June/July 2026

Dementia together

Alzheimer's Society

In this issue

Passion for poetry,
life turned upside down,
find a clinical trial
and much more

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Welcome

We have some exciting news to share with you! After this and August/September's issues of Dementia together, you'll start to receive Society magazine. Society magazine shares people's experiences of dementia alongside news, ideas and research developments. It comes out twice a year, going to many more people than Dementia together.

It will take a society to beat dementia, so the January edition of Society magazine will look at community and the role it plays in the diagnosis, treatment and prevention of dementia.

Society will be less frequent, but Alzheimer's Society remains here for you. **See page 38** for ways to stay in touch with us, and with other people affected by dementia.

We'll have more information about these new developments in the August/September issue of Dementia together, along with more ideas to ensure you have the continued advice and support that you need.

In the meantime, I hope you enjoy this issue – as ever, your feedback and ideas are always valued.

Danny Ratnaike, Editor

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

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

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

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

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

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Alzheimer's Society Dementia Friends
Join me today
dementiafriends.org.uk


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Directions

Day in day out, Alzheimer's Society services are changing lives for the better – thanks to your support. We received a wonderful email from Jenni, who described how support from dementia advisor Daniel had been a 'life-changing experience'.

A lone carer for her husband Barry, she shared feelings of impatience, frustration, anger and guilt – and exhaustion. With new strategies and coping mechanisms from a carer support programme run by Daniel, their environment is now more peaceful and relaxed, and so much has improved.

Their story is a powerful reminder of the vital role our support teams play and how, every day, they are changing lives, whether online, over the phone or in local communities.

Over the last 12 months, our Dementia Support Line has supported around 22,500 people. We also helped around 90,000 people through our local services and groups.

These numbers bring into sharp focus the difficulties so many people are facing behind closed doors.

For too long dementia has been pushed to the sidelines.

We are calling on the UK government to reduce the number of people dying of dementia, improve access to early and accurate diagnosis, prepare the NHS to deliver new treatments, and provide high-quality dementia training for the social care workforce. Please support our call by signing the open letter at **alzheimers.org.uk/open-letter**

Our supporters never cease to amaze me. We had over 600 people running the London Marathon for us in April.

June marks the start of the Forget Me Not Appeal, our biggest fundraising appeal of the year.

Thank you for wearing your Forget Me Not badge and for all your ongoing support!

Michelle Dyson, Chief Executive

News

Training gap

Alzheimer's Society has released a new report on the levels and quality of dementia training among social care workers in the UK and our recommendations on how to improve it.

Despite some progress, we've found that staff in England, Wales and Northern Ireland are not receiving the depth and quality of training needed to support people with dementia well.

Over half of care workers in England and Northern Ireland and over a third in Wales start their roles with no dementia training. If they do receive it, it only lasts around one to two hours.

We are calling on the government to implement an ambitious dementia plan that makes specialist training mandatory for all relevant social care staff.

We have support from care workers themselves – they have overwhelmingly told us that they want to be better equipped to do their jobs.

Our CEO Michelle Dyson said, 'Without high quality dementia training, social care will remain dangerously inconsistent, leaving families unsure whether loved ones will be supported with dignity and expertise.'

Find out more at **alzheimers.org.uk/training-gap**

Forget Me Not Appeal

June sees the return of our Forget Me Not Appeal. Join us in wearing your Forget Me Not and standing with everyone affected by dementia.

Donate, wear your badge with pride, and help raise vital funds for life-changing support and research. Thank you to everyone who has already given, fundraised and shown their support – you are making a real difference.

Be part of the society that will beat dementia for good.

Find out more and get involved at **alzheimers.org.uk/ForgetMeNotTogether**

Keep on running

Thanks to all the amazing runners who've fundraised for us so far this year at events around the UK, including the London Landmarks Half Marathon and Manchester Marathon.

There's still time to join our team at running events this year or to organise your own running challenge.

Find out how to run for us and sign up for a free fundraising pack at alzheimers.org.uk/running or call 0300 222 5808.

Open letter update

We're thrilled to have hit 30,000 signatures on our open letter calling on the government to deliver a bold plan for dementia in England.

Thanks to the thousands of you who added your names!

Your support will help us send a powerful message to the government that the Modern Service Framework for Dementia and Frailty must deliver for everyone affected by dementia.

Senedd election

We secured commitments on dementia in the manifestos of every party that now holds seats in the new Senedd (Welsh Parliament) following the election in early May.

This means we are in the best possible position to make sure that dementia is a priority in Wales, and ensure that a new dementia strategy for Wales is published as soon as possible.

NI roadmap

At a special event for politicians, professionals and people affected by dementia, we called for the development of a dedicated dementia strategy in Northern Ireland.

To mark Dementia Action Week in May, we brought together Members of the Legislative Assembly and people from the health and social care sector at Stormont as we unveiled our 'Roadmap for Change'.

The stories of people with lived experience of dementia were front and centre, underlining the urgent need for change.

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

Society magazine

We're proud to share an exciting development in how we keep in touch with you – in January, you'll start to receive Society magazine.

Society comes out twice a year, featuring real-life stories about people who are living with dementia, supporting relatives and friends, and making a difference in their communities.

It also shares the latest news about dementia research, along with a wealth of helpful resources, tips and ideas.

Society magazine is an important way for us to keep in touch with a large number of people. This includes people who are dealing with dementia in their own lives – or who have been affected by it – and those who have other strong connections to what we do and why we do it.

After the August/September issue of Dementia together, January's Society magazine will be about community – all the different ways we come together to make a difference in how dementia affects our own lives and other people's.

We'll have more information in the final issue of Dementia together, and what to do if you have any questions or need to update any details.

If you're dealing with dementia in your day-to-day life and want more regular contact, Alzheimer's Society is here for you – **see page 38** for ways to stay in touch.

Wales council tax change

If you live in Wales, new changes have come into force when claiming a reduction in council tax or an exemption from paying it.

A diagnosis of dementia may now be recognised as a 'significant cognitive impairment' in Wales council tax rules. This can reduce your household bill by up to half or, in some cases, exempt you entirely.

To qualify, you must be formally diagnosed as having a significant cognitive impairment by a doctor or medical practitioner.

Councils in England will eventually use the same title for their council tax rules.

For information on council tax in Wales, visit gov.wales/council-tax

Supporting innovation

We've kicked off the latest rounds of our innovation programmes to develop products that support people affected by dementia.

Launchpad is a six-month programme aimed at innovators who are in the early stages of growing their ideas. Our year-long Accelerator programme is for people further along with their concepts, providing business support and up to £100,000 investment.

There are exciting innovators in our latest cohorts. These include Circadacara, which is working on smart lightbulbs that help with sundowning symptoms and Just Once, a service that supports carers' assessments.

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

Trek to beat dementia

Our Trek26 events have begun and there's still time to grab your hiking boots to take on a challenge.

Thousands of amazing supporters have already trekked 13 or 26 miles in stunning settings across the UK. You can join events coming up over the summer in the Lake District, Cotswolds and many more locations.

We'll be with you every step of the way, from a free breakfast to huge cheers at the finish line.

To find your Trek26 event, search 'Trek26', visit alzheimers.org.uk/Trek26Together or call 0300 222 5808. Use code LASTCHANCE to save 20% off your registration.

BA partnership

Alzheimer's Society is once again benefiting from onboard donations across all British Airways flights.

The collaboration started in May and will run through to December.

It is a fantastic opportunity to fundraise for vital services and research, as well as to raise awareness.

The Society has been named one of five principal charity partners for BA.

Through the generosity of passengers and crew, we hope to raise over £150,000 to help support people affected by dementia.

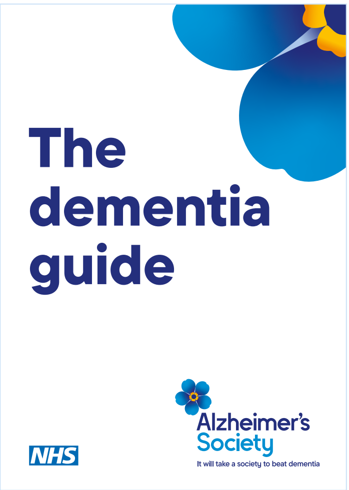
Relive the glory of ’66

It’s one of the greatest occasions in English sport and you can watch it again, in full colour and with contributions from Alzheimer’s Society, on Channel 4.

On 6 June, the 1966 World Cup Final will be broadcast, in association with SunLife Insurance. It will be available on All 4, Channel 4’s on-demand channel, for a year.

As well as unique content from us, there will also be contributions from star striker Sir Geoff Hurst and our Ambassador, celebrity football fanatic David Baddiel.

New-look publications



The dementia guide

Alzheimer’s Society

It will take a society to beat dementia

NHS

Two of our most popular print publications have been refreshed with help from people affected by dementia and are now available to order or download.

Our Dementia guide (872) is for people dealing with a recent diagnosis. It can help you understand more about dementia and the treatments, support and services available to you.

Keeping safe and independent at home (819) is full of practical advice and ways to help you to live safely and comfortably at home when you have dementia.

See **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933** to order.

Join our conference

Alzheimer’s Society’s 2026 Annual Conference on 17 September is all about how evidence, innovation and lived experience can drive change and improve outcomes.

There’s still time to sign up and join us online or in person at Convene in Bishopsgate, London.

The event welcomes people affected by dementia as well as health and social care leaders, policymakers, researchers and campaigners.

Tickets for people affected by dementia are available at a reduced rate – visit alzheimers.org.uk/annual-conference or call 0330 333 0804.

Celebrating our volunteers

We’re marking Volunteers’ Week from 1–7 June, the annual UK-wide celebration of volunteers.

It’s the perfect opportunity to thank our hundreds of amazing volunteers who give their all, day-in day-out, to support people affected by dementia.

From cheering on our fundraising walkers and runners to providing phone support that helps people feel less isolated and helping deliver Dementia Friends sessions (see more on pages 22–23), we couldn’t do what we do without your tireless work.

Thank you all!

Listen up

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

We release a new episode every time an issue of the magazine comes out, bringing articles to life in people’s own voices.

In the last episode we heard all about the joy of singing with the charity Forget-me-not Chorus and a new episode will be out in early June.

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

Memory Walk 2026

Join a Memory Walk near you this autumn for a fundraising walk to remember.

It’s not just a walk – it’s a time to remember those loved and lost, and to meet other people whose lives have been affected by dementia too.

There’s a brilliant atmosphere at every event, including an energetic Zumba warm-up and feel-good music.

Every step will help fund essential treatments and groundbreaking research into a cure.

Sign up to an event or organise your own at a place that’s meaningful to you by visiting alzheimers.org.uk/MemoryWalkTogether or call **0300 222 5808**.

Don’t miss...

Myra wants more understanding and consideration for people with dementia who live alone. See page 17.

Austėja is researching why some people are more vulnerable to Alzheimer’s than others. See page 21.

