December 2025/January 2026

# Dementia together

Alzheimer's Society

## In this issue

Moments of joy, staying hopeful, finding lost accounts and much more

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# Welcome

**Who do we have in mind as readers when we're planning and creating Dementia together magazine?**

We're thinking of people living with dementia and the carers, family and friends around them who are dealing with the condition each day. Those of you who benefit from a new magazine arriving – to know you're not alone, and for ideas to improve your own and others' lives.

That could be from seeing someone else finding hope and joy despite the challenges of their situation. It may be from seeing that other people also have the kinds of struggles that you do.

It can also be from learning where to get more advice and support – or perhaps a reminder to reach out when you need that help. It might be from being inspired to get involved and have your say in various ways.

I hope this issue of the magazine provides the feeling of connection and the inspiring ideas that could make a difference to you today.

Whatever you get from the magazine, we want to make sure it's as helpful, relevant and interesting as it can be. If you have any comments or ideas, then we'd love to hear from you – please use the magazine contacts below.

**Danny Ratnaike, Magazine Editor**

## Need support? Call 0333 150 3456 or visit alzheimers.org.uk/getsupport

Dementia together is the Alzheimer's Society magazine for people dealing with dementia day to day. Contact us on **magazine@alzheimers.org.uk**, **020 7264 2667** or **020 3929 5117**, or write to us at Magazine Editor, Alzheimer's Society, Suite 2, 1st Floor East Wing, Plumer House, Tailyour Road, Plymouth PL6 5FS.

Sign up to get each new magazine by email or – if you're in the UK, Isle of Man, Channel Islands or Republic of Ireland – in print or on CD through the post. Please email **magazine@alzheimers.org.uk** or call **0330 333 0804** to subscribe or update your details.

You can also sign up to the print magazine at **alzheimers.org.uk/subscribe**

See **alzheimers.org.uk/magazine** for online articles, the latest PDF and podcasts.

SCAN ME

## Donate

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**You can also donate online or call 0330 333 0804.**

Funds raised by players of People's Postcode Lottery support the production of Dementia together magazine.

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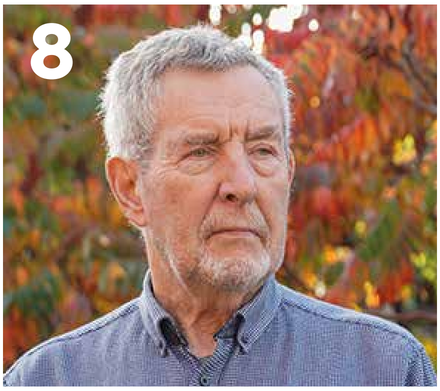
Fundraising and general enquiries 0330 333 0804.
Alzheimer's Society is a registered charity in England and Wales (296645) and the Isle of Man (1128).

# Contents



# Directions

**I am thrilled to be Alzheimer's Society's new Chief Executive. The weeks since I joined have already filled me with inspiration and hope.**

Three of my grandparents had dementia, so I have no illusions about the human impact of this cruel disease. As the leading cause of death in the UK, the challenge that dementia presents to all of us is enormous. But there is a real sense right now that the stars are aligning, a real sense of hope from all the research that is coming to fruition.

The Society, with its work spanning research, support and influencing, is in a unique position to understand and respond to this, so leading the charity at this pivotal time is a great opportunity.

As I start my role, it is a priority for me to get out and meet some of the amazing people involved in our vital support and groundbreaking research.

So far, this has included a visit to Merton Memory Hub in south London, where people affected by dementia get all kinds of one-to-one and group support in an environment designed especially for them.

I have also met brilliant researchers at the UK Dementia Trials Network, the University of Cambridge and Queen Mary University of London. Along with many others, their innovative work is creating a future where dementia no longer devastates lives.

I am so impressed by the scale and ambition of what we are doing together, and I look forward to meeting many more of the people – like you – who make this possible. Thank you!

**Michelle Dyson,**
**Chief Executive**

# News

## New BSL support

Alzheimer's Society is now using video interpretation to make sure that people who use British Sign Language (BSL) can access our advice and support.

Deaf BSL users can now contact our Dementia Support Line using SignVideo, through our website or the SignVideo app. This means they can get advice and support from our dementia advisers through a video call with an interpreter on their phone, tablet or laptop.

Our dementia advisers can also use the service to support conversations in BSL during home visits.

We've been working with the British Deaf Association and people from the Deaf community, including those affected by dementia. We're developing our dementia information in BSL and training our frontline teams.

Visit **alzheimers.org.uk/accessible-options** to find out more about SignVideo, Text Relay and support in languages other than English.

## Reimagine Christmas

Although Christmas is meant to be a time of fun and celebration, it's a challenging time for millions of people affected by dementia in the UK.

Changes in routine over the festive period can be overwhelming for people with dementia and create extra pressures for their carers.

In the lead up to Christmas last year, 23,000 people called our Dementia Support Line for advice.

But we believe that with support from our services including our Dementia Support Line and dementia advisers, families affected by dementia can begin to 'reimagine' a joyful Christmas once again.

Look out for our new campaign called Reimagine Christmas, featuring Lesley and her three daughters Katie, Emma and Laura.

# Pitch perfect

Football fans with dementia made history at Wembley Stadium in October. They joined England and Wales players on the pitch before the Alzheimer's Society International.

As part of our partnership with the Football Association, 22 'mascots' walked out alongside players, who also wore special shirts with missing names in the second half. Read Susan's experience of being a mascot on page 13.

# Dementia priority in Wales

We hosted an event at the Plaid Cymru conference in October, along with health spokesperson Mabon ap Gwynfor, to underline the importance of a new Dementia Action Plan in Wales.

With elections to the Senedd (Welsh Parliament) in spring 2026, events like this are an important way to hold politicians to account and ensure dementia is prioritised.

# Party conferences

Alzheimer's Society was at Labour, Conservative and Liberal Democrat party conferences this autumn, making sure decision makers understand the impact of the UK's biggest killer.

Thanks to the thousands of you who contacted your MPs to urge them to meet us, we spoke with over 120 of them.

This included high profile politicians, such as Secretary of State for Health and Social Care Wes Streeting, Minister for Care Stephen Kinnock and leader of the Liberal Democrats Sir Ed Davey.

We also met with many councillors and other attendees, including Eluned Morgan, First Minister of Wales.

# NI health meeting

We used our second meeting with Mike Farrar, Interim Permanent Secretary of the Department of Health, to highlight a need for better facilities and greater investment in Northern Ireland.

We spoke about the lack of research facilities and the need to invest in scanning equipment, so dementia can be diagnosed earlier and more accurately.

We agreed that dementia must be prioritised as the government plans its budget, and that lasting change requires continual investment.

Join us as a campaigner and help us challenge and change the issues faced by people living with dementia – visit **alzheimers.org.uk/campaign**

# Fast and accurate MRI scans

A study part-funded by the Society has shown it's possible to cut the length of an MRI brain scan from 20 to under 7 minutes to diagnose dementia accurately.

With further testing, this could be an important step in making scans more widely available, reducing costs and improving people's experiences of diagnosis.

MRI scans help to rule out other things that might be causing a person's symptoms. MRIs also help to identify what type of dementia they have.

With more disease-modifying medications entering clinical trials than ever before, it's likely more people will need MRI scans both before and during treatment.

The study at University College London tested a faster method of scanning in a real-world memory clinic. Importantly, specialists reviewing the shorter scans reached the same conclusions as they did using standard scans.

The team is now working to adapt these faster scans for use across different MRI systems, with the aim of making them available in clinics everywhere.

Richard Oakley, our Associate Director of Research and Innovation, says, 'While MRIs aren't the only way to diagnose dementia, very few people with concerns about their cognitive health are offered one as part of the diagnosis process, mainly because they are expensive and not widely available.

'So far, this shortened MRI scan has been tested at one specialist centre with one type of MRI scanner, so more research is needed to make sure this works across different types of scanners and a diverse range of people. We're hugely encouraged by this progress and eager to see how it continues.'

# New Accelerator Programme partners

We're excited to welcome three new partners to our Accelerator Programme.

Over the next year, they'll receive our support to grow their businesses so that they make a difference for people affected by dementia faster.

Kneu Health is a smartphone app that helps people monitor and manage their dementia symptoms.

Hydro Care, a digital tool for the toilet, helps carers remotely track hydration levels and spot changes.

Finally, Neuroresponse is a service that gives people better access to healthcare professionals, so urinary tract infections can be detected earlier.

We help Accelerator Programme partners with investment, learning and other support.

Find out more about our Accelerator Programme at **alzheimers.org.uk/accelerator**

# Monzo milestone

A huge thank you to the thousands of Monzo customers who've helped us raise £30,000.

In 2024, we were selected to be one of the charities Monzo customers can donate to using their banking app.

That means it's super-easy for people to donate to us and support our vital work.

If you use the Monzo app or know someone who does, find us in the list of charities when you tap the 'Donate to charity' button on your home screen.

# New running partnership

Photograph: Andy Bate

We're proud to have been selected by AJ Bell as the official charity partner of its Great Run Series in 2026 and 2027.

This includes the Great North Run from Newcastle upon Tyne to South Shields – the biggest half marathon in the world – the Great South Run in Portsmouth and others.

When you run for Alzheimer's Society, you're running to support people facing their biggest challenge, to fund groundbreaking research and end the devastation caused by dementia.

Find your nearest AJ Bell Great Run at **alzheimers.org.uk/aj-bell-great-runs** or call **0300 222 5808**.

# See us in healthcare hubs

We've launched a new campaign in healthcare hubs across the country to reach people who need our help but don't know about us yet.

You'll notice our posters, leaflets and ads on digital screens in pharmacies, hospitals and GP surgeries.

We're making sure that more people than ever know that we're here for them, and that they can access our advice and support.

## Listen to our podcast

Hear people speak for themselves in our Dementia together podcast.

We release a new episode with each issue of the magazine, filling in extra details told in people's own voices.

The last episode featured Robin and Kathy, the first-place winners of our 2025 poetry competition, and a new episode will be out in early December.

Listen at **alzheimers.org.uk/podcast** or subscribe on your podcast app – search 'Alzheimer's Society' to find us.

## Memory Walk

This autumn, almost 16,000 participants laced up their trainers and took part in Memory Walks across the country.

Several hundred organised their own Memory Walks with family and friends.

Our walkers faced every type of weather from blinding sunshine to fog, dark clouds and pouring rain.

But nothing could dim the smiles of our walkers – we're in awe of your determination.

So far, our amazing walkers have raised over £1.9 million, which will go towards funding innovative research and life-changing care. Thank you to everyone who took part, volunteered or contributed!

## Online LPAs and CHC appeals

Need help making a Lasting power of attorney (LPA) but can't access the online form or a printer? Our free digital assistance service can support you.

You'll have to pay the Office of the Public Guardian £92 for each form when you register your LPAs with them, unless you qualify for a reduction or exemption. If you're making a health and welfare LPA and a property and finance LPA, that's two forms.

We can also offer guidance if you're appealing a decision about NHS Continuing Healthcare (CHC).

Call our Dementia Support Line on **0333 150 3456** to find out more about our LPA and CHC support services.

## Care & Dementia Expo

Learn about latest developments in dementia care at the Care & Dementia Expo at the NEC Birmingham on 25–26 March 2026.

Taking place in partnership with Alzheimer's Society, it's part of a bigger disability, accessibility and independent living event called Naidex.

Care & Dementia Expo tickets are free, and you'll hear from dementia experts, find out about useful training and more.

Book your free tickets today at **naidex.co.uk/careanddementia**

## Welcome to our research nurses

We're excited to welcome our first dementia research nurses, who'll help to encourage more people affected by dementia to take part in research.

They are part of the UK's first dedicated team of dementia research nurses. The team is located over 20 locations, through our £3 million three-year pilot alongside the UK Dementia Trials Network.

Sittana Abdelmagid (pictured), Dementia Research Nurse at University College London Hospitals, says, 'I hope my role will give people living with dementia and their families a stronger voice in research, empowering them to feel included, valued and supported.'

