April/May 2026

Dementia together

Alzheimer's Society

In this issue

Still making music, creating a care team, delayed assessments and much more

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Welcome

As the days grow longer, we can feel a renewed sense of possibility. Whether it's noticing new blossoms on a familiar walk or catching up with someone who understands, we hope you find comfort, hope and moments of joy this season.

We also hope this magazine brings worthwhile and inspiring moments to your day – even on tougher days – and reminds you that you're not alone.

Living with dementia, or supporting someone who is, can feel overwhelming and isolating. Our aim is to offer connection, clarity and practical ideas that you can trust.

Inside this issue, you'll read about people who've found strength in unexpected places. There's advice to help navigate important decisions, from our experts and from people dealing with dementia in their day-to-day lives. And we celebrate the power of community, with groups and initiatives making a difference in often simple but meaningful ways.

Whether you're a carer, a family member or living with dementia yourself, we hope you'll feel supported, understood and encouraged as you read.

Thank you for spending time with us. We're glad you're here, and we hope this issue brings a touch of warmth to your spring.

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.

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

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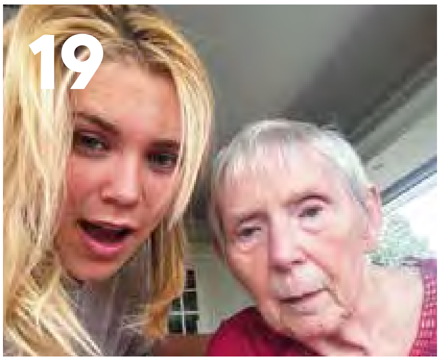
Contents



Directions

One of the most poignant moments I have experienced since starting my role was at a recent Singing for the Brain session.

A carer there told me that, three years ago, before her husband started coming to the sessions, he had lost the power to speak. Now he sings.

Baroness Casey, leading the Casey Commission on Adult Social Care, visited the same session. She felt the hope in the room and thought the same positive spirit should be applied to tackling the challenges faced by people with dementia.

Baroness Casey has since called on the government to act urgently on dementia, challenging them to boost investment in research and appoint new leadership. Like us, she wants the government to apply the same ambition to dementia as seen in tackling diseases like cancer. Her support is incredibly important.

People with dementia want to live independently for longer. The Longitude Prize on Dementia was launched with this goal in mind. Entrepreneurs across the globe responded and, in March, a worthy winner was announced. Read about the exciting ways CrossSense aims to transform the lives of people with dementia on page 6.

There are 1 million people in the UK living with dementia, yet for too long dementia has been sidelined. Coming up soon is our Forget Me Not Appeal when we ask you to wear your forget-me-not badges in remembrance and support. Every badge worn brings us closer to research breakthroughs that will improve how we diagnose, treat and care for people living with dementia today and in the future.

Michelle Dyson,
Chief Executive

News

Commission impact: 'From despair to hope'

People affected by dementia are having an impact on what adult social care will look like in future by speaking with the Casey Commission.

The independent commission, chaired by Baroness Casey, will make recommendations to government on how to reform the care system.

Earlier this year, we involved eight people with lived experience of dementia in a roundtable discussion with the commission. Together, we shared the realities of the current system and what needs to change.

A month later, Baroness Casey gave an update on the commission's progress. She made it clear that dementia must be a national priority, calling for a shift 'from despair to hope'. She recommended an 18-week target for getting a dementia diagnosis and the appointment of a new Dementia Tsar.

Baroness Casey was deeply moved after attending a Singing for the Brain session in Alexandra Palace, north London.

She said, 'If we can match the hope I saw in that room in our national response to dementia, we can build a system with the same resolve shown by those fighting this disease.'

Take on a Trek26

Grab your hiking boots and take on your greatest challenge yet!

Join our team to trek 26 or 13 miles in one of 13 stunning locations across the UK, including the Northumberland coast and the Cotswolds, and help us beat dementia.

You're guaranteed breathtaking views and lots of support on the day from the Society and your fellow trekkers.

To find a Trek26 event and sign up, visit **alzheimers.org.uk/Trek26Together** or call **0300 222 5808**. Use the code LASTCHANCE to save 20% off your registration.

Forget Me Not Appeal

Every Forget Me Not tells a story. But when we all wear it, it becomes something far greater. It's a movement of hope, of action and unity.

Get involved by donating and wearing your Forget Me Not this June – a visible reminder that it will take a society to beat dementia.

Find out more and donate at **alzheimers.org.uk/ForgetMeNotTogether** or call **0330 333 0804**.

Party conferences

In Wales, we've been busy during spring party political conference season.

Our team has been out and about at conferences held so far – Welsh Conservatives, Plaid Cymru and Welsh Liberal Democrats.

The team's big focus was promoting the new Dementia Strategy for Wales, making sure it's a priority for all the political parties as they head towards Senedd (Welsh Parliament) elections in May.

Draft budget consultation

Together with campaigners in Northern Ireland, we responded to a recent draft budget consultation to ensure the voices of people affected by dementia are heard.

We highlighted the increased demand for dementia diagnosis, care and support, projected to rise by 51% in the next 15 years.

What makes this Department of Finance budget different is that it covers several years. Compared to single-year planning, this offers a greater opportunity to transform public services.

Thank you to all the campaigners who worked with us!

Open letter

In an open letter, our campaigners have called on the government to deliver a bold and ambitious plan for dementia in England.

The government is working on the Modern Service Framework for Dementia and Frailty, and we want to ensure it delivers for everyone affected by dementia.

It's a once-in-a-generation opportunity to influence the story of dementia, now and for years to come. We're grateful to everyone who added their name.

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

Finger-prick test: new study

A new international study, Bio-Hermes-002, will see if a simple finger-prick blood test could give people with Alzheimer's a quicker diagnosis.

The researchers are testing whether very small blood samples, collected on a special card, can reliably detect early signs of Alzheimer's disease.

The test measures three proteins associated with Alzheimer's – p-tau217, GFAP and NfL. The results will be compared with established ways to diagnose the disease, such as PET and MRI brain scans, as well as other newer tests.

The study plans to involve around 1,000 participants from the UK, US and Canada. They'll include people with no symptoms, as well as those with mild cognitive impairment and early-stage Alzheimer's. At least a quarter will come from under-represented ethnic groups, to ensure the test works accurately for everyone.

With emerging new treatments that appear to work best in the earliest stages of Alzheimer's disease, diagnosing it early is becoming increasingly important.

'At the moment, diagnosis often relies on cognitive testing and clinical assessment, and in some cases brain scans or a lumbar puncture,' says Alice Carstairs, Research Communications Officer at the Society.

'These can be expensive, invasive and difficult for many people to access, and all of this can contribute to the long diagnosis periods people can experience.'

Bio-Hermes-002 is led by LifeArc and the Global Alzheimer's Platform Foundation, with support from the UK Dementia Research Institute.

Alzheimer's Society is also leading research into quick, effective blood tests through the Blood Biomarker Challenge. This multimillion-pound initiative aims to make blood tests for Alzheimer's and other types of dementia routinely available on the NHS within a few years. It's led in partnership by us, Alzheimer's Research UK, the National Institute for Health and Care Research, Gates Ventures and players of People's Postcode Lottery.

Dementia Run Club

We've launched Dementia Run Club to celebrate our charity partnership with the AJ Bell Great Run Series 2026/27.

Dementia Run Club members will take on the 45th AJ Bell Great North Run on 13 September to fundraise for Alzheimer's Society.

All 10 runners have a personal or professional connection to dementia, including Shannon, who is running for her nan Babs, and dementia researcher Harry.

Read about Jane, a club member living with dementia, on page 12.

Find your nearest AJ Bell Great Run at **alzheimers.org.uk/dementia-run-club** or call **0300 222 5808**.

Half-million milestone for EDF

Since becoming our partner in 2024, colleagues at EDF (UK) have raised over £500,000 through bake sales, bike rides and bingo nights.

Over 1,200 colleagues have also become Dementia Friends and we've been working together to help the business better support their customers affected by dementia.

We're very proud to announce that our partnership has been extended until the end of 2027. It will continue our work to better support their customers and aim to raise £1 million to help end the devastation of dementia.

Longitude Prize: A dream come true

The Longitude Prize on Dementia has awarded £1 million to social enterprise CrossSense to develop its personalised AI-powered assistant for smart glasses.

CrossSense's AI companion, called Wispy, identifies everyday objects and guides people living with early-stage dementia through daily activities, supporting them to live safely in their own homes for longer.

Szczepan Orlins, CEO at CrossSense, said: 'Winning the Longitude Prize on Dementia is a dream come true... the prize's support has accelerated CrossSense in ways that wouldn't have been possible otherwise.'

The global prize was launched in 2022 to drive the creation of personalised, technology-based tools to help people living with dementia maintain their independence at home. In 2024, 24 promising innovations were whittled down to five finalists.

The prize is funded by the Society and Innovate UK and delivered by Challenge Works.

For more about the prize, the finalists and the winner, see **alzheimers.org.uk/longitude-prize**

Listen up

Hear from people who feature in our articles in the Dementia together podcast.

We release a new episode with each issue of the magazine, bringing articles to life in people's own voices. The last episode featured John who's found a new passion for broadcasting since his dementia diagnosis and a new episode will be out in early April.

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

New inequalities programme

Alzheimer's Society has awarded £2 million to a pioneering new research programme that aims to tackle unfair health inequalities and improve access to care for people with dementia and their families.

A person's experience of dementia care is too often shaped by where they live, the language they speak, or whether they can afford additional support.

The GRACE programme will test a package of resources designed to support people with dementia to achieve personalised goals such as sleeping better or being more active. The research aims to ensure that everyone – no matter who they are or where they live – can access excellent dementia care.

Join our annual conference

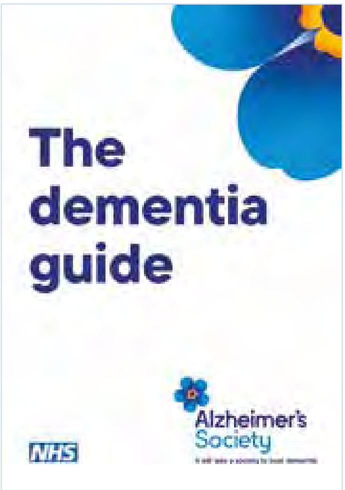
Join us online or in person at Alzheimer's Society's Annual Conference on 17 September.

Taking place at Convene in Bishopsgate, London, it will bring together health and social care leaders, policymakers, researchers, campaigners and people affected by dementia.

This year's event will explore how evidence, innovation and lived experience can drive change and better outcomes.

Early bird registration runs throughout April, with a reduced rate for people affected by dementia. Visit **alzheimers.org.uk/annual-conference** or call **0330 333 0804**.

New dementia guide out



A new version of our guide for people dealing with a recent dementia diagnosis is now available to order or download.

We worked with around 150 people living with dementia to make sure The dementia guide covers everything you need to know.

As well as topics such as treatments and planning ahead, the guide covers the most common emotional and practical questions that people have after receiving a diagnosis.

For The dementia guide (872), see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Virtual gifts

If you want to give someone a gift that's truly meaningful, how about our Shop's new virtual gift range?

By sending a virtual gift you are donating towards Alzheimer's Society's essential services or vital research.

For example, £20 could help us answer three calls on our Dementia Support Line, while £75 could cover the cost of five hours of Singing for the Brain sessions.

They are delivered by email and make perfect last-minute gifts.

Simply enter your message, your name and the recipient's details at **shop.alzheimers.org.uk/virtual-gifts**

New LPA day

The first ever national Lasting Power of Attorney (LPA) Day is on 22 April this year.

Organised by Carers UK, the day will highlight the importance of planning ahead. It's a great opportunity to spark conversations that people often find tricky to initiate.

To find out more about Lasting Power of Attorney Day, visit **powerofattorneyday.org.uk** For advice, order or download our Lasting power of attorney factsheet (472) **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Our free digital assistance service can help you to complete online power of attorney forms if you don't have online access or a printer.

Call our Dementia Support Line on **0333 150 3456** to find out more.