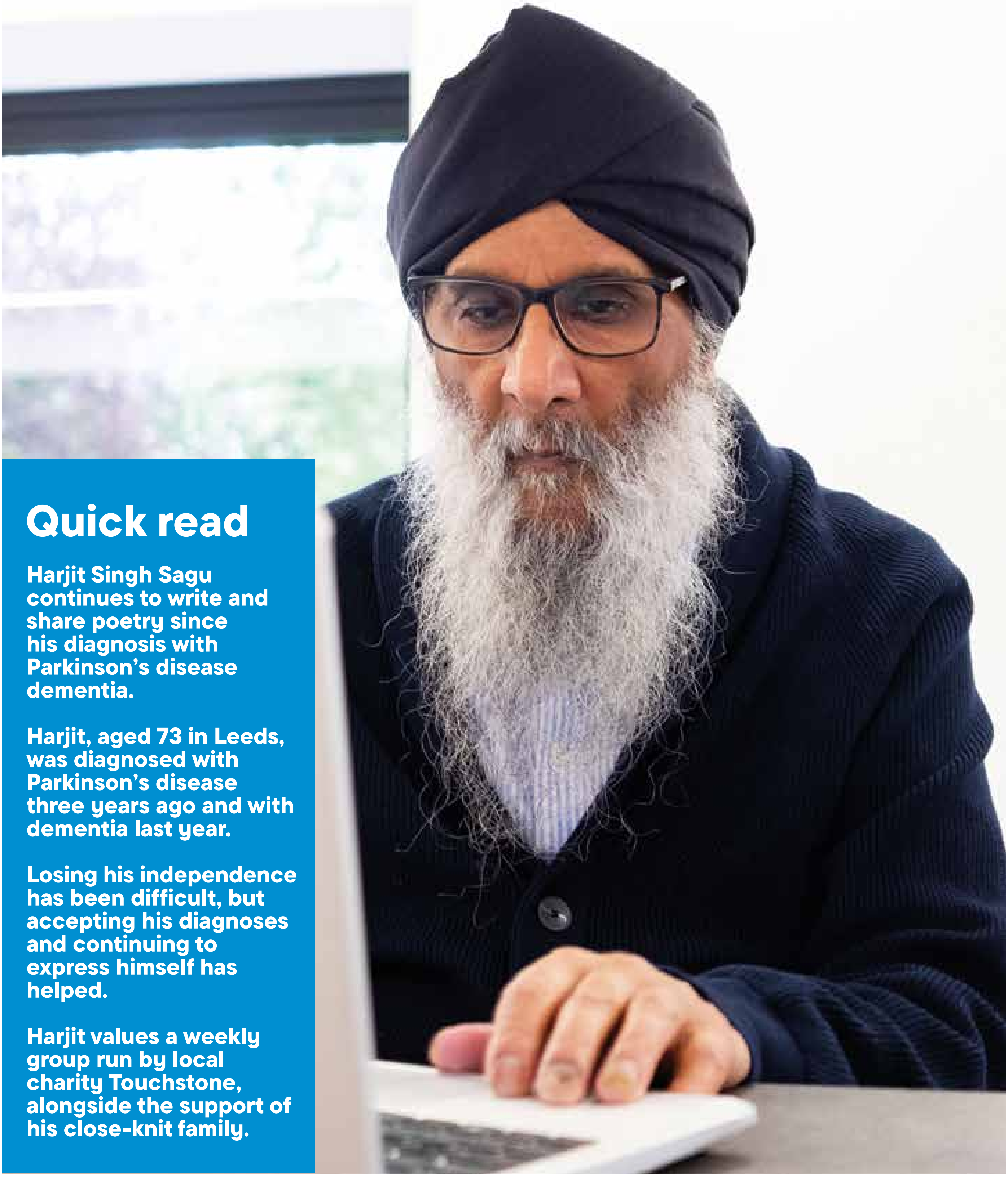
People with dementia try out two specially designed mobile phones at a Solihull group. See page 28.

How can you support a person with dementia who seems to be hoarding things? See page 34.

How can you keep in touch with the Society and other people affected by dementia? See page 38.

Passion for poetry

Harjit Singh Sagu, in Leeds, says losing his independence since developing Parkinson's disease dementia has been hard. Margaret Rooke learns how his poetry has helped.



Quick read

Harjit Singh Sagu continues to write and share poetry since his diagnosis with Parkinson's disease dementia.

Harjit, aged 73 in Leeds, was diagnosed with Parkinson's disease three years ago and with dementia last year.

Losing his independence has been difficult, but accepting his diagnoses and continuing to express himself has helped.

Harjit values a weekly group run by local charity Touchstone, alongside the support of his close-knit family.

Photographs: Paul David Drabble

Being told you have dementia, when you already have a diagnosis of Parkinson's disease, is a lot to take on board.

For Harjit Singh Sagu, who's been independent all his life, knowing he would need to be cared for by others felt especially brutal.

But despite this Harjit, who's 73 and lives in Leeds with his wife Jasbir, has a special talent that carries him through all his worst times. It continues to bring him and those around him a special joy.

For as long as he can remember, poetry has been his great love, not just reading and reciting poems, but writing them too.

'From the age of seven, I always had a passion for poetry,' he remembers. 'I read poetry books and recited them at events in Punjab, in India.

'I still spend hours every day reading poetry and I try to write a poem every day,' he adds.

Harjit's daughter Vicki explains, 'It's how my dad reflects after an event, or after something happens in his life.

'Once he had a bicker with my mum, and then he wrote a poem about that. It's like a reflective moment about what's happening to him.'

Harjit also uses poetry to teach others, for instance about Punjabi and Sikh history, or the importance of telling the truth, or of men articulating their emotions – in a culture that often does not encourage this in men. His poems are even used to teach Punjabi to children in Sikh temples.

Everything important to him is expressed in the lines he writes.

Ready audience

Harjit was born in Punjab and came to the UK to live with his father and stepmother when he was 12.

'I didn't meet my birth mother again until I was 37,' he says about this tragic separation.

After school, he started work as an apprentice mechanical engineer, then moved to London to work at Ford as a car sprayer.

He returned to Yorkshire to care for his father, who had fallen ill. Harjit stayed in Leeds for the rest of his life, as an engineer, business owner – and poet.

Wherever Harjit worked, he always carried a piece of paper in a pocket to jot down thoughts that might work well in verse. Even when his bosses asked him what he was up to, he carried on.

Harjit first met Jasbir in 1973 while in India, and they married the following year. They now have three children and six grandchildren.

Granddaughter Preet says, 'My grandfather won't walk two steps without my grandma. They are each other's heartbeat.'

This explains why, when his wife once had to work on a Sunday – even though this was the special day they always spent together – Harjit wrote a poem about the distance this created between them on that one day.

Vicki remembers Harjit's impact on her and her brothers when they were young.

'Every Friday we'd go to the local library with our dad, and we'd get about six or seven books each and read them all week. Then we'd go back the following Friday, until we developed that passion for reading that he has.'

Losing independence

Harjit was diagnosed with Parkinson's disease three years ago, and Parkinson's disease dementia last year. Jasbir had noticed his confusion and failing memory and suggested he speak to the doctor.

'The hardest thing was losing my independence,' says Harjit, with a tear in his eye.

'I have always had a clean driving licence, but once when I was driving, I thought I saw someone overtaking me on the left. They weren't there.

'I reported this, and that's when they took my licence away. That was the biggest thing for me, the worst thing.'

Harjit had to overcome many feelings of denial about dementia and accept that this was now part of his life. When he could do this, his life greatly improved.

Now, Harjit attends a weekly dementia group for South Asian people, run by local charity Touchstone, which he loves being part of – and where he has found a new audience. He spends a great deal of time before each meet-up deciding which poem to recite to them that week.

He described his dementia journey to the group one week in his poem 'Me and My Companion, Dementia.'

In this poem, he expresses, 'The journey ahead destined to be long,' and that, 'One day, without warning came darkness, bringing with it unfathomable winds.'

‘A shining light’

For many years, Harjit was a volunteer for Touchstone, which helps older people and runs gatherings and yoga sessions. He didn’t expect to be a service user himself.

But he describes Touchstone in the poem as ‘a shining light’.

‘Darkness faded away, as if a dream,’ he wrote. ‘So many souls, witness to my journey.’

The support from Touchstone is what had enabled him, after the shock of being diagnosed, to reconnect with his poetry, and its members were a willing audience to the words he expressed to them:

Sometimes I read alone.
Sometimes, with all
Thousands of travellers.
Our destination the same
Once who were alone
Now stand united.

This poem, like his others, was written in Punjabi. Vicki translated it into English and it was shared in a local Alzheimer’s Society newsletter.

Harjit says attending the Touchstone group is a special time for him.

> **“You’ll often find Harjit in his garden… or with his close-knit family around him.”**

‘It puts my mind away from other things,’ he explains. Instead of falling into a negative cycle, he can place his thoughts elsewhere.

Many other audiences are on hand to hear his poetry.

‘Leeds City Council organised a special event for people with dementia and their carers, and I was on stage reciting a poem for them.’

He always chooses his subject matter carefully. At a large occasion to celebrate International Women’s Day, Harjit read out a poem about women. Although he is part of what feels like a male dominated culture, Harjit is an individual thinker and sees life on his own terms.

‘Typically, in the Asian community,’ says Vicki, ‘there can be a bit more favouritism for the boys, but my dad loves everyone, from the girls in his family to the older women he meets in the Sikh temples.

‘He writes loads of poems about the importance of women and what they bring to life. He is a role model for other men in the Sikh community.

‘I think for all of us, Dad’s story is inspiring,’ she adds. ‘He’s gone through so much in life, but even now he remains so positive. I often feel like, with his dementia and his Parkinson’s, he doesn’t let that become an obstacle.

‘He’ll still go to the local temple every Sunday. He’ll still go to yoga twice a week. He will read his poetry.

‘He goes on long walks. He is very resilient.’

Breaking stigma

Something very special, and significant for Harjit, is that he wants to break the stigma attached to neurological conditions in the Asian community.

So he talks at temples and takes part in charity walks, a sign of the passion he has always had for helping others. His last was the Three Peaks Challenge. His next is a hike up Yr Wyddfa (Snowdon), raising funds for the global Sikh charity Khalsa Aid.

You'll often find Harjit in his garden, continuing to keep it beautiful, or with his close-knit family around him.

But mostly you'll find him at his laptop, writing his next poem. Soon, thanks to popular demand, his poems will be printed in a book, to gain an even wider audience.

Harjit doesn't let his diagnoses define him.

'My advice to others is to keep your mind clear,' he says. 'Keep yourself distracted.'

'He's like a ray of sunshine for us all,' adds Vicki. 'A light of hope for all the others with dementia.'

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.

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**.

Donate

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

Share and inspire

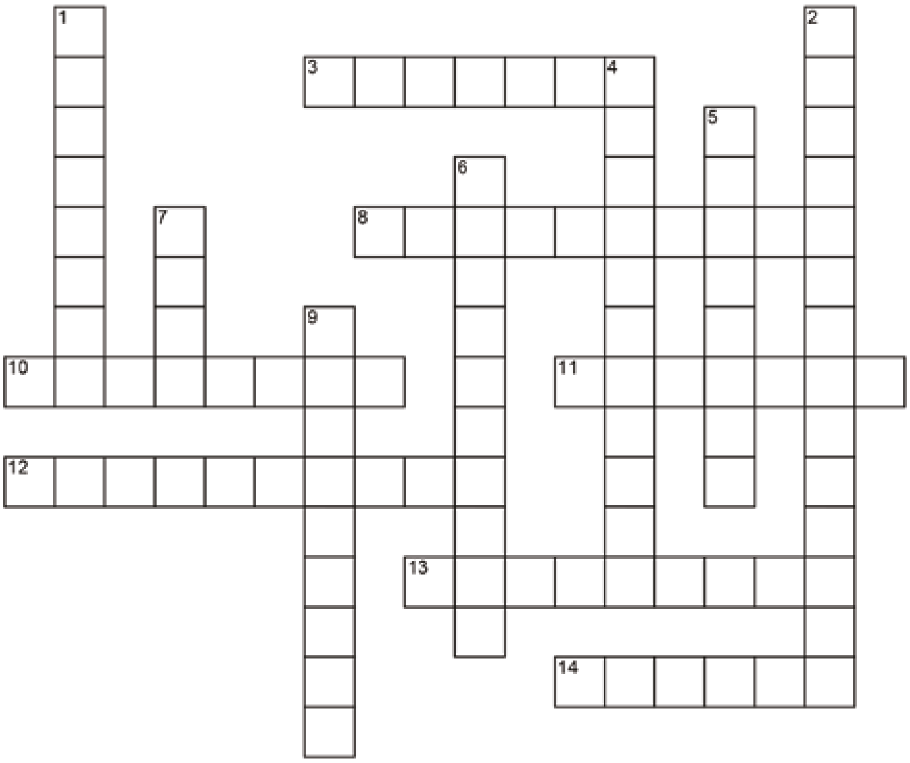
Views, updates and ideas – for and by you.

