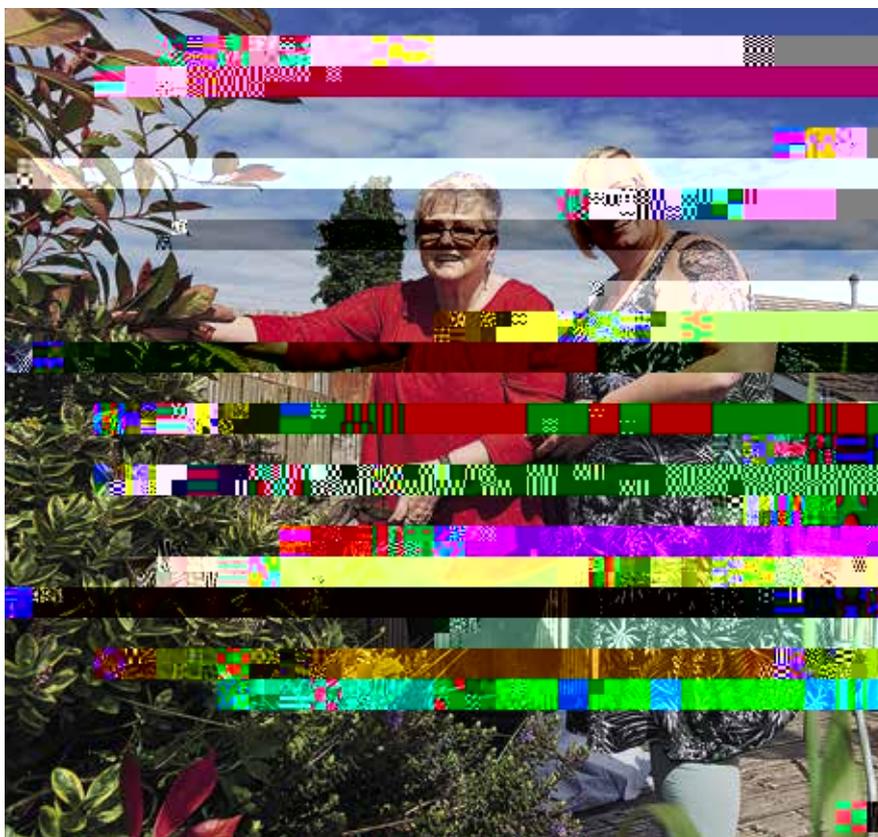


Looking at the articles in this magazine, there's a lot of talk about fighting back, taking courage and looking ahead.

If you're dealing with your own or someone else's dementia every day, it doesn't always feel like these things are an option. Sometimes we need to accept when something simply can't be done, or that not feeling good is a part of life (not the only part, but a part nevertheless).



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News



In the press: Working out risk

Several media outlets recently reported on an online calculator that can tell you what your risk of getting dementia is. But how accurate is it?

Working out a person's chance of developing dementia is usually done by healthcare professionals, because it involves complex techniques like genetic testing and assessment of other risk factors.

Researchers in Canada wanted to make it easier and quicker for people to find out their risk. Their calculator uses information such as age, ethnicity and how active someone is, to give over 55s their risk of developing dementia in the next five years.

Clare Jonas, Research Communications Officer at the Society, said, 'Risk calculators like this are becoming more and more accurate as our understanding improves.

'However, this calculator can't predict risk perfectly and there's still no sure-fire way to predict whether someone will go on to develop the condition. It doesn't include all the different factors that can affect your risk level, and it's based on whether the people who took part were diagnosed with dementia, not whether they had it.

'This is a problem because not everyone with dementia will get a diagnosis, so the calculator may underestimate the risk.

'If you're concerned about your risk level you should always speak to your GP, so that they can offer you more help and information.'

For our **Dementia: Reducing your risk (35)** booklet, go to alzheimers.org.uk/publications or call **0300 303 5933**.

Northern Ireland Conference risks

Don



Quick read

Mary Best, 70, is maintaining a positive outlook and embracing new opportunities following her diagnosis with Alzheimer's in 2017.

For Mary, receiving a diagnosis meant she knew what was wrong and how she could fight it.

Mary, who lives in Belfast, stays active and involved by supporting the work of Alzheimer's Society, attending a day centre and going on courses.

She encourages anyone who is worried about their memory to get it checked out, adding that there is life after dementia.

You can fight it

An Alzheimer's diagnosis has meant a change of attitude and outlook for Mary Best. Gareth Bracken meets a woman who is embracing new opportunities.

I don't believe in looking forward – I can't know what I'll be like in a year's time, so why worry about it,' says Mary Best, who has Alzheimer's disease. 'The more you worry, the worse you'll be, is the way I look at it.'

Mary, who lives in Belfast, has adopted a positive attitude and approach, which includes being open about her diagnosis, proactively seeking support, and staying as active and involved as possible.

'You have to come to terms with it,' she says. 'Take each day as it comes and be thankful for it.'

Foster family

Mary, now 70, grew up near Enniskillen, County Fermanagh, in the south-west of Northern Ireland.

'I was fostered when I was two years of age – it wasn't good,' she says. 'In them days, you were just given to people and they got money for looking after you. They didn't treat me too well.'

Mary married in her mid-20s but after that ended in divorce, she was cut off from her two children and didn't see her daughter Fiona for 10 years.

'There was always a stigma that foster children weren't good to their own children,' she says. 'But thankfully Fiona and I are as thick as thieves now.'

Mary was a prisoner in Holloway prison in London for three years in the late 70s, but mostly worked in care homes, looking after older people.

'It was hard work, but I really enjoyed it,' she says.

Mary has five grandchildren, including one in Australia. Her second husband, Henry, died before her dementia diagnosis.

These days, Mary enjoys reading, crocheting and playing card games online.

'Anything to keep my brain occupied,' she says.

Blank map

Mary first noticed problems with her memory when she started to struggle with her spelling.

'I was always quite good at it, but then I was asking my husband and daughter how to spell things that I should have known,' she says. 'I was also making stupid mistakes when driving, like a

missed turning. I would get agitated at myself.'