Don't miss…

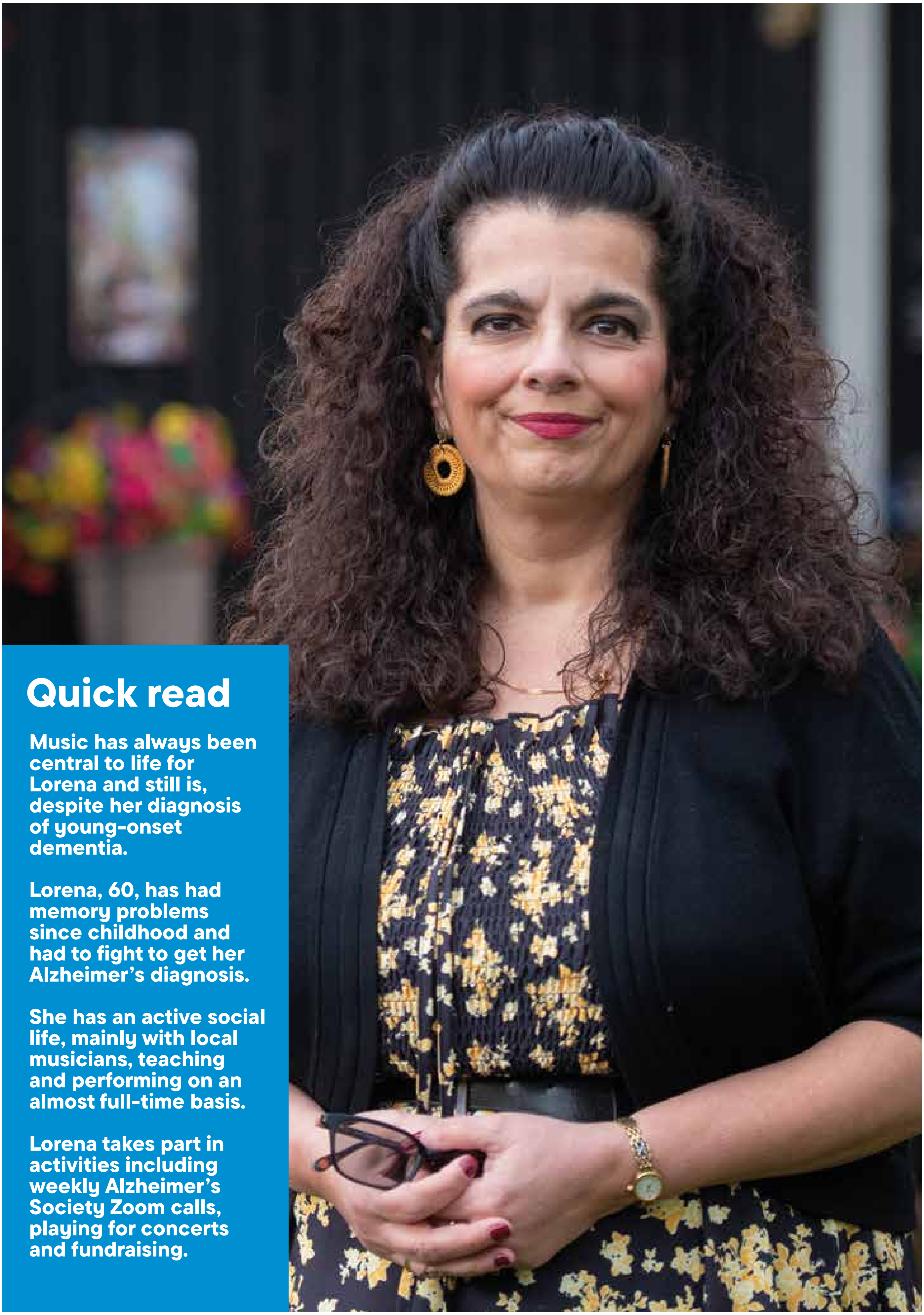
Pete wants more understanding about the everyday struggles of person with dementia. **See page 17.**

Ian is researching how to fight dementia by boosting the brain's natural cleaning processes. **See page 21.**

Forget-me-not Chorus is bringing joy to people's lives through choirs in Wales and Cornwall. **See page 22.**

People affected by dementia try out products designed to be absorbing and relaxing. **See page 28.**

How long should you need to wait for local authority assessments? **See page 34.**



Quick read

Music has always been central to life for Lorena and still is, despite her diagnosis of young-onset dementia.

Lorena, 60, has had memory problems since childhood and had to fight to get her Alzheimer’s diagnosis.

She has an active social life, mainly with local musicians, teaching and performing on an almost full-time basis.

Lorena takes part in activities including weekly Alzheimer’s Society Zoom calls, playing for concerts and fundraising.

From the beginning

Lorena, from Essex, is grateful that her dementia hasn't affected her ability to perform and teach music. She speaks to Margaret Rooke about doing what you love.

Since she was young, music has played a vital part of Lorena's life. Now at 60, and with young-onset dementia, this hasn't altered at all.

A grand piano takes pride of place in her light, airy living room. This is where her musician friends come over for soirées. Her partner of 40 years, Bryan, is also a pianist.

'Many of them are reputed musicians,' Lorena adds. 'There is a local artisan pub that employs all the best players. I teach every evening so, when finished, I go and listen to them playing. This comprises much of my social life,' she says.

'We all have a great time together and share a close bond.'

Lorena has a purpose-built music room where she teaches 35 students piano, violin and music to degree standard. She also plays in hotels and restaurants.

'I shy away from being watched as a solo performer,' she says, 'but I don't mind sitting behind a piano in a hotel or restaurant. Or in a church when employed for weddings and funerals on organ.'

Born to music

Lorena is relieved that dementia hasn't dented her appreciation or knowledge of music. She is also grateful to her music-loving parents for giving her the best start in life.

'Dad, being Italian, loved classical music, and Mum had a good ear. We used to play duets together. My parents weren't professional musicians but they encouraged me all the way,' she says.

'I had my first piano lesson aged six. I was very fortunate that my teacher was unsighted. He trained me to rely on my ears.

'Although he couldn't see, he used to spookily realise errors – "Lorena, your third finger is on G, put your fourth finger on it." I owe my highly attuned "ear" to him, alongside innate ability.'

> **I don't think those close to me believe it, because I've always had such a bad memory. Nevertheless, my sister is my lifeline.**

Lorena gained her first degree at the Royal College of Music, followed by Goldsmith's College, University of London. She spent 21 years as head of music in secondary schools, semi-retiring to start her own business – Bluebell Music Academy – teaching instruments, including accredited exams, theory, GCSEs, A levels and helping with dissertations for degrees.

Memory problems

Lorena's memory problems started when she was a child.

'I had meningitis and was in a coma for a short while. I emerged from it with slight damage to one of the temporal lobes in the memory area of my brain.

'I've always had a bad memory and used to get reprimanded at school for not concentrating. However, I did well in my O and A levels.

'It is now at a stage where my brain completely deletes information. I cannot recall where and when I went on holiday, and even who I was with.'

Lorena relies on careful notes to keep track of her students, especially since many of them have unfamiliar names from a range of cultures.

'My memory is such that until they arrive, I sometimes do not know if

I will be teaching a boy or girl. Sadly, this is the nature of my Alzheimer's, but I do keep copious notes pertaining to each lesson.'

Diagnosis text

Four years ago, Lorena was referred to a consultant neurologist in London. He identified problems with her temporal lobes and diagnosed young-onset dementia. He then retired, leaving Lorena without help or a formal acknowledgement of her diagnosis.

'He had no successor, so I personally had to request, even plead, for a referral for an MRI from the GP.'

Finally, she was given an MRI scan. She then received a short text message formalising a temporal lobe Alzheimer's diagnosis.

'I wasn't satisfied with the text,' says Lorena, 'so I returned to the doctor requesting a formal letter. I finally got this three years later.'

There was no follow-up after the letter – she was told the neurologist had done his job. However, she had the diagnosis in writing now.

'I knew I had Alzheimer's,' she says. 'There was even slight relief that there was a reason for my very poor brain function. I knew it was too weak to be a result of the menopause or natural ageing.'

Lists and memoirs

Lorena says the only help she has received since diagnosis is from Alzheimer's Society, and she is grateful for this.

'Luckily, I do not have depression. But I do have a little cry when I have put my foot in it yet again.

'I am frustrated and embarrassed when I have not recalled something important and am becoming increasingly solitary through choice. Alzheimer's has made me feel safer and happier on my own.

'I rely totally on lists and write everything down, all colour coded. Things I must do are in red pen, conversations in green and my pupils are in black. If I were ever to lose my diary or my phone, I wouldn't have a clue about, well... everything.'

She's writing her memoirs too, a journal of good and bad days.

'I am a good writer and my organisation keeps me intact.'

Lorena monitors herself through her diaries and writing. For instance, she has recently discovered that it can take her longer now to find a word she's searching for.

Circles of friends

Some people in Lorena's life have not accepted her dementia diagnosis.

'I don't think those close to me believe it, because I've always had such a bad memory. Nevertheless, my sister is my lifeline.

'She's very good at reminding me what not to say. For example, "Don't say it's nice to meet you, because you've met him twice already."'

Lorena now finds it hard to socialise with people who talk about past events.

'I can't join in because I have no recollection at all, so I can come across as being moody, just sitting there quietly.'

She finds it easier with her musician friends, since they largely speak in the present together.

Her 60th birthday party was a cheery event. She's proud that she organised this herself, for 100 guests. The partygoers included members of

> **“I live for today and ensure I do everything I want to do and enjoy. This is all one can do to stay content in the circumstances.”**

the Alzheimer’s Society group she has joined.

‘The group talks every Friday on Zoom and have become good friends. I am close to one lady in particular; she has also been a professional. They are all lovely people, very knowledgeable and ready to share advice.

‘I seem to be the worst “memory-wise” of them all. They say, “How did you get on last week?” I scurry to get my diary out.’

She even helps one member of the group with her piano learning.

Ups and downs

Lorena loves Italy, and has been on holiday alone there three times, though this has had its difficulties.

‘I get very lost. Last time I stayed in a villa at the foot of a mountain. There was a concert in the piazza one evening and I was dressed up, complete with high heels. Afterwards I could not find my way back, despite my reminder photographs.

‘I went up one way, then down another. It took from 12am to five in the morning to find my abode. I was so very frustrated and upset. I was dirty and my feet hurt.’

Back in the UK, she takes every Friday off and travels outside of her hometown to meet friends, see a show, musical, dance, art galleries or something else cultural. She loves London and enjoys a walk in the woods or countryside drive.

She says she doesn’t know enough about dementia to give advice to others, though she is happy to share her personal experience.

‘I think I’m still fresh to acceptance, since it wasn’t too long ago that I received the text. But if somebody joined our group and they were new to their diagnosis, I’d probably befriend and invite them to ring me anytime.

‘I live for today and ensure I do everything I want to do and enjoy. This is all one can do to accept and stay content in the circumstances.’

For our Understanding young-onset dementia (688) booklet, see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

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

Donate

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

Share and inspire

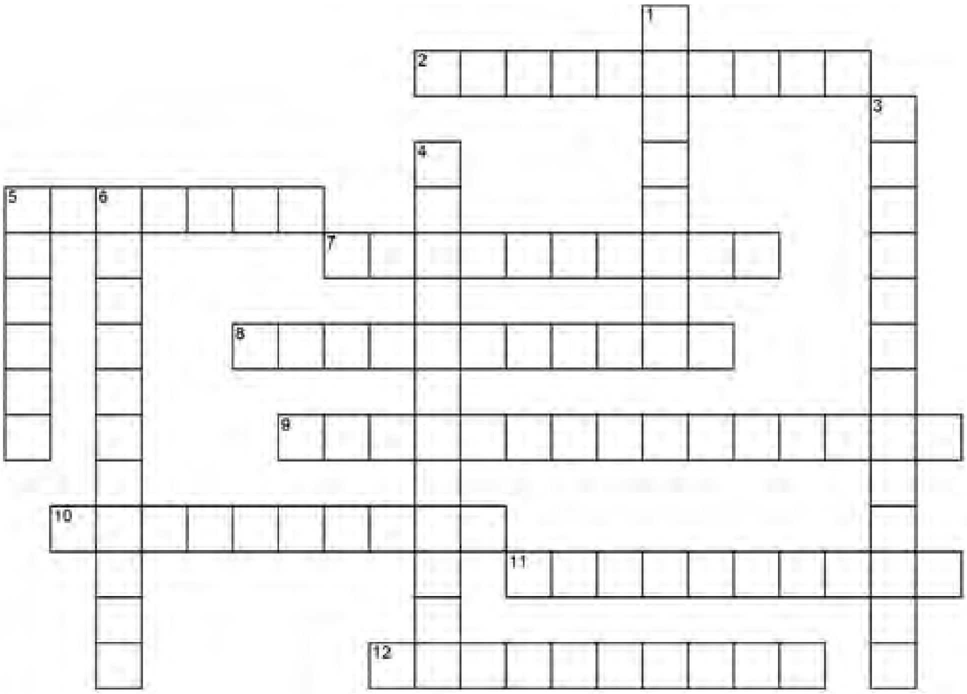
Views, updates and ideas – for and by you.