Anagramword: Sea and coastal birds

Pete Middleton's latest puzzle features sea and coastal birds – many found around Britain and Ireland, and a few favourites from farther afield.

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

3 Sniff up some of these cute little birds (7)
8 Most rancor is reserved by anglers for these sleek fishing birds (10)
10 Less Gaul would be nice when these blighters steal my chips or ice cream (8)
11 A pencil whose beak can hold more than its belly can (7)
12 Yak stew kit make some of these noisy birds (10)
13 Glum Eliot reveals the secret of this cliff diving sea bird (9)
14 Armful, but easily turned into a seabird (6)

DOWN

1 Ease gale to locate a maritime raptor (3,5)
2 Exams earn wrath, but can be reassembled into the name of this species (4,10)
4 Report smelt fishy but turned into an agile little black sea bird (5,6)
5 Up ensign! for a group of these birds (8)
6 A crack suit can be reassembled to provide the name of this seasonal visitor to the Scottish islands (6,4)
7 Hags reassemble to become a sleek diving bird (4)
9 A star slob, but a wonderful long-haul flyer (9)

Pride begins in Falmouth

Alzheimer's Society was at Falmouth Pride 2026 with our clear message for LGBTQ+ people: 'Dementia doesn't discriminate. Neither do we.'

Falmouth Pride, part of Cornwall Pride, brought live entertainment, community stalls and music to the town's Event Square on 25 April.

Nicola Rowberry, local Dementia Adviser, said, 'It was a beautiful day spent in the sun. Raising our banner high for the Society, we made connections and spoke to many people about their own journeys with dementia.

'It's important for Alzheimer's Society to be at Pride events because it shows we unite together as a society, and are determined to make a difference where we can in every aspect of care and support regardless of gender and identity.

'It shows we listen and helps bridge the gap between local services and those living with dementia, who may be in a minority group who would otherwise be unsure about reaching out for help.

'I hope that, by being present, we empower and encourage people to access local support and share their stories and experiences of living with or alongside dementia.'

Wherever they can, our local teams will be at other Pride events this summer, so keep an eye out for Alzheimer's Society at yours.

For our booklet LGBTQ+: Living with dementia (1511) and factsheet Supporting an LGBTQ+ person with dementia (480), see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Never done before: Archery

Since losing her sight and receiving a dementia diagnosis, Trish Gracesmith, 60, in West Bromwich, has taken up archery:

I have a condition called antiphospholipid syndrome (APS), which is where your immune system attacks proteins in your blood. It causes multiple strokes and damage to the joints, brain and all sorts. The damage caused by my strokes means that, after gradually losing my sight over the years, I am now registered blind.

I was also diagnosed with vascular dementia when I was 44. When I first developed memory problems, my doctor initially put it down to the stress and tiredness of bringing up five children.

Sense of freedom

I was feeling rather sorry for myself when a friend of mine who is visually impaired asked me if I wanted to try archery.

I said, 'I couldn't hit a target when I could see!'

When I was growing up, it was something I'd always wanted to try and I did appreciate Robin Hood films, so I thought I'd go for it.

There are several ways archery can be adapted when you are blind or visually impaired, depending on your needs. For example, I have a spotter, someone who is sighted and helps me stay safe, and I use a tripod for my bow.

I was just praying I wouldn't embarrass anyone at my first session. But I ended up hitting the target well. I instantly felt a real sense of freedom. After having my family, I'd never had a real chance to concentrate on me. This was something that could help me feel more active and positive.

> **“I literally fell into competing after a guy from Archery GB came along to one of our sessions and suggested I started.”**

Finding confidence

After that, I tried to find an archery course and a club I could join. It took me a long while to find a club that would give me a chance.

I literally fell into competing after a guy from Archery GB came along to one of our sessions and suggested I started.

I don't think it was so much my talent but my energy and passion for the sport that he saw.

I competed in my first competition in 2021 and there's been no stopping me since. I've broken records and I've represented Great Britain at international competitions, including one in Andorra. I can now aim for the Paralympics if I really want to.

It doesn't ever feel like a competition, more like a day out with friends!

Learning experiences

When I pick up the bow, it feels like a physical reboot.

I train two to three times a week if I can and I'm learning all the time – I'm certain the routine of archery is good for my brain. I've met an amazing bunch of people too.

It's great to stay busy. It means I'm not sitting and dwelling.

I've recently qualified as a level 1 archery coach. Through our regional Sight Loss Council, I also do blind tennis and ten pin bowling as well. I'm also a member of a young-onset dementia group.

I want to stay active and make plans for as long as I can.

I'd encourage other people by saying what did you want to do before life got in the way? Try something that catches your imagination.

OK, life might be different for you but can still do something that makes you feel good.

Onset, diagnosis and now

Karen Barber, 65, in Essex, shares her thoughts about life before her dementia symptoms, before diagnosis and since.

Who were you before onset?

Before the fog of dementia set in, I had lots of 'get-up-and-go' and I was a multi-tasker.

For over a decade, I was a senior civil servant, eventually becoming the office manager for a chief executive. I managed a team of four and oversaw high-pressure, complex workloads in HM Passport Office and Revenue and Customs.

Outside of work, I liked travelling and I was a regular at the gym. Life was busy and I loved it.

Who were you before diagnosis?

In my 50s, the skills that came naturally to me, such as organising, coordinating, remembering, began to slip away. I made mistakes I shouldn't have made.

My GPs were dismissive, putting my symptoms down to menopause, stress, and anxiety.

Because I lacked a diagnosis, I was dismissed from work for poor performance, despite an exemplary record of appraisals and promotions. I lost my salary and a subsequent tribunal case.

Without a medical diagnosis, I was denied medical retirement and forced to fight for six years to receive a pension that was ultimately not backdated.

It took ten years of fighting and private testing to finally hear the words: 'you have young-onset dementia and Parkinson's'. I was 56.

Who are you now?

I need complex medical support and I am fed through a tube in my stomach for all nutrition and medication.

I've found navigating the rigid social care system really challenging.

I recently underwent a six-hour continuity of care assessment that felt utterly unfit for purpose.

There's a damaging myth that if you can walk, you don't need 24-hour care. This ignores the cognitive effects of dementia and the specialised needs of younger people. Systems tend to be designed for older people, leaving those of us in middle age in a terrifying vacuum of support. As the numbers of people with young-onset dementia rise, there's a brewing crisis that cannot be ignored.

Despite everything that's happened, I still have fight. I am determined to change things for other people and to raise awareness.

I would not be where I am today without my peer support group.

Their encouragement gave me the confidence to step out of the shadows and reclaim my skills. Earlier in 2026, I founded the Young Minds Dementia Group in Clacton-on-Sea.

I channel my years of civil service experience into this group. I use my networking and organising skills to provide activities, information and give a voice to those who have been forgotten.

I am ambitious – I want to see these groups across all of Essex. I have even taken my fight to Parliament, where I spoke about our broken social care system.

I speak out, not just for myself, but for every person without a voice. It's not acceptable that we receive inadequate care.

Dementia has taken much, but it hasn't taken my spirit. I'm currently learning to play the piano and am about to take my grade 1 exam. It just shows that even with a dementia diagnosis, you can still learn, still achieve and still contribute.

3NDWG: legacy and change

As the 3 Nations Dementia Working Group (3NDWG) prepares for change, its steering committee met in Bristol to celebrate its many achievements over the last nine years.

Since being founded by Hilary Doxford, Chris Roberts and Keith Oliver, 3NDWG quickly established itself as a trusted voice and supportive community for people affected by dementia.

Although 3NDWG is winding down, its members will be launching a new independent social group for people living with a dementia diagnosis.

The group has influenced work at all levels, contributing to the NHS Long Term Plan and Prime Minister's 2020 Challenge, as well as working with the Royal College of Psychiatrists, World Dementia Council and many others.

3NDWG delivered Dementia Friends sessions to MPs and in local communities, and members shared their insights and experiences at UK, European and global conferences and events. This included planning and speaking at a number of workshops and plenary sessions.

The group has co-created resources with Alzheimer's Society to involve people with lived experience of dementia, as well as Dementia Statements that helped to shape how we work.

From 2020–2025, 3NDWG also delivered a full programme of 79 webinars that attracted over 111,000 views. These covered topics ranging from music and positivity to assistive technology and hospital care.

As the group's steering committee met in spring, its members shared their reflections and memories in a final webinar. This included a moving tribute to the late Nigel Hullah, the group's much missed Chair.

You can watch 3NDWG webinars, including the final one, at youtube.com/@3NDWGwebinars

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 6 July for the August/September issue (wording may be edited).

Reviewing projects with impact

People with lived experience of dementia have helped identify projects to be funded by EMPOWER Dementia Network+. This is a UK-wide network committed to reducing inequalities in dementia care and research. It uses co-production in inclusive ways.

Through Alzheimer's Society, 16 lived experts who support our researchers agreed to review projects that applied to the EMPOWER Small Research Network Fund.

These projects aim to establish how community-based initiatives can address inequalities in dementia care.

Sue Boex, one of the reviewers, says, 'The quality of the projects was good, and I was impressed by the passion expressed by the researchers to make a difference to the lives of people with dementia in a more direct and thoughtful way.'

Reviewers focused on how each project could affect the lives of people with dementia, and researchers' plans to involve people with lived experience throughout.

Andy Bradshaw, the network's manager, says, 'Meaningfully involving lived experts in reviewing was important in supporting us to fund projects that matter most to people directly affected by dementia.'

The seven successful projects will be announced in June.

Find out more about EMPOWER Dementia Network+ at empowerdementia.co.uk

Making a will

Can you make a will after you've been diagnosed with dementia – and should you?

Thinking about making a will can feel difficult. Even more so if you're overwhelmed with emotions after a dementia diagnosis.

But making a will means that the people or causes you want to inherit from you can do that. It also makes things easier for those close to you after you die.

However, no one should force you to make a will – it must be your choice.

Mental capacity

Many people with dementia do make wills, but the sooner you do it, the better.

For your wishes to be followed, you need to have 'mental capacity' to make your will at the time you make it. As your dementia progresses, it will become harder to show that you had this.

Using a solicitor

It's a good idea to get help from a solicitor or other legal professional, such as a legal executive. They can help you to express your wishes clearly and avoid mistakes.

They can also help to confirm that you had mental capacity to make the will if this is challenged later.

Think about using a solicitor who has a good understanding of dementia.

What if there's no will?

If you don't have a will, your spouse or civil partner will be first in line to inherit from you. Any children you have will be next in line. If you don't have either, then other relatives might inherit.