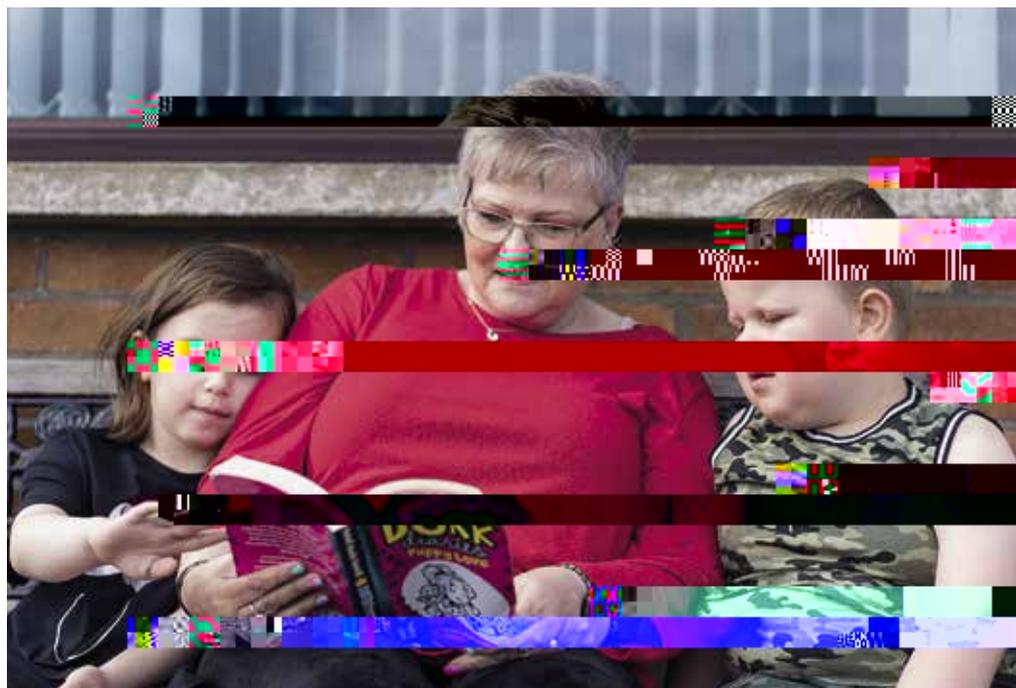
Having felt 'very depressed and frustrated' at what she was experiencing, receiving a diagnosis of Alzheimer's disease in 2017 was actually a relief.

'I knew there was something wrong, but I didn't know what,' says Mary.

'When I was told, I knew how it was, how to fight it. Before that it was like holding a blank map, I had to go somewhere but there were no directions.'

Gain something

Mary continues to face challenges with her short-term memory, which prompted a change in lifestyle.



'I switched off the TV and started using my brain more,' she says. 'I think that's the best way to fight it – don't let your brain stagnate.'

She has also altered her outlook.

'I used to worry about what people thought, but now I just think, "You only live once,"' says Mary, who also uses hearing aids and a walking stick, as well as a rollator for longer walks.

'I'm a great believer that if you lose something, you gain something,' she continues.

'If I hadn't had something, I wouldn't have met the people I've met – people with dementia and Alzheimer's Society staff – who have been more than brilliant.'

Have your say

The suggestion to contact Alzheimer's Society was made by Queen's University in Belfast, who Mary had approached about donating her body to science.

'The Society have been a fantastic help,' says Mary, who is involved with our work in several ways.

She is a member of a Dementia Voice local group, made up of people with dementia who influence Alzheimer's Society's and other organisations' work. They

do this by sharing their personal experiences, knowledge and skills to shape a wide range of projects and topics chosen by them.

'It's good to have your say,' says Mary, whose group has given feedback about a new bank card and tested out mobility scooters.

Mary was also a judge for the Dementia Friendly Awards and has been to Stormont to speak to politicians.

'I was there to give my input about what it's like to have Alzheimer's and what I thought they should be doing,' she says. 'It was good to tell my story and give them an insight into what people with dementia are going through.'

'Sometimes I think politicians are in a wee bubble – they don't know how the other half live. If they don't know anything about it, they can't be expected to do the things they need to do.'

Providing purpose

Mary enjoys going to a local day centre for people with dementia, which has been a valuable source of support.

'Before that I was sitting in the house, thinking what's the use in getting dressed,' she says. 'It gives you purpose, something to look forward to. I've made friends and the staff are brilliant.'

'That was the only good thing during the last lockdown, that the centre reopened in April. I got a bit depressed before that.'

Although the pandemic has affected her activities and interaction, Mary – who has had both of her COVID vaccinations – is trying to keep things in perspective.

'People missed going on holidays, but I missed having a hug, the small things, she says. 'I also miss going places through Alzheimer's Society, but at the same time, people have had it worse than me.'

Keep going

Mary receives excellent support from her daughter and son-in-law, which has continued through the pandemic.

'Fiona gets my shopping and Joe does the weeding and gardening. There's nothing they wouldn't do for me,' she says. 'Sometimes I feel awful even having to ask, but I don't know what I'd do without them. I'd be lost.'

Mary also appreciates regular phone calls from Margaret, a support volunteer who she was initially put in touch with by Alzheimer's Society. Before the pandemic they would meet for coffee or go to the cinema or garden centre.

'I don't have any sisters, but Margaret is my age,' says Mary. 'For people living on their own, or for somebody with nobody, it's good to have somebody.'



Mary and her daughter Fiona.

Use your experience of dementia to help shape our work – visit [alzheimers.org.uk/dementiavoice](https://www.alzheimers.org.uk/dementiavoice)

Mary currently attends community development sessions at a Women's Centre, where she gives her views on local issues. She is also on a photography course that will see her work form part of an exhibition.

'While you can keep doing something, you do it,' she says.

Not the end

As we hopefully continue to emerge from the pandemic, Mary feels that people with dementia can play a vital role in making others more aware of the condition.

'Dementia awareness can be lacking,' she says. 'It's got a lot better than what it was, but I think the pandemic has set things back. People are more into their own problems, like have they got a job.

'But there's a lot more can be done and some of that's up to us.'