Anagramword: Historic sites

May is Local and Community History Month, run by the Historical Association, and there's no shortage of historic sites across Britain and Ireland.

Our latest puzzle from Pete Middleton features just a few of them. 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

2 Ruby nectar turns out to be the place where the 'turbulent priest' was killed (10)
5 Stab elf to uncover the place where the Titanic was built (7)
7 Rambo hasn't bathed in this ancient place, or taken 'the cure' there (5,5)
8 Subtly groan after climbing the Tor here (11)
9 The crab indulges to reveal the Scottish site of the 'one o'clock gun' (9,6)
10 Farce ran on at this ancient Welsh castle (10)
11 Do in vandal to discover the name of this Roman dig site (10)
12 One gets hen unravelled to name this ancient place (10)

DOWN

1 Wrote Rex to ask the current name of the Roman town of Viroconium (8)
3 Drool often now if you've visited the capital's favourite tourist attraction (5,2,6)
4 Ouch! Rant to MP to find Henry's palace (7,5)
5 Tablet taken to show the site of a historic conflict (6)
6 Finer island you'll never see than this historic home of monks in the North East (11)

Mission to run

A woman with dementia in South East Wales is part of a team running the AJ Bell Great North Run on 13 September for Alzheimer's Society.

Jane Buckels, in Abergavenny, is one of 10 people with a personal connection to dementia who have joined our Dementia Run Club.

'It's my mission to present a positive face to a dementia diagnosis and to encourage people to seek an early diagnosis,' says Jane.

'I speak openly about having Alzheimer's but always stress that my early diagnosis is the reason that I am still able to do what I do.'

After an ankle injury last year made her stop running, aiming for the Great North Run has given Jane a much-needed boost to get back into it.

'I'm a bit wishy-washy unless I have a target!' she says.

Although still working on her ankle, Jane plans to build her strength and stamina to complete a couch-to-5k programme before half marathon training.

'For myself, I hope to hit my target and run the Great North Run. The aim is to run it all, but it will be part run, part walk if the ankle says, "No."

'Hopefully the club will raise lots of funds and get people talking about dementia in positive ways.'

Never done before: A voice to share

Since his dementia diagnosis, Fred Hartshorn in Norwich has found the confidence to perform on his own:

I've always loved music and been musical. I learned to play the guitar when I was around 16 and, when I was 18, I became a disc jockey. From the late 1960s until the early 80s, I was Funky Fred.

DJ-ing was a sideline I had alongside my career in engineering. I did weddings, birthdays and I also had a couple of residencies around Leicestershire and Warwickshire. I mainly played disco, but then when punk came along, I started doing Northern Soul.

I loved doing it but, as the kids grew up, it wasn't so easy to get out and I had to give my van and everything up. After that, I used to play my guitar in a few folk groups but that's about it.

Diagnosis journey

My diagnosis journey has been hard.

During the pandemic, I was told I had Alzheimer's disease and we were left to it – there was no support or follow-up.

Then three years ago, I was sent to a memory clinic in Leicestershire and they told me it wasn't Alzheimer's, it was dementia with Lewy bodies. But now, my doctors in Norwich do think it's Alzheimer's without them ever meeting me.

This experience of not really knowing what's wrong has been tough and confusing.

> **“This experience of not really knowing what's wrong has been tough and confusing.”**

But I'm trying to make the best of things, to take every day as it comes.

Music continues to be important to me. I can't remember passwords, but you give me a music quiz and I'll come up with all the answers!

I love musical theatre – the Sound of Music, Les Mis and South Pacific – but my real passion is rock, like Status Quo, Queen and Cream.

I play the piano and keyboards, guitar, banjo, harmonica... and I can play the fool sometimes too!

Finding my voice

I've always liked to challenge myself. When I was in my 50s, I did a BSc in computing and mathematics through the Open University.

But since I developed dementia, I've also lost all my inhibitions.

I used to be scared of singing out loud – I was sort of a shy person – but that's gone now.

I go to a dementia singing group at my local library, I'd also play the keyboard for them if they'd let me! We had a talent show – I took my guitar and sang 'Streets of London' in front of 40 people.

I've also tried karaoke for the first time at a respite home. A few people said, 'You can do this, Fred, you've got a nice voice,' and so I got up and did 'My Way' by Frank Sinatra. I got a massive round of applause. I'd like to do it again.

I'd have never done this before dementia but I've got no fear now.

Singing on my own is an empowering experience. It makes me feel positive and I can be as loud as I like!

Onset, diagnosis and now

Dave Gater, in Northamptonshire, shares his thoughts about life before his dementia symptoms, before diagnosis and since.

Who were you before onset?

Up to retirement, I spent 15 years in security, working across building sites, hotels and supermarkets. Before that I worked in food retail.

I was born in London and so was my wife Dianne. We married 55 years ago, when we were both 18.

We didn't fancy living in a high-rise flat, so we moved to Peterborough, where they were building new houses. We have three grown-up daughters, nine grandchildren and seven great-grandchildren.

I didn't grow up in a religious house, but my faith became one of the pillars of my life.

One of my other enduring passions is football. When I was 13, I was at the 1966 World Cup final. True to my London roots, I'm still a big Chelsea fan.

I have long-standing health problems due to having dextrocardia, where my heart is on the wrong side of my body, but I've always been physically fit. I love gardening, and I'm into trains and the history of railways in a big way.

Who were you before diagnosis?

Life was busy. As well as working, I was a councillor on a small council in a neighbouring village.

I noticed I was becoming forgetful and unable to concentrate where I was working. I left stuff unlocked and the entry barrier up!

When I was 68, I thought, 'I can't do this any more,' and I retired.

A few months after retiring, during the Covid pandemic, I went to my GP about my concerns.

My mum and my mother-in-law developed dementia, so I'd seen it firsthand.

After some tests, I was told I had Alzheimer's and left to my own devices. I understand there were pandemic restrictions, but there was no follow-up and no support offered.

I decided I wasn't going to sit and wallow.

My eldest daughter, who was a nursing assistant at the time, said to Dianne, 'He's coping too well.' She thought bottling things up could lead to a breakdown, because she'd seen it before.

She was right, things came to a head and I went to a dark place. I ended up being sectioned and spending time on a mental health ward.

Who are you now?

Finding Alzheimer's Society and getting involved in various projects, including the reader panel, keeps me feeling upbeat.

I've also been involved with academic work, including a creative writing project at the University of Surrey. That's been fabulous – we produced a book and I've got several stories in it.

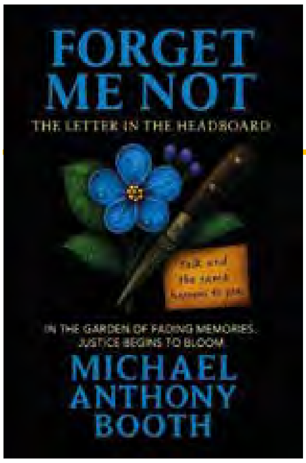
I'd never imagined this would be possible. I have dyslexia and, at school, the teachers gave up on me so I gave up on studying. I wasn't diagnosed with dyslexia until my 40s.

I'm in a bit of a limbo with my dementia diagnosis, as I've been told it might be mild cognitive impairment.

This is a difficult situation, but it is what it is. Many people have frustrating diagnosis experiences. I don't believe enough is being done by the government to fund the care we need.

I've still got my faith, my gardening and my love of trains! I've also been involved with fundraising for Alzheimer's Society at a local club. It was an amazing team effort, led by the club secretary, and we raised over £1,800. I'd love to get involved in more fundraising.

Staying active and involved is so important. I'd encourage others to do the same if they're able, because you get a lot out of it. But don't put pressure on yourself.



New novel: Letter in the Headboard

A man with dementia in County Durham has published his debut novel – the first in a planned mystery series.

Forget Me Not: Letter in the Headboard, by Michael Anthony Booth, is out at the end of April and available for pre-order now.

Michael says, 'Writing a novel while living with dementia isn't supposed to be possible. I can see why – it was not easy!'

In the story, a retired military police officer, who has dementia, holds the key to a murder investigation in a coastal north-east town.

Michael says, 'Moira is based on the female version of me – my symptoms, my fears, my confusion, my determination. Writing her story was emotional, sometimes painful.

'It was necessary because I want the reader to truly experience what it feels like to live with dementia from the inside.'

Michael credits the support of his wife Aline – his 'rock' – in writing the book.

'She helped me keep the story real, grounded and emotionally true. Her support is woven into every chapter, and a character called Trina.'

Forget Me Not: Letter in the Headboard is available in paperback at amazon.co.uk for £11.99.

BRIDGES for Dementia Network+

A new research initiative is looking for people with lived experience of dementia to co-design tools that will help them stay independent and well.

BRIDGES for Dementia Network+ brings together expertise from across the arts, health, social care and technology to find practical solutions.

Howard Gordon, who lives with dementia and is on BRIDGES' advisory board, says, 'You can't take a one-size-fits-all approach to technology for people with dementia.

'When designing the technology, you should take a blank sheet of paper and ask people living with dementia what their needs are.'

Jennifer MacRitchie, BRIDGES Director, adds, 'Together with our partners, we're building a community dedicated to dignity, better care and a brighter future for dementia support.

'We would like people with lived experience to be involved in all aspects of our work, from taking part in the advisory board, acting as advisers on co-design workshops or reviewing research proposals for funding.'

BRIDGES is a national initiative led by the University of Sheffield. It's one of eight interdisciplinary networks funded by Alzheimer's Society, the ESRC, EPSRC and NIHR.

Find out how to get involved in UK-wide activities at bridgesfordementia.org

Mr D: Singing for the Brain

A Singing for the Brain regular in South East Wales has written a song that's since been recorded professionally.

Geraint Roberts, from Caerphilly, attends Ystrad Mynach Singing for the Brain and wrote Mr D about his experiences of dementia. He has logopenic aphasia, a rarer type of dementia where people's early symptoms often relate to language.

'It feels fabulous when everyone sings it in the group,' says Geraint, who had thought about writing the song for a long time. 'I want to use it to help others like me who have dementia.'

Geraint gained the support needed to have his song produced by professionals.

It was sung by Mike Sterling, star of many West End productions including The Phantom of the Opera, with Geraint and the Singing for the Brain group on backing vocals. They recorded Mr D at Shabbey Road Studios in Caerphilly, with musicians Nigel Hart and Al Steele.

In the song, Geraint speaks to his dementia, 'Mr D', about enjoying music and Singing for the Brain. He tells it, 'I choose to live my life without fear.'

Listen to Mr D at youtube.com/@philmozz

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 4 May for the June/July issue (wording may be edited).

Being more active

How can you get more exercise and movement when you have a dementia diagnosis?

Regular movement can boost your mood, improve sleep and help you stay independent. It doesn't have to be strenuous or complicated – small steps can make a big impact.

Speak to your GP before trying something new. That's especially important if you also have heart problems or other health issues.

If you're newly diagnosed with a heart or other health condition, ask your GP about exercise you're already doing as well as new activities.

Types of exercise

Depending on your ability, you could try a combination of these:

- Cardiovascular exercise – anything that raises your heart rate.
- Strength exercises, which could use weights or resistance bands.
- Balance and flexibility exercises to help stay steady and move in comfort.

What to try?

A daily walk, gentle stretching or dancing can all help. Try different ideas to see what works for you.

Build activity into your routine to make it easier to maintain.

If you'd prefer doing something with others, is there a class you can take or someone who could join you?

How much?

Listen to your body. Take breaks and drink water. Stop anything that causes pain or makes you feel unwell, dizzy or short of breath.

Speak to your doctor about what would benefit you. They might refer you to a physiotherapist.