If you have a partner who isn't your spouse or civil partner, they won't automatically inherit anything. As with anyone else, they could only inherit a house or something else if they own it jointly with you.

Your tips

'I think it's essential to make a will, because if you have not made one, then the legal system of intestacy moves in. That may mean things you wanted are completely overlooked.

'People can be reluctant because they don't want to face the inevitable fact that we all go at some time. What can also inhibit making a will is where you have differences of opinion, say about what should happen to joint property.

'After a dementia diagnosis, act quickly – even if it's just to confirm a will that's already been made.

'If there is a family dispute, any excuse to challenge it may be taken. Make the will with a solicitor, rather than a homemade one you can buy off the shelf in a newspaper shop. The solicitor will make sure there's a proper paper trail.

'Remember also that there are three legal systems in the UK, and obligations to family members differ in each.

'If you're not giving something to a family member who might feel entitled to it, I would record why not. Not to say that "young Fred would drink it all or put it on the horses", but maybe that you've looked after him for years and he's well set up now.

'Ensure that executors are asked before the will is made and that they agree to act as executors. I feel that two executors are advisable for reasons of workload and avoiding allegations of taking advantage of the estate.

'Know where the will is. People put things away "safely" when no one else knows where "safe" is. And people with dementia can put things in obscure places, as I know from frequent searching for objects my husband has taken and stored… somewhere.'

Teresa Doherty Benton

Find a lawyer who has experience in supporting vulnerable and older people at **lifetimelawyers.org.uk** or call **020 8234 6186**.

For our free guide to gifts in wills, please see **alzheimers.org.uk/willguide** or call **0370 011 0290**.

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

Opinion:
Living alone with dementia

Myra says people living alone with dementia are an increasing minority who need to be recognised, as their needs can be different.

Myra, aged 70, lives alone with mixed dementia.

I have a strong family history of dementia. Each generation down both sides of the family had some form of dementia and I was a carer for them.

Even people with the same type of dementia don't have the same difficulties so there is no 'one size fits all'. Everyone is a unique individual.

When I started doing things that weren't normal for me, I began to wonder if I was developing dementia, so I went to my GP who asked questions and referred me to the memory clinic.

Eventually, I was diagnosed with mixed dementia – Alzheimer's and vascular dementia. Getting a diagnosis was a relief rather than frightening.

No family or carers

By this time I had no family anywhere in the world and no carers. Actually having the disease gave me an entirely different perspective on what it's like – very different from the difficult job of being a carer.

Two people I trusted already had powers of attorney for me, but they aren't my carers and we don't always know where each other is.

They are my 'supporters' – a term we prefer rather than 'family and carers' when you don't have any. They are now stepping in to help me with budgeting, as I'm inclined to make mistakes.

I'm fortunate to have a lot of insight, but that will go as the disease develops. I know that as faculties disappear they won't come back, which can be upsetting. There are days when I get completely confused, so I shut myself away until a better day.

My life, my decisions

One big difference if you are alone is that other people have nobody else to ask for information about you. Any information has to come from the person themselves or via things they have written down – a fact not always appreciated by workers.

I have filled in a 'This is me' booklet to take with me as needed. It helps people to know how to relate to me and gives basic information they might need.

As a very pragmatic person, I have planned ahead. I have found myself a support group, who know me well and will be able to notice when things are going wrong. I have made sure the people I've appointed through powers of attorney know in writing what my future wishes are.

Unless something gets me first, I know and accept that I'll eventually have to go into a care home and have done a bit of research into that.

More of us now

With the fragmentation of society and families, more people now live alone with dementia. Dementia advisers tell me they are getting more calls now from people who are living alone with dementia and have different needs. When I speak to other people, including professionals, they say this is an area that needs looking into much more.

I have a lot of coping strategies so people don't always realise I have dementia, but it sometimes shows itself now.

I have a strong Christian faith and I know God will come with me as things deteriorate. I see this as another phase of life. Many things I used to do have gone, but I enjoy meeting up with people I know and doing what I can.

Don't write me off – I'm still me! I'm living differently, but well with my dementia.

This is me

'This is me' is a simple leaflet to record details that help health and social care professionals better understand a person. See **alzheimers.org.uk/thisisme** or call **0300 303 5933**.

Saying what I feel

John Amos, in Hertfordshire, has been involved with all kinds of campaigning, including sharing his experiences with an independent commission.

I was fortunate to retire from my job in my 50s. Afterwards, my wife Lesley and I spent quality time with our family, enjoying our hobbies and travelling.

It was a treasured time. Had we worked into our 60s, we wouldn't have had any time together in a good way.

Because we spent lots of time at home together, I started to recognise subtle changes with the way Lesley was behaving. She was forgetting things, couldn't work things like the TV remote and wasn't able to do puzzles, which she used to love.

Lesley didn't want to go to the doctors and kept claiming there was nothing wrong. But I, and other people, knew that there was.

Hard to cope

Eventually, Lesley was diagnosed with young onset Alzheimer's in 2012. She was 62.

Caring for her as she gradually deteriorated was so difficult, particularly when she started experiencing seizures and being aggressive.

It's hard to know what to do when your wife starts hitting you and saying, 'You don't live here.' That's when I first contacted Alzheimer's Society for advice.

The Society also supported me when it was recommended that Lesley go into a nursing home in 2014. It was a reluctant decision for her benefit and mine.

Speaking out

I'd never done any campaigning before. I'm not a public speaker.

I am placid, but when I wasn't allowed to visit her care home during the pandemic it really annoyed and upset me.

I thought that it was so unjust that I couldn't visit, like thousands of other people in a similar situation.

I contacted my MP, the council and government, as many people as I could, to campaign for people to visit their relatives in care homes. I also campaigned for free Covid testing for care home visitors.

Sharing my story

Since Lesley died in 2022, I continue to speak out.

I just want to share my story. I'd like people to understand that it's not just older people that get dementia and it's not just a loss of memory. It's a loss of character.

I also want to highlight that carers and family members can be forgotten.

I've been to events in Westminster, including a meeting with about 50 MPs. I've been to Downing Street. I'm also a research volunteer and I go to groups to encourage people to leave money in their wills for dementia research. I'm still writing to my own MP too.

When I was asked if I'd like to take part in the Casey Commission and share my experiences, I didn't hesitate to say 'yes'. This is an independent inquiry that will make recommendations to the government on reforming the social care system.

Encouraging others

There's lots I could have said if we'd had more time. But what I really wanted to get across is the injustice of funding, and the challenges of navigating the social care system.

When Lesley had seizures, the NHS paid for her care. Then after receiving medication to eliminate these, she no longer qualified. We had to self-fund, which was totally unfair because she still had dementia.

I think this hit home with Baroness Casey. She came up to me afterwards and thanked me.

A short time after the event, she mentioned my story in a speech to healthcare leaders, which made me feel great.

I've recently shared my experiences with Society supporters to encourage them to sign an open letter, calling on the government to deliver a bold dementia plan in England.

I'm surprised by the things I've done. I think Lesley would be too!

When I speak with others about dementia, I'm open about it but I'm also determined to get my message across.

I'll keep fighting. If someone asks me to volunteer and I'm able, I'm there. It's my way of paying back.

We involved eight people affected by dementia in a discussion with the Casey Commission earlier this year. Afterwards, its Chair Baroness Casey called for dementia to be a national priority and for a shift 'from despair to hope'.

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

A way of letting go

To celebrate loved ones and raise funds, Kevin Osbon and his wife Victoria embarked on a physically and emotionally tough journey along the Camino Way.

My wife Victoria and I had been on the verge of booking the trip of a lifetime to New Zealand. But in the space of just three devastating months, everything changed.

My father, who had been unwell for some time, passed away.

Then, in quick succession, we lost my warm and vibrant Aunt Carmel, one of my closest friends Derek, who supported me through some of the hardest moments in my life, and our neighbour Margaret, an adopted grandmother to our five children. All three had been diagnosed with dementia.

My relationship with my father had always been complicated, although we'd tried to reconnect. In different ways, Carmel, Derek and Margaret filled the gap left and they were all incredibly important to me.

Something meaningful

In the quiet that followed, Victoria and I decided we wanted to do something meaningful to honour Carmel, Derek and Margaret, and that's when the idea of taking on the Camino Frances was born.

Fundraising has always been important to me.

Over the past 20 years, I've taken on lots of different challenges across the world, including climbing Kilimanjaro and Mont Blanc and trekking to Everest Base Camp and crossing the Sahara Desert.

But this time, we wanted something different, something deeply personal.

Intense and challenging

Camino Frances is the most popular pilgrim route of the Camino de Santiago, which translates as the Way of Saint James. It goes from a French village close to the Spanish border to the Cathedral of Santiago de Compostela in northwest Spain.

Preparing for the trek was intense. We knew we'd be walking up to 15 miles a day for several weeks, so training became part of daily life. Not a day went by without us doing at least 10,000 steps. We also did longer walks, including the Wainwright Coast to Coast.

The journey itself was physically and emotionally demanding. There were days when it felt impossible to keep going, but somehow we always did. Along the way, we found incredible camaraderie – people from all over the world supporting each other.

It gave us space to process our grief. At first, the physical exhaustion seemed to match the emotional weight we carried. But over time, things began to shift. Reflection turned into acceptance and pain into something lighter.

One of the most powerful moments was at the Cruz de Ferro, the Iron Cross, in the mountains of northern Spain. There, I left four stones to represent each person we'd lost. I carried them from the start so leaving them felt symbolic – a way of letting go of some of the grief and anger.

Deep appreciation

It took 35 days to walk the 565-mile route, that's over 1.2 million steps between us. I lost 14kg in weight! By the time we reached Santiago de Compostela, we felt changed.

Finishing was emotional but also quietly reflective.

We felt more at peace, with a renewed appreciation for life and the people in it. We celebrated with fellow pilgrims, many of whom have become lifelong friends, but also took time to sit alone and take it all in.

We were thrilled to raise over £6,000 for Alzheimer's Society.

If I have one piece of advice to other people about taking on a fundraising challenge, it's this: do something that pushes you but also benefits you and others. Do something that makes a difference on more than one level.

I've continued fundraising, including taking part in a Strictly-style dance event that raised £5,500 for children with neuroblastoma.

For now, I'm recovering from shoulder surgery and taking a short break from challenges, but I know I'll be back!

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

Find a clinical trial

A new online tool makes it easier for people with dementia or mild cognitive impairment to find clinical trials to join.

Clockwise from top: Dáithí, Deborah McGlynn, Keith Aungiers, Inês Rodrigues

'There is a gulf between what researchers might write about their work and how that appears to the "man in the street",' says Keith Aungiers in Newcastle.

Keith is one of many who have helped ensure the Clinical Trial Finder can bridge this gap. People with dementia or mild cognitive impairment can use this new online tool to find trials they could take part in.

Keith retired early aged 59 to look after his wife, who was later diagnosed with Alzheimer's. He was her sole carer for five years before she moved into a care home.

'Throughout my career, I was often involved in the start of things but never saw what happened to them in the end,' says Keith.

'With the Clinical Trial Finder, it's actually great to see it out there and say well, I played a part in that.'

Safe and effective

Researchers need clinical trials to find out whether a new drug, device or approach is safe and effective to be used by people.

The Clinical Trial Finder makes it simple to explore ongoing trials and learn who is eligible to take part. It was developed as part of a broader partnership between Alzheimer's Society and the UK Dementia Trials Network (UKDTN).