## Don't miss...

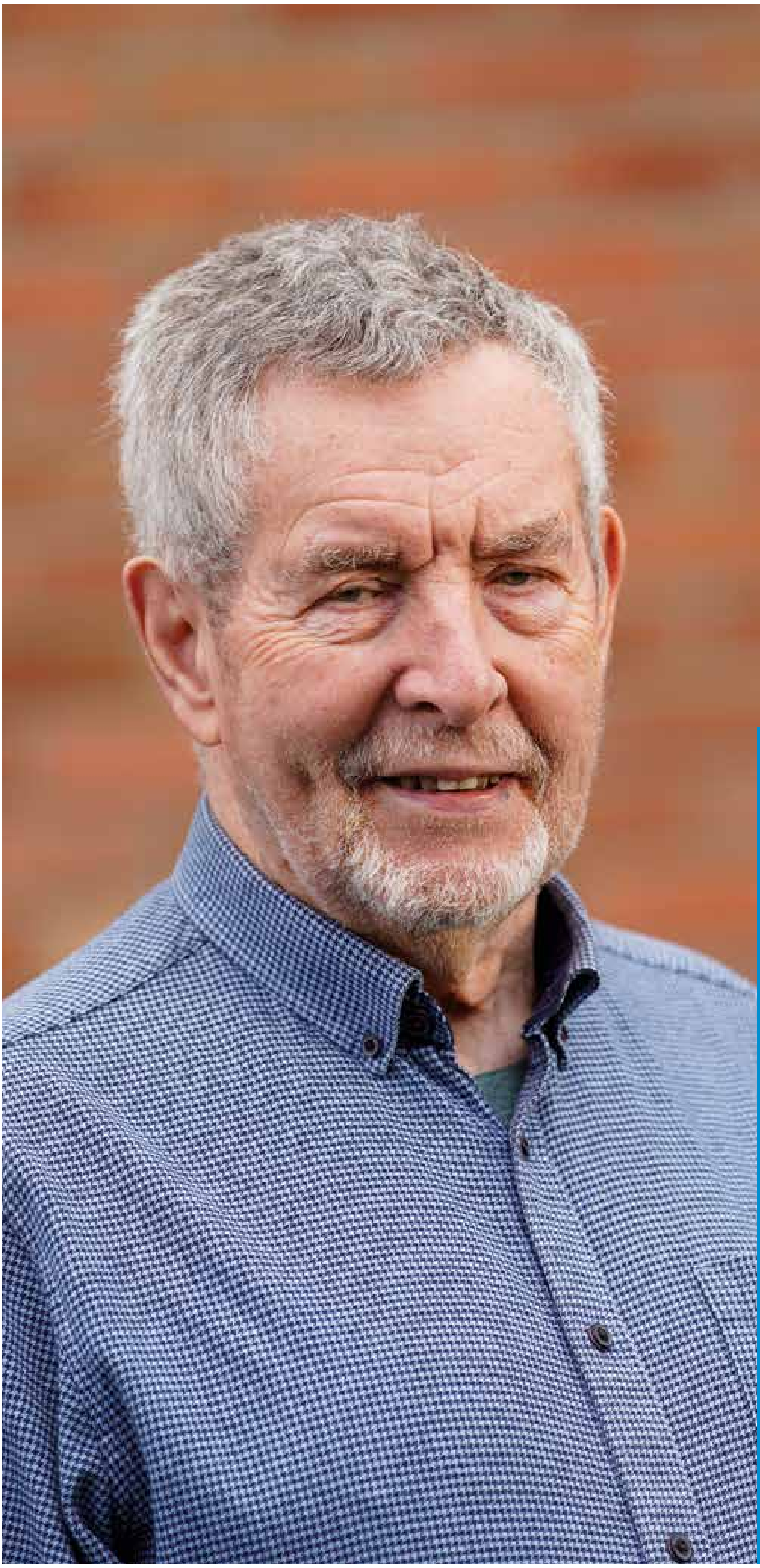
Julie and David say everyone should receive dementia support at the point of diagnosis. **See page 17.**

How can you take part in research? Every mind matters for dementia research! **See page 21.**

Dementia Disco brings people of all ages together to dance, sing and enjoy. **See page 24.**

People affected by dementia let us know what they think about gift ideas from our shop. **See page 28.**

How can you trace someone's accounts and investments if they've appointed you as their attorney? **See page 34.**



Photographs: Alistair Heap

## Quick read

**Ian Johns, in Bristol, has dementia with Lewy bodies and tries to keep a positive mindset.**

**His diagnosis came after a series of distressing events, following by months waiting for scans and results.**

**He and his wife Jane focus on moments of joy and finding opportunities to do things that are meaningful.**

**They take part in the Time for Dementia programme to help educate future healthcare professionals.**

# Much to live for

**Ian Johns, in Bristol, has a positive approach to living with dementia with Lewy bodies. Margaret Rooke hears how he and his wife draw on moments of joy and achievement.**

**Anyone looking for ways to feel upbeat while living with dementia may have something to learn from Ian Johns.**

At 82, he lives with his wife Jane, who's a retired teacher. The couple describe what they call their 'golden moments' – times that feel like blessings and stop them giving in to difficult feelings.

Ian, who has dementia with Lewy bodies, says, 'I would say without question, that having a positive mindset has worked for us – and we've done this together.'

'It's simple things,' adds Jane. 'When we're out, it might cost a tenner, but we'll have a coffee or go for lunch. We might have just spent a lot of money on a new Hoover, but we're still going to have lunch out.'

## Precious time

Ian knows why this way of living in the moment is so important to him, and it's not just because of dementia.

When Ian was 26, his father died at 53 of a heart attack, with no warning. A tragedy that, 56 years on, still reminds him that the time we have is precious.

Ian grew up in Pontypool, South Wales, then a town reliant on heavy industry and coalmining. His mother was determined he would not be a miner.

Instead, Ian took an apprenticeship in electrical engineering and started a successful career, including 10 years at a local hospital.

'Believe it or not, my job title was "exceptionally skilled electrician",' he laughs.

'Only 10 or 12 of 2,000 electricians in the health service had "exceptionally skilled" status. It was because the hospital had its own generators and its own coal – quite a set up, and I felt like I was doing something positive.'

Ian also had an interest in lift engineering and moved to London for a new job. There he also found the love of his life.

'I hit the jackpot and met Jane,' he says.

## Fixing faults

Ian spent the rest of his working life driving from one broken-down lift to the next.

'I'd be in north London, then Torquay, then Birmingham. Now faults can be fixed by pressing a button on a computer, but not then.'

The couple moved to Bristol, and now have two sons and two granddaughters.

'I never thought I'd see you with a crown on your head. Our eldest granddaughter's properly into princesses,' says Jane, who's 68.

'She loves the rough and tumble, too. We had great fun in the summer in the garden.'

When Ian's own boys were young, he often saw them only at weekends.

'I'd be gone at perhaps 6am and get home at 7.30pm. But when I could see them, we did a lot. We went to London and the Natural History Museum, the Tower of London, Imperial War Museum, the V&A...'

Ian passed his love of rugby and love of music to his sons, one of whom is a bass guitarist.

> **Believe it or not, my job title was "exceptionally skilled electrician".**

'When he was younger,' says Ian, 'I was his roadie, driving him to different venues, including Glastonbury and the Secret Garden Party.

'Once we waited until 4am in an empty Tesco car park until we could pick him up, with the police keeping an eye on us.'

Jane adds, 'You were always doing something for them. "Dad the electricity isn't working", "Dad my car's not working", "Dad I've got a puncture and the wheel won't come off." You turned up and sorted it out.'

'I never hesitated,' explains Ian. 'Probably because I was an only child, and I had to look after myself. There wasn't anyone to help me.

'Obviously I wanted to keep the boys safe, so I didn't see it as a burden.'

## New struggles

Ian has always been someone who can fix and mend. But then he noticed he couldn't do everything he used to, and he struggled with his memory.

'I'd put something down and couldn't think where it was.'

The couple put this down to age, but then saw that his reflexes when driving weren't as sharp.

Next Ian suffered a psychotic episode, becoming obsessed with a minor financial issue to the extent that he became incoherent.

'The hospital found a urinary infection and a respiratory infection,' Jane reminds him.

'You were having the most shocking hallucinations. You said I wasn't your wife, I was an actress.

'You turned into a shell of a man, shuffling along. I didn't think I'd ever get you back.'

Ian was 'sectioned' twice. 'I had two blocks of ECT treatment, one of 13, one of 14. It's not nice to have.'

## Being diagnosed

Their next struggle was to find out what was wrong with him.

The infections were long gone. Ian waited eight months for a brain scan. Two months after that, the doctor confirmed dementia with Lewy bodies.

'When I first heard, it was just like hearing a number, I think because things happened so gradually,' says Ian.

'Since then, we've gone to various groups and seen people who are much worse off than me, and then it hits home.

'When you're young and healthy you think you're indestructible. As you get older, this door shuts and another door shuts.

'Other doors are still open, but it's finding them. I'm fortunate because Jane is superb.'

Jane says, 'A day or two after the diagnosis, we agreed we were going to make the most of it. We would find things we could do.

'We used to love going to the cinema. Now we watch films at home so we can pause them, and I can explain them. The other day we went to the cinema during the daytime when it wasn't busy.'

Ian agrees, 'You have to say, "Right, we are going to do this."

'Next weekend we're going to a wellbeing gym to use some resistance machines.'

## One thing at a time

Some days the couple wake up and feel that there's a mountain to climb. Then they do one thing at a time – brush their teeth, get dressed. Before they know it, they are into the day.

'Then the black mood has lifted,' says Jane, 'just by changing your approach.'

'It's easy to say, "I'll lay down for another 10 minutes,"' says Ian, 'Instead I cut the lawn, get up in the attic to put stuff up there…'

They have a daily planner for tasks that need to be done.

'It keeps us ticking over,' says Ian.

'The hardest thing for me is not driving,' he says. 'I passed my test at 17 and I've driven in all different countries.

'But you can never act as if life is over. If you have a family and they're healthy, that's all you can ask.'

Ian and Jane have been helped by information on the Alzheimer's Society website and links to local support groups.

They're also involved in educating students, including mental health nurses, occupational therapists and physiotherapists, through Time for Dementia.

One example they use with students is how Ian is more confident about a train journey if he knows the layout of the carriage in advance, where they'll sit, and where the doors and toilets are. Jane draws a map so he can orientate himself.

Similarly, a person with dementia might need to understand the layout of a consulting room.

Ian adds, 'I've told them you've got to give us a second to process something. And don't start shouting. We can hear, you know.'

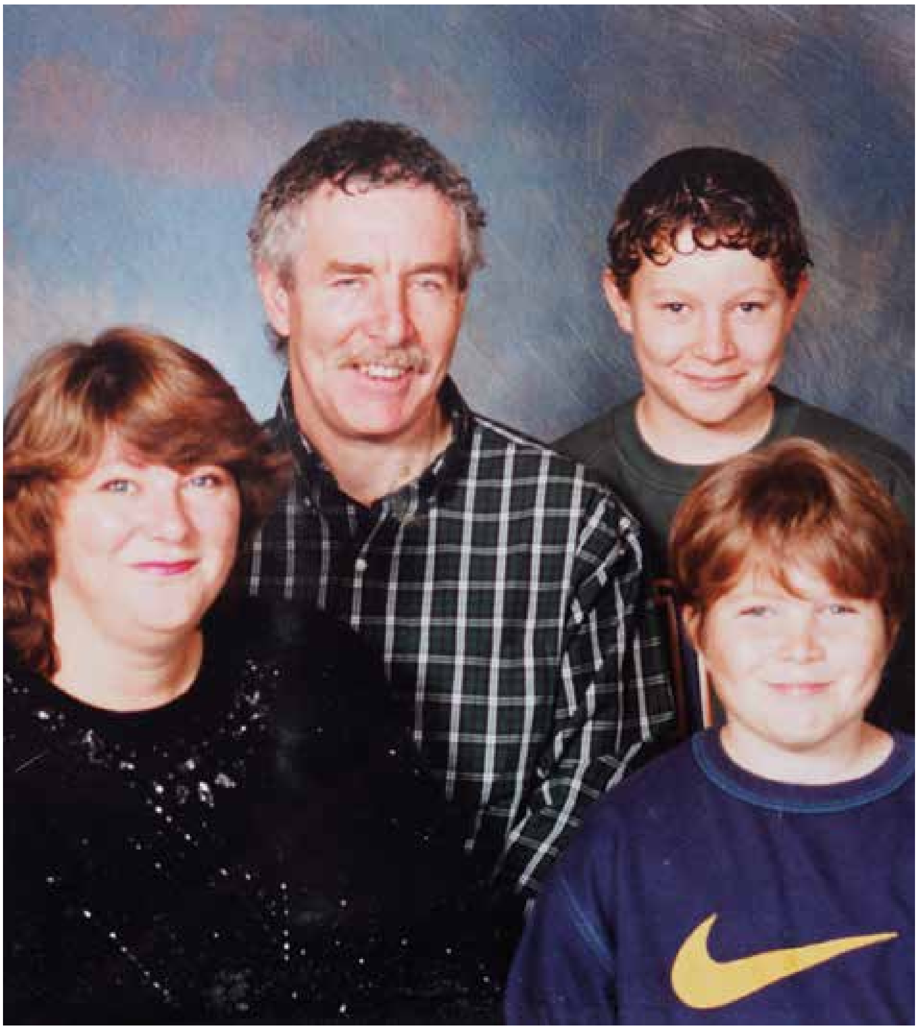
### No pressure

Ian is proud of his first-class lift repairs. He's proud too of how he's coping with dementia.

