone else who’s caring for a person with posterior cortical atrophy, even though it’s a less common type of dementia.

There for you

Talking Point’s benefits include knowing that other people are in a similar boat to you. It can be reassuring to have a place where you feel safe to vent about what you’re thinking and feeling and not worry about being judged by anyone.

Other people’s views and experiences can provide a valuable perspective on your own circumstances. Members can also share specific tips and point you to useful information as your situation changes or between your appointments with professionals.

This can all help decisions about how to approach a particular issue, or it could simply make it easier for you to get through that day (or that night).

Talking Point is also a place to be inspired by just how many people are willing to be there for you when you need it the most.

Visit alzheimers.org.uk/talkingpoint to join. One new member, **Metalpetal**, says, ‘I feel much, much more content since I found this wonderful forum. In just the last couple of days since I’ve joined, it’s been so helpful.’



Talking Point is free and open 24/7 – see alzheimers.org.uk/talkingpoint



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

Our dementia advisers will connect you to the support you need, 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)

Registered charity No. 296645

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

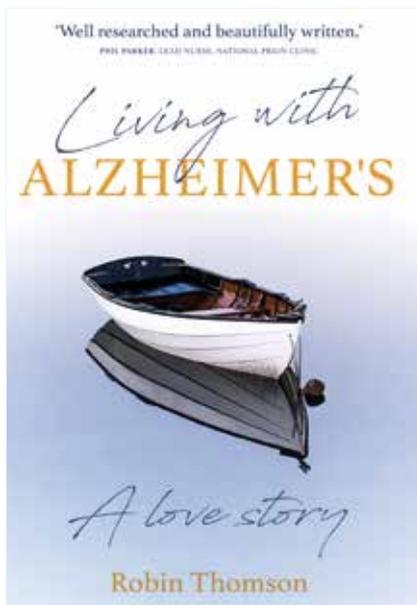
Person living with dementia





We hear what readers think about a memoir from a former Alzheimer's Society service user whose wife had dementia.

A love story



Living with Alzheimer's: A love story is Robin Thomson's account of caring for his wife Shoko, who died in 2018. Through it, Robin – a former Alzheimer's Society service user – describes their changing relationship, navigating care systems and the support of friends.

'I enjoyed reading this candid, open and well written account of how Robin found the experience of living with his wife's dementia,' says Caroline Branney, who manages our Dementia Knowledge Centre.

Jane Nicholls in Wiltshire says, 'The book is not a "heavy read" and I was able to identify with much of what was described. The book acknowledges that one person's experience will undoubtedly be different to another's, but there are common themes and issues faced.'

Robin and Shoko lived and worked in India for 20 years before moving to London, and understanding something of their earlier lives added a valuable perspective for Lorna Ridgway, a reader in Buckinghamshire.

'It was a privilege to read such a personal account of one couple's life journey,' says Lorna. 'To hear about life before Alzheimer's, to meet Robin and Shoko, their interesting lives and travels was invaluable. Continuing post diagnosis and as life changed, made me both laugh and cry.'

Another reader, P Kenley in Cumbria, says, 'It's a very emotive book and I can relate to much of it.'

Sickness and health

Caroline says, 'Robin describes how, after diagnosis, the couple and their family had no real idea of what lay ahead and how the initial memory loss would impact almost all areas of Shoko's life.'

'There are references to other books he read about dementia throughout, and a list at the end as well as a summary of practical tips.'

'I must take note of the message distract and divert,' adds P Kenley.

Lorna says, 'The book offers an insight into the multifaceted, individualised care that is needed to help families who are affected by Alzheimer's. It highlights the difficulties of accessing help at the right time or knowing when the right time is.'

'As a nurse for many years, I appreciate some of the difficulties discussed. I applaud the ideas Robin had to resolve issues sympathetically – such as driving around the block – and agree there is a need for joined-up, accessible care, tailored to individual needs.'