Through this, Alzheimer's Society UKDTN Dementia Research Nurses are being introduced in up to 20 NHS sites across the UK. They are making it easier for all kinds of people affected by dementia to become aware of and get involved in research.

In a recent survey, over 90% of people told us that clinical trials and research should be discussed as a standard part of dementia treatment and care. However, few are given this opportunity.

Deborah McGlynn, Dementia Research Nurse in Glasgow, has seen the impact of dementia within her own family.

'Clinical trials are how new treatments are discovered, and every single person who takes part helps move us one step closer,' she says.

'It isn't about scientists in distant labs. It's about ordinary people making an extraordinary difference.'

Inês Rodrigues, Dementia Research Nurse in Southampton, adds, 'I wish more people knew that taking part in research can be a meaningful part of their care journey.

'Research is voluntary, but it's also vital to improving diagnosis, treatment and support for people affected by dementia.'

Enormous potential

Improvements to the Clinical Trial Finder will continue and more trials will be added in the future.

Dáithí, who was also involved in helping to shape the development of the tool, says, 'The potential for how impactful it can be is enormous.'

As a trans non-binary person with dementia, Dáithí was especially keen to make sure the tool is inclusive. Dementia research needs people from all communities to take part.

'This opportunity to be seen and heard as a whole person living with dementia, including my identity, was hugely important.'

They raised the need for clear, plain English explanations of what each trial involves, including risks, benefits and time commitments up front.

Input from Dáithí, Keith and others all fed directly into how the Clinical Trial Finder was designed and refined.

'I felt heard and listened to, it was really great,' says Dáithí.

Deborah says, 'Every study, every participant and every data point contributes to a future with better outcomes for people living with dementia.

'That sense of shared purpose and progress is both motivating and deeply meaningful.'

Take part in dementia research

For the Clinical Trial Finder and other ways to take part in dementia research, see **alzheimers.org.uk/take-part-dementia-research** or call **0333 150 3456** and ask for our Research Participation team.

Patience and focus

Working to understand why the symptoms of Alzheimer's disease develop at different speeds.

Austėja Dapkutė has always been interested in understanding how diseases develop and affect the body.

After studying in Lithuania and working around the world, Austėja, a neurologist, is now an Alzheimer's Society Clinical Training Fellow at the University of Oxford.

Her research is all about trying to understand why some people are more vulnerable to Alzheimer's disease than others.

Her motivation to work in dementia research is very personal.

'My grandmother developed dementia and seeing how it affected her and our family was deeply painful. Even as a specialist, I felt there was very little I could do.

'That experience made me want to contribute to research that could lead to better understanding and treatments.'

Understanding resilience

By studying the brain's immune cells, which are known to be very important in Alzheimer's, Austėja is looking at why people develop symptoms at different speeds.

'In the lab, I study cells with the same genetic background as patients and expose them to conditions similar to Alzheimer's.'

Austėja then compares how these cells respond and if this correlates with information from brain scans, blood markers and memory tests.

The aim is to understand why some people seem to be more resilient, even when they are at higher genetic risk.

'If we can learn what protects them, it may help us find new ways to slow down or prevent dementia in others in the future,' she adds.

Strong community

Austėja's days are a mix of laboratory work and computer-based analysis. Her detailed work requires great patience and focus.

But she also thrives on teamwork and the collective energy around dementia research.

'I am surrounded by people at different stages of their research careers. I also work with collaborators who bring different expertise to the project.

'From my personal experience, having a strong community around you makes a real difference.'

Appreciation and hope

Austėja says that support from the Society has been valuable in many ways.

For example, it's helped shape her research and make it more relevant to people affected by dementia.

Her fellowship has also opened up new academic opportunities and she's now studying for a doctorate in clinical neurosciences.

'This gives me access to excellent collaborations and research facilities. It also supports me in maintaining my clinical skills, which is very important to me.'

While acknowledging the difficulties, Austėja says she wants to share her positivity about dementia research.

'I want to emphasise that research is moving forward all the time. We are learning more about dementia every day.

'So while it is incredibly challenging, there is real reason to stay hopeful that, with continued support for research, we will find better ways to treat and prevent dementia.'

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**.

Hearts and minds

To mark Volunteers' Week 2026 (1–7 June), Antonia Kanczula reports on Dementia Friends and its passionate volunteers, who are increasing understanding and inspiring change.

Quick read

Since the initiative was first set up in England in 2013, almost 3.9 million people have become Dementia Friends.

People taking part in an online or in-person Dementia Friends session learn about dementia and how they can help.

After attending a session, 87% of people feel motivated to do something to support others in their communities.

The programme plans to recruit more Dementia Friends Ambassadors – volunteers who run sessions across the UK.

'The more people who become Dementia Friends, the closer we get to building communities that are compassionate and supportive,' says Simon, a Dementia Friends Ambassador.

Like many Dementia Friends Ambassadors, Simon was inspired to volunteer after supporting a close relative through dementia and describes it as 'a simple yet meaningful way' to make a difference.

And that's Dementia Friends in a nutshell.

Launched in 2013 as part of the then Prime Minister's Challenge on Dementia, the original aim was to create 1 million Dementia Friends, explains Mary McColgan, Strategic Programme Manager.

'The focus was to change people's perceptions of dementia and transform the way the nation thinks, acts and talks about the condition.'

Growing and evolving

Within just two years, Dementia Friends exceeded its 1 million target and there's been no stopping the initiative over the past decade.

Today, there are almost 3.9 million Dementia Friends and counting. In addition, over 500 tireless Dementia Friends Ambassadors volunteer their time to run around 3,000 sessions each year.

As time has passed and the initiative has snowballed, the aims remain constant, says Mary.

'Whether you attend a face-to-face or virtual Dementia Friends session or watch our short online video, Dementia Friends is about learning more about dementia and the small ways you can help.'

Breaking barriers

Making sessions both easy to access and easy to digest is key to the initiative's approach.

Anyone living in England, Wales, Northern Ireland, Guernsey and Isle of Man can become a Dementia Friend. You can join as an individual or request a Dementia Friends session for your group or organisation, and you don't need any special training or previous knowledge of dementia.

Dementia Friends sessions can take place online and in varied locations – from schools and businesses to care homes and community spaces.

This adaptability means Dementia Friends has been able to break barriers and reach people, including the Deaf community and ethnic groups in which dementia may be stigmatised.

Connecting with so many different communities is incredibly beneficial, explains Carol Bowsher, a Community Development Coordinator who delivers sessions in Birmingham.

'By talking more about dementia, encouraging people to become Dementia Friends, and working closely with different communities, we can help bring dementia out into the open and ensure everyone has access to the information, advice and support they need.'

Emdad, a Dementia Friends Ambassador in London, started running sessions over a decade ago. He says he thrives on the variety of his volunteer role.

> **We can help bring dementia out into the open and ensure everyone has access to the information, advice and support they need.**

‘My approach is for everybody, although because of my background, I can reach out to the Asian community, in particular.

‘I’ve held sessions at banks and in the mayor’s parlour of a town hall, for matchday stewards at a football club, at a charity mountain climbing group, in town halls, mosques and community centres.

‘I’m a practising Muslim but I went to a Sunday service at church, and I’ve also held a session at a synagogue.’

Ripple effect

People affected by dementia tell us that better public understanding of the condition can help improve their lives. In fact, half of all respondents to the Society’s 2025 lived experience survey said it is key.

So it’s encouraging to know that becoming a Dementia Friend can impact massively on attitudes and behaviours.

After attending a session, Dementia Friends tell us that they are more knowledgeable about dementia and, as a result, more confident about engaging with a person living with dementia.

Around 87% also say they feel motivated to do something to support people affected by dementia in their communities.

The collective impact of these everyday actions, such as wearing the Dementia Friends badges or starting conversations about dementia, is huge and ripples out, says Mary.

‘This includes community actions and mobilising support for Alzheimer’s Society by becoming fundraisers, volunteers and campaigners.’

Mark first became a Dementia Friend when he was responsible for a strategy to care for vulnerable customers at a leading high street bank. Since then, he’s been inspired to support others where he lives.

‘Being a Dementia Friend is all about lending a helping hand and looking for opportunities to show kindness wherever possible.

‘I have supported a neighbour who was recently diagnosed with dementia by mowing her lawn, helping her with her computer and when she locked herself out of her home.’

Not standing still

The Dementia Friends team is always looking ahead and for opportunities to build on the programme’s amazing achievements.

In 2025, a new brand was unveiled alongside a new guiding message, ‘A little understanding makes a big difference,’ to show that everyone can play a part in supporting people affected by dementia.

There’s also an exciting new strategy in the pipeline, says Mary.

‘We want to deepen the understanding of dementia in communities, in workplaces and networks and enable more people to recognise dementia as an urgent issue.

‘We also want to inspire earlier action to support people affected by the condition and build up support for wider changes we need to see.’

The team plans to recruit around 300 more ambassadors by spring 2027 and encourage people of all ages from a wide range of backgrounds to get involved, adds Justine Sanders, Dementia Friends Programme Manager.

‘As we strive to make more people aware of dementia and what they can do to support people affected by dementia, we will need more volunteers to help us address the stigma of the disease and encourage everyone to make a difference for people in their community and beyond.’

Feeling inspired? Discover how you can become a Dementia Friend at **alzheimers.org.uk/FriendsTogether**

Find out about opportunities to volunteer as a Dementia Friends Ambassador at **careers.alzheimers.org.uk** or email **dementiafriends@alzheimers.org.uk** for more information.

‘A friend in the house’

A £1 million prize has gone to a personalised AI assistant for smart glasses for people with early-stage dementia. Heather Stephen reports on the difference it could make.

Quick read

CrossSense has won the £1 million Longitude Prize on Dementia with an AI-powered assistant for smart glasses.

The AI companion guides people through daily activities, helping them live safely in their own homes for longer.

CrossSense beat 174 other inventions from around the world to win the prize.

The prize money will support CrossSense to make its revolutionary product available early next year.

Software designer Szczepan Orlins watched his grandmother struggle with her memory for years. CrossSense, the AI invention he helped create, may have made life easier for her.

‘Three of us in the team have family experience of dementia, and we wanted to create a meaningful innovation to help people stay independent longer,’ he says.

The CrossSense journey started 11 years ago, when team members came across research showing the cognitive benefits of AI smart glasses. However, it took a long time for the technology to catch up.

‘When we first trialled smart glasses in 2019, we used goggles which fed back information from Wikipedia,’ says CrossSense Ltd CEO Szczepan. ‘But they were not intuitive and were very clunky.’

Seven years on, the invention now uses super-light glasses weighing just a few grams. After three years of trials involving 300 people with early-stage dementia, the AI companion called Wispy was born.

AI companion

Wispy sees what the wearer sees, hears what they say and remembers how they like to do things.

For instance, the device will recognise a mug and remind the user of the steps to make a cup of tea. It may give verbal prompts when plants need watering and give reminders of appointments and when to take medication.

In trials, three out of four people reported a significant improvement in quality of life.

Szczepan says, ‘The product improves confidence and wellbeing, and has benefits for cognition and social bonds.

‘People who trialled it were dubious about how it would work, but they said it was an eye-opener how much simpler it was to use than smartphones and other devices they had tried.’

Longitude Prize

CrossSense beat 174 other inventions from around the world to bag the prestigious Longitude Prize on Dementia. The £1 million prize money will help bring this exciting product to market at the start of next year.