'A lack of confidence is a heavy thing. You think, "Should I do this, or should I leave it for someone else?"

'You have to have confidence and sometimes you need someone to help you. It takes longer to get there, but there's no pressure.

'We can never say, "We've got this diagnosis, life is over." We look at our life and the positives and dismiss the negatives one by one. We have too much to live for.'



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

Help improve future healthcare professionals' understanding through Time for Dementia – visit **alzheimers.org.uk/TimeForDementiaTogether** or call **07562 430204**.

## Donate

Your donation helps us to support more people like Ian to live as well as possible. **Donate online** or call **0330 333 0804**.

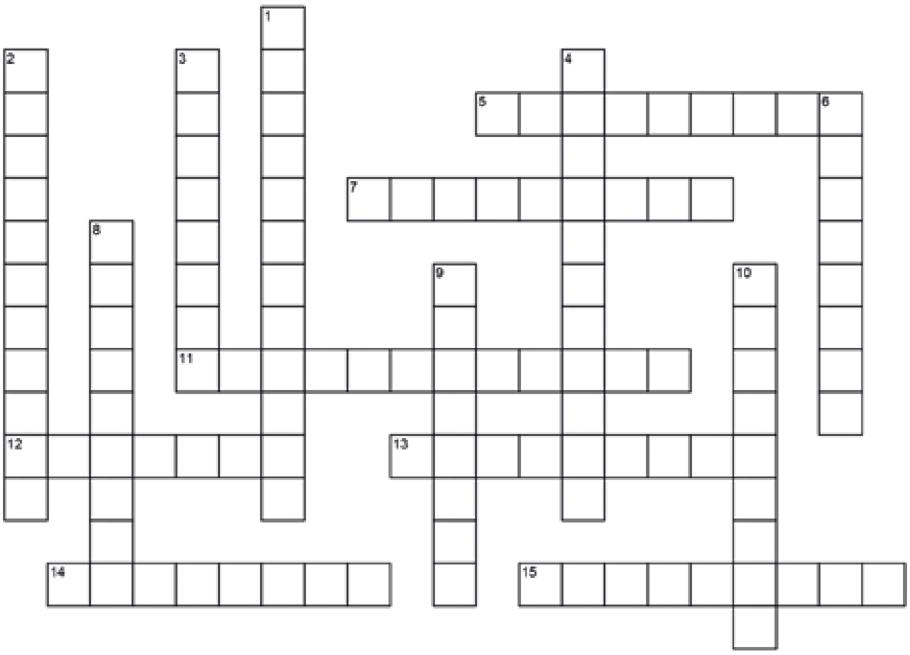
# Share and inspire

**Views, updates and ideas – for and by you.**

## Anagramword: Favourite foods

Pete Middleton has favourite foods on his mind, something many of us can relate to! Each clue begins with words that are an anagram of the answer, along with a clue to its meaning. How many can you solve?

(answers will be in next issue – see page 39 for the answers to last issue's puzzle)



**ACROSS**

**5** Shout 'dung' and tuck into these tasty jam-filled beauties (9)
**7** Cool cheat becomes a comforting confection (9)
**11** All sour gases are very popular in Greggs (7,5)
**12** Heard CD, then enjoyed this and some crackers (7)
**13** No racists enjoy this French breakfast treat (9)
**14** Is it cubs? No, it's those things we love to dunk (8)
**15** Bury rebel often found in a muffin (9)

**DOWN**

**1** Crikey! Crunch! I didn't expect that with my takeaway (7,5)
**2** Oddest PC kit makes a traditional steamed pudding (7,4)
**3** New biros can be made into a chocolatey traybake (8)
**4** I flung shell to make this traditional breakfast (4,7)
**6** Dash in WC to eat a BLT (8)
**8** Past eight, yet not too late for this pasta dish (9)
**9** Mice race to eat this dessert (3,5)
**10** Eat for BSE carved up and served as a Sunday roast (5,4)

## Correction: The wrong spoon!

Apologies to anyone who tried last issue's spicy date and walnut cake recipe and was confused by an error we made in the list of ingredients.

As one reader, Rose, helpfully pointed out, half a tablespoon of bicarbonate of soda would have been far too much! Of course, it was meant to be half a teaspoon (as it was in the original recipe of her mother's that Pat had shared with us).

See pages 36–37 to read about Rose's own mother's recipe collection and to try a simple dessert idea from Del and Margaret.

## Share

Share your views, feedback and news – please email **magazine@alzheimers.org.uk** or write to the address on page 2. We can consider contributions received by 5 January for the February/March issue (wording may be edited).

# Never done before: Football mascot

**Susan Kelly in Bristol was one of 22 'mascots' at the Alzheimer's Society England v Wales international friendly (see page 5):**

I love football, my team is Bristol Rovers. I regularly go to matches but I've never been a mascot or even dreamed about it. I thought it was just for small children, not grown-ups!

I go to a dementia group once a month and Jane, who organises it, knows I like football and said, 'Would you like to go to Wembley?'

I jumped at the chance, but I didn't know I was going to be a mascot at that stage. I found out about that later.

## Surprise and excitement

It was a shock to be asked about being an Alzheimer's Society mascot, but I wasn't nervous about it. I was just surprised they'd chosen me.

I don't think I have inhibitions anymore. I don't worry about things. I just do what I have to do, stay busy and enjoy life. I've got dementia but I still want to keep doing stuff.

I would encourage people with dementia to give new things a go. Dementia can open doors.

I go into schools and talk to pupils about dementia – that's an opportunity I wouldn't have had otherwise.

And I definitely wouldn't have had the mascot experience without dementia.

## The big day

The whole day was so exciting and it was great to share it with my sister Sandra, who was invited too as she's classed as my carer. We were treated like VIPs all day. I will never forget walking onto the pitch and singing the national anthem for as long as I live.

> **“I will never forget walking onto the pitch and singing the national anthem for as long as I live.”**

The sound of 78,000 people was absolutely immense. I remember lots of young people waving to us as we walked out of the tunnel, I loved that. I didn't feel any nerves.

I was just trying to soak up the atmosphere!

I walked out with England's goalkeeper, Jordan Pickford, and we were behind Declan Rice.

I said to Jordan, 'Can I hold your hand?' and he said, 'Course you can.'

He was absolutely wonderful and really supportive.

He kept putting his hand on my shoulder to make sure I was alright and pointing to where we had to go.

It was great being with the other mascots. We've all got dementia but different types and we're at different stages, but we felt like a little family.

The whole event was a great way to raise awareness.

For people in the crowd and at home to see us walk out, and then for the players in the second half to have nameless shirts, was so powerful and will have started lots of conversations, I'm sure.

## Treasured experience

I keep looking at photos from the day. I kept my T-shirt and I've got a few programmes. Sandra's kept her pass and she says that she's been converted to football now!

As well as all the memories, I made a good friend that day, Shelly, one of the other mascots who is a big Norwich City fan. We're going to stay in contact.

I've been recognised by a few people since the day, which is funny. It doesn't bother me that more people know that I have dementia.

I can't thank everyone involved in organising the day enough. Everyone was just so warm and wonderful. It was simply an amazing experience.

# Onset, diagnosis and now

## Sue Beeson, in Worcestershire, shares thoughts about life before her dementia symptoms, before diagnosis and since.

### Who were you before onset?

I had a busy career in teaching and then in training. I was a primary school teacher and a head teacher in two schools, before I stepped back from teaching in my early 50s.

After this, I went into consultancy, specialising in staff development for schools and businesses, and became managing director of a small company before retiring in my 60s.

I'm someone who likes to stay busy and creative, so my retirement was full. I've always been musical, playing the piano and harp and singing, as well as being an avid reader, writing poetry and prose, gardening and caring for various pets.

I lived overseas as a child and we didn't have a TV, and I think that activities such as reading, writing and art were embedded in my brain then.

### Who were you before diagnosis?

I was volunteering lots of my time, including supporting with horse riding lessons for people with disabilities.

But I noticed I was getting forgetful and, having experienced dementia in my family with my grandparents, parents and uncle, I went to my doctors.

Initial tests found that I was in the right parameters of memory capacity for my age. But I was eventually diagnosed in 2023 with the Big A, my pet name for my new life companion. I knew what was coming and tried to face it in a grounded way.

While I was a head teacher, I trained as a counsellor and learned 'solutions focused' techniques.

This continues to influence my approach to life. You can choose to stay on 'Problem Island' or get a new boat and work out a way forward, which is essentially what I did when I got my diagnosis.

### Who are you now?

I'm still me, just more tired, often confused and grumpy when I forget where things are!

Creativity is still part of my life. I write poems and prose about my experiences of the joys of ageing and living with dementia.

I had a stroke last year so, while I can still (just about) sing and play my instruments, I've lost a lot of my 'finger memory' and the ability to sight-read music and words together. I've begun to re-home my instruments and no longer sing in a choir, but I still enjoy listening to music.

I've continued to volunteer – one of my dogs is a therapy dog and I take her into a local primary school twice a week to provide support for the children and staff.

My partner passed away earlier this year and I'm adjusting to this sudden change. I'm in the process of moving into supported housing. I don't want my daughter to go through what I did persuading my parents to move, so I am taking the lead.

I'm determined to raise awareness about early dementia diagnosis and to support fundraising. I've been fortunate to get involved in various projects through the Association for Dementia Studies at the University of Worcester, our local dementia service and Alzheimer's Society.

After a diagnosis, it's too easy to sit and say, 'Oh poor me, I can't do this or that.'

I take each day as it comes, reminding myself that the only constant is change and that there are thousands of people in a worse place than I am. I try to keep facing the sun – my friends, family, pets and hobbies – that way I don't see the shadows!

## New Black, African and Caribbean group

We're proud to announce the launch of a new monthly online group for Black, African and Caribbean people affected by dementia.

The Black, African and Caribbean Dementia Thematic Group began in autumn, creating a safe and inclusive space for people with dementia, carers and former carers, families and community members.

The group shares lived experiences and cultural perspectives, and it will influence projects and services to become more inclusive and responsive. As well as supporting each other, group members will work together to build relationships in the community.

Meetings are on Zoom on the first or second Tuesday of every month from 2pm to 3.30pm.

Basil Barron, Involvement Officer at the Society, says, 'This group has been created to explore and address the unique experiences, challenges and strengths within Black, African and Caribbean communities affected by dementia, and make sure Black voices are heard.

'We're looking forward to building momentum together.'

If you're interested in the Black, African and Caribbean Dementia Thematic Group and want to find out more, please email **yoursay@alzheimers.org.uk**

## Research Network: reviewing applications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Our Research Network has been looking at applications to help make sure the research that we fund is relevant and credible, with the potential to transform lives.

The network includes almost 200 volunteers with experience of living with a dementia diagnosis or caring for someone who does.

Network volunteers are involved in many different ways, recently taking part in Expert Review Panels as part of our 2025/26 round of research grants. These panels bring together scientific experts and Research Network members to review and provide feedback on funding applications.

Research Network volunteer Sue said, 'I really have enjoyed taking part in the Expert Review Panels. I feel my views as a lay person with lived experience are valued.'

Carol, another network volunteer, added, 'I enjoy attending the Expert Review Panels. I am able to feedback the comments and concerns from the Research Network reviews. The Expert Panel value the feedback and takes our views seriously.'

Are you interested in the work of the Research Network? To find out more, please email **ResearchNetwork@alzheimers.org.uk**

## Online music: m4dRADIO relaunch

A free online radio station for people affected by dementia has relaunched to make it even easier to enjoy its 24/7 non-stop music.

m4dRADIO has six channels so you can choose a stream of music from the 1940s, 50s, 60s, 70s, 80s or a mix of decades. With no interruptions from news, ads or presenters, the schedule changes through the seasons – so expect familiar Christmas songs and carols during December!

Special 10am 'Move it Monday' and 'Feelgood Friday' playlists are designed for people to enjoy together with movements. There'll also be more playlists and music memories from celebrities, which in the past have included Society Ambassadors Anne-Marie Duff OBE and Sir Tony Robinson.

m4dRADIO is run by Music for Dementia, a campaign to make music an integral part of the support that people with dementia have around them. The station was first set up during the pandemic in response to the challenges of lockdown.