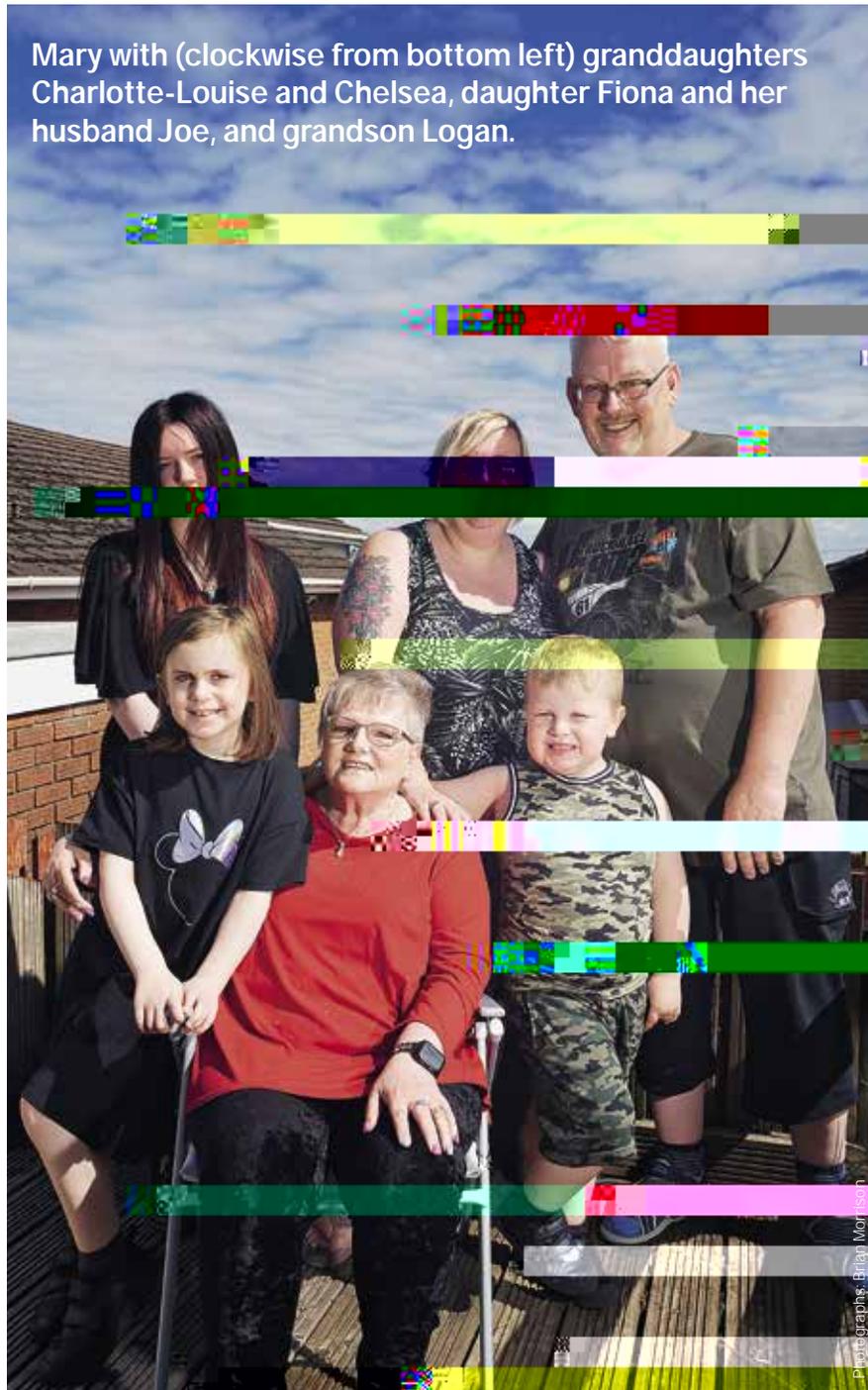
Mary also sees no reason for people to hide their dementia diagnosis from others.

'What's the use?' she says. 'What have you to worry about letting people know?'

And Mary advises anyone who has concerns about their memory to take positive steps towards getting the right help and support.

'If someone's worried there's something wrong – like I was – get a diagnosis. A quicker diagnosis means more peace of mind, then you can ght it,' she says.

'It's not the end of the world. There's a life after dementia.'



Mary with (clockwise from bottom left) granddaughters Charlotte-Louise and Chelsea, daughter Fiona and her husband Joe, and grandson Logan.

See [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory) to find support near you.


What can you do to help?
You can inspire people like Mary to speak out about dementia by donating to help run Dementia Voice groups. Please give what you can today.

Posterior cortical atrophy
(PCA) affects my life
massively. I do try and do
things to combat the symptoms.

A better future

Karen Beattie in Abergele in north Wales explains why she and her husband Rob are leaving a gift to the Society in their wills.

My husband Rob was

An affirming space

John Hammond in Brighton tells us how he's drawing on his experiences to improve support for LGBTQ+ people affected by dementia.



When my mum was diagnosed with Alzheimer's, I was completely lost. I was given a leaflet and the consultant said, 'Read this, it will tell you everything you need to know.' But it didn't.

Before her diagnosis, I had no understanding or appreciation of dementia. As became apparent, dementia is complex and it affected Mum in many ways.

I contacted Alzheimer's Society. They helped me throughout. An incredible dementia support worker provided a listening ear about my mum's rapid change in her condition. I could keep checking in with them to ask questions about Mum's symptoms. This was very reassuring.

I wanted to give something back, desperately, as soon as I was able to, and I've been volunteering with the Society for around five years. I believe wholeheartedly in its approach and wanted to be a part of that.

I've helped to co-facilitate carer support sessions and peer support groups. I'm also involved with the Research Network and Volunteer Advisory Panel. Most recently I've been working with Alzheimer's Society in thinking how the LGBTQ+ area of its online community, Talking Point, can be more engaging.

Specific support

I'm also Operations and Development Manager at Brighton & Hove LGBT Switchboard, and we saw the need for support that's specific to LGBTQ+ (lesbian, gay, bisexual, trans and queer) people affected by dementia.

Our Rainbow Café, born from our older person's project, provides an opportunity for LGBTQ+ people who are affected by dementia to support each other.

Some people have had very negative experiences of services. Many have lived through times when their identities will have been criminalised or pathologised. LGBTQ+ people disproportionately live alone and are disproportionately affected by social isolation, mental health conditions and alcohol use – all risk factors for dementia.

I find that many of our Rainbow Café members have a family of choice rather than a family of origin.