> **Dignity is very important. Wispy doesn’t spoon-feed you but gives you gentle encouragement and reminders to enhance your life.**

The glasses, which can incorporate hearing aids and prescription lenses, will cost £1,000 and there’s a £50 monthly fee to use the Wispy app.

The inventors hope that, as evidence emerges about its value, the invention will be picked up by the NHS and the social care sector.

Since it needs wifi, the product is currently designed for use at home.

However, there are hopes it may be used further afield in the future.

It is so intuitive that Szczepan predicts, ‘It could continue to be useful as the disease progresses and step up support as the AI learns more about what the user needs.’

‘Blown away’

Carole Grieg, 70, from Sutton has Alzheimer’s and says she was ‘blown away’ when she trialled the device.

‘I am always looking for things that can help me with the challenges of dementia and I thought the glasses were very exciting.

‘As dementia progresses it can feel like descending into a chaotic world, but these glasses are like having a friend in the house which gives you support and helps you stay independent.’

The glasses talk Carole through everyday tasks like cleaning her teeth and can answer questions like, ‘I would like to go out today. How is the weather?’

She was impressed to learn that there was scientific evidence that regular use of the glasses improved memory, and is excited about plans to adapt them for use outside the home.

Breakthrough product

Simon Lord, Head of Innovation at Alzheimer’s Society, describes CrossSense as ‘revolutionary’.

‘We are very excited by this breakthrough product. It helps people with dementia to engage in meaningful activities, which is important in staving off cognitive decline.’

He says the invention also supports carers by reducing their day-to-day involvement, allowing people with dementia to enjoy more quality time with their friends and family.

‘AI is an incredibly useful tool, and this product has the added benefit of cognitive stimulation and collaboration with the user, which we’ve never seen before.’

Carole says the ability of Wispy to learn about you as an individual and to speak with you sets it apart.

‘Dignity is very important. Wispy doesn’t spoon-feed you but gives you gentle encouragement and reminders to enhance your life,’ she says.

‘Putting these glasses on is like a moment of clarity and is like putting on a lightbulb.

‘It isn’t a cure, but when people live in confusion this is something which can give them hope.’

CrossSense is looking for people with early-stage dementia to try the product free for four weeks this autumn to get more feedback about it. If interested, visit **CrossSense.com** and click ‘Join the pilot’.

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

Book group:
Still Me

We read a book helping people who are supporting someone with dementia to navigate the condition while caring for themselves too.

Still Me: A neuroscientist's guide to caring for someone with dementia, by Sabina Brennan (Green Tree, 2025), 288 pages, £10.99, ISBN: 9781399421393. Also available as an ebook.

Still Me, by Sabina Brennan, is a book that draws on many different perspectives in order to share helpful advice for carers.

Kristo, from our Dementia Support Forum, says, 'The author has personal experience as a carer for a relative with dementia and in a professional capacity in her work in the field of neuroscience.

'She uses case studies as a starting point to discuss possible outcomes and solutions. In some instances, she returns to the case studies to describe the impact of advice.'

Brenda, another of our reviewers, says, 'I was initially slightly daunted at tackling a book written by a neuroscientist, but it will now become the go-to book on my dementia shelf.'

AS, a reader in West Sussex, agrees, 'I think the book would be a really useful, informative resource to read in full soon after a person is diagnosed with dementia.

'As time goes by and behaviours change, the book is an excellent resource for dipping into relevant sections for understanding, advice, ideas etc on what one can do or try.'

'Still Me is a very readable book,' says David in Denbighshire.

'Its subject matter is well structured and headed, making it easy to navigate to a topic of interest.'

David says he's been on a 'steep learning curve' since his wife's diagnosis. He often feels overwhelmed with information from many sources, and frustrated that he can't find specific tips again later on.

'The clear, well-structured nature of this particular book enables me to retrieve and reread advice,' he says.

Clear and relatable

An anonymous reader in Kent says, 'My husband was diagnosed with Alzheimer's in August 2022 and since then I have read many books on the subject.

'Still Me is written clearly and has lots of helpful information. Sometimes I found that the book supported actions that I had taken, and I also got ideas for different approaches.'

AS says that, while the medical facts in the book are helpful, its insights from carers and relatives means that it's also relatable.

She says, 'Reading the book, there were times when I questioned myself as to whether I could or should have done things differently for a more positive outcome.

'At other times I was reassured I was "doing my best in the way that was or should be the best for my relative".'

'Every single page resonated with me,' says Brenda. 'It was so accessible, with short sections covering insightful information a care partner needs on their dementia journey.

'There were many thought-provoking sections encouraging people to assess their caring situation, with useful guidance on how changing your mindset could help with changing circumstances.

'There were many examples of other carers' experiences offering room for reflection on your own behaviour and how this might impact on your relative living with dementia.'

Kristo says, 'There is some excellent advice and really practical examples on self-care for carers.

'As carers we so often are told to take care of ourselves, but it is hard to know how to ask for help.

> **As carers we so often are told to take care of ourselves, but it is hard to know how to ask for help.**

'This book gives lists of ideas, plus scripts on how to word your requests to friends and relatives. I will definitely be trying some of these.'

Further scenarios

AS says the book doesn't address how to support a person who is in denial about their dementia, and who refuses to take advantage of opportunities to keep active and involved.

'Almost all of the people's stories seemed to relate to a full-time caregiver in a "living with" situation.'

She notes, 'I appreciate it would be impossible to cover all scenarios.'

Kristo says she struggles with the book's point that people with dementia remain the same person, beyond any issues there may be in communicating with them.

'Personally I find this concept difficult. I have seen so much of my own relative with dementia disappear, and I find it very difficult to reconcile the author's opinion with my own experience.'

However, she adds, 'Some of the tips on different methods of communication are definitely ones that I will try.'

David says, 'What makes this book so valuable is that I feel throughout my reading that I am connecting with Sabina the person.

'She "gets it". She understands the various obvious and subtle aspects of caring for a loved one with dementia.

'She offers sound advice and practical strategies, easily accessed in a "pick and mix" basis, recognising that "one size doesn't fit all" in caring and support strategies.'

Recommended read

As well as recommending Still Me to carers and relatives of people with dementia, AS says, 'I'd also recommend it as reading material for health providers who are doing an adult social care training course, or qualifications including a degree.'

'This book is one I will refer to regularly as my wife journeys through this disease,' says David.

'I highly recommend this book for carers of people with dementia.'

Brenda says, 'The author's words will live on in my head and I will return to this book many times in the years ahead.'

For our booklet Caring for a person with dementia: A practical guide (600) and factsheet Carers – looking after yourself (523), see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Dementia Support Forum

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

Simple mobile phones

A group of people with dementia in Solihull try out two specially designed mobile phones.

We took two mobile phones to show Solihull's Dementia Voice Local Group. There are many of these groups around the country, meeting regularly to influence our and others' work.

Both phones are designed to be simple to use for people with dementia and other conditions. They also have features to help people to stay independent while keeping connected and safe.

Using mobiles

Almost every group member said they use mobile phones – all smartphones, with large touchscreens and a range of apps. However, they tend to use them for phone calls more than anything else.

'If it rings I answer it, and I'll call people on it,' said Neil, 'but that's it.'

Jim said he doesn't call other people very often, using his mobile mostly for incoming calls.

'I can't see the point of texting,' said Paul. 'You spend ages writing it and then see you've spelled it wrong!'

None of the group use their smartphones for social media or to browse the web. Many still use landline phones at home.

Some group members use their phones to take photos.

'It's a record of things you've done,' said Neil. 'You can remember back to holidays.'

Jim said he shares photos with family members using his phone, and Sally knows people who use their phone camera as a memory aid.

Howard admitted he's lost confidence with his phone, and he wasn't sure that any model would suit him now.

'I'm not very good with the phone now,' he said. 'It gets on my nerves.'

Rachel noted that, even with simple devices, you still usually need to learn something new to use them.

'It's all about familiarity, isn't it?' added Paul. 'And it's annoying if you can't learn it easily.'

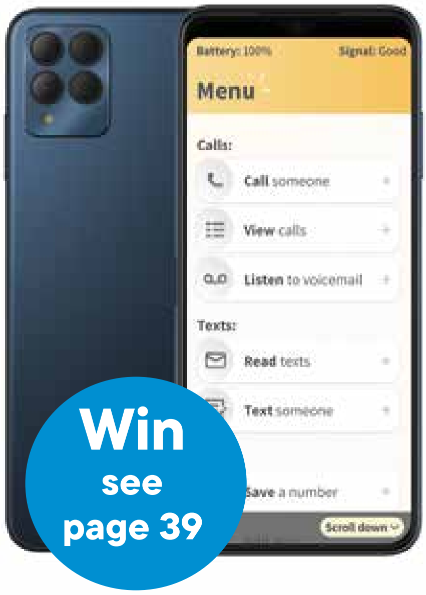
Chatsie

The Chatsie smartphone is designed to be quick to set up and intuitive to use.

Its screen uses a larger text size than any other smartphone. Its menus also have a bit more explanation, for example 'Call someone' instead of just 'Call'.

But its remote support really sets it apart. If you need help with the phone, you can send a code to a trusted friend or family member, which they can use to access your phone's settings through a website. There's also a free support line.

Neil liked Chatsie's simple and clear menus.



Win see page 39

> **“It's all about familiarity, isn't it? And it's annoying if you can't learn it easily.”**

'I like that,' agreed Terry. 'It's a useful phone.'

Mervin thought it felt on the heavy side, though most of the group found its weight fine.

Terry said, 'I really like that you can dictate a message and it will send it as a text.'

Neil was pleased it can also send voice messages. It comes with a stylus pen as well, which some people would prefer to use on its touchscreen.

While most phones don't come with written instructions nowadays, Chatsie has a booklet with clear pictures to help explain how to use it.

The group liked how clear and straightforward the instructions were, though Howard said he'd still struggle with them. Mervin added that he'd prefer it if someone read them out to him.

Chatsie costs £249.17 with VAT relief, which Terry thought is good value.

Jim said, 'It sounds expensive, but all phones are now, aren't they?'

Doro Leva X10

The Doro Leva X10 mobile phone only gives its user the most straightforward options to deal with in that moment. Anything more complex can be selected while it's being set up.

It has a clear display with only minimal buttons – it doesn't even have a number keypad. Instead there are four large speed-dial buttons, and you can write the names of who they've been programmed to call beside them. The buttons are raised so you can feel them easily.

Depending on what best suits the person using it, the phone can be set up to only call the four speed-dial numbers.

Alternatively, you can programme in many more contacts, which can be selected and called by scrolling through a menu.

Terry, asking about scam calls, was glad to hear that you can also block all 0800 and 0300 numbers on the Doro Leva X10. Of course, many of these numbers are not scams!

The phone has an SOS button on its back. You can press and hold this to call and message up to three nominated 'helpers'. As well as asking for help, these messages can also share your location with them.

At any other time, these nominated 'helpers' can also request your location to be shared with them by texting the phone with a code.

Although Paul liked the idea of a simple phone, he suggested you could also change the settings on your existing smartphone to make it much simpler to use.

The difference with the Doro Leva X10 is that it has very simple menus and there are fewer steps to do anything. It's also harder to accidentally change settings or get lost among too many options.

Like Chatsie, this Doro phone comes with written instructions. Many group members found them less simple to use – Jim said they were wordy for him, and John thought the text was small.

'I prefer visual aids,' added Terry.

Mervin thought that both the Doro phone and Chatsie seemed to be well made.

At a price of £124.99 with VAT relief, the group said they would recommend the Doro Leva X10 for people who'd benefit from its simplicity.