Listen to m4dRADIO at **m4dradio.com** on your smartphone, tablet or laptop, or through Alexa or a Yoto player.

## Share

Share your views, feedback and news – email **magazine@alzheimers.org.uk** or write to the address on page 2. We can consider contributions received by 5 January for the February/March issue (wording may be edited).

# Healthy mouths

## What can you do now to help prevent later problems with your teeth and mouth?

How healthy our teeth and mouths are can have a big impact on how well we feel.

A dementia diagnosis does not mean you're going to have sudden dental or oral problems. But they are common when people have more advanced dementia. Things you do now can help to reduce or prevent problems later.

### Why it matters

It can be difficult to keep up mouth care as dementia progresses. Having check-ups and treatments can also become complicated.

That means it's easier to develop tooth decay, sensitive teeth and gum disease. These may cause discomfort or pain and can make it harder to eat properly.

Dry mouth is sometimes a side effect of medications, or it can be a part of getting older or not staying hydrated. It could make it harder to speak, chew or swallow, and may lead to fungal infections.

Dentures can also be a problem if they get lost, aren't cleaned regularly or aren't fitted properly.

### Plan and check up

Tell your dentist you'd like to plan to prevent later problems. Perhaps there's a procedure you're likely to need in coming years and which it would help to have sooner.

Have regular check-ups. Do this even if you take great care of your mouth. Small problems can lead to more serious issues if not dealt with, so it's worth picking them up quickly.

Dentists are more understanding nowadays about people's fears or previous bad experiences. Talk to them about any worries that you have.

If you need an NHS dentist and they have a waiting list, get onto it now to have the least delay in getting seen.

## Your tips

'Keep an eye on your gums, especially the pieces hidden by your lips.

'I had a growth which I just left as it was painless. It had to be taken to be checked, and a quarter of my gum was removed just in case.

'Luckily, it was benign. My dementia means I don't feel pain in my gums, so I had a lucky escape

'I was informed that it was probably due to medicine side effects, however as I'm on a cocktail of tablets (21 a day), they could not be sure.'
**Martin Robertson**

'Trying to get a dentist nowadays is difficult, and it's very difficult for people to actually afford dental treatment. The government and NHS need to address this.

'How many people are informed on diagnosis that teeth and oral health are an issue?' **Martyn Colebourne**

'I'm lucky I've got an NHS dentist. Since I've had dementia, I think I've had six crowns, with root canal treatment.' **Tim Little**

'I spoke with our dentist about my husband's condition. His teeth are in really good shape and we want to keep them that way, but I know his teeth cleaning is not so good these days.

'She suggested mouthwash – keeping the gums healthy is imperative. He's only swallowed the mouthwash once, but I do need to keep an eye just in case. I already have a water flosser, although he needs help with that and it won't suit as he progresses.'
**Small Clanger (forum name)**

For our Dental and mouth care (448) factsheet, see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

People affected by dementia share ideas and advice on our Dementia Support Forum – visit **alzheimers.org.uk/ForumTogether**

# Opinion:
# No one should feel alone

## Julie and David Kerr in County Antrim want everyone to receive dementia support at the point of diagnosis.

**Before lockdown, Julie was forgetting things – going to the wrong place, forgetting what she'd gone to the shops for, missing shifts at work.**

Initially, it was put down to menopause and ageing. But we went back to the hospital for scans and, in 2022, she received a diagnosis of early-onset dementia.

Julie's mam had dementia, so we knew about the condition, but no way did we think she might have it too. After giving us the diagnosis, the doctor stood up.

We thought he was going to get us some support leaflets or invite someone in to speak with us.

He opened the door and said, 'You'll be able to find out more about it on the internet,' then closed the door behind us.

We just looked at each other and burst into tears.

### Lost and alone

You can't give people a diagnosis and tell them, 'That's it, away you go.'

Maybe he was having a bad day. But it was so wrong to deliver the news in this way, especially something so life changing as dementia.

Even if he'd handed us a leaflet, just simple gestures, we wouldn't have left feeling so bad.

When David was diagnosed with heart disease, he was given a dedicated heart nurse after he was discharged from hospital.

Why isn't there a similar approach with dementia?

### Finding our way

For the first six months after that appointment, we were completely lost. We didn't know what to do or where to go.

We were rock bottom and didn't speak to anyone.

Then our daughter found a wee notice at our library about a local Dementia NI support group for Julie – we thought it wouldn't harm to give it a go.

Being among other people with dementia who understood everything we were going through was amazing.

From that day we got our lives back. It was like flicking a switch that day and just everything started.

But it shouldn't have been up to us to find a way through on our own.

### Power of support

When you receive your diagnosis, you should be given information on where to go and what to do next.

All the better if it was delivered by someone who is trained.

You might not be ready to act on what they tell you – everyone's different – but at least the option is there.

You shouldn't have to look for support yourself. It's such a difficult time, you don't always have strength.

When Julie finally found support, it transformed everything.

It gave her the confidence to speak to her boss, to stay active and even to go back to her doctor about the side effects she was getting with her medication. Without it, she'd be stuck at home watching TV like her mam.

Now we are taking part in Time for Dementia, where we speak with healthcare students so they have more understanding of dementia.

By speaking about our experiences, we hope to make a small change in the way they might deal with dementia patients in the future.

If we can help one person have a better journey than us, it's worthwhile.

Help improve future healthcare professionals' understanding through Time for Dementia – visit **alzheimers.org.uk/TimeForDementiaTogether** or call **07562 430204**.

# In Mum's memory

## Tricia Forrest-Morley is channelling the frustrations she felt after her mum's dementia diagnosis into fighting for change.

Join us as a campaigner and help us challenge and change the issues faced by people living with dementia – visit **alzheimers.org.uk/campaign**

**I didn't know much about dementia until my mum was diagnosed in 2013, just before her 80th birthday.**

It was overwhelming to leave the memory clinic after her diagnosis – it felt like we were being told, 'Go and get on with it.'

Mum also wanted us to keep her condition private because of the stigma attached to it.

From then on, we encountered so many challenges and barriers, things that weren't right or that we had to fight for. From everyday frustrations, such as people not including Mum in conversations, to not being able to find dementia trained carers as her symptoms progressed and places that were dementia friendly.

### Using my voice

When you consider dementia is the number one killer in the UK, you'd think politicians would be doing more about it, wouldn't you?

I wanted to use my drive to change things, to make other people's journeys that little bit easier.

My campaigning work started when I called Alzheimer's Society for advice on something and I joined a mailing list. I was emailed about contacting my MP and it started from there.

Although I felt absolutely stretched caring for my mum and working part-time, I found time to campaign.

I researched in the evenings when I should have been asleep!

Since then, I've done various projects with the Society, including speaking at the annual conference.

### Every opportunity

I also do initiatives off my own back – if I see an opportunity, I follow it up. For example, I'm a volunteer at a National Trust property, so I had meetings with them about making the site more dementia friendly.

I've contacted Suffolk police about its approach to dealing with people with dementia who go missing and promoting the use of GPS trackers.

I've also worked with my local hospital charity, speaking at an event to raise money to fund an activities coordinator for patients with dementia.

Everyone's journey with dementia is different but everyone needs support. This prompted me to arrange an event with my MP in October 2023 to raise awareness about dementia and to signpost help and support people might not be aware of.

I believe that everyone should be given a 'signposting' pack following their diagnosis, so they know where to turn for help at every step of their dementia journey.

### Small steps

Mum passed away in February 2021. It brings me comfort to know that I'm doing something in her memory to help other people.

I'd love to see more understanding about dementia, among healthcare professionals as well as the public.

I believe the more you learn about the condition, the kinder you can be to those people who are living with it.

It's dreadful to think that, even now, 12 years on from my mum's diagnosis, there is still so much stigma and fear attached to the disease.

I will carry on doing what I can to change things.

I haven't done anything that will set the world on fire! But imagine if we could all just do a little bit like I am doing – it will help us on the way to a bigger outcome.

# Heart and sole

## Phill Hayward from Birkenhead says it was his grandad who inspired him to run 10k barefoot every day for a year.

**My challenge came about because I wanted to mark the 10th year of my grandad Roy being diagnosed with Alzheimer's.**

He was like a second father to me growing up. My dad was in the navy and away a lot, so I'd spend lots of time with grandad. He'd pick me up from school and we'd go to the football, play golf or fish together.

For the first three years after his diagnosis, he was still pretty energetic.

However, his symptoms steadily got worse and eventually he became housebound. He always remembered who I was though, which was special.

### Unique idea

I'm a PE teacher and I've always been active – I like to push myself.

Seeing my granddad deteriorate motivated me. I wanted to do something to grab people's attention.

During the Covid pandemic, I ran 10k every day for a year to raise money for a mental health charity and I thought to myself, 'How can I top that?'

I had the idea to run barefoot before I'd thought about the finer details! You can go anywhere in trainers but not in bare feet.

### Challenging start

The first two weeks of my challenge in July 2024 were tough.

It was hard to find the right surface to run on and my feet ended up sore and cut.

I tried the beach thinking it'd be gentle on my feet and it was the worst – slippy and the shells were so painful to run on! I tried a local park but there was animal poo to contend with.

One night, the police even stopped me and asked, 'Are you alright, mate?'

### Local support

Gradually, I got into a routine. I did a lot of repetitive runs, often around my school's grounds.

I'm naturally quite a shy person but to raise the profile of my fundraising, I posted live to social media every day.

The support I got was brilliant. I had so many great conversations, people stopping me in the street, patting me on the back and shaking my hand.

The children I teach were an amazing support too. I want them to have the relationship I had with my grandad.

There were only a few occasions I thought I couldn't carry on.

One of those days was when my grandad died in early summer 2025.

It was so difficult to find the motivation to run that day. I still don't think I've fully grieved for him.

### Power of positivity

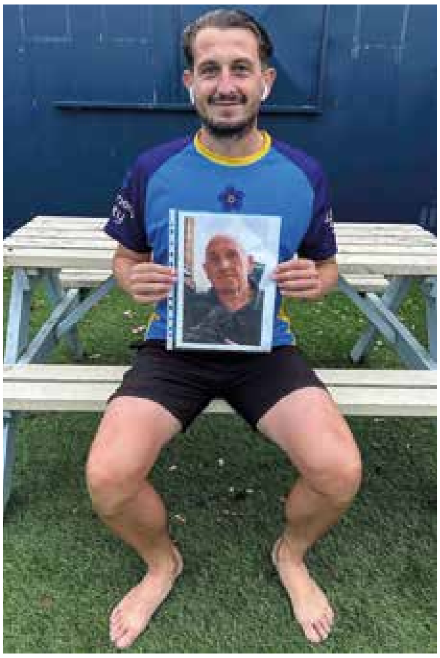
It was a relief to finally finish but I miss the headspace I got from my daily run. It was time I could think and decompress. I raised close to £16,000, which is just phenomenal.

My mum's applied to the Guinness Book of Records to get me recognised for travelling the longest distance in bare feet over the course of a year.

It's amazing to raise awareness about dementia but I didn't do it for the accolades. I just like to help people.

If you're thinking of setting yourself a fundraising challenge, my advice is pick something you'll enjoy. Try to keep the people you're helping in your mind when you need a pick-me-up.

I like to set myself challenges so although I'm not sure precisely what it will be, I'm sure I'll do something else. Watch this space.



Get a free fundraising pack to help organise your own fundraising – visit **alzheimers.org.uk/fundraising-support** or call **0330 333 0804**.

# Measure, predict, support

## Devices that collect and analyse data could help people with dementia to live independently for longer.

**Magdalena Kolanko says her passion to help people affected by dementia was kickstarted early on in her career as a doctor.**

A neurologist and Society-funded clinical research fellow, Magdalena is keen to develop new ways to provide care and support.

'I experienced first-hand the devastating effects of dementia on patients and their families, as well as appreciating the huge scale of the problem,' she says.

'I was also struck by the limited effectiveness of current therapeutic options.'

### Tech potential

Magdalena splits her time between working in the NHS and completing her PhD at Imperial College London.

She researches how digital technology could improve people's lives at the pioneering Centre for Care Research & Technology, part of the UK Dementia Research Institute (DRI).

Magdalena is looking at how devices can analyse and predict a person's behaviour, to help make sure they're getting the right support.

'We use devices such as sleep mats or wall-mounted activity sensors to collect data about people's behaviours then analyse it using artificial intelligence (AI) models to make predictions about what they might do,' she explains.