Your entire self

The Rainbow Café is a safe, affirming space for LGBTQ+ people to come together. It's very welcoming, and there's no need to keep coming out. You can

be free, be your entire self in a support service. Dementia is tough, but there's a certain amount of celebration at our social meetings – celebrating people's life stories.

At Switchboard, we pride ourselves on working with Alzheimer's Society and many other organisations. We provide training and awareness, we're partnering with researchers and we're currently extending the Rainbow Café into West Sussex as well. It's an expanding project – it's exciting!

For our LGBTQ: Living with dementia (1511) booklet and Supporting a lesbian, gay, bisexual or trans person with dementia (480) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933.

To find out more about Brighton & Hove LGBT Switchboard's Rainbow Café, visit www.switchboard.org.uk or call on 01273 234009.

Favourite things?

Film – Little Miss Sunshine.

Way to spend time – I've recently

**Helen Mayne, 55 in
North Tyneside**

I love reading
books by LJ
Ross, set in
Northumberland
and the North
East. I read on
Kindle and I play
audio books

when driving around in my job.

Reading is my way of relaxing
after a busy or stressful day, and

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Q&A: Liz Brown

Liz Brown in Worcestershire, aged 75 with vascular dementia.

What's changed most since your diagnosis?

Since my diagnosis my life has changed in many ways. Lots of things that I used to do without thinking are now, on the whole, much more difficult. It is hard to accept that my future is now so unknown.

What would you take to your desert island?

I love music – all sorts of music – and poetry, which I love to read and write. I hope I'd have the opportunity to relax and enjoy my favourite things. To do this, I'd want to take books, paper and pens, but also a radio. It would be impossible to choose between them!

How has Alzheimer's Society helped you?

Over the last years, it's been part of the rock that I've relied on. I've needed help with all kinds of things. I'm blessed with two volunteers – Tracy and Liane. I miss Tracy taking me out every week, though she phones instead, and Liane has called me every week since the pandemic started. The Society gives me the help that no one else can, and it has done right from the start.

What song or tune sums up your life so far?

Hero by Mariah Carey. From listening to that, I feel that somewhere inside I have got the strength to carry on. The song points out that the hero lies in you – it's good to listen to when things feel hopeless, it's a very strong song.



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

What single thing improves your quality of life?

That's easy – my daughter, who cares and supports me through the good times and, especially, the bad. We do things together, she makes me laugh and she is my rock. I am very lucky!

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

I'd choose a part of my life – my teenage years. All the starts and new beginnings, solid friendships, time to relax and look forward to the future. Starting out – that for me was a good time.

What is your most treasured possession?

My motorised wheelchair, which helps me maintain some independence and a chance to be part of life. I call her Bertha, my best friend, and I've had her nine years now. Even with my limitations, she gives me the ability to pop to the shop, go to the park to watch the ducks – gives me a little bit of freedom.



We are here for you

Phone support

0333 150 3456
Monday to Friday, 9am to 5pm
Saturday, 10am to 4pm
Sunday and Bank Holidays, 11am to 3pm

Online support

24/7 support on our website
and app
Email support: help@alzheimers.org.uk
Live chat: www.alzheimers.org.uk

Face to face support

Local support groups and services
across the UK
Find out more: www.alzheimers.org.uk

Contact us today

0333 150 3456

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

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

Patricia, 68



**Alzheimer's
Society**

United
Against
Dementia

All change

Kirstie MacLean Kalonji, Sector Engagement Policy Manager, shares how people affected by dementia are influencing vital change.

In the four years I've been at Alzheimer's Society, my focus has been on helping to make a real difference to people affected by dementia in their everyday lives. Getting their concerns heard by organisations across all sectors is a vital part of this.

Transport is a particular priority at the moment, but there are so many other aspects of life that we've been working on too. Making sure that people can still get face-to-face and telephone support as more services move online is an increasingly important area for us.

Working closely with our Dementia Voice team means I can gather viewpoints from a range of people living with dementia, their families and carers. This highlights the challenges that people face in real life, so we can help different sectors understand what they need to do to have a positive impact.

Better journeys

Many people have had negative experiences on public transport because of a lack of understanding about dementia from other passengers or staff. People affected by dementia have made it clear to us that COVID-19 has only increased their concerns.

We're supporting the relaunch of the Department for Transport's 'It's Everyone's Journey' campaign. This promotes positive behaviour on public transport, including being patient and ready to help your fellow passengers.

People affected by dementia have reminded us that – whether there's a pandemic or not – how we choose to behave and treat others is a priority. This is especially true when people are often rushing about, intent on getting to their destination!

We've also worked on new guidance for bus and train staff. This highlights many important points, such as understanding that not all disabilities are visible and that many people will need them to communicate slowly and clearly.

Not all online

So many activities and services had to go online due to coronavirus, and this was incredibly helpful for many of us.

However, some people aren't able to take advantage of online options, and many who've had to do so would much prefer returning to in-person contact in future. There's a similar situation for people who want to continue using cash for purchases instead of cards or online payments.

When Transport for London stopped accepting cash in 70% of its stations during the pandemic, we used feedback from people affected by dementia to convince them to reverse this. They also dropped plans to make all stations permanently cashless.

We hope for similar successes as we keep sharing people's insights about the need for 'offline' options. This includes ways for people to keep their homes warm, and many other areas.

In your area

A team from Torfaen, south Wales has raised almost £6,000 for Alzheimer's Society by running an incredible 100km in one day.

Lloyd Bartley took on the Cotswold Way Challenge ultramarathon at the end of June with his brother Rhys and friends Richard Appleby, Gareth Rusby-Davies, David Jenkins, Richard Darch and Tom Sterling.

Lloyd said, 'We chose this charity as my dad has early-onset dementia. He's 66 – not an age many of us associate with dementia.'

'My dad's dementia has had a big impact on my family. My mum is now my dad's full-time carer and has to help him with every aspect of his day-to-day life.'

Although completing the ultramarathon was hard, it was more than worth it at the end.

'We all managed to finish the challenge,' said Lloyd. 'There were quite a few injuries along the way, with some of us suffering more than others.'

'My parents were at the finish line to see my brother and I finish, which was amazing. It was a massive sense of achievement.'

A supporter in Coleraine, Northern Ireland, has raised over £2,000 for the Society in memory of her mum, who had Alzheimer's and died aged 74 last year.

