

August/September 2026

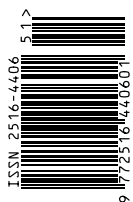
# Dementia together



Alzheimer's  
Society

## In this issue

The best we can do,  
Companionship service,  
stark reality and  
much more



**Final issue**  
See pages 36–37

# Welcome



## **W**elcome to the final issue of **Dementia together** magazine.

If you get the magazine by post, you'll receive **Society** magazine twice a year from January instead. I'll be handing the baton over to Kelly Fisher, and you can hear from her about what to expect from **Society** magazine on page 38.

On pages 36–37 there are more details about the change, and about various ways to keep in touch with other people affected by dementia and with us.

For my part, it's been an absolute honour to edit this magazine and its predecessor, **Living with dementia**, for the last 15 years. The world has changed immensely since the late and deeply respected Rachael Doeg handed me the reins, and the magazine's development has continued to reflect this.

A massive thank you to the great many generous and passionate people who've shared their stories, perspectives and ideas with us. Working with panels of people affected by dementia on two co-produced special issues has been a standout privilege and joy.

Thanks also to everyone who has written, edited and helped in other ways to make each issue a reality – particularly our longtime designer Andrew Harrison.

And of course, thank you to all our readers, including you. Wherever you are in your experience of dementia and your connection to Alzheimer's Society, please know: you are not alone.

**Danny Ratnaike, Editor**



**Need support? Call 0333 150 3456  
or visit [alzheimers.org.uk/getsupport](https://alzheimers.org.uk/getsupport)**



## Donate

Scan this QR code using your mobile phone.

**Donate online** or call **0330 333 0804**.

Fundraising and general enquiries 0330 333 0804.

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

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## Directions

**I**t was profoundly moving to watch the documentary about former Channel 4 journalist Jon Snow coming to terms with his dementia diagnosis.

Jon Snow: A Last Big Story, created in partnership with Alzheimer's Society, shows the realities of this new normal for Jon and his wife Precious.

One of the most striking things I noticed was the difference that an early diagnosis made for Jon. His diagnosis unlocked care, support and access to a clinical trial.

This is not the case for so many people living with dementia.

It can take years for someone to receive a diagnosis. Meanwhile, they are unable to get support and treatment early on, when it can make a real difference to someone's quality of life.

I'm clear that our role at Alzheimer's Society is to work towards a better future in which everyone has access to an early and accurate diagnosis, and new treatments as they become available. For those receiving care, it must be delivered by a workforce skilled in high-quality dementia care.

Dementia has never been treated with the same urgency as other major conditions. To beat the devastation of dementia, dementia must become a government priority, and we have refined our Help and Hope strategy with that goal in mind.

During June, many of you will have worn your Forget Me Not badge and soon many will take part in a Memory Walk. Whether you take part in remembrance or in hope, your participation is a visible reminder that it will take a society to beat dementia. Thank you for your incredible support.

**Michelle Dyson, Chief Executive**

# News

## Unlocking progress

We've published two new reports about the barriers people face getting a dementia diagnosis and accessing recommended treatment – and the reforms needed to bring about change.

Our Unlocking the Door reports underline how people routinely wait too long for a dementia diagnosis. People also receive less recommended treatment and support than clinical guidance says they should.

In the reports, we highlight what changes are necessary to drive improvement and the steps needed to achieve them. These include clear diagnosis targets, investing in and supporting the dementia workforce, and building health systems ready for innovation.

Michelle Dyson, our CEO, says, 'Dementia care in the UK is stuck in a system of delay, denial and neglect. In the digital age of instant answers, people are still waiting far too long for a diagnosis of the country's biggest killer.'

'That would never be tolerated in cancer care, yet for dementia it has become routine.'

## Forget Me Not success

Thanks to everyone who donated, wore badges and supported our Forget Me Not Appeal in June. So far, we've raised £1.5 million and counting.

There were so many highlights during the month, from a Forget Me Not display on the iconic Piccadilly Lights in central London, to touching support from our celebrity supporters and ambassadors. There were also discussions of dementia on high-profile TV shows including Loose Women and This Morning.