Although Howard hadn't at first thought a simpler phone could help him, he was impressed by the idea of only having four clearly labelled speed-dial buttons.

'That would be helpful,' he said. 'It could have my daughter's name and three grandsons. I'm a bit more interested now...'

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

- Chatsie mobile phone – white (new model) – £299.00 or £249.17 with VAT relief.
- Doro Leva X10 mobile phone – £149.99 or £124.99 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 our Using technology to help with everyday life (437) factsheet, see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Life turned upside down

Terry Byrne wants a lot more support for carers, many of whom are at breaking point. He tells Heather Stephen how his wife's dementia has affected their life together.

Terry Byrne was working part time as a fitness instructor when he met the love of his life across a crowded exercise hall.

'I was going through a separation and Jen had lost her husband six months before,' says Terry, from Christchurch in Dorset.

'She used to come to my classes, and we got to know each other. Eventually we started seeing each other. We just hit it off, and gradually sadness turned to happiness.'

As Terry, now 70, had a highly paid management role, the couple had a good life – going out for dinner every Friday and holidaying three times a year.

'I loved going to the Caribbean, and persuaded Jen to give it a go. She was quite nervous about going as she'd never been so far from home,' he says.

'The first time she headed out there she loved it and after that we went every year. We also holidayed in Malta and Portugal.

'We had a full life together. Jen was the love of my life and every moment we were devoted to each other.

'Jen was very special. She was a redhead and quite fiery. She didn't suffer fools but was a lot of fun and I loved her to bits. I still do.'

Things not right

The couple married in 2015 and, just three years later, Terry began to notice changes.

'She was a dog groomer and started forgetting appointments. I knew things weren't right and the clincher came when she locked herself out of the house with the dogs in the rain.'

Quick read

Terry Byrne's life was turned upside down when his wife Jen was diagnosed with dementia.

Terry, in Dorset, had to give up his well-paid job, and felt guilty when Jen moved into care later on.

He says there's not enough financial support and that people's fear and ignorance can leave you isolated.

Terry wants better public awareness, and for the state to address social care and give carers a fair deal.

> **I know we are coming to the end of our journey and I know I will struggle when she's gone as 90% of my life will disappear.**

After test results at the memory clinic, Jen was referred to a specialist who told her she had Alzheimer's.

'He was quite brutal about it,' says Terry. 'We went into denial but things went downhill from then on.'

Within a few months Terry realised he would have to give up his job as a regional sales manager, as it wasn't safe to leave Jen alone. But the couple were unprepared for the impact on their finances.

'My income reduced by a massive amount overnight,' he says. 'I was under retirement age so all we had to live on was £67 a week carers allowance, attendance allowance and two tiny pensions.

'Luckily I had my severance pay, but it didn't take long before it ran out. The social care system is a total disgrace.

'To get attendance allowance you have to fill out a multipage complicated form. Luckily I was able to complete it, but my advice to any carer applying is to get help, talk to the Society or agencies such as Age UK.

'The system makes you run through barbed wire to get anything but it just does not give enough.'

Permanent damage

After a series of mini strokes left Jen with reduced peripheral vision, she was also diagnosed with vascular dementia. This had a significant impact on her dementia symptoms.

Terry describes caring as a '24/7 job'.

'People don't realise what it's like until they've done it. You don't sleep, it is seven days a week and it is relentless.

'As time went on, Jen started to show aggressive behaviour. She trashed the bedroom and threw a stool and bottles at me. She would do the toilet on the coffee table and wanted to be with me all the time.

'Putting her to bed and her sleeping would give me some respite. But, as she had no concept of time or when it was in the day, she would often get up, then I would turn around and she would be standing there.'

Terry says he tried to carry on going on holiday, but it was so stressful they had to stop.

'We went abroad for the last time eight years ago, but I spent the whole time terrified about losing her and what would happen if something happened to me. Jen could not cope alone.

'I bought a camper van and thought we could go on holiday here instead. But it became more and more difficult, she was unable to be left while I did necessary tasks and was incapable of helping. I had no choice, I had to sell it.'

Physical impact

Terry says people often don't realise that dementia has a physical impact.

He says Jen's body was starting to shut down. She put on a lot of weight, as she would forget that she'd already eaten. Over the years she has lost control of her legs, she cannot feed herself and she is incontinent.

'One of the hardest things about caring is the loneliness,' he says. 'Lots of friends and family disappeared off the face of the earth. People are frightened.'

What helped in the early days was being able to drop Jen off at a day care centre two or three times a week.

This carried on during Covid, as respite workers came to the house and meant that Terry could have a few hours to go running and decompress.

He says the Alzheimer's Society dementia adviser was fantastic in the beginning, and a great source of information.

He adds that the support worker from the community mental health team (CMHT) was a 'lifesaver'.

'She cared for me as much as she did Jen. I don't know what I would have done without her. I would recommend getting in touch with your CMHT as early as possible after diagnosis.'

On her advice, Terry requested a meeting to decide if moving into a care home would be in Jen's – and his – best interest.

He desperately wanted to carry on caring for her at home but it was becoming too much – especially when lockdown meant there were no face-to-face visits.

'Those extra six months I kept her at home were the worst of my life. One day I remember I ran to the window and screamed, "I can't do this anymore!"'

Feelings of guilt

When Jen finally went into the home in 2021, Terry struggled with feelings of guilt.

When she became more aggressive, she was 'sectioned' and, after six months in a specialist dementia hospital, she was transferred to a specialist nursing home.

Terry says being 'sectioned' was a blessing, as it meant that specialists sorted out her medication and her nursing care was fully funded.

Although Jen hasn't recognised Terry for the last two years, he still visits every day.

'She is non-verbal, doubly incontinent and has lost the use of her legs, but I still love her,' he says.

'I know we are coming to the end of our journey and I know I will struggle when she's gone as 90% of my life will disappear.'

Although Terry has lost many of his friends from the past he has made new ones – fellow carers who understand – and he keeps sane through running.

'I did 14 marathons when I was younger. I had a catastrophic injury and couldn't run for four years but now I'm back and it is the only thing which clears my mind.'

When Jen went into the home Terry was able to go back to work but wanted something more flexible. So he trained as a care assistant at a centre for people with learning disabilities.

Ultimately the role didn't allow him to visit Jen as much as he liked but he says, 'I loved it. It was the best year of my working life.'

Breathe again

To better support Jen, Terry studied and read as much as he could about dementia. He put his knowledge to good use as an Alzheimer's Society Companion Call volunteer, making weekly calls to people going through a similar experience.

Every five or six weeks, Terry takes a break from visits.

'Originally I felt so guilty not going, but I realised I needed it and I could breathe again,' he says.

When Jen was newly diagnosed, the couple drew up lasting powers of attorney and redrafted their wills.

'You should arrange these when your partner still has "competence".'

Terry says stigma and lack of understanding can cause carers to withdraw. But he says the more people talk about dementia, the easier it will be.

He wrote poetry about the challenges of being a carer as an outlet, urging others, 'Don't be a shrinking violet. People hide from dementia, but it is important to share with the world so people can realise exactly what it's like.'

> **"I did 14 marathons when I was younger. I had a catastrophic injury and couldn't run for four years but now I'm back and it is the only thing which clears my mind."**

He says, 'Use dementia cafés and look into day centres, but most of all don't be ashamed – ask for help.

'Asking for help is a real strength – do it. Talk to other people caring for someone with dementia. We understand, you only do that when you've lived it.

'There is life during and after dementia.'

For our booklet Caring for a person with dementia: A practical guide (600) and factsheet Carers – looking after yourself (523) see **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Support line

Call our Dementia Support Line on **0333 150 3456** for personalised advice.

? Ask an expert

‘My sister has dementia and is hoarding things – she never wants to throw anything away. What can I do to help her?’

Hoarding

FreeImages.com/datarec

There are different reasons why a person with dementia might hoard things. It could be one of many obsessive or compulsive things that they do, or it may happen on its own.

If it’s possible to figure out what needs or feelings lie behind your sister’s hoarding, you may be able to work out ways to help her.

In or out of sight

Having lots of clutter about or hiding things in unusual places can look like hoarding.

Is your sister keeping things where she can see and find them easily? This might be to help her deal with her dementia symptoms. Could she use see-through storage boxes or cupboard doors instead?

Some people become paranoid or suspicious because of their dementia. They may want things out of drawers and cupboards so they can see and keep track of them. Or they might keep them hidden away so nobody else can get to them. In these situations, it could help to reassure them that their things are safe.

Less plentiful times

Sometimes, people with dementia believe they’re back in an earlier time of their life. This is known as ‘time-shifting’.

Does your sister think she’s in a time when there weren’t enough necessities? That might mean she doesn’t want to throw things away, even if it’s out-of-date food.

If so, gently remind her that she has enough at home. Would she agree to you arranging regular deliveries of online shopping? Or could someone go shopping with her to remind her what she has already?

Fixations

Some people with dementia can fixate on certain items. This may mean they buy the same things over and over again, or visit the same websites to make the same purchases.

If there’s an underlying need behind the fixation, finding other ways to address this need can help.

If your sister fixates on items that comfort her, could you help her to feel comfortable in other ways? This could be about physical or emotional comfort.

If she’s hoarding games or activities, can you help her to feel more stimulated throughout the day?

Control and habit

For some, hoarding objects can be a way to feel they’re keeping some control over their life. If this is the case, gently reassuring your sister might help.

If she appears to be depressed or anxious, speak to the GP about counselling or therapy.

Remember that hoarding might simply be something a person has always done. If your sister is continuing a habit from before, are there things that helped her with it in the past? You might need to adapt these to take her dementia symptoms into account.

Keeping safe

Sometimes, hoarding can put a person’s safety or wellbeing at risk.

For example, if your sister can no longer wash her hands because the sink is full of items. Or if she cannot get into her kitchen or toilet.

If that’s the case, then it’s important to speak to the GP or social services as soon as you can.

For our Changes in behaviour (525) factsheet, visit **alzheimers.org.uk/PublicationsTogether** or call **0300 303 5933**.

Readers share advice for other carers about dealing with sleep problems that they, the person with dementia or both are having.

Sleeping difficulties

'If I am tossing and turning for a long time I get up and go downstairs, usually with the dog following. I make myself a cup of cocoa and cuddle the dog for 10 or 20 minutes and relax and then go back to bed. I usually manage to go to sleep fairly quickly then.' **Signora C**

'Have exactly the same routine each evening. For example: evening meal, one hour TV, bath, chamomile tea or hot milky drink (not caffeine or alcohol), read or listen to music in bed.

'Use audio books or an app to support sleep, there are lots to choose. The body gets used to routine. If you only get 4 hours and want to build up, adjust timings by half hour each fortnight.' **KarenW26**

'When my father wakes in the night he likes to know what time it is. But he has started to not always be able to make sense of the clock face, or of what the time means even if he can read it correctly.

'Once he became uncertain of the time he would have a disrupted night, sometimes getting up and dressed because he thought it might be time for breakfast, and sometimes worried he would miss the alarm and put all his morning routine out.

'He has an iPhone, so I suggested he ask Siri to tell him the time. This helped a bit, but Siri doesn't say whether it's am or pm, and as he goes to bed very early, and often nods off in his chair at any time of the day, fathoming whether it's evening or early morning did seem to be fazing him.

'I got him a push-button speaking clock which does say "am" or "pm", and that has helped a lot. But he was still getting in a muddle with the words and making them agree with the visuals on his clock, watch and iPhone.