Better and worse

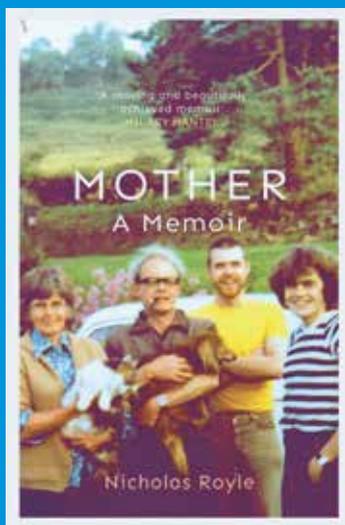
'Robin found the unpredictability of the condition difficult,' says Caroline, 'and Shoko became anxious and dependant.'

'However, there are still some happy times. When Robin agrees to get outside help because Shoko is having difficulty sleeping and can no longer help around the house, they eventually find a wonderful lady who becomes close to Shoko and is able to help with some of the logistical and emotional challenges.'

Lorna says, 'This is a must-read for anyone who has an interest in Alzheimer's or those undertaking their own journey. It offers an insight into the condition, support, ideas, wisdom, coping strategies and links to helpful information. Once finished, you'll need to read it again – I did!'

Living with Alzheimer's: A love story, by Robin Thomson (Instant Apostle 2020), 192 pages, £8.99, ISBN: 9781912726196.

At home and online



Your turn

For the next issue, we invite you to read *Mother: A memoir* by Nicholas Royle (Myriad 2020), 224 pages, £8.99, ISBN: 9781912408573. Also available as an ebook.

Hilary Mantel calls this book 'A tender and graceful study of parents and children', but we want to know what you think about it. Email magazine@alzheimers.org.uk by 6 July so we can share it in our next issue.

Distancing with Dementia

Find and share ideas to live well with dementia during the coronavirus pandemic on the Distancing with Dementia website. Set up by the Dementia Change Action Network (DCAN), it also features blogs from people affected by dementia and others.

Visit www.distancingwithdementia.org.uk

Youth activities

Our Activities and actions toolkit helps children and young people learn about dementia and what they can do to support people affected by the condition, especially while social distancing and isolating.

See alzheimers.org.uk/youngpeople for COVID-19 free downloadable resources.

LGBT+ ideas

Opening Doors London is sharing 'Online Activities to do from Home' ideas collected with older lesbian, gay, bisexual and trans (LGBT+) people in mind. These include links to podcasts, films and plays, as well as cookery and fitness ideas.

Go to www.openingdoorslondon.org.uk

Sporting memories

Sporting Memories Network has a wealth of resources to help people reminisce about watching or playing sport – the Sporting Pink e-newsletter, Sporting Memories Weekly videos, quizzes and puzzles, exercise ideas and more.

See www.sportingmemoriesnetwork.com

Connecting people, connecting support

Occupational therapists and designers share tried and tested activity ideas and resources online – everything from music, poetry and relaxation to weaving, technology and telling your story.

Visit www.connectingpeopleconnectingsupport.online

The Storybox Project

The Storybox Project is a fun activities programme to engage and include people with dementia, designed for families as well as groups. Subscribers get new ideas every week, and you can get two months' free access if you sign up now.

Find out more at www.smallthings.org.uk/families



Book giveaway and 30% discount

We have five copies of *Mother: A memoir* to give away – email magazine@alzheimers.org.uk by 17 June quoting 'Mother' for a chance to win one (see p39 for terms and conditions).

Get 30% off *Mother: A memoir*, with free UK postage and packing, when you order from www.myriadeditions.com and use our special readers' code ASM30.



Talking Point members share how they've been dealing with the impact of the coronavirus pandemic.

Coping with coronavirus

'Dad is 86 and physically fit. He lives on his own in a flat and is used to going out for a newspaper and to Sainsbury's local. He has frozen ready meals for his evening meal. I have had real problems stopping him going out in spite of big signs etc. I know he won't have a clue about social distancing.

'I have set alarms on my phone and call him in the morning to remind him not to go out and to get slices of frozen bread out to defrost (this conversation takes forever). I've also bought cup-a-soups, as I think he can deal with those. He can't get his head round the virus thing, but I have organised things so that he hasn't a reason to go out... unless he starts going out again for a paper.' **CaIT**

'The care home provide a daily app so we can see what fluid and food and daily care she is receiving, but these updates are only as good as the operator. The algorithms only allow information built into the computer, so although you can see information you have to read between the lines. This can be just as upsetting – being present allows you to see them and they know you are there.