The doctor or physiotherapist could also give you exercises to do while sitting or in bed.

There are many ideas about exercise online and in the media which get people talking. Remember that a plan that's right for someone else may not be right for you.

Be kind to yourself and celebrate every success.

Your tips

'It's important to keep your body as fit as you can and to go outside each day, weather permitting. I feel better for it – there's no good just sitting down watching the TV.

'Start off sensibly and see how you go. Do something you enjoy – if you like being outside then do that, some might prefer doing something indoors.

'I enjoy walking most days. I've lived in the area all my life and I can find my way. I also go litter picking once a week with a friend, sometimes for six or seven miles.

'My wife says I'm much brighter and more alert when I get back, and I've usually got lots to tell her.

'I played hockey until I was in my late 50s and always enjoyed cycling – I did London to Paris and other long rides.

'Cycling on my own is difficult now, but I cycle with another friend each week. Now the weather's better we cycle to Bath on the cycle path, about 30 miles there and back.

'There's a coffee stop and it's nice to meet up with other friends – guys I've known for a while through cycling.

I met one of them at a walking group, but that finished and he started cycling with me.'

Kim Fitzgerald, Bristol

'About a year after diagnosis, following a positive start, I went into a bit of a decline. I was shaken out of it by the radio doctor basically saying that older people can become weaker because they don't move enough and lose muscle mass.

'That was the start of me getting fit again and I haven't looked back.

'It doesn't have to be hardcore gym work. Movement and activity are the key to stimulate the body and mind.' **Jane Buckels, Abergavenny**

For our Physical activity, movement and exercise (529) 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:
Look beyond the mask

Pete Middleton wants people to be more understanding of themselves when struggling, and of others even when they appear to be fine.

Pete, in Northamptonshire, is living with young-onset dementia.

In the dementia community, we have a specific term for the act of appearing composed while struggling internally: showtiming.

When I speak at webinars, podcasts or conferences, I often come across as charming, witty and confident. To an observer, I have everything under control.

However, behind that mask, my heart is pounding. I am desperately searching for names and scanning the room for any hint to help me navigate the conversation.

While I may look relaxed, I am actually gripped by exhaustion and anxiety. The mental toll leaves me completely drained afterwards.

The cost of performance

Showtiming is not exactly lying, but it is a form of hiding. I rely on every social skill and 'fake it till you make it' strategy in my arsenal to fill the gaps left by cognitive decline. It is mentally punishing work.

When people tell me, 'But you look fine!' they usually intend it as a compliment. To me, however, it feels like my daily struggle is being erased.

It makes my invisible challenges feel brushed aside, as if my pain is being ignored because it isn't visually obvious.

The role of cognitive reserve

The ability to maintain this appearance stems from cognitive reserve. Think of this as a mental savings account built through years of education, work, hobbies and social connections. This reserve allows the brain to use past learning and flexibility to work around damage or changes.

For many people with young-onset dementia, a strong cognitive reserve allows us to mask difficulties for a long time. It helps us to find workarounds, substitute words and lean on instinct to keep up appearances.

But there is a significant catch. Because I am so good at 'holding it together', doctors missed my early symptoms and friends sometimes think I am being dramatic. It is deeply disappointing when people doubt your reality because you are working so hard to function.

If you have a diagnosis of dementia, or are caring for a person living with dementia, you'll know exactly what I'm talking about. You often have to 'showtime' too – putting on a mask for a while and carrying on like a trooper when you know that you will feel the effects later. The 'brave face' syndrome.

Moving beyond masks

I have learned that, just because I can push through a situation, it does not mean I always should.

I am beginning to allow myself to take off the mask. Admitting that I am struggling or need a break is not a sign of failure. It is actually an act of courage and self-kindness.

The real challenge for society is creating space for people to be themselves without the pressure to impress or perform.

If we foster an environment of genuine understanding, fewer people will feel the need to put on an act just to be believed.

A call for compassion

We need a world where compassion is more important than expectations.

The next time you meet someone with dementia or a caregiver who seems to be 'fine', look beyond the surface.

Instead of expressing surprise at their appearance, offer real support. Ask how you can truly help.

Let's work together to ensure that no one has to hide their struggle just to receive the validation and support they deserve.

Giving and gaining

Since first learning about Dementia Friends, there's been no stopping Val Down, in Hampshire, on her mission to increase people's understanding of dementia.

During a Dementia Friends session at Eastleigh Rotary Club, where I'm a member, I thought to myself, 'I could do that.'

I'm a people person. I was in education for 30 years – a headteacher for the last nine of those – before starting my own training company.

I was already working with a lot of businesses and educational organisations, and it was clear to me that Dementia Friends was another way I could use these connections to give back.

I spoke with someone from Alzheimer's Society and I was on a course the following week.

Opened my eyes

When I first got involved in Dementia Friends, I didn't think I had a personal connection to dementia. But volunteering has opened my eyes.

Over time, I've realised just how many people I know who are or have been affected. My father had Parkinson's but I now think that it was probably Parkinson's dementia.

I'm a Dementia Friends Ambassador and, to date, I've run 200 sessions – it's just part of my retirement now! I travel all over the place. If people ask me to go, I go.

Most of what I do is in care homes, usually with the staff, family members and other visitors, but I also go into schools. For example, I've just been to a sixth form college to support a module on dementia for students studying health and social care.

Building momentum

I would encourage everybody to give some time up to do some volunteering. The way I look at it, you might think you're giving back but you're gaining as well.

You come out feeling lighter and happier than when you went in. That's the feeling of having done something good.

Dementia Friends isn't my only volunteering role. I also help with activities at eight different care homes.

My two volunteer roles have recently overlapped. At one of the care homes where I volunteer, we've just launched a challenge to create 50 new Dementia Friends by spring.

We're trying to get more family members to attend sessions. We're also reaching out to local businesses, such as solicitors and financial advisers, who deal with power of attorney and wills and regularly meet people affected by dementia.

Rewarding experience

I really enjoy giving people the space to ask candid questions about dementia and to share their experiences.

It's particularly rewarding to support young people – one experience that's stayed with me is helping a girl process what was happening to her grandma.

People often don't understand how to talk to people with dementia. If I can help them feel more comfortable doing this, then I've achieved something worthwhile.

I aim to create a welcoming environment. I want to give people permission to ask the things that have probably been bugging them but they were too afraid to ask.

The real joy is knowing that when people leave my sessions, they go on to raise more awareness and support other people.

Become a Dementia Friend

Dementia Friends is all about increasing people's understanding of dementia and inspiring everyone to make a difference for people affected by the condition in their communities.

Find out more at **alzheimers.org.uk/FriendsTogether**

Tears of joy

After her grandma's dementia diagnosis, Abi-Lou Foster, 20, in Shropshire, vowed to raise funds and awareness, and recently completed a skydive.

My grannie Jean – we call her Jeannie – is just adorable. As a child, I spent lots of time with her and I think of her as a guiding force in my life. She was always happy, bubbly, busy doing things and had lots of friends.

She first developed dementia symptoms around 10 years ago and sadly her health has gone downhill very quickly.

She's now in the late stages of Alzheimer's, dementia with Lewy bodies and Parkinson's disease. She can't talk or eat, drink or do anything on her own.

Occasionally, she'll smile and grin and I can tell she still absolutely adores me, but she's just a shell of herself.

Lack of awareness

I am really surprised and frustrated about public understanding of dementia.

People seem to think it's just about forgetting where you've put your keys. They don't understand the impact and the heartbreak.

So when I decided to start fundraising for Alzheimer's Society, I wanted to raise awareness too – not just about how dementia affects the person with a diagnosis but everyone around them too.

My family has had to literally upend everything, made so many sacrifices to care for my grannie and ensure she can live out the rest of her days as comfortably as possible.

I want people to be aware of what carers like my granddad and mum do day in, day out.

I've fundraised several different times for the Society, I did a 5k run when I was about 12 and I've taken part in Elf Day.

But I wanted to do something with a greater impact – make people stop and think. That's why I decided to do a skydive. Although I'm pretty active, I wouldn't say I'm into adrenaline sports!

Amazing experience

My skydive was cancelled three times because of bad weather.

If I'd had any doubts about doing it, the delays might have convinced me to back out. But they made me more motivated.

When the day finally arrived, I had some nerves but the main thing I felt was pride.

Everything's a bit of a blur, but I won't forget the fact that I cried when I was going up in the plane because my grannie Jeannie came to the airfield with the rest of my family.

When I fell out of the plane harnessed to my instructor, my mind raced and filled with memories of Grannie. I remember looking down, trying to find where she was waiting and thinking, 'I'm doing this for you!'

It was an amazing experience. I felt so much pride in what I'd achieved and cried tears of joy afterwards. It made me feel like a whole new person and I felt on top of the world for days.

Not finished yet

I raised around £700 from my skydive, which is brilliant, but I want to do more. I'm considering doing another skydive!

I've been trying to think of different ways I can get more people to understand dementia better.

I'd encourage everyone to get involved in fundraising. You don't have to fall out of a plane, just start small and find something you feel comfortable with.

You can feel so helpless when a person close to you is diagnosed with dementia, fundraising is a way to feel like you're making a difference.

Unfortunately, it is too late for my family, but I hope my efforts will go some way to ensuring a better future for people affected by dementia.

Join one of our organised skydive events or plan your own – please visit **alzheimers.org.uk/skydives** or call **0300 222 5808**.

Researching help for carers

Finding the most effective ways to support carers relies on involving people who know what being a carer is really like.


De Ward

It's vital that we know what best supports people who care for a family member or friend with dementia.

This needs research that involves carers themselves, though the demands of caring make this a challenge.

'You're so consumed with trying to understand the disease, and the physical and mental impact that it has,' says De Ward, in the Midlands. 'It took me quite a while to think about getting involved in research.'

De's mum was nearly 90 when she was diagnosed with Alzheimer's, and her twin sister was 64 when she got her vascular dementia diagnosis – both within the last three years.

'Sometimes you feel like there's nowhere to turn,' she says.

De only recently began taking part in a study called EnTech, but she's already felt the benefit of speaking with researchers who are supportive and understanding.

'The earlier you can get involved, the better.'

Making a difference

EnTech is studying how online support can help carers. Sarah Fearn, at the University of Southampton, is one of its chief investigators.

She says, 'We are speaking to a lot of different people who care for someone with dementia, from people who have never used the internet before to people who regularly use the internet to help them with caring for someone with dementia.'

EnTech's team includes two people with experience of being a carer – Jane Ward and Amanda Wollam – to help ensure it stays relevant.

Amanda says, 'One of the difficulties carers face can be finding time to access groups for support, so would benefit from online resources they can use whenever they have time.'

'Online support has some real benefits in that it is available 24/7 in the carer's own home,' adds Jane, 'and having support available immediately can reduce the carer's stress both in moments of crisis but also generally as a security blanket.'

In another study, Ayesha Dar is researching what makes a difference for distance carers – something services currently don't have enough guidance on.

'My study looks at how health and social care can better support distance carers and the people with dementia they support from afar,' says Ayesha, at UCL (University College London).

'By listening to carers' experiences, the research aims to show practitioners what really helps, so care becomes more supportive, coordinated and person-centred.'

Ayesha is clear about how much this work relies on carers taking part.

'By sharing your voice, you can help services better understand what really matters to families and carers, and make a meaningful difference to future care and support.'

Rewarding experience

'Every one of us has different experiences and the more of us who are willing to share our own experiences, the better understanding researchers will have of dementia,' says Jane.

'It's an incredibly rewarding experience, knowing you are making a real difference in the care and treatment of people affected by dementia.'

Amanda says, 'Participation is a positive way of ensuring that services which are developed are relevant and take into account the views of not just scientists, but of members of the public.'

'If researchers haven't got the people to take part, it's not going to go anywhere, is it?' notes De.

Another EnTech participant adds, 'If it is worthwhile, if researchers can gain something from it, then that is good and I am happy to help.'

Take part in dementia research

Studies are looking for people who don't have dementia as well as those who do. Call **0333 150 3456** and ask for our Research Participation team, or email **joindementiaresearch@alzheimers.org.uk**

Bold and innovative

Is there a way to boost the brain's natural cleaning processes that might impact the development of dementia?

Ian Harrison has a long-held drive to fight dementia after seeing its devasting effects firsthand.