'A chance comment and I realised that not all his timepieces were using the same format. So out with the analogue watch, and set all the digital devices to 12-hour clock.

'After a long chat with the doc, we did also increase his evening melatonin, and between those three things – time formats all the same, push-button speaking clock and a bit more sleep hormone, his sleep has improved considerably.' **switchy**

'Dad would get up in the night 3 or 4 times, get fully dressed having never looked at his watch or fancy clock.

'Initially, I just wanted to cut out the getting dressed undressed part.

'The fix was, I put him to bed at night and told him I would take care of his daytime clothes, "So, if you wake up and your clothes aren't there, it's still nighttime and you go back to sleep."

'It's taken his lack of time recognition out of the equation and seems to be taken as a more solid and obvious prompt to go back to bed. Will see how long that works.' **GlennGlenn**

'If I can't sleep I "enjoy" it. Accept it, turn light on – it's my time. Read, write, watch TV even if it's 2am.

'Instead of lying in the dark and worrying, I do something for me. At least the next day I feel I have had my life back – a tiny bit of freedom.

'Routine for sleep and meals has been our saviour. Always letting the daylight in, blinds down once dark. Bed always at 10pm.

'This disease is so unpredictable, things change and different behaviours occur. One set of problems turn into a different set. There is no answer.

'You need patience and realisation that they can't control any of it. It's not done to anger me. It's uncontrollable. It's a rollercoaster. Whatever works for you both do it.' **KathyC**

Next time

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

Noticeboard

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

Letters:

Great interest

I thought I'd share pictures of my mum Florestine on Bank Holiday Monday, who has Alzheimer's, reading with great interest our Alzheimer's Society Dementia together magazine.

She was deeply engrossed and throughout would point out what was being said in an article or section.

Thank you for making the magazine an interesting read for her as well as for me.
Valerie Hunkins, West Yorkshire

Thank you so much for sharing this, it brought such a warm glow to everyone in the team and we hope it does for other readers too!

This is the impact we're confident you'll continue to feel when reading Society magazine from January onwards (see page 6).

As well as the inspiring stories and ideas you'll be getting in Society magazine, see page 38 for other ideas about keeping in touch with us and other people affected by dementia.

Wheelchair travel

I noticed a contribution in the last edition of Dementia together that a couple was unable to travel because of having to use wheelchairs and hoist. I know of a couple of holiday companies that provide care for these kind of difficulties.

The first, with which I have firsthand experience with my husband is Limitless Travel (**limitlesstravel.org**, **0800 711 7112**). This company was absolutely fantastic, caring not just for my husband but also for me. Fortunately I'm fit and healthy, but the carers made sure that I got a rest each day and were constantly on hand to help. The carers were a delightful and caring group of people.

The other company is Dementia Adventure (**dementiaadventure.org**, **01245 237548**). I only have glowing reports from friends with partners with dementia about this.
Helen


Darren Kidd, Presseye Belfast, Big Mountain Productions BBC

Caring Matters

From 23–30 May, Caring Matters shone a light on the experiences of unpaid carers in content across BBC channels – catch up on programmes on iPlayer and Sounds.

At the heart of the week, a new series began in which Natalie Cassidy – best known for playing Sonia Fowler on EastEnders – fulfils her longstanding ambition to train as a carer. Over eight episodes, Natalie Cassidy: Caring Together follows the actor as she enrols at one of the UK's top health and social care colleges.

TV show Morning Live supported Caring Matters with practical advice throughout the week, emphasising the need for carers to look after themselves and where to get help.

There were also special episodes of Songs of Praise, Bargain Hunt and Asian Network Trending, and caring storylines on EastEnders and The Archers.

Thabrez Khan from our Time for Dementia team, which helps prepare future healthcare professionals to better understand dementia, took part in filming a video for the BBC's social media channels. He talked about his personal experience and tips for caring for a person with dementia.

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 6 July for the August/September issue (wording may be edited).

Wales memories app updated

New objects and stories have been added to a bilingual app, drawing on museum collections and community work to support even more people affected by dementia in Wales.

The app, called My House of Memories, now has more content for people from a range of communities. You can browse objects and save favourites, as well as add your own images.

Lizzie Ward, Programme Manager, said, 'We have added relevant material reflecting the global majority and other underrepresented communities in Wales, to allow more people to connect through stories that mean something to them.

'We have already added some amazing stories from within the LGBTQ+ community through our work with museums across Wales and England, so now we're excited to highlight objects from even more communities in Wales that have been collected by the people who have lived those memories themselves.

'We hope these new additions to the app will continue making an impact through generating conversation and making genuine conversations and connections between people living with dementia and their loved ones.'

My House of Memories app was created by National Museums Liverpool's House of Memories programme. Bilingual content for people in Wales has been developed with Welsh Government funding.

Find out more at liverpoolmuseums.org.uk/my-house-of-memories-app

Free Dementia Community webinars

Dementia Community hosts free webinars on subjects of interest to people affected by dementia as well as to care professionals.

You can register to join the webinars live on Zoom, 2–3pm every few weeks, or you can watch past recordings.

The webinar on 8 June is called Distressed Behaviour isn't Random: From Firefighting to Foresight. Behavioural analysts from smart tech company emwillcare will share insights and answer questions about understanding and reducing distressed behaviour in people with dementia.

The 22 June webinar will be Creative Dementia: 'Arts gave me a voice', with David Truswell offering fresh thinking about creativity and service design, and Ronald Amanze, a music producer living with dementia. Maria Pasiecznik Parsons and Richard Coaten will bring a wider view of the health and wellbeing benefits of arts.

Recent webinars have included Association for Dementia Studies researchers talking about resources to support family carers, Sporting Memories on the impact of their activities, and dementia nurse consultant Zena Aldridge challenging misconceptions about dementia diagnosis.

Dementia Community is a membership cooperative that also produces the Journal of Dementia Care and UK Dementia Congress.

Find out more about Dementia Community webinars at journalofdementiacare.co.uk/webinars

Deadheaded: mother and son memoir

A new book weaves two accounts, told years apart and across generations, into one 'honest, raw and unexpectedly funny' memoir about Alzheimer's.

Deadheaded alternates between Valerie Bingham's writing while caring for her husband, and her son Miles's reflections after losing both parents to Alzheimer's.

Miles, who has run two marathons for the Society, says, 'My mother had written honestly and bravely about my father's decline, but she began her own journey with Alzheimer's in a cruel symmetry neither of us could have imagined.

'Her memoir captured one half of the story; the other half was still waiting to be told.

'And then there was the final, extraordinary fact: both of my parents donated their brains to medical research – a generous, quietly radical decision.

'Their final act made me realise that their story wasn't just personal; it had a wider purpose. It deserved to be understood, shared, extended.'

Deadheaded is available in paperback and as an ebook – find out more at **deadheaded.co.uk** or ask your local bookstore (ISBN 9781917970136).

Ways to stay in touch

How can you keep in contact with Alzheimer's Society and with other people affected by dementia?

Many people can feel isolated after a dementia diagnosis. Whether it's you who has dementia or someone you're supporting, it's important to know that you're not alone.

If you're dealing with dementia in your day-to-day life, Alzheimer's Society is here for you.

Companionship service

When dementia changes your life, a friendly chat with someone who cares can be everything.

Our Companionship programme is run by trained volunteers, who can give you emotional support and connect you with other help.

At the heart of the service are Companionship calls, where you'll be paired with one of our friendly volunteers for weekly phone conversations over a 12-month period.

These calls can give you a safe and relaxed space to share whatever's on your mind, and feel heard by someone who understands what you're going through.

Beyond phone calls, Companionship can also introduce you to useful online groups, encourage you to take part in discussions on our Dementia Support Forum, and bring you together with other people facing similar challenges, so you can build confidence together.

Through all the ways it connects people, Companionship provides comfort and community. If you're feeling isolated or are struggling to cope, sign yourself up for Companionship at **alzheimers.org.uk/companion-calls** or by calling the Dementia Support Line on **0333 150 3456**.

Dementia Support Forum

Our Dementia Support Forum is a helpful online community where anyone who is affected by dementia can receive valuable support. It's free, and it's open day or night.

The forum is a welcoming, supportive place where people ask for advice, read about each other's experiences, offload concerns and share helpful information.

To have a look around the forum and take part, visit **forum.alzheimers.org.uk**

Find groups near you

Are there activity groups or social groups for people with dementia and carers near you? These can be a good way to meet and catch up with people who understand the everyday realities of dementia.

Use our dementia directory to find local groups – and other support – in England, Wales and Northern Ireland. See **alzheimers.org.uk/dementiadirectory**

You could also call our Dementia Support Line on **0333 150 3456** to help find groups and services in your area.

Regular support email

Sign up for the Society's news and support email for helpful and interesting updates twice a month. These include the latest dementia advice, resources, real stories and more.

Visit **alzheimers.org.uk** and scroll down towards the bottom of the page, where you can sign up by entering your email and name.

Information and advice

Call our Dementia Support Line on **0333 150 3456** to speak to a dementia adviser. They can offer practical advice and emotional support, and they could connect you to other sources of help.

For information about dementia and advice for people affected by the condition, see **alzheimers.org.uk**

You can order and download our booklets, factsheets and helpful tools by visiting **alzheimers.org.uk/PublicationsTogether** or by calling **0300 303 5933**.

Competitions

Chatsie smartphone

We have a Chatsie smartphone (see pages 28–29) for one lucky winner drawn from correct entries.

Q: What can a trusted friend or family member do with the code you send them with your Chatsie smartphone?

A. They can use it to decode any jargon that they hear from politicians.

B. If they call a secret number and whisper the code into the phone, they will become a spy.

C. They can use the code to access your phone's settings through a website.

Forget-me-not socks

We have a pair of our new Forget-me-not socks for three winners drawn from correct entries.

Q: How many petals are there on the forget-me-not used in Alzheimer's Society branded products?

A. There's only one petal – the rest have been pulled off.

B. There are five petals on each flower.

C. There are either 11, 23 or 59 petals, depending on what product the flower is on.

Send us your competition answers with your name and address by end of 5 July – email **magazine@alzheimers.org.uk** or write to the address on page 2.

April/May winners and answers

Curiosity Box and Fiddle books

S Smith in Berkshire won a Curiosity Box, while J Miles in Essex and D Marsh in Lancashire each won a Fiddle book. Answer: Objects in the Curiosity Box for you to explore and use include a large wooden dice, a spinning top and picture cards.

Forget-me-not canvas shopper

E Gill in Northamptonshire, P Ayres and E Turner in Hertfordshire, H Liversedge in Merseyside and S Crawford in County Tyrone each won a Forget-me-not canvas shopper. Answer: Three items that have famously been made from canvas include tents, sails and surfaces for oil paintings.

Book giveaway

S Thomas in Essex, J Gaskell in South Yorkshire, S Thomas in Tyne and Wear, A Ingold in West Midland and B McMurdo in Berwickshire each won a copy of Still Me, by Sabina Brennan.

Anagramword

Across: Canterbury, Belfast, Roman Baths, Glastonbury, Edinburgh Castle, Caernarfon, Vindolanda, Stonehenge.

Down: Wroxeter, Tower of London, Hampton Court, Battle, Lindisfarne.

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.

Alzheimer's Society

Memory Walk

A walk, a community, a day to remember.

Join one of 12 Memory Walks across the UK this Autumn or organise your own in a place that's meaningful to you.

We'll support you every step of the way.

Sign up to your local walk at
alzheimers.org.uk/MemoryWalkTogether