For Cathy McColgan, Cupcake Day in June wasn't only a way to raise funds. It was also a way to bring family and friends together to honour her mum Sally, whose funeral had been restricted due to coronavirus.

Cathy said, 'Mummy brought four of us up singlehandedly since I was maybe nine years old. She went without to make sure we had what we needed.'

Cathy invited a close group of friends and family to come to the fundraiser and it was the first time she had seen many of them since her mum died.

'It was great to see people again and they were so generous. I set up a one-way system so people came in the front door and out the back, and it was all socially distanced with masks and sanitiser.'

'We had cupcakes, gluten free cupcakes, fruitcake, Victoria sponge, mince pies that were all homemade and then people donated shop bought stuff too.'

For fundraising ideas throughout the year, see alzheimers.org.uk/fundraise or call **0330 333 0804**.



Culture for all

London has established the world's first Dementia Friendly Venues Charter, with over 40 major theatres, museums and other venues already on board.

Venues will make themselves more accessible to people affected by dementia through sensory tours, inclusive performances, relaxed sessions, clear signage, chill out zones and staff training.

Organisations signed up to the charter also join a Dementia Friendly Arts and Culture Network, hosted by the Museum of London, that will share best practice and help staff and volunteers become Dementia Friends. Alzheimer's Society will give them further support to become more dementia friendly.

Sadiq Khan, Mayor of London, said, 'As our city begins to reopen and our campaign to attract visitors gets into full swing, I want to send a clear message that our cultural venues are here to welcome people with dementia and we all have a part to play to ensure our capital is a more welcoming place.'

Kate Lee, our CEO, added, 'Venues like the Museum of London are leading the way, and we'd like to

Why dementia, why the Society?

I worked in adult social care for several years and was really shocked to see that dementia was often not recorded as a reason for providing support. That meant the risk of under-resourcing dementia was real and large.

I also found that dementia is not acknowledged as a health condition but as a social care matter, which can cause huge barriers to peoples' ability to access financial and other support.

When I saw a role advertised at Alzheimer's Society, I knew I had to go for it. It presented an opportunity to take my prior learning and knowledge and to use it in a way that could create real, positive change.

How to fill an unexpected day off?

Stephen and I would head up to Bamburgh. I'd enjoy a Guinness in the Victoria Hotel then lose myself walking on the wide, open, sandy beaches, staring at the horizon and admiring what is my favourite Northumberland castle.

Proudest achievement?

I learned to ride a bike about two weeks ago – that made me very proud! Also getting a degree in three years through the Open University while working full time and being a single parent to two children.

I would also throw in those two children, they make me immensely proud. My son has dyspraxia and dyslexia but got a law degree and my daughter took it upon herself to move to Australia, travel around Japan and now lives in New Zealand.

Worst advice you've been given?

Someone once advised me to consider elocution lessons, as I wouldn't get on in life with a Geordie accent. I did not take the advice and every time I saw them after that I amplified my accent – I mean, tell Ant and Dec that!

Biggest priority for coming months?

Making sure we provide the best possible support we can for people affected by dementia, which includes making sure the Society is a great place to work and volunteer.

Most important thing learned from a person with dementia?

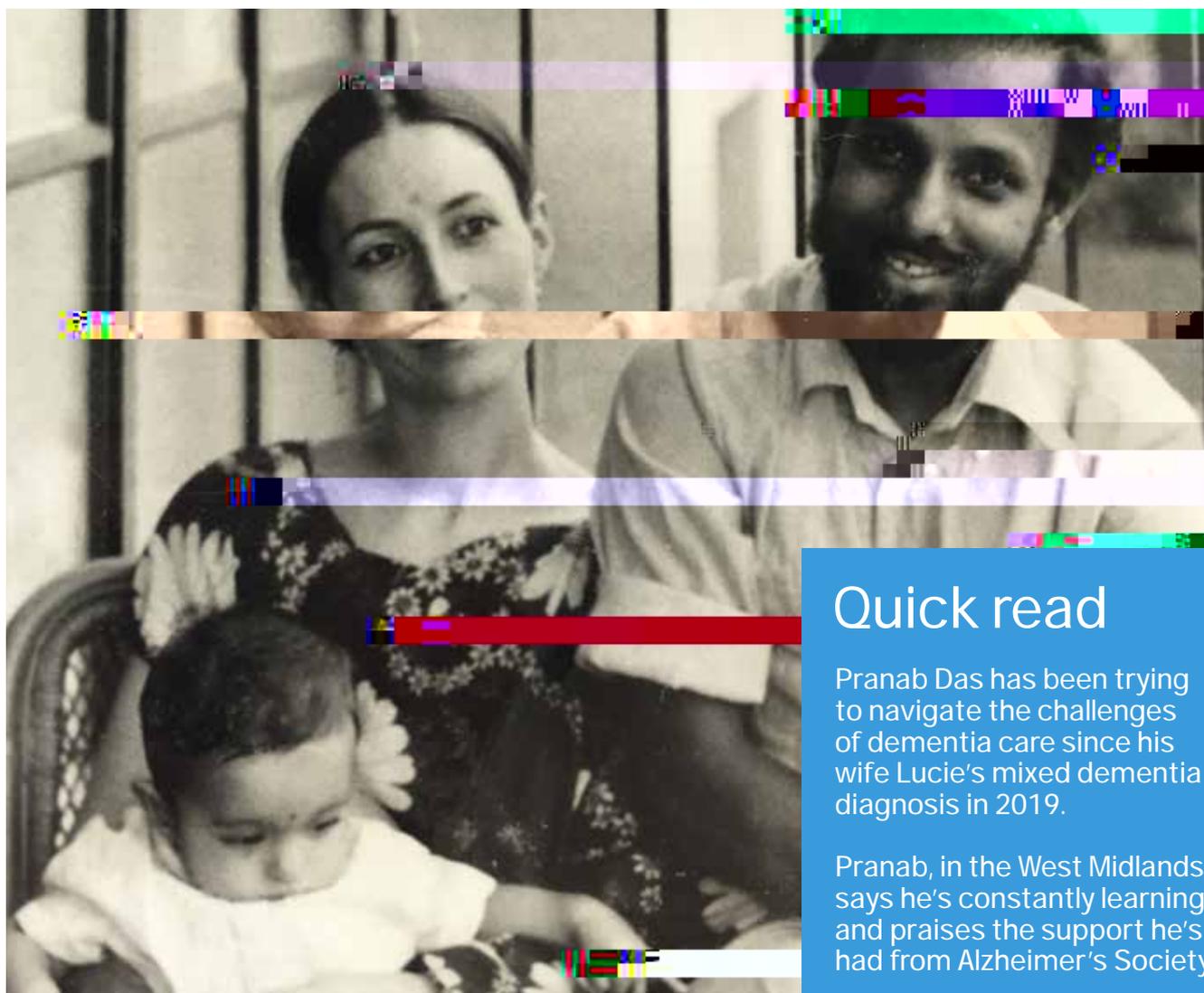
This one is really tricky, there are so many I could draw upon. Given that, I am going to say that the most important thing has been: everyone who has dementia has a unique, individual experience and is a unique individual.