As well as collecting this data in people's own homes, the UK DRI has a 'living lab', which is basically a small model flat.

'It's fitted with a whole range of sensors and digital technologies and here we can test people performing real-life tasks such as making a cup of tea or preparing toast.'

### Early signs

The aim of collecting and analysing data about a person's behaviour is to pick up any early signs that they need more support.

This could help people to stay independent for longer, as well as reducing unnecessary hospital visits and stays.

'For example,' says Magdalena, 'we have developed an easy and reliable way of measuring nighttime heart rate, breathing and behaviour, using a small under-mattress sensor.'

Given the information from this device, an AI model has learned to identify signs that a person is developing an infection.

'I showed that our model can reliably detect early signs of Covid and other respiratory infections, and it often flags up any serious deterioration in health, so people can be assessed and receive early treatment.'

This system is already being offered to people with dementia in west London so they can be monitored at home.

### Diverse talent

Research is most productive when people work together, and Magdalena's study touches on all kinds of areas.

She collaborates with a varied team of healthcare professionals, including occupational therapists, physiotherapists, dementia nurses and sleep specialists. But she also works with experts from wider ranging fields, such as engineers and computer scientists.

'This means we can translate our research – even the most technical aspects of it – into real-life interventions.'

That keeps a focus on what people with dementia would actually find most useful in everyday life.

'I particularly enjoy working with

The 'living lab' at the UK DRI.

our designers, who help us to make our software and devices dementia friendly.'

### Transforming care

Balancing busy work and home lives can be challenging, says Magdalena. However, seeing the positive impact of her work on people's lives keeps her motivated.

She is also buoyed by the support she receives from Alzheimer's Society. 'The training fellowship I was awarded has not only funded my PhD research, but also allowed me to expand my work with digital health technology into new areas of dementia care.'

Overall, Magdalena feels upbeat about how technology could transform care for people with dementia. There's particular potential in linking information from devices in people's homes with wider health services.

'In addition to enabling people to continue to live safely in their own home, this will improve quality of life and potentially save money.

'With most people wishing to remain at home, I hope these new technologies and innovations will help keep people safe and independent for longer.'

## Donate

Your donation helps us to fund research into all forms of dementia, from prevention to breakthrough drug treatments. **Donate online** or call **0330 333 0804**.

# Take part in research

## Dementia researchers rely on all kinds of people participating in studies – how can you join them?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For many years, research into dementia lagged behind other health conditions. But thanks to the participation of many people like you, strides are being made that were hard to imagine before.

The range of recent and ongoing dementia research is mindboggling.

While some focus on tests to improve diagnosis, others are creating apps and devices to manage symptoms and care. Other studies are developing new treatments which actually change the course of diseases that cause dementia.

Across these areas, there's little that could be achieved without people taking part in research.

Sharon Boulter, Research Participation Officer at the Society, encourages people to get in touch to find out more.

'We want to enable you to find out what types of studies you could participate in,' says Sharon.

'People are often surprised by how easy it is to register their interest so they can hear about opportunities.'

Join Dementia Research provides an important way to do this. Anyone over 18 in the UK can sign up to be matched with studies that need volunteers. You can even register someone else on their behalf if you have their consent or power of attorney.

There's no obligation to take part in a study you're matched with – you decide when something comes up that you'd like to be a part of.

Sharon underlines how researchers are looking for all kinds of participants.

'Research is like trying to solve a complicated jigsaw puzzle,' she says. 'You may have a piece of the puzzle that can help researchers complete some of the picture.

'Every mind matters – you don't need to have a diagnosis of dementia to participate.

'There are a wide variety of studies you can take part in. You might be invited to complete an online survey, join a focus group, listen to music, take a blood test, trial new medications, or even try out innovative technology like virtual reality.'

### Find out more

What dementia research could you take part in? Call **0333 150 3456** and ask for our Research Participation team, or email **joindementiaresearch@alzheimers.org.uk**

# Cutting-edge ideas

**A new collaboration is helping dementia professionals to turn their ideas into real-world innovations for people affected by dementia. Antonia Kanczula finds out more.**

**The idea that high-tech progress can help people affected by dementia isn't a futuristic concept – it's already happening.**

As part of our quest to boost innovation, we launched a programme last year to draw on the cutting-edge ideas of NHS staff, care professionals and entrepreneurs working in health and care.

## Quick read

**Alzheimer's Society is working with the NHS to help dementia professionals to develop groundbreaking innovations.**

**The Dementia Innovators Programme is a collaboration between us and the NHS Clinical Entrepreneur Programme.**

**The first cohort of people taking part have ideas that span dementia prevention, detection, diagnosis, daily living and care.**

**Participants are supported by the Society in many ways, including access to experts, and say that it's been a hugely beneficial experience.**

The Dementia Innovators Programme is a collaboration between the Society and the pioneering NHS Clinical Entrepreneur Programme.

Fiona Carragher, our Chief Policy and Research Officer, says, 'It's all about harnessing the clinical experiences and innovative solutions of healthcare professionals to bring about change for the UK's biggest killer.'

## New collaboration

This is the first time there's been a collaboration between the NHS Clinical Entrepreneur Programme and a health charity, reflecting a recognition of the expected impact of innovations in dementia.

Participants get full access to the NHS programme, which has helped create over 500 start-ups since its launch in 2016. These include expert mentoring, networking and training opportunities.

People taking part through the new dementia programme also get a unique package of additional support from Alzheimer's Society.

Steven McFadyen, our Acting Innovation Programme Manager, says, 'We offer support in designing new products and solutions for dementia and provide access to dementia experts and people with lived experience.'


Devika Wood

The Dementia Innovators Programme has a fresh approach, adds Fiona.

'It's one that fits with our ambition to get a product or solution to every person affected by dementia and the systems that support them.'

## First cohort

The first cohort of 10 dementia entrepreneurs is being supported by the Society until spring 2026.

They have innovative ideas that span prevention, detection and diagnosis as well as daily living and care.

'The breadth of ideas is really exciting,' says Steven. 'They range from innovations that personalise treatment of urinary tract infections or help families to share playlists, to training for medical staff to provide culturally sensitive dementia support.'

Devika Wood, CEO of Brain+, is one of the first cohort with an online platform called Ayla. This is designed to help more professionals offer effective cognitive stimulation therapy (CST) to people with dementia.

She is enthused by the experience of being involved in the programme.

'With access to the Society's expertise and to people affected by dementia, we have gathered so much knowledge. It's been enlightening and the support we've had is second to none.'

## Innovations in care

CST is usually most suitable for people in the early to middle stages of dementia. It involves structured group sessions with activities that stimulate concentration, communication and memory skills.

Find out more about our innovation work at **alzheimers.org.uk/innovation**

But many people are never offered CST. Ayla aims to enable more services and providers to deliver it simply and safely.

'Our big dream is that everyone diagnosed with dementia is offered CST, so they have the chance to delay cognitive decline,' explains Devika.

She is motivated by personal experience.

'My granny was like a mum to me. When she developed dementia, I became a young carer for 12 years.

'There's nothing worse than witnessing somebody who is a huge role model just disappear before your eyes.

'It left a profound impact on me. I am driven to change the way that people live with dementia, especially our approach and attitude to accessing services.'

## Legal expertise

Oliver Asha is another participant driven by personal experience and a passion to help others.

As a solicitor with a specialism in wills, he was used to advising clients to get capacity assessments.

But when his grandad was diagnosed with vascular dementia, he saw that the process was more difficult than he had assumed.


Oliver Asha

'I realised that there are serious barriers to people being able to protect their decisions, and that these barriers might dissuade them from trying to make an important decision around their will or power of attorney.'

One thing that particularly struck Oliver were the challenges for people with dementia who live alone.

This led Oliver to create a digital tool called Capacity Vault, which creates verified evidence of people's decisions and stores them securely.

'Our system understands the decision someone is making and applies the correct legal test to show their capacity to make it, conveniently and at a fraction of the cost.'

He says the energy and the knowledge he's gained so far during the programme have been immense, including the Society's support in making Capacity Vault more accessible.

'I am hoping we can go on and use our technology to help in other areas, such as supporting research and the process for signing up for clinical trials.'

## Inspiring change

Fiona believes the positivity and energy created by the Dementia Innovators Programme will ripple out to create even wider change.

'Innovations will emerge from this programme which can not only reduce the impact of dementia on our healthcare system, but will inspire more entrepreneurs to design products and services that will make a real difference to people's lives.'

Visit **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933** for our Using technology to help with everyday life (437) factsheet.

# Joy on the dancefloor

**Two siblings created Dementia Disco after they couldn't find a music activity their dad would enjoy. Antonia Kanczula attends an event that's going from strength to strength.**

## Quick read

**Dementia Disco events in Stockport create an enjoyable space for people affected by dementia to dance and sing together.**

**The idea was prompted by difficulties in finding music events and activities for younger people living with dementia.**

**All ages are welcome, and Dementia Disco music requests range from classic rock and roll to Taylor Swift.**

**Dementia Disco now offers mobile discos in care homes and hopes to expand into new areas.**

'It's just so lovely hearing from people about the difference it makes to come to our events,' says Kate Darby in Stockport, Dementia Disco's co-founder and CEO.

'Quite recently, a lady with dementia who had danced all night came right up to me, looked me straight in the eye, and said, "I've had the best time," and gave me a cuddle. It was so special.'

This is exactly the response Kate and her brother Nick Shaw hoped for when they first had a kernel of an idea, after their dad's diagnosis with Alzheimer's disease.

'He was only 66 years and we'd take him to all the wonderful support groups in the area,' explains Nick.

'They were lovely and friendly, but they were catering towards an older audience. Dad didn't want to sing around a piano and he just wouldn't engage.

'He loved music from the 60s, 70s and 80s, things like Bruce Springsteen, Dire Straits and Fleetwood Mac.'

### Taking off

Thinking that their dad wouldn't be alone in wanting a different kind of music event, the siblings came up with Dementia Disco.

And it quickly snowballed from an idea into reality, explains Kate.

'Nick told our friend Phil, whose grandma Margaret also had dementia, about the idea. She absolutely loved it and wanted to get involved.

'She had a contact at a local social club in Heaton Mersey, whose dad had dementia. She ended up letting us use the venue for free and even offered to make food for the evening.'

After flyering the local area to raise awareness, this first event in July 2019 attracted 40 people and was simply incredible, recalls Kate.

'People got up and danced – we weren't sure if they would and we had lots of music requests come in.

'We thought, "We're onto something here," and carried on doing that monthly disco until Covid came along.'

### Uplifting experience

During lockdown, the team transferred their events online, tentatively restarting real-life events in 2022 with an extra venue.

There's been no stopping since then.

As well as expanding events around Stockport, Dementia Disco now offers mobile discos at care homes and a joyous annual trip to the iconic Blackpool Tower Ballroom.

One of the things the team is most proud of is that their events are a safe space.

They give people with dementia and their families and friends – children are welcome – an opportunity to just relax and have fun.

'You might have three generations on our dance floor and it gives everyone a little bit of escape,' says Kate.

The benefits are physical as well as emotional.

'In surveys about the impact of coming to our events, people have told us that our events can help a person with dementia feel calmer and less anxious, meaning they have a better night's sleep.

'In turn, this benefits the people caring for them too.'

### Warm and friendly

Dementia Disco's 30-strong volunteer crew includes Jean England.

As well as being a dance enthusiast, dancing six times a week, she has a very personal reason for volunteering.

'My mum had dementia and there was nothing like this for her – I wish there had been. I think it's brilliant.

'It's such a friendly place, everyone is supportive, everyone knows what you're going through.

'My main role is getting people up on the dance floor, encouraging anyone who wants to dance but is maybe a bit reluctant. Or we'll have a

sing together if they are not able to get up.

'I've got so many highlights since I started volunteering. I leave on a high after every event. It gives me a real buzz.'

Johnny Noel used to bring his late wife Hilda along to Dementia Disco.

Since she died, he has continued to attend, encouraging friends to come along too.

'My wife died just over two years ago. She had mixed dementia and we used to love coming together.

'One of the only positives of her having dementia was that I started going to lots of events and getting more involved in my community.

'So when Kate and Nick wanted to get more serious about Dementia Disco, they asked me to be a trustee. I was thrilled, I love it.'

## Making a difference

Although Dementia Disco is all about having fun, the team is also passionate about raising awareness of dementia.

'And about the importance of music and dance to improve the lives of people affected by dementia,' adds Kate.

Through a Dance Against Dementia campaign, to urge the government to make dementia a priority, their local community came alive with dance.

They logged over 5,600 dances, including a 12-mile dance-a-thon and dance flashmob.