But beyond these public moments were thousands of acts of quiet generosity and tenacity from our tireless volunteers and supporters. We couldn't have done it without you!



# Trek26: You did it!

A huge thank you to our amazing trekkers in this year's Trek26.

This summer, over 18,000 incredible people laced up their hiking boots and trekked 13 or 26 miles in 13 stunning locations across the UK. They faced pouring rain and intense heat with enthusiasm and a shared determination to beat dementia.

Inspired to join in next year? Visit [alzheimers.org.uk/Trek26Together](http://alzheimers.org.uk/Trek26Together) or call **0300 222 5808**.



## Parliamentary walking football

Amid World Cup fever, we organised a unique football match at Westminster to launch a new dementia report.

We fielded a team of people affected by dementia against the UK Parliamentary Football Club in a walking football match, using the event to publicise our new World Café report. This makes recommendations to shape the Modern Service Framework for Dementia and Frailty – a critical opportunity to transform dementia care.

The report is based on a workshop we held for policymakers and people affected by dementia.

## Wales: you have spoken

Results from our survey of over 1,000 people in Wales show the strong case for the devolved government to make dementia a priority.

Around 9 in 10 people (88%) told us that the Welsh government needs to do more to help people living with dementia.

Over 8 in 10 (83%) think it should make dementia a national healthcare priority, and over two-thirds (69%) think dementia is overlooked or underfunded compared to other chronic conditions.

## New NI booklet

The Belfast Health and Social Care Trust has launched a new Dementia Information Booklet, co-produced with people living with dementia, carers, Alzheimer's Society and Dementia NI.

Designed to support people living with dementia and those caring for them, it's packed with information on local services, as well as practical advice.

It is shaped by real experiences and informed by our campaigners' work to improve support. We're thrilled that it will be rolled out across all health and social care trusts in Northern Ireland.

Join us as a campaigner and help to create change for people living with dementia – please visit [alzheimers.org.uk/campaign](http://alzheimers.org.uk/campaign)

## ‘Brain hearing’ test hope



A new study led by researchers at the UCL Queen Square Institute of Neurology in London has developed a ‘brain hearing’ test. Rather than measuring how well the ears detect sound, it looks at how the brain processes it.

Participants listened to different sounds played into each ear at the same time – such as thunder in one ear and pouring water in the other – before choosing matching images on a sheet in front of them.

The study found that people living with most forms of dementia found it harder to get the test right than other volunteers. This suggests it could one day help to diagnose dementia.

Crucially, the test does not rely on words or language. Using everyday sounds and images instead, it’s a more inclusive way to assess how the brain is functioning. It could help clinicians to identify dementia earlier, while also improving the experience of diagnosis for people from different cultural and language backgrounds.

Michelle Dyson, our CEO says, ‘Now the first treatments that can slow Alzheimer’s disease are emerging, early and accurate diagnosis has never been more important.’

‘With further research in larger, more diverse populations, a simple, accessible test like this could be used by clinicians in the future to support a diagnosis alongside other cognitive tests and clinical observations.’

While more research is needed before this test could be used in clinics, the findings offer exciting hope for a future of more accurate diagnosis for people in all our communities.

Visit [alzheimers.org.uk/research](https://alzheimers.org.uk/research) to find out more about dementia research and how to get involved.

## Jon Snow’s diagnosis

Legendary news host Jon Snow and his wife Precious opened up about his dementia diagnosis in a new documentary, created for Channel 4 in association with Alzheimer’s Society.

In *Jon Snow: A Last Big Story*, Jon comes out of retirement to expose an unreported mining disaster in Zambia while navigating life with Alzheimer’s.

Following Jon’s diagnosis announcement and the premiere of the documentary on TV, we saw a sharp rise in website visits and views of our dementia symptoms checklist, a tool to help people discuss concerns with a GP.

Our CEO Michelle Dyson says, ‘Jon’s decision to talk publicly about his dementia diagnosis is a real act of courage and his story will resonate with so many.’

You can stream *Jon Snow: A Last Big Story* now on [channel4.com](https://www.channel4.com)

## FA partnership: extra time

We’re excited to announce that our partnership with the Football Association has been extended to run until the end of the 2027–28 season.