'The care home allows us to have a window visit, but this is heart-wrenching too, to be so close but not hold their hand.' **hrh**

'I feel that I am in a sort of limbo, coping but beginning to realise that this is going to go on for a long time for

my age group (80+). Where is my husband? He is in another world where I cannot go, and I am struggling to grieve because I have to keep going day by day. I am pretty contented – although I am alone most of the time, I don't mind my own company. I am beginning to wonder if life will be much different when we can enter more normal life, and that is depressing.

'There was a huge amount of audiovisual contact during the first week or two of the lockdown, but as the weeks go on everyone is in the same boat, starting to feel it and contact has really dropped off. I contact people myself and they seem pleased to hear from me, I get the impression that they need the comfort.' **Grahamstown**

'I've discovered Zoom and Houseparty. I particularly like Zoom as you can use it on the laptop. Easy to download and free. It's nice to actually be able to see people when you talk to them. We are at least used to this kind of life more than non-carers who might have a busier social life.

'My answer for feeling down is putting my favourite music on, preferably quite loud. Luckily my person with dementia also likes music.' **White Rose**

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

Next issue

What advice would you give someone worried about the long-term impact of the coronavirus pandemic on people with dementia and their carers? Email magazine@alzheimers.org.uk



Exercise at home

For all of us, regular physical activity is a key part of staying fit and well. Readjusting how we enjoy getting exercise is an ordinary part of life, but it's especially important as dementia progresses and if we need to stay at home due to coronavirus.

Many people have benefited from online workout videos since lockdown, including by joining Joe Wicks's live sessions at www.youtube.com/thebodycoachtv – he and others on YouTube offer exercises that don't require any special equipment, with full body and seated sessions for older people and people with restricted movement. For a retro feel, you can even find Jane Fonda Workouts or Mr Motivator's GMTV slots online!

Make sure that any furniture you're sitting on or using for support is stable and strong. Wear comfortable clothing, keep water to hand and go at your own pace.

Specially designed to be dementia friendly – including music chosen to prompt reminiscence – Love to Move's chair-based activity videos and a helpful booklet are available at www.britishgymnasticsfoundation.org/lovetomove

Exercise doesn't have to come from a workout. Some people enjoy keeping active through housework or gardening, or by clearing a space and putting their favourite music on to dance or move around to.

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

Our latest Publications catalogue

Do you have a diagnosis of dementia? Are you a carer? Maybe you just want some general information about living with dementia.

Whatever questions, changes or challenges dementia brings, our publications will help you find your way. Newly updated, our 2020 catalogue includes:

- practical guides
- booklets
- detailed factsheets
- more languages and formats.

Order your free copy today by calling **0300 303 5933** or email orders@alzheimers.org.uk quoting code PL1





Over 3 million
people have become
Dementia Friends

Will you join them?

Visit dementiafriends.org.uk
to get involved



At home pack



We have a bundle of Active Minds products – Animal bingo, Animal snap, Link and think Transport and Cat's Whiskers 35-piece jigsaw puzzle – for one winner and Link and think games for two runners-up drawn from correct entries received by 12 July.

Q: Things you can get from our online shop include:

- A. Products to help around the home and gifts for all the family.**
- B. Raindrops on roses and whiskers on kittens.**
- C. Romantic sponges and oysters down in Oyster bay.**

Email answers with your name and address to 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.

Branded sports top

We have an Alzheimer's Society sports top for one lucky winner and branded reusable coffee cups for two runners-up drawn from correct entries received by 5 July.

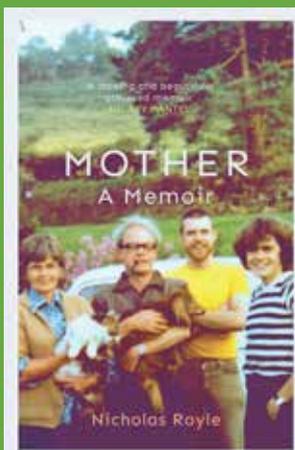
Q: Available Alzheimer's Society branded sports tops include:

- A. Ski thermals, wetsuit tops, fencing jackets and horse racing silks.**
- B. Running T-shirts, running vests, cycling jerseys and trek T-shirts.**
- C. Spinning tops, carrot tops, clifftops and big tops.**



Book giveaway

See p35 for a chance to win a copy of *Mother: A memoir*, by Nicholas Royle.