'When I was a teenager, two of my grandparents were diagnosed with dementia. My paternal grandfather had Alzheimer's disease and my maternal grandmother had dementia with Lewy bodies,' says Ian, now at UCL (University College London).

'I remember my parents telling me that there were no medicines that would make them better, and that they were just going to get more poorly with time.

'This seemed so baffling to me at the time, as so many medical conditions are treatable, but why not dementia?'

Following his passion

At university, Ian studied pharmacology to understand more about how drugs work. He then went on to specialise in brain diseases.

'My aim being to make a difference to those living with these diseases and their loved ones.'

Fast forward to now, Ian recently became Alzheimer's Society's second ever Carol Jennings Fellow. This fellowship was created in memory of our former Vice-President's passionate campaign work.

Ian's current focus is studying the brain's natural cleaning system, called the glymphatic system.

During sleep, the glymphatic system works to flush out waste from the brain. This waste includes amyloid, a protein that builds up in the brains of people with Alzheimer's.

However, as we age, this cleaning system becomes less effective.

Potential new drug

Ian wants to see if there's a way of targeting the glymphatic system to help it reduce the build-up of harmful proteins.

With his team, he's looking at a new drug, called TGN-073, and its potential to boost the cleaning process and help slow or prevent memory loss.

If successful, Ian says it could change the way dementia is treated and managed. It could also unlock new approaches to treating other diseases.

'If we're able to show that this concept has potential, it opens up the possibility of its targeting in other neurodegenerative diseases in which proteins build up in the brain, such as Parkinson's disease and Huntington's disease.'

A very exciting field

Ian feels incredibly optimistic about his work and about wider developments in dementia research.

'This is a very exciting field to be in, and I can't wait to see what the coming years will bring.

'We have seen huge advances in dementia treatment in recent years, and that is all down to early investment in bold and innovative research ideas.'

He describes the support and funding he receives from the Society as 'empowering'.

'I'm deeply aware that behind every pound donated is a person or family affected by dementia.

'It's that personal connection that fuels my commitment to pushing this research forward. We are all working toward the same goal: a world without the heartbreak of dementia.'

'I'm just so grateful to Alzheimer's Society for putting its faith in me.'

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**.

Pure escapism

Forget-me-not Chorus helps people affected by dementia to experience singing in a choir, with the laughter and friendship that goes with it. Antonia Kanczula finds out more.

Living with dementia or caring for a person with a diagnosis can be profoundly isolating.

Finding a regular activity that you enjoy has the potential to be transformative, helping you feel more connected and content.

Offering people affected by dementia a window of escapism is what the Wales-based charity Forget-me-not Chorus is all about.

Quick read

Forget-me-not Chorus first launched in 2011 to bring the benefits of singing in a choir to people affected by dementia in Cardiff.

Since becoming an independent charity in 2013, it's gone from strength to strength and now runs a range of activities at different locations.

Its sessions, which are led by professional musicians, are free to attend and you don't need any singing experience to join.

Choristers – people who join Forget-me-not Chorus sessions – say they are a great opportunity to relax and socialise.

Through a range of singing activities, including community choirs, it's focused on enriching people's lives, explains Katherine Harri, its Director of Development and Communications.

'We believe passionately in the power of song to support families living with and alongside dementia,' she explains.

'For a few hours, dementia takes a back seat, people connect, find support and friendship, and build new memories among others who understand.'

Strength to strength

Back in 2011, Forget-me-not Chorus was a pilot project in Cardiff, created by a partnership between Alzheimer's Society and Welsh National Opera.

Offering free, accessible and welcoming singing sessions proved to be a big hit.

In fact, such was the impact on its 40 plus attendees, it felt too precious to wind down the sessions after the pilot ended, says Katherine.

'The project leads felt they couldn't leave the project there – there was an obvious need and huge enthusiasm for it.'

Forget-me-not Chorus officially registered as a charity in 2013 and has continued to grow and flourish ever since.

'It is wonderful to see how a small pilot project has been developed into an organisation that now supports hundreds of people living with and alongside dementia,' says Helen Cook, Young Onset Dementia Adviser for Alzheimer's Society Cymru in Cardiff and the Vale.

Friendly and welcoming

Accessibility is key to the Forget-me-not Chorus formula.

You don't need a referral to attend its regular in-person community singing sessions.

They're free and open to anyone living with any type of dementia, and their family and friends.

You don't even need any singing experience and everyone attending is called a 'chorister'.

> **This is a shared activity where the labels of ‘carer’ or ‘person with dementia’ are left at the door.**

They still run in Cardiff, where the charity is based. They’re also now in several other locations in Wales, including Newport, as well as St Austell in Cornwall.

Each two-hour session begins with a gentle warm-up, then songs are taught by ear by music professionals, who are supported by local volunteers called ‘singing buddies’.

Everyone is encouraged to go their own pace and taking time out to chat is a priority. This means sessions can be an opportunity to form friendships and find support.

‘We’ve developed quite a special way of working,’ says Katherine.

‘Everybody participates as equals, away from the pressure of medical appointments and care routines within a really safe and understanding space.’

‘This is a shared activity where the labels of “carer” or “person with dementia” are left at the door.’

It’s an opportunity to escape into song, say the choristers.

‘Our rehearsal space is a chance for us all to be ourselves, have fun and enjoy the world of music and song without any mention of hospitals, doctors or dementia.’

Another describes it as escapism.

‘No matter how many hurdles I have to manoeuvre my way through, it is always worth it once my mum and I are there. We are in the moment. No pressure just singing.’

Open to all

Forget-me-not Chorus works hard to remove the barriers that get in the way of people enjoying the benefits of singing.

Online sessions and free pre-recorded resources are available for those unable to attend in-person choirs.

‘We are also currently running a daytime project in Cardiff and the Vale called Clocks Change,’ adds Katherine.

The charity has also designed singing services for care homes and hospitals, working across two university health board regions in Wales.

‘Our feedback and evaluation show that these services are really powerful in creating a sense of community within care and hospital settings,’ adds Katherine.

Shared joy

Although the charity has bold ambitions to grow and evolve – it’s on the cusp of starting new sessions in Llanelli, Carmarthenshire – staying rooted in its communities is important.

Alzheimer’s Society continues to be involved, explains Helen.

‘In spring 2025, alongside Forget-me-not Chorus, we collaborated with the NHS to run a 12-week project for people living with young-onset dementia and their families in Cardiff and Vale of Glamorgan.

‘Forget-me-not Chorus also ran a special session at the one-year anniversary celebration of the Society’s Sporting Memories group at Cardiff Rugby, which was a huge success.’

With so much to celebrate from the past decade, it’s impossible to narrow down the highlights, adds Katherine.

‘For me, I think it’s the fact that we’ve grown, but we’re still a small energetic team that feels connected to all our choristers that’s so special.’

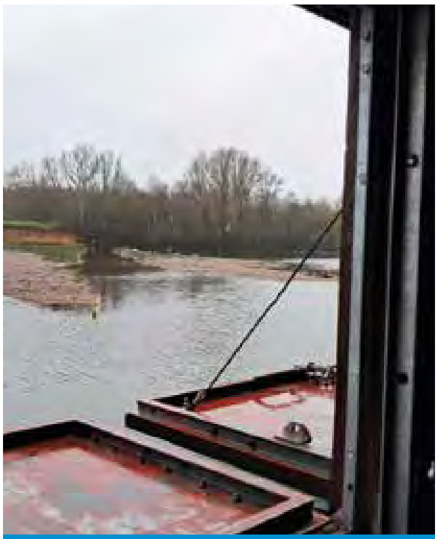
Visit **forgetmenotchorus.com** to find out more about Forget-me-not Chorus sessions.

Singing for the Brain sessions offer singing alongside exercises and activities – see **alzheimers.org.uk/singingforthebrain** or call **0333 150 3456** to find a group near you.

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

Looking up

Can the sanctuary of a bird hide enhance the wellbeing of people affected by dementia? Antonia Kanczula joins a dementia-friendly birdwatching group to learn more.



Quick read

Personal experiences of dementia led to the creation of a dementia-friendly birdwatching group in the West Midlands.

It meets weekly at RSPB Sandwell Valley nature reserve and anyone affected by dementia is welcome.

There's no pressure on members to know a lot about birds, the focus is on creating a safe space where they can relax.

Members of the group describe feeling calmer and more content after birdwatching sessions.

Close to Birmingham's hectic city centre but a world away, RSPB Sandwell Valley is a 25-acre oasis of calm. It was created in the 1980s to help encourage wildlife and nature back to the area.

You can take a bus from the Bullring in central Birmingham to watch bullfinches – and tens of other bird species – in around half an hour.

A mix of meadows, lakes, marshes and woodland that are buzzing with wildlife, the reserve offers a range of activities, including nature writing and guided walks.

Relatively new to its events calendar is a weekly dementia-friendly birdwatching group, summed up by its founder Steve Tidman, from Age UK Birmingham, as 'social, safe and welcoming'.

'It's all about getting people back out, enjoying nature, simple as that.'

Personal connection

Steve's inspiration for setting up the group is his nature-loving dad Jeff, who has mixed dementia.

'My dad instilled a love of birds in me and birdwatching still brings him lots of joy. When I started working in this area of Birmingham, the idea to start a dementia-friendly group was obvious to me.'

'I came to the RPSB with the idea, they loved it and, as they say, the rest is history. We have been meeting for over a year now and, as far as I know, we're the only group in the country for people affected by dementia.'

After drumming up interest locally and catching the attention of BBC local news, the group – people living with dementia and carers – can swell to around 20 on warmer days.

Friendliness first

You don't need Chris Packham levels of birding knowledge or even own a pair of binoculars to join the group – everyone's welcome.

The focus is on creating a safe space for members and giving them the opportunity to relax, says RSPB volunteer Dave Footitt.

Both his late wife and his mum were diagnosed with dementia, so he also has a strong personal connection.

'It doesn't matter where you come from, what walk of life, you are welcome.

'We know everyone by name and they know us by name too. It's almost like a social club.'

The group meet in the reserve's visitor centre and take the short amble to an accessible hide, which overlooks a lake.

This short walk is part of the whole experience, says Steve.

'We take it really slowly and listen to the birds, just take in the beautiful chorus of tweeting from say robins, blackbirds and goldfinches. Every so often a particular birdsong sparks up a memory for someone.'

In the hide, there's no pressure to get involved and no need to be quiet too. Unlike some hides, you don't need to sit in silence or tiptoe in, says RSPB volunteer Colin.

'In fact, at times, it can get quite excitable in there.

'Over time, people have started to recognise birds and it's a thrilling experience. Even more so when we see new bird or one that's more elusive, like a stunning kingfisher.'

Dave says the anticipation that an unexpected species might drop into the reserve is energising.

'It brings an added dimension every week, because two sessions are never the same.'

Opening up

Just as the group's bird identification skills have grown over the time, so have the bonds between members, says Dave.

'Within a few weeks of the group starting, people were starting to recognise birds. They would shout out, "There's a great crested grebe!" and you could feel the sense of satisfaction and interaction building between members.'

In Steve's opinion, the hide is a form of therapy.

'Mother Nature is the best therapist. She's free of charge, she lets you be, she's non-judgemental and doesn't discriminate.'

RSPB volunteer Justine has noticed how people, both those living with dementia and their carers, leave the nature reserve looking and feeling visibly relaxed.

She knows the pressure only too well. Her dad, who first sparked her interest in birdwatching, also lived with dementia.

'Our members who have dementia may not remember what they've done or why they feel happy, but they still know they're happy.

'I know it's very difficult when you're caring for a person who's living with dementia, it can be so overwhelming.

'This group gives carers a bit of respite, bringing them into contact with other people that are in the same position and there's a sense of togetherness.'

Group member Linda agrees.

'It's so nice to be around people who understand. Everyone is very kind and helpful, it's calming and peaceful.'

Pauline loved coming here with her husband, who had mixed dementia.

'We found great joy in visiting the hide, looking at the expanse of water and all the types of birds coming through and trying to identify them.

'It is a restful and calming place. My husband has recently died but I will continue to visit as it's also a place for reflection.'

Future plans

Everyone involved in running the group would like to see its model rolled elsewhere.

'I'd love to see it grow as an activity at other nature reserves,' says Steve.

'Our other great hope is that there will be more research on the benefits of birdwatching for people affected by dementia.