Since the partnership started in 2021, it has raised £1.6 million for our research and support services. It has also increased public understanding of dementia through four Alzheimer’s Society international fixtures and led to dementia-friendly changes at Wembley Stadium.

To celebrate the extension, England’s men’s and women’s senior head coaches, Thomas Tuchel and Sarina Wiegman, proudly wore Forget Me Not badges.

We can’t wait to see what we can achieve together in the next two years!

## An incredible Omaze million

Our recent Omaze Million Pound House Draw campaign generated an incredible £1 million donation for Alzheimer’s Society.

It’s part of our five-year partnership with Omaze that’s worth £4.5 million, which will help thousands more people access our dementia advisers and support our three doctoral training centres.

Featuring celebrity ambassadors alongside people affected by dementia, the campaign helped raise awareness of dementia on a huge scale, reaching an estimated 44 million people.

## Volunteer at Memory Walk



If you’re looking for an inspiring way to support us, volunteering at one of our Memory Walk events is a truly unique experience.

Whether they’re marshalling routes or helping at event sites, our volunteers are the backbone of Memory Walk.

It takes over 800 volunteers to help run our 12 events across the UK, clapping and cheering over 16,500 supporters as they walk to fight dementia.

Want to join them? To find your local Memory Walk and sign up as a volunteer visit [alzheimers.org.uk/MemoryWalkTogether](https://alzheimers.org.uk/MemoryWalkTogether) or call **0300 222 5808**.

## New: Shop by need

A new function on our online shop makes it even easier to find the dementia-friendly products you need to help deal with common challenges.

Simply click on 'Shop by need' on the Alzheimer's Society shop website to filter products that help with everything from hydration to walking safety and getting dressed.

Visit [alzheimers.org.uk/ShopTogether](https://alzheimers.org.uk/ShopTogether)

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## Bestway Healthcare

We're delighted to announce a new partnership with Bestway Healthcare, which operates over 650 Well Pharmacy branches across the UK.

It's an exciting opportunity to raise awareness and vital funds to fight dementia. It will also explore how community pharmacies can better support people affected by dementia.

Alongside new opportunities to connect people affected by dementia with trusted advice, information and support, we plan to offer Dementia Friends training to pharmacy staff and encourage them to fundraise and volunteer.

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## King's Honours

Congratulations to our Patron, Professor Carol Brayne, CBE who has been recognised in this year's King's Birthday Honours list.

Carol will receive a Damehood for services to medicine, medical research and public health.

Based at the University of Cambridge, Carol is a pioneering researcher, who has led several large, long-term research studies on dementia. She was also Co-Chair of the Alzheimer's Society's Research Advisory Committee until 2022.

## Join us at conference!

There's still time to join the Alzheimer's Society Annual Conference 2026 on 17 September, either online or in person at Convene in Bishopsgate, London.

Breakthroughs in research, new treatments and major changes across health and social care are creating opportunities for real change. We're all looking forward to exploring how this energy can be channelled into transforming diagnosis, treatment, care and support for everyone affected by dementia.

As well as health and social care leaders, policymakers, researchers and campaigners, the conference welcomes people affected by dementia and tickets are available to you at a reduced rate.

Visit [alzheimers.org.uk/annual-conference](https://alzheimers.org.uk/annual-conference) or call **0330 333 0804**.

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## Powering health service innovation

We're partnering with the NHS Innovation Accelerator programme to help speed up dementia innovation in the health service and ultimately improve lives.

The programme, a flagship NHS England initiative, supports innovators to scale their ideas for new devices, tools and ways to deliver care.

Through our partnership, we want to ensure that more dementia innovations progress from the drawing board to everyday use.

By supporting entrepreneurs to navigate NHS systems, it's a brilliant opportunity to address some of the biggest challenges in dementia, including diagnosis, treatment, care and independent living.



## More to listen to

Our final Dementia together magazine podcast will be out soon – listen at [alzheimers.org.uk/podcast](https://alzheimers.org.uk/podcast) or search 'Alzheimer's Society' to find and subscribe to us on your podcast app.

The June/July episode featured tireless dementia campaigner John Amos and August/September's will be available in early August.