Most looking forward to?

The ability to be a bit more spontaneous!

Take courage

Pranab Das has been trying to navigate the challenges of dementia care since his wife's diagnosis. Gareth Bracken speaks to a husband who will never stop showing love.



Quick read

Pranab Das has been trying to navigate the challenges of dementia care since his wife Lucie's mixed dementia diagnosis in 2019.

Pranab, in the West Midlands, says he's constantly learning, and praises the support he's had from Alzheimer's Society.

He's had bad experiences with both social services and homecare agencies.

Pranab hopes that his story will inspire others caring for a relative with dementia to take courage and continue showing their love.

For me, every day is a new day – it's continuous learning,' says Pranab Das, whose wife, Lucie, has mixed dementia.

Supporting Lucie has been a 'big education' for Pranab. He wants her to be able to remain at home, but has faced challenges trying to find the right professional care.

Despite all of this, and his worries about the future, Pranab strives to always be there for his wife.

'I do wonder, what is going to happen? Where is this going to lead? It's very sad and sometimes

says. 'These relationships are so important, but the managers don't seem to want to build them.

'Care agencies boast about their dementia expertise, but no one is an expert.'

Pranab, who made an official complaint against one agency, feels that making money can come before providing a good service.

'I had to pay for the care unless it's cancelled 12 hours before, but Lucie isn't always in the right mood for a carer to visit. I can't predict 12 hours in advance with a person with dementia.'

Like a daughter

Pranab was referred to Alzheimer's Society by a social worker, and has received excellent support from Kiran Daman, a Dementia Support Worker.

'Kiran is tremendous,' says Pranab. 'She's almost like a daughter to me. If I don't hear from her, I get nervous!'

Kiran advises Pranab on how best to support both Lucie and himself.

'Lucie used to be aggressive and was spitting at me, but Kiran told me how to handle it,' says Pranab. 'She said to leave the room and come back as if nothing happened. And she was right.

'Kiran has also taught me to be patient. I'm an ill-tempered person, agitated very easily. She helped me to become tolerant and calm.'

Meanwhile the pandemic has created new challenges for Pranab who, along with Lucie, had his second COVID vaccination in April.

'The pandemic has made everything worse,' he says. 'My daughter used to visit once a month from Paris, but now I have her and my granddaughter Mila on the phone trying to get Lucie to eat.'

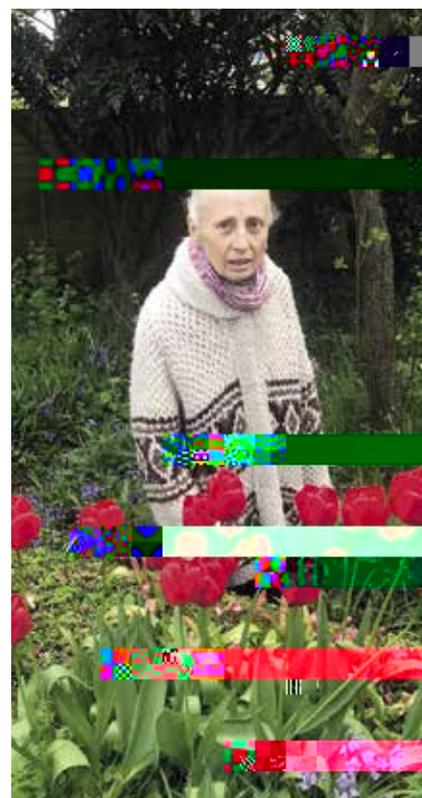
//
People with dementia are not completely obscured. They still have creativity, it's just all mixed up. They can still feel your warmth, so don't ever stop giving them love.
//

Don't stop

As he continues doing all he can to ensure that Lucie receives the best possible care and support, Pranab hopes his story will inspire others to keep going.

'I never dreamt this would happen. I'm still on the journey and every day is a new experience,' he says. 'You face the despair, but you have to be courageous.'

'People with dementia are not completely obscured. They still have creativity, it's just all mixed up. They can still feel your warmth, so don't ever stop giving them love.'



**What can you
do to help?**

You can help ensure
that more carers
like Pranab receive
the support that
they need. Please

The focus has been on living well with dementia, and quite rightly so. But we do need to focus on the other side of the coin, and dying well with dementia is a very important part of that.'

Those were the words of Keith Oliver – an Alzheimer’s Society Ambassador who lives with dementia – during a recent discussion about planning for the end of life.

These sorts of conversations can be difficult for anyone, and especially for a person with dementia who may not want to dwell on how their condition will progress. However, there are also benefits to having a plan in place, such as the peace of mind that comes from knowing that your wishes and preferences are recorded and will be respected.

Dying well

The 3 Nations Dementia Working

privilege to walk the path with many during their living well and their dying well' in the 25 years she was a GP.

Jennifer, who has dementia, underlined the importance of people having a say in their future.

'I'm aware of the many assumptions that are made about dying well,' she said. 'Sadly, often relatives put their own wishes first or don't even bother to ask people what they might want.'

'The biggest challenge to me



Better sleep

Many people living with dementia have disturbed sleep. This can include sleeping less and walking about at night, and feeling excessively

'It was really enlightening,' said one daughter. 'There were things that I would overlook that I didn't realise were that important.'

Another daughter, who lives with her mum, said the programme worked really well for both of them.

'Even people at work noticed a difference with me, because I was sleeping at night,' she said.