'Alongside a dance professional, we're now working on a plan to encourage people to dance every day for their mental and physical wellbeing.'

There are other big ideas in the pipeline, including more events in and around Greater Manchester. They're also working to create a 'run your own disco' pack to enable more people around the country to start their own event.

They're not standing still with their existing events either.

As well as introducing live slideshows at events, with pictures of historical events, music artists and disco goers' photos, they're keeping up with changing music tastes, says Nick.

'We've had requests for Taylor Swift and Chappell Roan, but a big moment recently was our first request for a 90s house track.

'If you imagine a person coming of age in the early 1990s, going to raves in their teens, they will be our disco crowd soon. We're not far from holding our first Dementia Disco rave special.'

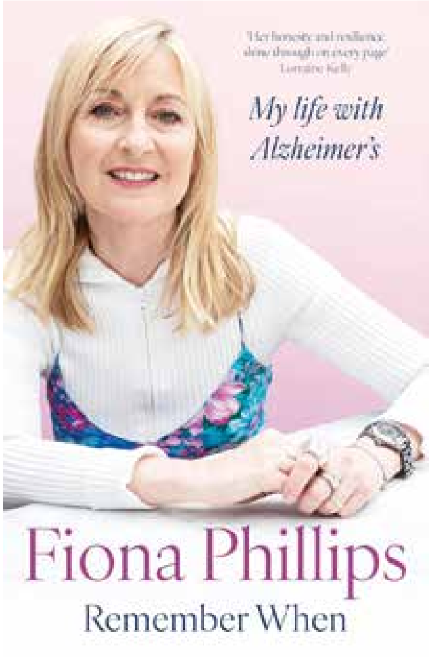
To find out more about Dementia Disco, visit **dementiadisco.org**

Want to keep active in 2026? Join Let's Dance, founded by Angela Rippon CBE, for its second National Day of Dance on 8 March – find out more at **lets-dance.org.uk**

For our Physical activity, movement and exercise (529) factsheet, please visit **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

# Book group:
# Remember When

**We read a compelling memoir from a well-known TV presenter who was diagnosed with young-onset Alzheimer's at age 61.**



Remember When: My life with Alzheimer's by Fiona Phillips (Macmillan, 2025), 336 pages, £22.00, ISBN: 9781035074877. Also available as an ebook and audiobook, paperback due out in 2026.

**Fiona Phillips, a longtime supporter of Alzheimer's Society, became one of our ambassadors in 2007. Having experienced dementia with both her parents, she was diagnosed with early-onset Alzheimers herself in 2022.**

It's no surprise her memoir is a bestseller, but our reviewers clearly thought this is well deserved.

'I haven't stopped thinking about this book since I put it down,' says Donna Stephens in Hampshire. 'How Fiona was so brave to face her own one-way journey after supporting both parents on the same doomed path.

'It reminded me many times of the lives of people who share their stories on the Society's Dementia Support Forum – the pain, the bewilderment, the anger… so many emotions.'

Toto2 in East Sussex says, 'I have never read a book that made me cry so much.

'The brutal honesty of how things started with Fiona's mum reminded me of my mum. It was so similar, and all the signs were there, but you never realised.'

Sally Newell says, 'It was heart wrenching that she had to go through Alzheimer's with both of her parents before also getting the disease.

'However, being able to describe three different presentations gave me a real insight into how the disease affects people differently.'

Mary adds, 'This book held me captivated while Fiona took me on a rollercoaster journey through her life.

'No ghostwriter used but written by her with total honesty about the help from her brother and a friend with memories of childhood and career.'

## Family history

Ann Molyneux in Peterborough says, 'Fiona writes about her first experience with Alzheimer's at 19, when her beloved grandmother succumbed to the disease at 60.

'Then she watches the same thing happen to her mum and dad.'

'I enjoyed reading about Fiona's early life,' says SeaSwallow, 'how her career developed and her family life, but it was so sad to read about the difficulties that she had caring for her parents only to be diagnosed herself.'

'She tries her best to look after her parents, who live a long way from her,' says Donna, 'simultaneously holding down a very demanding job and caring for her own family.'

Toto2 says, 'The way Fiona described when her mum passed was raw but relatable, as this happened with my mum. She waited until we all left before she passed too.

'The most upsetting part for me was Fiona's dad when he was admitted to a unit, and the way Fiona described how her bright and clever dad turned into a "zombie" due to the medication they kept "pumping" into him.'

## Two perspectives

Donna says, 'The book is written from both Fiona's and her husband Martin's perspectives, which adds great depth and dimension.'

'It shows how someone with dementia recalls an occasion and the way someone caring sees things,' says Toto2.

'This is what would make this book a must-read for anyone starting this journey, as it gives the reader both sides.'

'Her husband's perspective gave depth to the book,' says Sally, 'but also was the greatest source of sadness because, although he says it's not about him, he is having to live every day and describes the heartache and daily challenges.'

SeaSwallow says, 'This way of writing really highlighted though the way that Fiona's ability to express herself had diminished as the book progressed, one of the very sad things that was highlighted in the book.'

## Relatable and real

Toto2 says, ‘I remember Fiona from her TV days and have always loved her bubbly professional way of dealing with people. To see how angry she got with her parents’ conditions made her more relatable and not just someone from TV.’

‘Fiona’s own diagnosis comes after much searching for reasons why she was getting such “brain fog” and, like her mother, the menopause is blamed at first,’ says Donna.

‘It seems incredible that links weren’t made, but denial is a kind of self-protection.’

SeaSwallow notes, ‘Martin states that he understood that, because they were relatively well off, they were able to afford carers, which many people could not do so.

‘But he also stressed just how difficult it is caring for someone and also navigating the care and health systems, and you could really feel his frustration at times.’

## Progression and end

Ann says, ‘Fiona knows there are memories attached to her family home in south London, where her children grew up, but finds they are out of reach.

‘She must rely on newspaper and magazine cuttings and YouTube clips to recall her broadcasting career. She remembers how carefree she was in her 20s and how different things are now, how overwhelming. She’s glad she never knew how things would turn out.’

Donna says, ‘I could feel Fiona slipping away towards the final parts of her memoir, with Martin taking up the reins.

‘He writes a very frank account of how he now cares for his wife but is so touchingly mindful of protecting her dignity.’

Ann says, ‘In a heartbreaking confession Martin admits he misses his wife and notes that, by the end of the book, Fiona has forgotten that she is writing it.’

Toto2 says, ‘This book taught me things I thought I knew having been on this journey with my mum.

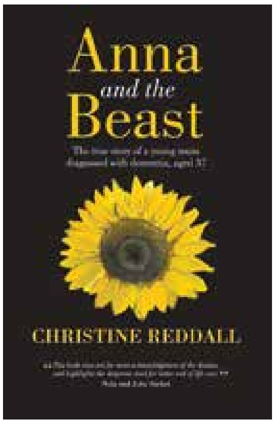
‘It makes me feel all the more proud of the way she fought with this disease until she could not fight anymore.’

‘I would recommend the book,’ adds Sally, ‘but it’s not an easy read. It’s a true reflection on how Alzheimer’s has affected three people in one family and the impact it has on everyone.

‘It does not have a positive, uplifting ending because that is not the trajectory of the disease – it is honest as Fiona has always wanted to be.’

SeaSwallow says, ‘This is a book that was well worth reading and hopefully, because of who they are, it will highlight just how awful this disease truly is.’

# Next time



For our next book group, we invite you to read Anna and the Beast, by Christine Reddall (Goldcrest, 2021), 330 pages, £10.99, ISBN: 9781913719043. Also available as an ebook.

Tell us what you think of this moving account by a mother whose daughter was diagnosed with frontotemporal dementia at the age of 37.

Email **magazine@alzheimers.org.uk** or write to the address on page 2 by the end of 4 January so we can share your comments in an upcoming magazine.

# Book giveaway

We have five copies of Anna and the Beast to give away – email **magazine@alzheimers.org.uk** or write to the address on page 2 by the end of 14 December quoting ‘Anna’ for a chance to win (see page 39 for terms and conditions).

# Ideas for gifts

**People affected by dementia in West Sussex look at gift ideas in the lead-up to Christmas and other festivities.**

**New Ones on the Block is a monthly group for people with young-onset dementia in Ferring, on the south coast of England. As a Dementia Voice local group, they influence the work of Alzheimer's Society and others.**

At a session that included partners and visitors, we asked the group for feedback about a range of gift ideas from our Society shop.

## OuiSi game

The OuiSi game (pronounced 'we-see') is a box of over 200 square cards, each with a different striking photographic image on one side.

There are many ways to play with them, described in the included guidebook. These range from matching similar patterns or shapes and linking ideas about what's pictured on cards, to placing a card on paper and creating a drawing that extends the image.

Sue liked that there are lots of ways to play and engage with the cards, and that you don't feel pressure as there's no right or wrong answer.

'It's good, I would play with them,' she said. 'People at different stages of dementia could join in.'

Angela said the various games would be good for the group she runs, which includes people with no speech and other verbal issues.

Cheryl, who used to work in a nursery, said, 'I liked looking at the pictures on the cards. The games would work with children too.'

## Cognitive Books

There are now three Cognitive Books – Looking Back at... Classic Coronation Street, The Beatles and The 1966 World Cup.

The books use colourful illustrations and rhyming descriptions to prompt reminiscence, whether viewed individually or as part of a story.

They contain quizzes and activities at the back and come with free audio versions.

Simon enjoyed hearing the audio for the Beatles book – read by Bill Nighy – while looking through it.

'I would like to listen to all of that,' he said, 'and probably sing along to it!

'I don't read books, I get distracted too easily. But the audio meant I was able to follow and turn the pages.'

Looking at the World Cup book, Tracy noted that Pete might struggle to read through it on his own, but that they could read it together.

'I liked that it had other events that happened in the same year,' she added.

Reg loved the 1966 theme.

'I remembered watching it, but only the final,' he said. 'So, it was interesting to see the quarter- and semi-finals in the book.'

Lizzie was impressed by the Coronation Street book and thought the access to audio versions made the price reasonable.

'The illustrations really look like the characters,' she said, 'and I really like the quizzes and other elements.'

Pete, a model railway enthusiast whose grandfather worked on the railways, thought a good subject for the next Cognitive Book would be trains.

'Loads of people like trains,' he said.

## Advent Activity

The Advent Activity is a beautifully crafted wooden circle covered in festive designs. Its large, numbered segments reveal pictures featuring the 12 Days of Christmas.

Helena and David joined Sue and Angela in turning over each segment and trying to recall which bit of the song it was about.

This produced a lot of fun – and discussion about what French hens look like!

They agreed it was well made, and thought people could sing along while going around the pieces.

'My mother's in her 90s,' said David, 'and she would love it.'

Sue noted, 'It would be useful to have the words of the song.'

Reg added, 'Actually, it would be good with the audio of the song.'

After sharing these ideas with the manufacturer, they responded by adding the full words to the song along with a link to a recording you can sing along to.

**Win** see page 39

## Mug, tray and biscuits

The last time we showed a panel Rosa two-handled mugs and trays, they liked the idea of creating versions with forget-me-nots on. This is the new pattern we took to Ferring.

The small melamine tray has a holder to keep the mug in place, and they can be bought separately or as a set. Drinking lids are also available, one with a spout and another with a discreet hole for sipping or a straw.

Cheryl liked the tray and mug, successfully testing it out with her cuppa and a biscuit.

Pete and Tracy also thought they could be useful.

'You could have the tray on your lap with your brew,' said Tracy. 'The two-handled mug would be good for his dad as well, as his hands are shaky.'

Group members noted that previous attendees with a hand tremor would also find the mug especially useful.

Reg thought the price was on the expensive side, though David asked, 'But what's the comparison? It's better quality than something you could get online.'

The group also enjoyed two packs of biscuits specially designed to be dipped into hot drinks – Christmas tea dunkers and Apple and blackcurrant crumble coffee dunkers.

Two other delicious flavours are also available – Lemon curd tea dunkers and Spiced Christmas coffee dunkers.

Visit **alzheimers.org.uk/ShopTogether** or call **0333 366 0035** for this and other helpful products (prices include VAT):

- OuiSi game – £29.99.
- Cognitive Books (Looking back at The Beatles, The 1966 World Cup or Classic Coronation Street) – £14.99.
- Advent Activity - £29.99 (or £24.99 with VAT relief – see below).
- Forget-me-not two handled mug and tray – £12.50 for the mug, £14.99 for the tray and £25.99 for the mug and tray set.
- Tea dunkers (Christmas tea or Lemon curd) or coffee dunkers (Apple and blackcurrant crumble or Spiced Christmas) – £4.25 for a packet of 10.