'We've had researchers from the University of Birmingham visit us already and we're waiting to find out what they discovered.'

In the meantime, Steve is focused on encouraging more people to the group, especially as spring and summer approach.

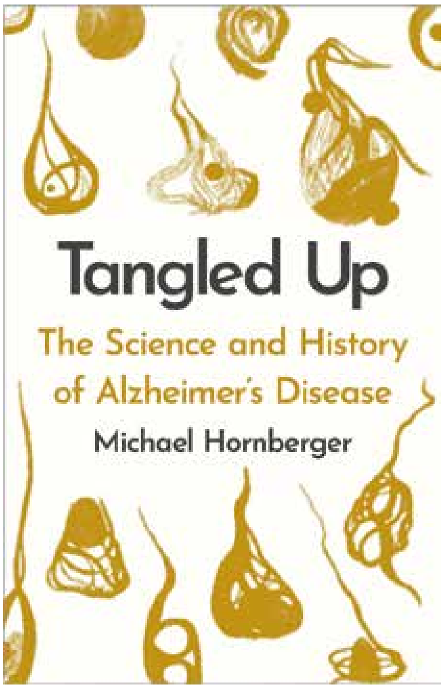
'On a warm day, with the breeze coming in from off the lake and swifts overhead, there's no better place to be.'

Find support near you at **alzheimers.org.uk/dementiadirectory** or call **0333 150 3456** for personalised advice.

For The activities handbook (77AC), visit **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Book group:
Tangled Up

We read a 'whistle-stop tour' of Alzheimer's, written by a neuroscientist, from its origins and diagnosis to reducing risk.



Tangled Up by Michael Hornberger (Canbury, 2025), 252 pages, £22.00, ISBN: 9781914487422. Also available as an ebook.

In Tangled Up, neuroscientist Professor Michael Hornberger takes an expansive approach. One he hopes will leave us feeling better informed about Alzheimer's disease and less afraid.

He opens his book by travelling back in time to the pioneering work of early researchers. He goes on to explore how Alzheimer's changes the brain, rare types of the disease, genetics and risk factors, and new research breakthroughs.

All in all, it's a comprehensive overview, says our reviewer Harry in Cheshire.

'This is an excellent instruction manual about the inner workings of a brain affected by Alzheimer's.'

Clear and accessible

Michael sets out to make the neuroscience of Alzheimer's more understandable, and he largely achieves this, says Harry.

'He comes across as someone with a deep understanding of Alzheimer's, with the added ability to explain a technical subject in no-nonsense terms.'

The formatting of the book helps simplify the information, adds reviewer Dunroamin.

'The book is presented well, with a firm and logical prologue citing aims and objectives.

'It's easy to read initially and reassuring for those with no prior knowledge. Chapters are short, with extremely helpful summaries for the different parts of the book.'

SeaSwallow agrees, 'One thing that I found particularly useful was the way that the author provided a summary of what had been discussed at the end of each part.'

Historical insights

All our reviewers found the history of Alzheimer's research incredibly thought-provoking.

'I particularly enjoyed the narrative style describing the work of Dr Alois Alzheimer and Dr Oskar Fischer in the 1900s,' says Jane from Kendal.

'It's fascinating that these men found out so much information about changes in the brain of Alzheimer's patients, but it was not until the 1970s that work into Alzheimer's research was reinvigorated.'

Dunroamin, who is living with Alzheimer's, agrees.

'I had never heard of Oskar Fischer prior to reading this book, and like all areas of science, I admired the communication and connections between the original researchers.'

Past to future

As the book progresses, it shifts from the past to promising current and future research, looking at the potential for better diagnosis and treatment of Alzheimer's disease.

Jane found the section on early diagnosis fascinating.

'If only more attention was given to diagnosing the disease before the damage to the brain was done, the lives of those diagnosed could be improved and prolonged,' she says.

Harry was captivated by the discussion about genetic risk and the risk factors we can and can't control.

'One of the interesting facts revealed in this book was that the lack of formal education could affect the likelihood of being diagnosed with Alzheimer's. Because this appears to be an obscure connection, Michael does explain in good detail why this is a factor.'

Reviewer John found the information on genetic links interesting for personal reasons.

'My mother, aunt and grandmother all developed Alzheimer's around the age of 65 years. I am currently 81 and showing no obvious signs of Alzheimer's, despite having atrial fibrillation and a stroke. I remain fit and able to play tennis and badminton.'

Cruel disease

Although our reviewers were intrigued by the exploration of 'non-modifiable' and 'modifiable' risk factors, it also raised concerns for Jane, who is carer for a person with early-onset dementia.

'It states that by focusing on the top four risk factors for Alzheimer's – obesity, getting enough exercise, eating a Mediterranean diet and getting enough sleep – the risk of developing Alzheimer's disease could be reduced by 40%.

'But I was left thinking if only it were that simple! I wouldn't want people reading this book to think they were responsible for getting this cruel disease.'

Despite the author's best efforts to keep things simple, our reviewers were also left confused by some technicalities.

'I found the references to figures and various graphs, out of context, very confusing,' comments John.

Some chapters left Harry scratching his head.

'Although to give Michael his due, he did explain things in easy terms.'

SeaSwallow agrees it's complicated in places and sometimes repetitive, but says they still learned plenty.

'By the very nature of the book, it is quite technical at times, which I did on occasions find difficult to follow.

'However, I did learn more about the nature of Alzheimer's disease, the changes within the brains of people affected and why it will be so difficult to find a cure.'

Insight and understanding

Tangled Up is for people who want to improve their understanding of Alzheimer's, and it's probably more enlightening and stimulating than comforting.

'The book would be useful for people interested in the rare forms of Alzheimer's,' adds SeaSwallow.

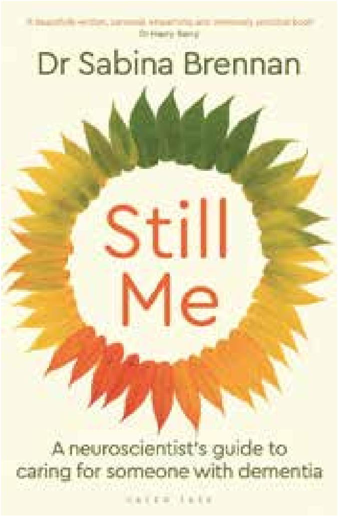
If you're currently affected by dementia, it's difficult for our reviewers to say whether you'd enjoy it. It comes down to you and your individual circumstances.

It could leave you feeling frustrated that you won't benefit now from future progress. But there are other aspects that could be helpful.

'For those families struggling to obtain a diagnosis, there is an extremely helpful paragraph that illustrates why diagnosis can be complex and prolonged,' says Dunroamin.

'For anyone caring for someone with Alzheimer's, this book will ring many bells and provides insight into why patients do the things they do,' adds Harry.

Next time



For our next book group, we invite you to read Still Me: A neuroscientist's guide to caring for someone with dementia, by Sabina Brennan (Green Tree, 2025), 288 pages, £18.99, ISBN: 9781399421386. Also available as an ebook, and the paperback is due out in May.

Tell us what you think of this book for people supporting someone with dementia, to help navigate the condition while caring for themselves too. Email **magazine@alzheimers.org.uk** or write to the address on p2 by the end of 4 May so we can share your comments in an upcoming magazine.

Book giveaway

We have five copies of Still Me to give away – email **magazine@alzheimers.org.uk** or write to the address on p2 by the end of 14 April quoting 'Still' for a chance to win (see p39 for terms and conditions).

Engaging and calming

People affected by dementia try out products that are designed to be absorbing and relaxing.

Win
see page 39

We visited a group of people with dementia on England's south coast to get their feedback on products from our online shop.

Dementia Voice local groups meet regularly to influence our and others' work. Worthing Town Cryers was one of the first of these to be established back in 2013.

Still going strong, the group welcomed us on a sunny spring day to look at three sensory products, designed to provide comfort and joy.

Curiosity Box

The Curiosity Box is designed to feel like an intriguing treasure chest or button tin, with a range of objects inside to explore and use. It comes with a tote bag and a card with hints and tips to help you get the most from it.

Exploring the box and its contents, group members noted their quality as well as effectiveness.

'It's interesting, with lots to do – lots to fiddle around with,' said Steve. 'It makes you relaxed and starts your brain thinking, "When have I used this?"'

Dave, throwing the large wooden dice, said, 'It's good to know I can throw a six! It makes me feel normal, and it takes me back.'

'It gives you something to talk about,' said Stan, 'and it would definitely help if someone's feeling restless.'

Jean said, 'The spinning top is lovely – you could play with it for hours, couldn't you? Takes you back to childhood.

'The purse reminds you of going out shopping, and the picture cards would be especially good if you've been a keen gardener.'

Stan said, 'You could thread the lace through one of the buttons and spin it like an old toy,' before doing just that and giving it to Jean to try.

She added, 'I'd like a small piece of material and a blunt needle with thread to sew the buttons on it.'

Stan pointed out that you could add other items to the box. 'You don't need to rely on what's in there. Family could add bits for the person using it.'

The price went down well, with Jean commenting, 'I thought it would be more than that!'

Fufuly

The Fufuly calming breathing cushion was researched and developed to help reduce stress and promote wellbeing. The soft plush cushion moves as if breathing with a soothing rhythm.

Passing the cushion around, people noted how valuable a cuddle can be.

'If you were feeling out of sorts or anxious, having a cuddle is always a good idea,' said Sue.

Stan said the cushion 'would bring comfort' and Alan thought it was 'fascinating'. But Clive said, 'I've got the wife to cuddle!'

Pam and Dave had tried the Fufuly at home for a few days before the session.

'Our first impression was that it looked interesting,' said Pam. 'It seems well made and the material is soft, gentle and pleasant to touch.'

However, the cushion's weight and depth made it impractical for them.

Pam said, 'Dave immediately dismissed it because of weight and size.'

> **It’s very well made,’ said Stan, ‘like everything from the Alzheimer’s Society shop.**

Win
see
page 39

Tim thought it wouldn’t feel as heavy once it’s on your lap, and Steve noted its weight ‘must be because of the workings inside’.

‘The cushion is quite heavy,’ said Clive, ‘but it would be relaxing.’

Steve agreed, ‘If you were feeling stressed, the cushion would help.’

The price seemed high to group members – a problem often faced with specially designed products.

Jean, joking she’d prefer a man-shaped cushion, added more seriously, ‘It’s a bit big for me and heavy, I’d like a smaller one.’

She was pleased to hear that ‘breathing’ cats and dogs are also available, and Pam said, ‘My sister-in-law had one – she always had it with her.’

‘It’s nice to know what’s there for further down the line,’ said Jean.

Fiddle book

The Fiddle book has soft, velvety covers and four inside panels with zippers, beads, ribbons, sequins and much more. There’s even space for a photo behind a felt pocket.

Steve said, ‘It brings back memories, helps your brain, makes you think.’

Alan agreed, ‘It’s good, keeps you awake.’

Jean liked the different colours and textures, saying, ‘It looks attractive.‘

Very posh!’ added Dave.

‘It’s very well made,’ said Stan, ‘like everything from the Alzheimer’s Society shop.’

Jean said one of the buttons inside the Fiddle book reminded her of the toggles she had on a childhood duffle coat.

She added, ‘You could count the beads on the ribbons, and do sums with them.

‘The zips would be better if there was a pocket in at least one of them, to put your hand in.’

Jean liked the space for a photo behind the felt pocket, though the felt was quite stiff and harder to unbutton.

Group members said the price was reasonable.

‘It would be especially helpful for someone who can’t get up and do things,’ said Jean.