Nothing worse

The main DREAMS:START study will see whether people with dementia living at home are sleeping better eight months after the sessions – and whether this improves their quality of life.

Researchers are recruiting 370 family carers in England whose relatives have sleep difficulties for a randomised trial. This means that a computer will decide who has DREAMS:START sessions and who only has more usual support.

One participant already recruited is Jane Güleç, who lives near York and whose aunt has dementia.

'My aunt is continually up and down in the night,' says Jane. 'On a bad night she can be wandering up and down the stairs, wondering where people are, or getting dressed and undressed. Sometimes she goes to bed already anticipating a bad night.'

'There's nothing worse than continually disrupted sleep for getting you down – it makes it much harder.'

'Anything I can do that might help my aunt, myself and people in the future is worth trying.'

Unique insight

DREAMS:START is funded by the National Institute for Health Research and supported by our Research Network. Network volunteers use their personal experiences of dementia to influence dementia research.

'Members offer a unique insight which motivates researchers and helps them to understand the priorities of people affected by dementia,' says Anna-Louise Smith, Research Engagement Manager at the Society.

Rossana Horsley is a Research Network volunteer who cared for her mother with dementia for three years.

'Sleep was a major issue. She would get up at night distressed and it was hard to calm her down, so my sleep was completely savaged,' says Rossana.

'The research really spoke to me, so I wanted to help if I could.'

Rossana has supported DREAMS:START in many ways since it began in 2015. This includes helping to shape the feasibility study and ensuring that resources – such as the manual used in sessions – are as user-friendly as possible.

'Sometimes research can be a bit technical, so I'm very much

presenting a lay person's perspective,' she says. 'I'm helping to re- ne things and put them into more accessible language. It feels my contribution is worthwhile.'

Get involved

Another Research Network volunteer, Jane Ward, is a carer of eight years who continues to experience issues with sleep. Her involvement in DREAMS:START has included advising on the recruitment of people to take part.

'We've discussed how to promote the study to groups who may not normally hear about research,' she says. 'We've also talked a lot about how people often don't understand that research isn't just about sticking

I was given a past copy of Dementia together magazine at a memory café and spotted a small paragraph promoting the priority service registers kept by water, gas and electricity providers.

I would strongly encourage people to register if they have health problems of any sort or are simply older. Although I cannot speak for gas, water or electrical distribution network operators (DNOs) other than Western Power Distribution, I have been a member of their customer panel for a long time and can assure you that they will look after you very well indeed.

The service is willingly and cheerfully given. Indeed, Western Power Distribution will offer advice and put you in contact with the appropriate people even for problems beyond loss of power. Once on their priority service register, people will be warned of potential losses and asked if they will need help. If they are critically dependent on electricity, a generator will appear within hours of a loss. For long outages, further help will be made available including hot meals via the Red Cross. Their staff are very well trained indeed and know how to approach someone with dementia. If you look at their control centre displays at house level, the houses of people with dementia are marked with a red heart!

To avoid any confusion, the DNO owns and operates the public electrical distribution network – all the poles, wires, underground

cables, substations etc right up to your house switchboard. You never pay the DNO directly – they charge the electricity supplier, who you pay.

The DNOs are trying to ensure that they have a common register with the gas and water people, although this is complicated by supply areas being different as well as by current data protection regulations. You will never be approached for commercial purposes when you are on the priority service register, although you will be phoned every two years or so to check that you still need to be on the register and that you are still present.

Michael Rowe, Somerset

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

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

The type of extra support depends on where you are – contact your electricity, gas and

Seen elsewhere...



When Feyi Raimi-Abraham couldn't find reminiscence products that were culturally relevant for her mother, who grew up in Trinidad, she set up the Black Dementia Company. They produce puzzles and activity books with imagery and topics selected specially for people with African or Caribbean heritage.

These are now available through our online shop and – with the help of Anndeloris Chacon at Bristol Black Carers and Trish Caverly at Bristol Dementia Wellbeing Service – we sent a range of them out to be tested by people at home.

Vintage images

There are seven 16-piece jigsaw puzzles, each with a vintage photo from a carefully chosen place and time – Trinidad 1960s, Nairobi 1960s, Shitta-Bey Mosque 1960, Caribbean 1963, Ewa, Lagos c.1950, Friends in Lagos c.1961 and Government Road, Nairobi 1957.

The people we contacted through Bristol Black Carers liked and identified with the packaging of all the products. They said it looked appealing while being clear about what's inside.

A carer said, 'The cover got my attention because it had Black people featured on it' – something specifically mentioned by one person with dementia too.

'Mum is enjoying the puzzles,' said another carer. 'We like the size of the puzzle, it's perfect.'

Many carers said the large jigsaw pieces were helpful, and a person with dementia commented, 'I find the puzzle pieces brilliant and easy to use.'

The puzzles all use photos that are either black and white or with limited colour, and this was also appreciated by our testers.

'The colours in black and white and it make things easier,' said a person living with dementia.

Although one carer said that helping their mother hold the pieces was straightforward, it was difficult to get her interest because she wasn't used to doing puzzles. However, they went down well with most of the people who tried them.

'My husband likes doing the puzzles and so does it as and when he got the time,' said one.

Pictures and words

The Tropical Colouring Book and Tropical Colouring Book Volume 2 each contain over 30 pages with illustrations of flowers, people and more that resonate with African and Caribbean cultures. They also have blank areas that can be used to draw more pictures.

The Wordsearch and More Book includes puzzles with tropical-themed words to be found in them, as well as short quizzes.

Our Bristol Black Carers contacts thought the colouring book images were great. One person with dementia said, 'Because of the size, it was easier to stay in the lines and there are a

lot of different drawings.'

Another said, 'It brought back memories for me as a child doing the colouring.'

Another Actual Inj memories fAnoter 1Bynd Ca

Twdrum

'The illustration of the hummingbird brought out a lovely conversation about the French name for the hummingbird, and the lady in the traditional dress reminded him of his mum, who was a seamstress, sewing dresses for the ladies back home.'

Of those who tried the wordsearches and quizzes,

Jan Hall's Dementia Essentials,

Eating and drinking factsheet

Our Eating and drinking (511) factsheet looks at ways dementia can affect eating and drinking, as well as tips to address the difficulties that a person with dementia may have. Visit [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications) or call 0300 303 5933.