You can buy the Advent Activity VAT free if it's for use by a person with dementia or other conditions. To save 20% on these and many other specially designed products, tick the box stating you're eligible for VAT relief at checkout.

For our Keeping active and involved (1506) booklet, see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

# Hope over fear

**For Amar Sunda, in Hertfordshire, it was a steep learning curve when her husband was diagnosed with dementia. Seven years on, she speaks to Heather Stephen about staying hopeful.**

**'Every evening I get in the bath with my Kindle, lock the door and stay there for an hour.'**

It might not sound like much, yet this simple act of self-care is one of the things that keeps 57-year-old Amar Sunda going.

Through the daily challenges of caring for someone with dementia, Amar hasn't always prioritised herself.

It has been seven years since her 59-year-old husband Parminder was diagnosed with frontotemporal dementia.

## Quick read

**Amar Sunda, in Hertfordshire, has had to learn a lot to adapt to her husband having frontotemporal dementia.**

**Parminder was diagnosed seven years ago, aged just 52.**

**Amar is determined to do what she can to raise dementia awareness and help other people.**

**She gets through each day with support from family and others, and by learning to care for herself.**

She recently took up exercise to boost her health and wellbeing, and she's already seeing the benefits.

'Caring is very difficult and you need to take time to reset,' she says.

'I do yoga, which I find calming, and recently I went on holiday for five days, leaving my children and the carer in charge, and came back like a new woman.'

### Learning and earning

Amar and Parminder's story began with an arranged Sikh wedding 35 years ago, and later a son and daughter.

Right from the start, Birmingham-born Amar paid her own way.

One of six daughters, she says her dad wanted them all to be educated.

'After school I studied for a legal secretarial diploma. Then it was straight into work at a law firm in Birmingham, and then a London firm for 27 years.'

Parminder spent 28 years with the Department of Trade and Industry, travelling the world to promote British companies.

After he took voluntary redundancy in 2015, Amar started noticing concerning behaviour.

'Someone we knew had an Indian restaurant and he approached them to go into partnership.

'I asked, "Why are you doing this? This is something we don't know anything about."

'But he wouldn't listen, and a couple of months later the business had to be sold and we lost the money.'

### Forgetting names

After picking up a few driving jobs, in 2017 Parminder started working as a postman. But a year later, Amar was alarmed when he started to forget the names of people they'd known for 30 years.

'I said, "You need to speak to a doctor." But the GP said there was nothing to worry about and that it was just something that happens when you get older.'

That didn't seem right to Amar. She started a job in finance the following year, which had medical insurance, so she took him to a private GP for a second opinion.

'The doctor carried out tests, and when we went for the results, he said, "I'm no expert but I think this is a cognitive matter," and said Parminder should be referred for more investigations, including a spinal tap and an MRI scan.

'After the second appointment, the hospital rang me and said it was conclusive that he had frontotemporal dementia, semantic variant.

'I thought, "Oh my God," and had a little cry in the kitchen. I didn't know anything about dementia, but I went into "mummy mode".

'I thought, "We can fix it, and as long as it doesn't get worse, we can manage this."

'I tried to talk to Parminder about it, but he said, "They don't know what they're talking about. They've got it all wrong."'

### Golden tablet

Parminder has struggled to accept the diagnosis, which is challenging for the family.

> **I do yoga, which I find calming, and recently I went on holiday for five days, leaving my children and the carer in charge, and came back like a new woman.**

'He sees dementia as like having a headache and is always looking for a quick cure – a golden tablet,' says Amar.

This belief in a cure led Parminder to jump in the car and head for A&E and his GP's surgery as often as once a week. He would drive to Leicester and back in one day to drop in on relatives.

But the DVLA ended up revoking his licence, and Amar was forced to sell her beloved Lexus. She now uses her daughter's Fiesta, which Parminder accepts he can't drive.

In 2020, Parminder was still working as a postal worker but kept coming home early and was off work for a while, without explaining why.

Eventually, Amar called his union rep and told them that Parminder had dementia.

'He said he already knew, they had referred him to an occupational therapist and were thinking of ways they could support him.'

Although his work were good at making adjustments, including to his schedule, it soon reached a point where this was no longer possible.

'It wasn't long before they called to say he had become agitated at work and had become aggressive.

'The union rep said he couldn't see a way back from that, and he was laid off in December 2022.'

## Support and funding

Losing Parminder's income was a major worry, but an Alzheimer's Society dementia adviser helped them apply for PIP (Personal independence payment) and secure a Blue Badge for parking.

An Admiral Nurse signposted them to support too, and a carer's assessment with the local authority resulted in funding for 10 hours' respite care a week.

As Amar is still working full-time, she has had to self-fund a further 40 hours of care a week, but she says it's money well spent.

'We are lucky the carer is a friend and someone we can trust, and who Parminder feels comfortable with. I don't have to worry about leaving him to go to the office.'

Amar says her employer has been flexible and understanding.

'They told me I could work from home as much as I needed to, and don't mind what hours I do as long as the work is done.'

Now living in Bishop's Stortford, Amar is also fortunate to have help from their adult children.

'Our son lives in Birmingham and comes over every other weekend, and our daughter travels from London in the week. We've got each other and juggle everything between us.'

But although Amar has felt supported in many ways, stress has taken its toll on her health. She has put on weight and is medicated for an autoimmune disorder and high cholesterol.

## Developing patience

It has been tough for Amar to watch Parminder change from a sociable, sport-loving man who loved to travel. He now needs rigid routine and has some unusual behaviours like smothering his food – including dessert – in ketchup. But she's philosophical.

'Life hasn't turned out how I hoped it would be, but it is still manageable,' she says. 'There are people in worse situations and I am grateful for everything I have.

'I have had to develop patience. If I hadn't, I would have been a lot more stressed.

'And from knowing nothing about dementia, I have had to become a bit of expert to advocate for him. Because if I didn't do it who would?'

One of the things that helps Amar stay positive is making a difference to others.

She's a member of our Dementia Voice group for people from South Asian Communities. Amar hopes to raise dementia awareness among South Asian communities, including by providing dementia information in temples.

'In India, there is a stigma about dementia. They call it a weakness of the head, and the attitudes stop people from going for help,' she says.

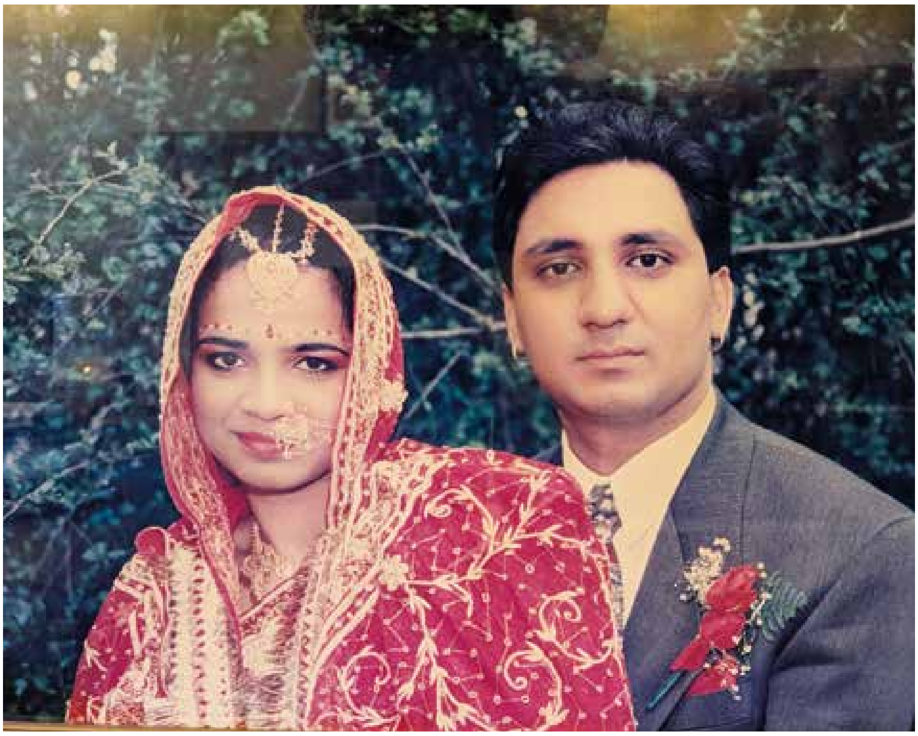
Amar believes there should be far more knowledge about dementia in the general population too.

'People hear the word dementia and back off. It's like cancer 20 years ago. People thought it was like signing a death warrant but now there is more awareness.

'I hope the same will happen for dementia. It is part of life and there is going to be a lot more of it.

'One in three of us will get it. It is not an old person's disease and I hope one day we won't be so scared.'

> **We are lucky the carer is a friend and someone we can trust, and who Parminder feels comfortable with.**



Visit **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933** for our:

- Carers – looking after yourself (523) factsheet.
- Caring for a person with dementia: A practical guide (600) booklet.
- What is frontotemporal dementia (FTD)? (404) factsheet.

Find out how you can use your experiences of dementia to help shape our and others' work – visit **alzheimers.org.uk/involvement**

# ? Ask an expert

**'My mum has dementia and gave me power of attorney. She needs me to manage her accounts and investments but can't recall their details. How can I find them?'**

# Finding lost accounts

### Start with what you have

Look carefully through whatever paperwork your mum has. You might need to be a bit of a detective to piece things together.

A bank or building society statement might show transfers to other accounts.

If your mum sent in tax returns or made a will, these could contain details about her investments.

Getting access to her online accounts may be more difficult. The bank should be able to help if you have a lasting power or attorney (LPA) in England and Wales or enduring power of attorney (EPA) in Northern Ireland.

Does your mum have a financial adviser? If so, ask them for more information.

### Tracing accounts and investments

There are many ways to find different kinds of accounts and investments. You'll need to show evidence of your LPA or EPA.

For bank and building society accounts:

- My Lost Account is a free service that searches for lost accounts and premium bonds. It's funded by the financial services industry – see **mylostaccount.org.uk** or call **01273 035060**.
- Gretel is also industry funded and free – visit **gretel.co.uk**

To find pensions:

- The Pension Tracing Service can help – if you can, make a list of all the employers your mum worked for. See **gov.uk/find-pension-contact-details** or call **0800 731 0175**.

- MoneyHelper has more information about tracing pensions. Visit **moneyhelper.org.uk** and click Pensions & retirement, then Pension problems and changes, or call **0800 011 3797**.

For shares, ask one of the main share registration companies:

- Computershare – you can visit **computershare.com**, call **0370 702 0003** if you're in Wales and England, or please call **0344 892 2596** in Northern Ireland.
- Equiniti at **equiniti.com** or call **0371 384 2030**.
- MUFG at **mpms.mufg.com** or call **0371 664 0300**.

To find unit trusts:

- Try the Unclaimed Assets Portal – see **theia.org/unclaimedassets** or call **020 7831 0898**.

If your mum might own property that you don't have details about:

- For property in Wales or England, contact the Land Registry – visit **gov.uk/land-registry** or you can call **0300 006 0411**, or **0300 006 0422** to speak in Welsh.
- In Northern Ireland, contact Land & Property Services – see **nidirect.gov.uk/lps-offices** or call **0300 200 7803**.

### Help with searches

Professional asset search companies can do these searches for you, but they will charge a fee. Be careful, as there are scams by people who pretend to offer this service.

Although you can do these searches yourself for free, some people feel it's worth paying to get it done all in one go. And sometimes a professional company might be able to find out more.

Always check the fees first. We can't recommend companies, but some examples are:

- Estatesearch at **estatesearch.co.uk** or call **0330 900 1700**.
- Finders (England and Wales only) at **findersinternational.com** or call **0800 085 8796**.

# Your answers

**Readers share advice for other carers about ways to save money on energy bills during the winter.**

# Saving energy

'We bought cosy electric blankets last year and they are much cheaper than turning on the electric heating while watching TV.

'We also use electric blankets on our beds. Wear jumpers and thermal vests, like we did when we were children.

'Now we just use an electric towel rail to dry towels after use and rarely ever use the tumble dryer now. However, if you're dealing with incontinence, I appreciate this might not be a positive way forward.' **Trish Davidson**

'Socks, gloves, hats and throws are what we use! Plus, have just had our loft insulation brought up to date, as was 20 years old.' **John**

'Get thermal curtains to help with draughts, put blankets on your knees and try a fleecy three-quarter length top with a hood. They are cosy over your normal clothes.