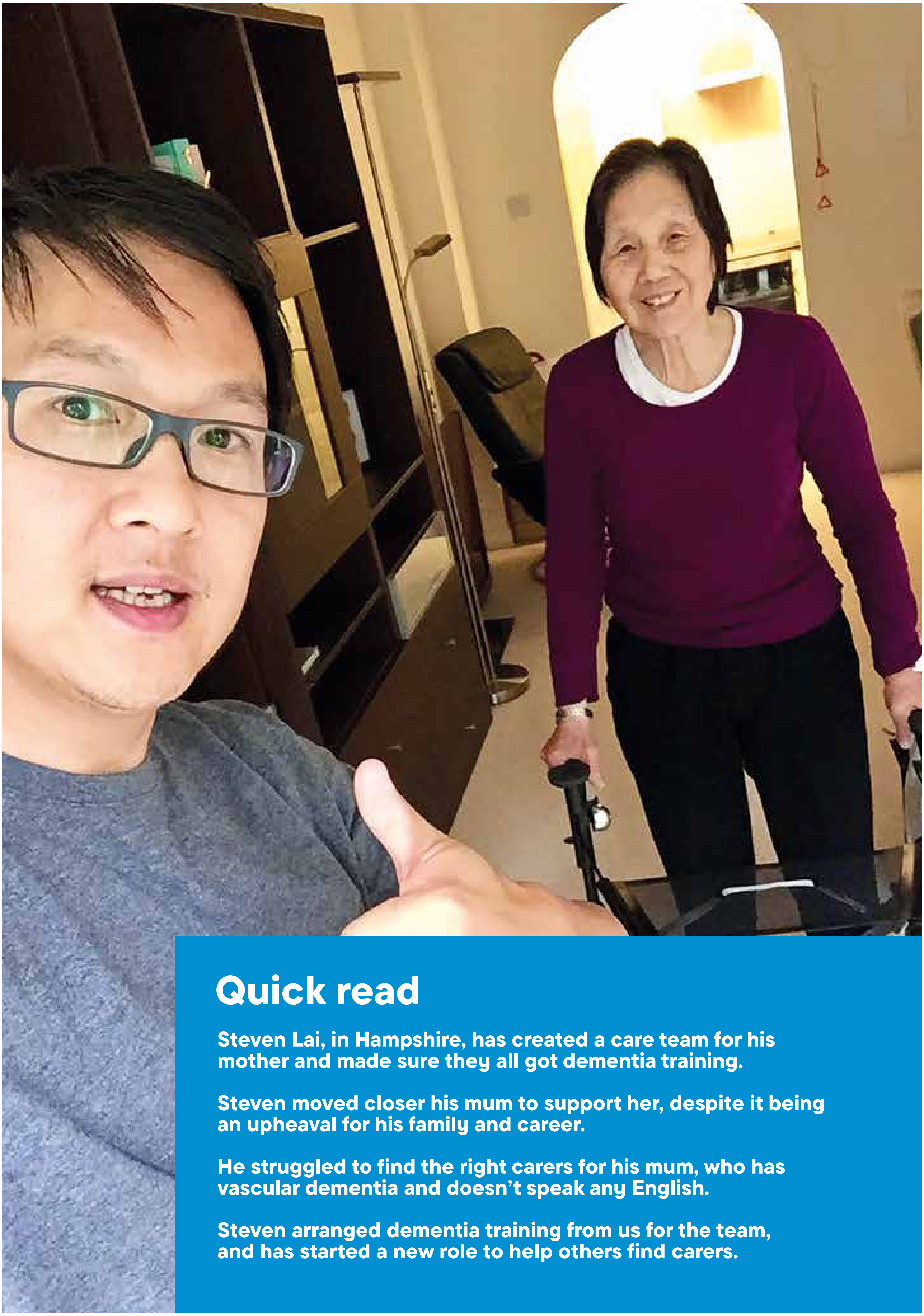
Visit **alzheimers.org.uk/ShopTogether** or call **0333 366 0035** for this and other helpful products (prices include VAT):

- Curiosity Box – £34.99 or £29.16 with VAT relief.
- Fufuly calming breathing cushion – £199.99 or £166.66 with VAT relief.
- Fiddle book – £25.50 or £21.25 with VAT relief.

You can buy these and many other specially designed products VAT free if they’re 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 The activities handbook (77AC) booklet, see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.



Quick read

Steven Lai, in Hampshire, has created a care team for his mother and made sure they all got dementia training.

Steven moved closer his mum to support her, despite it being an upheaval for his family and career.

He struggled to find the right carers for his mum, who has vascular dementia and doesn't speak any English.

Steven arranged dementia training from us for the team, and has started a new role to help others find carers.

A different life

Steven Lai created a care team for his mother and made sure they benefited from Alzheimer's Society training. Heather Stephen learns how he's finding solutions in a disconnected system.

'Finding someone to cook your mum a meal from a jobs site is nigh on impossible, but it shouldn't be that hard.'

So says Steven Lai, whose mission to create the right care team for his mother, Shing, included arranging dementia training.

His search didn't only provide insights and solutions. It also led him to a new role helping others to navigate the intricacies of finding support.

Becoming a carer

Steven was three when his family moved from China to the UK 50 years ago. Growing up in a small town in Hertfordshire, he studied photography at university and landed his first job in London.

But everything changed when his father died in 2009. Overnight, he took on the responsibility of becoming a carer for his mother.

'My mum had a stroke in 2005, which affected the mobility on her left side. My father cared for her, so when he passed away it left a really big hole.

'That was the start of my carer's journey and a different life for me.'

To be nearer his mum in Portsmouth, Steven moved to nearby Chichester. An upheaval from Surrey for him, his wife and young son, he also found it much harder to find work as a business consultant.

'I was an entrepreneurial professional and highly paid, but my work dried up after we moved, and I struggled to find a flexible role whilst caring for my mother.'

Steven says Carer's allowance and Child benefit far from covered the family's bills. They were forced to drain their life savings just to get by.

This financial cost is common among carers but Steven didn't feel he had any choice.

'In Chinese culture we look after our parents, and I knew I had to take on the responsibility for my mum.

'My mum doesn't speak any English and relied on my dad for everything, so she was in a difficult position.

'She was living in a house which was too big for her, she couldn't get up and down the stairs, and she was struggling with cooking and cleaning.'

A suitable team

One of Steven's greatest concerns for his mother was social isolation.

'No one was coming to see her, and she was just living out her days.'

Trying to source a suitable care team was massively challenging – particularly as Steven was looking for carers who could speak Chinese.

'My mother originally lived in Letchworth, which is a tiny place, so it was like trying to find a small number of fish in a very small pond.'

Steven had persuaded his mum, who is now 88, to move to Portsmouth, which has a sizeable Chinese community. But he still found it difficult to find the right people.

'Adult services have a Personal Assistant Job Noticeboard, but it is like a dating site and there is no way of knowing whether someone is a good fit. It is a broken system and just doesn't work.

'We had carers come and go,' he admits. 'We could find people who had the language but the passion for care wasn't there.'

He says another issue was that members of the Chinese community often wanted to be paid cash in hand, but the local authority's direct payments system required a contract.

'What you need is not someone who is doing it for the money, but someone who genuinely wants to care and has lived experience.'

Steven was lucky enough to find Chinese-speaking carer Patricia Chau five years ago. Last September, he found the newest member of his care team, Carol Hazikyriakos, with the help of Portsmouth City Council.

Although Carol doesn't speak Chinese, Steven says she communicates with Shing who knows basic words and uses a translation phone app.

And he says Carol's passion for care and cooking delicious meals for his mother more than makes up for the language barrier.

> **“Training has helped us to know how to approach challenging situations. We learnt to diffuse, distract and redirect.”**

Need for training

When Shing was diagnosed with vascular dementia last year, Steven realised he and his team needed upskilling. But he says it was challenging to find training.

He felt in-person training would allow them to ask their 'burning questions' about dementia, but the closest provider was in Stockport.

After some online detective work, Steven discovered that Alzheimer's Society offers training to organisations including care homes and agencies. So he phoned our training team.

Our training courses aren't usually for individuals, but we said we could help if Steven found a venue and arranged funding.

Steven secured funding from Skills for Care, the workforce development body for adult social care in England.

He also found the Portsmouth Carers Centre, which kindly offered the use of a training room without charge for unpaid carers.

'On top of finding funding and a venue, I had to find a time when everyone was available.

'It was a bit like herding cats!'

Life changing

Steven's efforts paid off. All three members of the care team found our training life changing in how they're able to support Shing.

Steven says it was meaningful that the trainer had lived experience and shared what he would do in difficult situations.

'Training has helped us to know how to approach challenging situations. We learnt to diffuse, distract and redirect.

'For instance, after training, Patricia cooked a Chinese dessert and my mum asked if it tasted so good because she had cooked it in her Pyrex saucepan.

'We'd given away those saucepans during her move but rather than distress her, Patricia said, "Oh auntie, Steven took those for safekeeping at his house."'

Steven said the training was also a great chance for the team to get together.

'We are normally "ships in the night" and never meet. So it was an opportunity to spend time together and get to know my team,' he explains.

Steven says there are not enough agencies providing this kind of face-to-face training, but he thinks it would make a world of difference to carers.

'Until it happens to you, you don't know how you will react to dementia behaviours. The training made a huge difference to us all and now we are much stronger as a team.'

Unexpected outcome

One unexpected outcome of his journey is that Steven was selected for a new role at Portsmouth City Council to build a local community of microproviders.

Microproviders are self-employed personal assistants – care workers who handle their own admin. This means that people looking for care don't have to take on the burden of payroll, paperwork and other employment responsibilities.

Still relatively new and not available everywhere, this type of paid care provides greater choice over what support you receive, when and how you want it and who provides it. It means you don't have to choose between either going with an agency or becoming an employer yourself.

The new role is perfectly suited to Steven.

'My superpower is lived experience. I spent six months navigating everything the hard way. I saw the potential and the amazing people out there who could help, but the system is disconnected and disparate.

'If you can create a community where you can find people who genuinely want to help and who have the experience, passion and unique skill set, then you can achieve something truly amazing.

'Finding a carer shouldn't be this difficult – and that's exactly what I'm determined to change.'

> **Finding a carer shouldn't be this difficult – and that's exactly what I'm determined to change.**

Call our Dementia Support Line on **0333 150 3456** for personalised advice.
To speak in Welsh, call **03300 947 400**.

To talk in other languages, call **0333 150 3456**, say the English word for your language and end the call. An interpreter will then call you back.

To read information from our one-page Helpsheets in traditional Chinese, visit **alzheimers.org.uk/information-in-your-language**

Dementia training

Alzheimer's Society provides expert dementia training services for people working across all sectors.
To find out more, see **alzheimers.org.uk/training** or call **020 7423 3538**.

‘I’ve been waiting six weeks for the local authority to complete a care and financial assessment. Is this normal or should I chase it up with them?’

Delayed assessment

It’s not unusual to wait weeks for a care assessment and a financial assessment. But there may still be good reasons for you to contact the local authority.

How long is too long?

There isn’t a fixed time that local authorities must complete assessments within. The law just says they must be ‘timely’, and it depends on the urgency of the situation.

Each country in the UK has an ombudsman to deal with complaints about local authorities.

In England and Wales, the ombudsman usually expects an assessment to take place within 4–6 weeks. But there is flexibility so that authorities can prioritise urgent requests.

In Northern Ireland, assessments should be done within 8 weeks.

The local authority should keep you informed and give you an ‘indicative timescale’ – how long they think you’ll need to wait. If they haven’t, then ask them.

Has your situation changed?

Let the local authority know if your situation has changed since you first contacted them. For example, if your health has been affected or if a friend or relative can no longer help you.

Ensure the authority knows about all your needs that aren’t being met and the impact this is having on you.

If the situation isn’t safe for you, they should assess you sooner or arrange for more support in the meantime.

What about unpaid costs?

The financial assessment usually takes place around the same time as the care assessment. But sometimes the financial assessment is done much later.

Local authorities must give you enough information to know roughly how much you’ll have to pay for care, based on your circumstances. If they haven’t, ask for this to avoid any surprises down the line.

A delayed financial assessment could mean that care you already have in place isn’t being paid for. If that happens, a homecare agency may say they’ll withdraw support or a care home may give an eviction notice.

Stress the urgency of this to the local authority. If there are no other ways to cover care costs, make this clear to them. Keep the care provider informed, so they know what is happening.

What if you’re paying costs?

If the financial assessment is delayed, you might be spending money on care that the local authority should be paying for.

It’s best to ask for the assessment at least six weeks before care costs reduce your savings to the ‘upper capital limit’. This is the point where you’re entitled to help with costs from the authority. Funding will usually only be backdated to when they did the assessment, not to when you asked for one.

But you could ask for backdated payments if you can show you contacted them well in advance and the assessment was delayed unreasonably.

Keeping track

Every time you have contact with the local authority, make a note of dates, staff names and correspondence. This can help keep track when you have a lot to think about.