The Memory Kitchen

An ebook from live-in care providers Qualitas Vitae Care features more than 70 illustrated recipes alongside helpful advice to deal with mealtime challenges. Buy for £9.75 from www.memorykitchen.store in PDF, Kindle or epub formats.

Anyone can get into debt, but managing money can become especially difficult as a person's dementia progresses. They might buy things they don't need because of memory problems or compulsive behaviour. They may also have extra bills – such as for care – and less money to pay them with.

Does the debt still count?

Generally,10 <



The 'perfect carer'

Next issue

Jigsaw puzzles

We have a Caribbean 1963 puzzle from the Black Dementia Company for one lucky winner and Friends in Lagos puzzle for a second drawn from correct entries received by 9 September, with Sister Grace cotton tea towels for five runners-up.

Q: What is soursop?

- A. A game.
- B. A type of dress.
- C. A fruit.



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

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

Book giveaway

See p35 for a chance to win a copy of *Love and Care*, by Shaun Deeney.



Book giveaway

The five readers who each won a copy of the updated *Dementia Essentials*, by Jan Hall, were AM Bird in West Midland, T Jolley in South Yorkshire, C Donnison in Northumberland, P Skeete in Greater London and C Morgan in Gwynedd.

Memory Walk T-shirt

We have Memory Walk T-shirts for three winners drawn from correct entries received by 2 September, and Memory Walk wristbands for five runners-up.



Q: Memory Walk is:

- A. Free to sign up for and open to everyone.
- B. Only for readers of *Dementia Together* magazine.
- C. Only for people who can run a marathon in high heels.

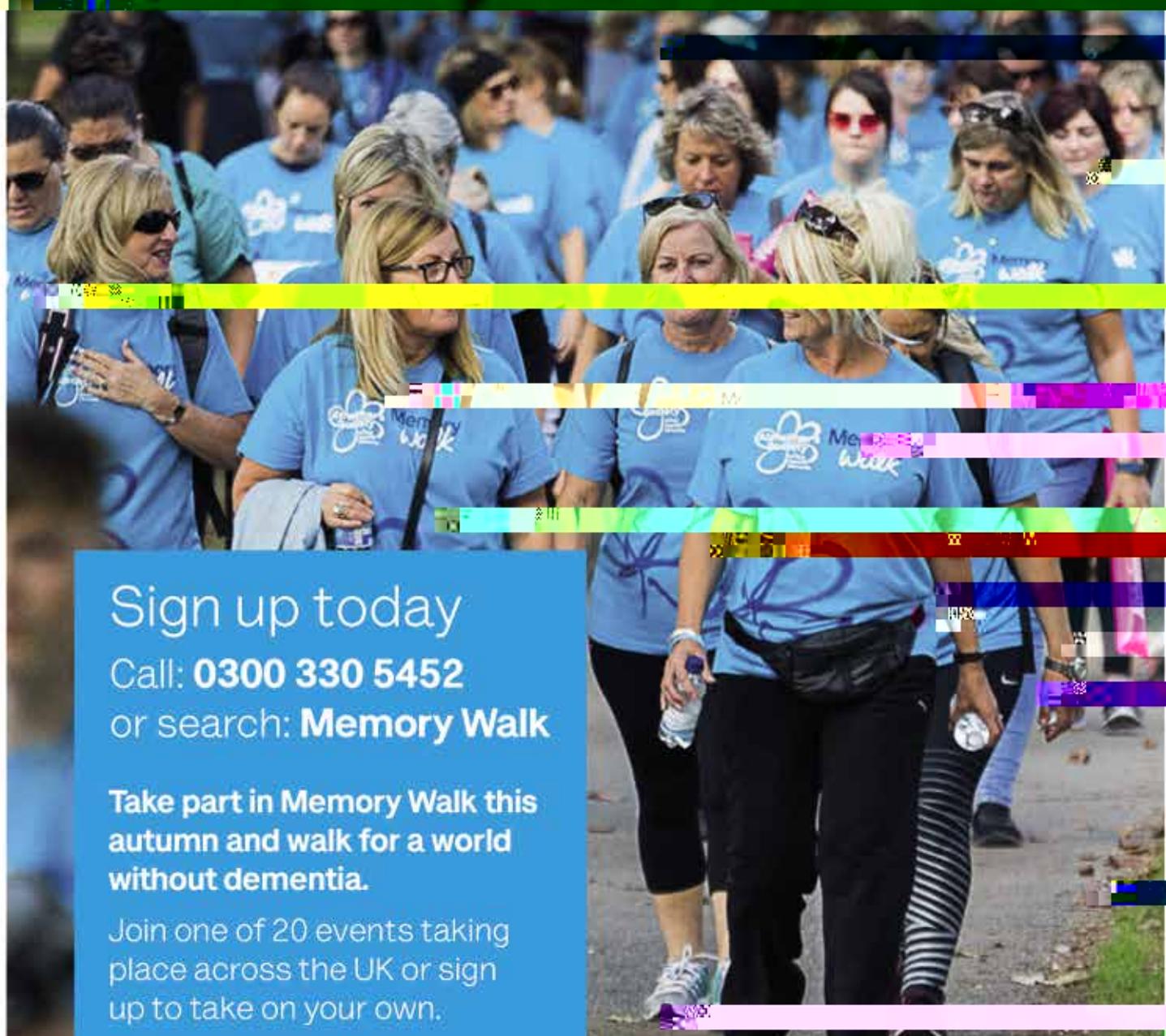
Better together mug competition

J Millar in Cheshire, D Hawkins in South Yorkshire, A Cross in Orkney, A Redhead in Northumberland and G Mortimer in West Yorkshire each won a Better together mug. Answer: The English words 'tea' and 'coffee' came to the language from Dutch.

Talking thermometer competition

T Jolley in South Yorkshire won an Ear and Forehead Talking Thermometer and S Thomas in Essex won a Non-contact Talking Thermometer, while P O'Leary in Greater London and A Redhead in Northumberland won pan pickle sets. Answer: A high temperature is usually considered to be 38°C or more.

Who will
you walk
for?



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

Take part in Memory Walk this autumn and walk for a world without dementia.

Join one of 20 events taking place across the UK or sign up to take on your own.

Who will you walk for?



Alzheimer's Society is registered charity no. 296645