'If your loved one with dementia is active, is it possible to move them out of sitting positions to increase circulation? It's beneficial to aiding warmth. Do some stretches where they can or seated, gentle exercises. Assist with walking if it's safe and you have space indoors.' **Gill Barratt**

'My mum is still living in her flat, which has individual electric panel heaters in each room. These cost an absolute fortune to run and, as they are pretty old, the thermostat doesn't work well.

'When she was well, she would just turn them on and off as needed.

'However she is now unable to do so, and I became very concerned she would sit in a freezing room or leave them on constantly in unoccupied rooms.

'I bought smart plugs for each radiator and temperature sensors. I can manage the devices remotely via the app and use smart automation, automating the plugs to switch on or off depending on the temperature measured by the sensor as well as the time of day.

'They also have cameras and smart light bulbs as well, so I have set up the lights to turn on in the lounge or bedroom when the camera detects motion.

'If we left all the radiators on all day, it would cost £70 per day, so the investment into the devices is more than worthwhile, as well as giving me peace of mind.' **Moui**

'If you've been with the same energy supplier for a while it's worth looking around to check tariffs with other suppliers.

'When my mum was living at home she had been with the same supplier for years and thought it was "too much trouble" to change to a different company and it would be more expensive.

'However, some of the other suppliers were offering better rates, resulting in quite a good monthly saving, so it's definitely worth shopping around if you're worried about heating bills.' **Louise7**

'I care for my brother who is 72 and has dementia. He is on a dual fuel plan.

'I signed him up for free energy supply on a weekend, meaning that between certain hours his energy is free. It's easy and simple to sign up.

'His home is kept at the same temperature 24/7, which also shows a good saving rather than turning it up and down.' **Martin**

Visit **alzheimers.org.uk/ForumTogether** to read more and join our Dementia Support Forum.

Call the Dementia Support Line on **0333 150 3456** to find out how our Gas Distribution Network partnership can help you with gas safety, the Priority Services Register, energy efficiency, getting your boiler checked and more.

## Next time

Do you have any advice on helping a person dress, or about planning to travel with a relative or friend who has dementia? Email **magazine@alzheimers.org.uk** or write to the address on page 2 by the end of 4 January.

# Noticeboard

**Your space for messages, posts, updates, opportunities, ideas and more.**

## Letters

### Mother's recipes

Your magazine goes from strength to strength, providing essential information, encouragement and entertainment to people with dementia and their families.

The handwritten recipe in the last issue was a poignant reminder of my own mother's collection – started painstakingly in a lined hardback book, added to over the years and stuffed haphazardly with clippings from magazines and newspapers until it all had to be tied together with string!

Sadly, Alzheimer's and vascular dementia put an end to her baking. Thanks again for a happy memory.

**Rose**

### Getting a CHC assessment

In 2022, my mother was diagnosed with Alzheimer's a year after falling and breaking her hip. I believe she had it a couple of years before diagnosis.

She has lived with my husband and I for two and a half years but started waking throughout the night and disturbing us.

In January 2025, she (self-funding) went into a care home. I felt guilty and after six weeks she came out to us and I cared for her, but this became more unmanageable. The original care home was full, so we had to put her in another one further away.

NHS continuing healthcare (CHC) assessed her but said she didn't meet criteria for help towards funding. Her original local care home had vacancies, so we put her back in there.

Her condition has worsened so I contacted CHC, who said they would reassess her after she's settled for six weeks. After 11 weeks, no one had assessed her. I put in a complaint to local and national government and hey ho – CHC will reassess her!

It should not have to take all of this chasing by relatives for their vulnerable loved ones. There should be proper procedures in place, A B C... simple!

**Jan F**

It's shocking just how much people often need to push to get the support they're entitled to receive.

NHS continuing healthcare (CHC) funding and care is for people in England who have a 'primary health need', as opposed to needs that mostly involve social care.

Our When does the NHS pay for care? (813) booklet explains who can get it, how it's assessed and appealing against a decision about CHC that you disagree with – please visit **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Our CHC Appeals Support Service can help people to appeal against a decision to refuse or withdraw CHC funding – call our Dementia Support Line on **0333 150 3456**.

## Share

Share your views, feedback and news – email **magazine@alzheimers.org.uk** or write to the address on page 2. We can consider contributions received by 5 January for the February/March issue (wording may be edited).

## Cardiff café milestone

The Sports and Memory Café in Cardiff marked its first anniversary with a joyful event in October.

The fortnightly group, a partnership between Alzheimer's Society and Cardiff Rugby Club Community Foundation, offers a wide range of activities.

Richie Maiorano, our Local Communities and Volunteering Lead for Wales, said, 'The event drew an incredible turnout, provided a fun-packed day full of activities for regular attendees, and gave us the opportunity to recognise and celebrate our volunteers, both within the partnership and wider groups and activities across Cardiff and the Vale.

'With over 50 attendees, Cardiff Rugby facilitators helped organise a beautiful buffet and we were joined by the uplifting Forget-Me-Not chorus. It was a truly special day, with people using this service and volunteers at the heart of every moment.'

Café attendees have enjoyed activities including boccia, tabletop curling and skittles, quizzes, club tours and cognitive stimulation through reminiscence and storytelling.

The group also recently launched a Carers' Corner – dedicated space where our dementia advisers offer ongoing support for carers, including signposting to further resources.

Richie adds, 'Here's to the next year, as we look to develop new partnerships with Cardiff Rugby's affiliate clubs across the region and continue to deliver a service that has come to mean so much for so many people.'

# Super easy sweet

Del in Essex shared a two-ingredient, three-step recipe for a dessert he makes for his partner Margaret, who has mixed dementia.

'Margaret says the best thing about the food I make is the bits that aren't burnt! So this simple recipe goes down really well, because even I can't burn this dessert.'

## Custard and sponge dessert

- **Empty a tin of custard or Ambrosia rice pudding into a microwaveable bowl.**
- **Add a bit of readymade sponge cake from the local shop, sliced up nice and small (Margaret likes strawberry flavoured sponge).**
- **Gently heat the bowl up in the microwave. Check the temperature isn't too hot, then tuck in!**

Margaret follows a restricted diet recommended by her speech therapist, and Del says, 'This is a perfect tasty dish which Margaret can manage really well and gets a lot of enjoyment from.

'Another dish that Margaret likes is bananas and custard. She was born in 1944 and you couldn't get bananas easily when she was young. To have bananas and custard was probably a real luxury!

'This all makes me think about other foods that seemed really exotic back in the 70s. I remember we used to put sultanas on our curry – very posh!'

Editor Danny, who tested the dessert recipe himself rather than give it to anyone else, says, 'What a great result! You can try different sponges and vary how well you mix it together, and add hundreds and thousands for an extra 70s flourish.'

**Sadly, Margaret died as we were about to go to press. We're hugely thankful to her and Del, who have shared their experiences in so many ways to help others. Our thoughts are with Del and everyone else touched by this loss.**

# Sheffield musical

A new musical exploring the impact of dementia on a family has debuted in Sheffield.

Described as 'a love letter' to all grandparents, How Could I Forget? was inspired by writer Joe Carnall Jnr's grandad, Shugs.

Joe says his music embraces the contrast between the deep sadness of his grandad's dementia journey and the many joyful moments.

'It was around the same time that my wife bought me an upright piano for my birthday.

'And, completely unintentionally, I began to map out the odd song to remember him by.'

The musical's lead characters, Jack and Jean McBride, are inspired by Joe's beloved grandparents. There are sad tears but plenty of happy tears too, says Joe.

'Although the show is unavoidably and intentionally emotional, I want people to leave feeling uplifted and leave looking forward. I want it to be a cathartic experience.'

The feedback has been quite overwhelming, adds Joe.

'It's only after the event that I've begun to feel the weight of responsibility that comes with writing about dementia.

'We've received so many comments simply thanking us for bringing this issue to the stage as well as a lot of praise for 'getting it right'.

'However, there have been some really moving comments about audience members being finally able to grieve and process what for most of us, including myself, is trauma that is so often simply accepted.'

Joe hopes to take the musical further afield in England in 2026 – sign up for email updates at **hcifmusical.co.uk** or follow @HCIFmusical on Instagram.

# Coming up

## What's coming up in Dementia together magazine, and ways you can get involved.

**Our plans for upcoming issues are shaping up to be full of helpful ideas, experiences and advice.**

The dark winter months can be challenging, especially in the mornings. We'll hear what a group in Hereford thought about clever gadgets from our shop that help with waking and sleeping.

We'll also be celebrating the joy of dance and looking ahead to National Day of Dance on 8 March, organised by Angela Rippon's campaign Let's Dance.

## We need your input too!

Please email us at **magazine@alzheimers.org.uk** or write to the address on page 2.

### For everyone

Have people's **recipes** in the last couple of issues reminded you of ones that were handed down to you? Or maybe there's a dish that brings back treasured memories, and which you'd like to share?

For our next **book group**, we're reading Anna and the Beast, by Christine Reddall. It's a moving memoir from a mother whose daughter had frontotemporal dementia. We'd love to know what you think of it – see page 27 for details, and for a chance to win a copy.

### If you have dementia

If you're living with a dementia diagnosis, has anything this issue inspired you to share something from your own experiences?

- Maybe you've found a **new passion** or done something since diagnosis you'd never have thought you'd do, like Susan on page 13?
- Do you have an **opinion** about dementia you'd like to get off your chest, as Julie and David have done on page 17?
- Or, like Sue on page 14, could you tell us **how your life changed** from before you had any symptoms of dementia, before getting a diagnosis, to then living with the condition?

Perhaps you've got favourite sporting memories you'd like to share? Or you'd like to shout about a music event you go to? Or has anything raised in our interview with Ian, on pages 8–11, made you stop and think?

### If you're a carer

We'd also love to hear from you if you support a partner, friend or relative who has dementia. Maybe there's something in our article about Amar, on pages 30–33, that resonated with you?

We're especially looking for your advice for other carers on two topics before 5 January:

- First, tips on **travelling** with a family member or friend who has dementia. Do you have any tips about helping them to prepare for a journey? Or advice on finding a travel company or dementia-friendly accommodation?
- What are your top tips on making a person with dementia feel more comfortable if you're helping them to **get dressed or undressed**? Have you found adapted clothing or products that reduce the stress? Or have you worked out a clever way to remove or put on clothes?

### What have we missed?

**Do you read the magazine and think, 'But what about… ?' Are we missing an important subject that you think we should cover?**

# Competitions

## Dunker biscuits

We have a selection of three packs of dunker biscuits (see pages 28–29) for four lucky winners drawn from correct entries.

**Q: Two of the following statements are true but we made up the other one. Which is false?**

**A. Ancient Romans dunked 'bis coctum' wafers in wine.**

**B. 16th Century British soldiers dunked 'hard tack' biscuits in beer.**

**C. British prime ministers aren't allowed to dunk their biscuits in tea or coffee, even in private.**

## Memory calendar

We have a Memory calendar 2026 for three winners drawn from correct entries. The Memory calendar has space on each day's page for your own reminders and notes.

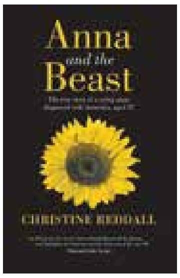
**Q: What is the calendar currently used in most parts of the world for non-religious purposes?**

**A. The Gregorian calendar.**

**B. The ancient Babylonian calendar.**

**C. The stardate system from Star Trek.**

Send us your competition answers with your name and address by end of 4 January – email **magazine@alzheimers.org.uk** or write to the address on page 2.



## Book givewaway

See page 27 for a chance to win a copy of Anna and the Beast by Christine Reddall.

## October/November winners and answers

### Idem smart clock

L Smith in Gwent won an Idem smart clock. Answer: Family and friends can keep in touch with someone through a Idem smart clock by using the app to send reminders, notes and photos, which then appear on the clock.

### Forget-me-not and snowflake bauble

A Palmer in Norfolk and an L Skelton in County Down, C Ryan in Greater Manchester and J Nicholls in Wiltshire each won a handmade ceramic Forget-me-not and snowflake bauble. Answer: Decorating Christmas trees, originally a Central European custom, was popularised in Britain and elsewhere after a newspaper published a picture of Queen Victoria's Christmas tree, hung with baubles.

### Book giveaway

A Taplin in Devon, C Daniel in West Sussex, M Carpenter in Essex, K Hoyle in Gloucestershire and J Piper in Hampshire each won a copy of Remember When, by Fiona Phillips.

### Anagramword

**Across:** Whiteboard, organiser, big buttons, fidget, aromatherapy, fall detectors, talking clocks, reminders.
**Down:** Wearables, dispenser, easy grip, personal tracker.

**Terms and conditions:** 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.

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