If you aren’t getting the information or care you need, and the authority doesn’t seem to be taking your concerns seriously, you may need to make a complaint.

This can be frustrating, but it’s sometimes necessary to keep you safe and well. Having your own records can support you with this.

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

- Assessment for care and support in England (418).
- Assessment for care and support in Wales (W418).
- Assessment for care and support in Northern Ireland (NI418).

Your answers

Readers share advice about planning to travel with a relative or friend who has dementia.

Planning travel

'I travelled often with my dad on trains and sometimes planes. I found calling the company useful to notify them that you are travelling with a person with dementia and would therefore require extra assistance.

'A quiet seating area preferably near the toilet and taking some earphones with downloads of soothing, calming music helped a great deal. As did simple snacks.

'Baby wipes for any spills. Drinks in a spill-proof cup or carton, and some simple yet interesting things to do like cards or puzzles.

'Once you let the company know they were always extra attentive and ensured they "checked in" with us every few hours to make sure we were comfortable.

'If you have room, an extra change of clothes in your hand luggage prepares you for any accidents.

'Lastly, relax and enjoy your journey, pointing out anything along the way that is of interest.' **Toto2**

'My kit list:

- Radar key for accessible loos.
- Paper towel roll.
- Two or three dustbin liners.
- Baby wipes.
- A full change of clothes each.
- Two or three disposable pull-up undies (and wear a pair on the trip), rip off at the sides.
- Fully charged mobile phone power bank.
- Snacks.
- Mini sports bottles of drinks.
- Ear defenders.'

Alisongs

'To date, I haven't experienced any issues using special assistance at Luton or Heathrow airports and it went very smoothly.

'The Civil Aviation Authority also has information on special assistance and how to access it [see **caa.co.uk** and click 'Passengers and public', then 'Special assistance'].

'You can inform the airline that you are travelling with someone with dementia, as it gives them a heads up.' **MaryP365**

'My mum (who has dementia) was medically advised not to fly beyond seven hours. My sister is in Australia so that's stopped all visits.

'My sister has also had experience of people with dementia flying there and having extreme delirium on arrival due to the impact on the brain. So my recommendation is try and break up the journey, giving days between each flight.' **lea.silkstone**

'I make short trips using a wheelchair accessible vehicle and a trip of a few hours or so is generally OK.

'My partner is incontinent and that's not a problem provided we are not away so long that she needs changing, then it's a nightmare because she needs a hoist. For the same reason, we can't travel away from home.

'Even with a portable hoist you need the right facilities, such as floors that a hoist can move over, hospital type bed etc.' **CDS**

'Things I always took with me in the car after one disastrous day out: a bucket, disinfectant, many cloths, a big bottle of water and a change of clothes for me and the person with dementia.

'Being "caught short" can happen to anybody, but when you've got dementia, it's not something that's easily dealt with unless you have help.

'Luckily, in our case, there was a very kind shopkeeper who gave us towels and disinfectant and leant us a bucket for me to clean up the public loo!' **Grable**

Next time

Do you have any advice on dealing with sleeping difficulties, or about adjusting to needing outside help? Email **magazine@alzheimers.org.uk** or write to the address on page 2 by 5 May.

Noticeboard

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

Letter: Writing group

When my brother and sister both died with Alzheimer's within a year of each other, I wanted a way to commemorate them and raise funds for the charity that provided so much support.

I can't knit toys, bake cakes or run a marathon, but as I chair a creative writing group I decided to independently publish two books and donate the royalties to Alzheimer's Society. The writing group celebrated its 10th anniversary in 2025, so it seemed an appropriate time to release our efforts onto the world.

Out of the Box, by Mapperley Library Writing Group, is a collection of short stories and poems, so named because we literally choose random themes out of a box. These produce a wide range of interpretations showing we are also quite good at thinking outside of the box!

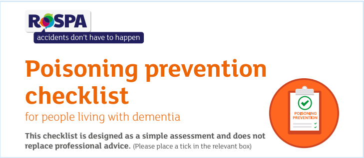
Pieces of You: Echoes of Love, Loss & Laughter contains stories inspired by my own experiences of loved ones with dementia. They are sad, funny and ultimately uplifting. I feel my brother and sister would be proud.

Publishing the books myself was hard work. It involved much shouting at the computer, throwing things across the room and eating lots of chocolate! It was a very steep learning curve but the end result was definitely worth it. I'm even considering publishing another collection later this year.

We've given talks and readings in libraries and to community groups, as well as having a stall at an Open Garden event, where we had to compete with a giant milling machine! So far we have raised over £300 for the charity and, with more events planned plus word-of-mouth recommendations, we hope to raise even more in the future.

Both books are available on Amazon UK by searching for 'Christine Latimer'.

Christine Latimer, Nottinghamshire


RoSPA
accidents don't have to happen

Poisoning prevention checklist
for people living with dementia

This checklist is designed as a simple assessment and does not replace professional advice. (Please place a tick in the relevant box)

RoSPA poisoning prevention checklist

The Royal Society for the Prevention of Accidents (RoSPA) has produced a checklist to help prevent accidental poisonings among people with dementia.

RoSPA called this a growing and often hidden danger in people's homes, with an increase in deaths from these kinds of accidents in recent years.

'Everyday items like cleaning sprays, laundry pods and medicines can be mistaken for food or drink in seconds, especially for people living with dementia,' they said.

RoSPA's key safety tips include to always use original containers, separate bottles that look alike, and keep all medicines organised and tracked. They also recommend reassessing the situation regularly as a person's abilities change over time.

Simon Wheeler, Senior Knowledge Officer at Alzheimer's Society, said, 'Staying safe is important for people with dementia who want to keep living at home for as long as possible, as well as for those who support them.

'As a person's dementia progresses, they might have trouble telling the difference between something that's safe to eat and something that isn't.

'If you want to reduce the risk of accidents, make sure that you store your cleaning products like laundry detergents safely in a cupboard and out of sight. Don't leave them out on a worktop or near any food or drinks, especially if they might be mistaken for sweets or drinks.'

For RoSPA's Poisoning prevention checklist for people living with dementia, see rospa.com/poisoning-dementia

Poems for her pictures

A carer in Devon has been sharing his poetry alongside the paintings of his wife, who was diagnosed with vascular dementia and Alzheimer's disease five years ago.

Carlos Dominguez says, 'About seven months ago one evening, once Wendy was in bed and whilst mulling over the day's events and listening to Radio 3, I found myself writing poetry about dementia and our lives over the past five years.

'I wrote for about 90 minutes non-stop, like a stream of consciousness. The last time I wrote a poem was 1975, for O level English and it was utter rubbish.

'I started to share these poems with my friends and family and got some amazing responses that I didn't expect. They suggested that I must publish, so my children organised a blog I could use.

'Wendy was an artist, and our home is our art gallery and was her studio too. Since the diagnosis, her art changed and evolved as the dementia has progressed.

'For the past year, she has stopped painting and has no interest in art at all. She won't even engage with "painting by numbers". She doesn't recognise any of the paintings that surround her every day as being her work.

'With that in mind, as a way to honour her craft and to keep the memory alive for others to share, I have created the poetry blog with one of her paintings for each poem I have written.'

Read Carlos's blog with his poems alongside Wendy's paintings at medium.com/@cdomin6633

LIFT Music app correction

A subscription to the LIFT Music app (featured in our last issue) costs £3 per month or £27 for a year after the free month's trial. For the iPad and iPhone app, which creates music from a person's gestures, search 'LIFT at Home' on Apple's App Store.

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 4 May for the June/July issue (wording may be edited).

Dementia support contacts

Contacts to get support, find information and stay in touch.

Through our support line, online and print information, expert dementia advisers and online community, we give advice and practical guidance for people affected by dementia.

Contact us for support

If you're living with dementia or worried about a diagnosis, or if you care for someone with dementia, our trained Dementia Support Line staff are ready to give you the support that you need.

We can offer advice on getting diagnosed, caring strategies, how to access social care, remaining independent for as long as possible and making a lasting power of attorney (LPA) and many other things.

We can also signpost to organisations who provide legal and financial advice, for things such as benefits and grants.

Call our Dementia Support Line on **0333 150 3456**. Open Monday to Wednesday 9am–8pm, Thursday and Friday 9am–5pm, and Saturday and Sunday 10am–4pm.

To speak in Welsh, call **03300 947 400**. Open Monday to Friday 9.15am–4pm.

To talk in other languages, call **0333 150 3456**, say the English word for your language and end the call. An interpreter will then call you back.

You can contact our dementia advisers using British Sign Language through SignVideo – see **alzheimers.org.uk/accessible-options**

If you have a textphone or an adapted computer, you can use Relay UK to call our English-speaking support line on **18001 0333 150 3456**.

Find services near you

Use our dementia directory to find local support services for people with dementia and their carers in England, Wales and Northern Ireland – see **alzheimers.org.uk/dementiadirectory**

Enter a location or postcode and choose types of service relevant to you, then see results for services at local venues, support in and from your own home, and more.

Connect with others online

Join Dementia Support Forum, our online community of people living with dementia, at **alzheimers.org.uk/ForumTogether**

It's free, open 24/7 and you can connect with others who understand what you're going through.

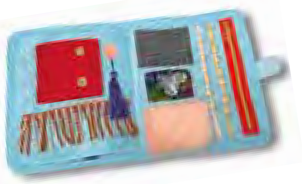
Dementia information and advice

Our support guides will take you through a range of topics. The amount of information might feel overwhelming, but you don't need to read it all at once.

For online information and advice, see **alzheimers.org.uk/get-support** For a wide range of publications and factsheets designed to support and inform anyone affected by dementia, visit **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Accessible information is available in a range of formats, including translations into different languages, Easy Read, BSL, audio versions and online videos – see **alzheimers.org.uk/accessible-resources**

Competitions



Curiosity Box and Fiddle books

We have a Curiosity Box (see pages 28–29) for one lucky winner and a Fiddle book for two runners-up drawn from correct entries.

Q: What objects are included in the Curiosity Box for you to explore and use?

A. A radio telescope, electron microscope and private jet.

B. A large wooden dice, a spinning top and picture cards.

C. A beach ball, a game of Twister and one of Monet's Water Lilies paintings.

Forget-me-not canvas shopper

We have Forget-me-not canvas shoppers for five winners drawn from correct entries.

Q: What three items have famously been made from canvas?

A. Rubber ducks, iron tacks and wooden flooring.

B. Breakfast, lunch and dinner.

C. Tents, sails and surfaces for oil paintings.

Send us your competition answers with your name and address by end of 4 May – email **magazine@alzheimers.org.uk** or write to the address on p2.

Book giveaway

See p27 for a chance to win a copy of Still Me by Sabina Brennan.

February/March winners and answers

Bide fall prevention device

H Courtney in Hertfordshire won a Bide fall prevention device. Answer: The bedside Bide device helps to prevent falls by playing a message reminding you to take care as you get up and move around.

Forget-me-not seed pack

S Wallis in Surrey, D Meppen in Cheshire, S Houghton in Lancashire, and A Ingold and an anonymous reader in Cambridgeshire each won an eco-friendly Forget-me-not flower seed pack. Answer: These seed packs are more eco-friendly than many others because they use a minimal amount of packaging, which is made from recyclable tomato fibre.

Book giveaway

A Cross in Lincolnshire, S Smith in Berkshire, L Rawlinson in Lancashire, A Cowan in Rutland, J Gaskell in South Yorkshire, K Baines in Shropshire, C Nott in Hertfordshire, R Weekes in Kent, an anonymous reader in Tyne and Wear, D Bebbington in Cheshire, M Volland and C and L van Essen in Cambridgeshire, RB in Essex and H Liversedge in Merseyside each won a copy of Tangled Up, by Michael Hornberger.

Anagramword

Across: Roald Dahl, historical, fantasy, narrative, creative, private eye, picaresque, epistolary.

Down: Science fiction, gothic, characters, inspiration, Dickens, romance, discovery, western.

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.

Get your badge today.

Alzheimer's Society

Forget Me Not Appeal

Every Forget Me Not tells a story.

Every badge helps beat dementia.

Get your badge and help beat dementia.

alzheimers.org.uk/forgetmenottogether

Registered with FUNDRAISING REGULATOR

Alzheimer's Society is a registered charity in England and Wales (296645); the Isle of Man (1128) and operates in Northern Ireland.