Reminder clock competition

R Peers in Buckinghamshire won a Rosebud reminder clock, and A Carroll in Lincolnshire and S Carr in South Yorkshire each won a Talking time pal. Answer: In 1094, the great polymath and genius Su Song completed his 40-foot-tall water-powered astronomical clock tower in Kaifeng.

Games and activities competition

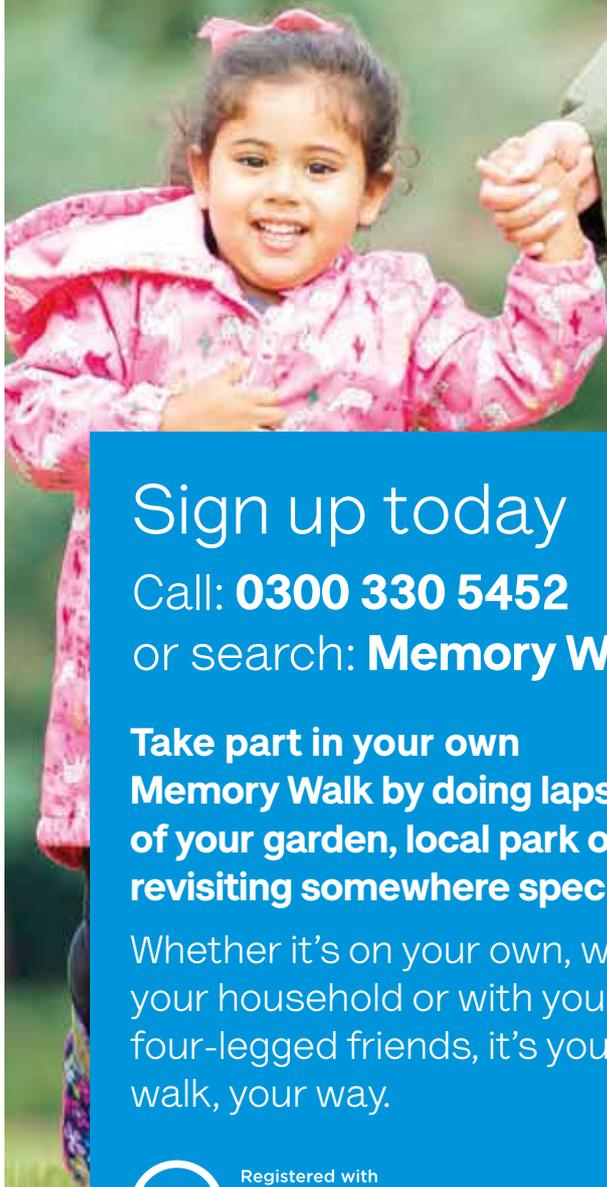
J Smith in Dorset won a Cat's Whiskers 35-piece jigsaw puzzle, A Carroll in Lincolnshire a Bathing Birds 35-piece jigsaw puzzle, K Lilley in Essex Snakes and Ladders/Ludo, and L Robey in Lincolnshire a Natural World Aquapaint set. Answer: Senet, the oldest known board game, has been found in tombs dating as far back as the 4th century BCE in Egypt.

Book giveaway

The five readers who each won a copy of *Living with Alzheimer's: A love story*, by Robin Thomson, were M Julian in Greater London, P Kenley in Cumbria, J Nicholls in Wiltshire, R Smith in Surrey and L Ridgway in Buckinghamshire.

April/May winners and answers

Who will you *walk* for?



Sign up today
Call: **0300 330 5452**
or search: **Memory Walk**

**Take part in your own
Memory Walk by doing laps
of your garden, local park or
revisiting somewhere special.**

Whether it's on your own, with
your household or with your
four-legged friends, it's your
walk, your way.



Alzheimer's Society is registered charity no. 296645



Organise Your Own
Memory
walk