We have new podcast ideas for the future, so make sure you're subscribed to hear about those!

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## Don't miss...

**Mary-Joy says dementia training for care staff is vital, but so much more is needed to improve care. See page 17.**

**For Julie, staying connected with people after her diagnosis has enabled her to make a difference for others. See page 18.**

**Our Companionship service offers contact and emotional support to people by phone and online. See page 22.**

**What is changing with the magazine, and how else can you keep in touch with us and other people? See page 36.**

**Kelly welcomes you to Society magazine, which our readers will receive twice a year from January. See page 38.**



## Quick read

**Annie Chinfen believes in making the most of the time you have to help both yourself and others.**

**Now 96, Annie was diagnosed with Alzheimer's nine years ago, following a scan after cancer treatment.**

**She is keen to share what she's learned from the many ups and downs of her long and eventful life.**

**Now living with her daughter in Essex, Annie keeps her brain and body as active as possible.**

# The best we can do

**Annie Chinfen, in Essex, trusts in helping yourself and helping others too. She tells Margaret Rooke about her long, eventful life and adapting to dementia.**

**S**he may be 96 and living with Alzheimer's, but Annie Chinfen remains clear about what she thinks is most important in life – to help yourself and to help others.

Annie learned these lessons during a long life, in a career as a nurse and time living with dementia.

She has survived a war and rioting. She was brought up with riches and had every penny taken away.

It has left her determined to make the most of life.

'I love to learn,' says Annie, 'and I'm still learning now.'

## War trauma

Annie was born in Hong Kong before the Second World War, to a rich family who owned department stores.

They had servants, gardeners, drivers and lived in luxury. It was common for wealthy men to have multiple wives, so Annie had many stepmothers and half-siblings.

Her carefree life was cut short when suddenly, at 10, Japan invaded Hong Kong.

'I looked out of my window saw a plane bombing the English ship in the harbour. My mother said, "Don't go to school. We stay here."

'We couldn't believe what was happening. It was frightening. I didn't know about life and death, and then my half-brother's girlfriend suddenly lost her whole family.

'If you passed a Japanese soldier and didn't bow, you were killed. Many others starved. People chopped down everything they could find for fuel. All English schools were shut, and a lot of English teachers and our headmistress were sent to prisoner of war camps.'

After the war, Annie and her brothers and sisters studied hard to catch up with the years they'd lost.

'I wanted to become a doctor because I had seen so much death. My dad believed girls should stay at home and marry someone rich. He said, "No."

'So I said, "Can I be a nurse?" He said that was a dirty job and he wouldn't talk to me, but my mum supported the idea and I went ahead.

'He was angry but eventually was proud of me. My parents both attended my graduation.'

## Hospital sister

Annie became a state registered nurse, passing general nursing and midwifery at the top of her class.

She was promoted quickly and became a sister, and a lecturer training other nurses.

'I learnt every minute. I watched the patients and saw when they recovered and when they died.

'I saw people refusing to get out of bed, even to sit in a chair. They thought, "You nurses must do everything, feed me, wash me. I'm not moving." I think that attitude shortened their lives, without them realising.

'I'm the opposite. I believe you must take care of yourself. Then you can get better – and take care of others too. When I trained nurses, I always told them that you treat the patient like your own children, parents or friends.'

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**I read every day, any book I like, especially if it's a storybook. With books, you try to imagine what the person is writing about.**

”

Annie's next move was to train nurses for the opening of Queen Elizabeth Hospital, one of the biggest in East Asia at that time. She was proud.

When Annie's father died, she found he had entrusted all his money and property to two of Annie's half-brothers and told them to care for the others. They announced they were going to use the money for themselves and moved everyone out of the family home.

Her mother had a heart attack nine months after her father's death. As she lay dying, Annie's mother asked her to look after her two younger brothers. Of course she agreed.

## 'Bus Stop Girl'

One day, Annie was introduced to Lloyd, a friend's brother, while waiting at a bus stop. Lloyd called her 'Bus Stop Girl' and knew instantly he wanted to marry her.

Annie told him she had to bring up her brothers. After this, she found she had a severe spine condition.

She didn't want to take advantage of Lloyd's kindness and said he needed to wait until her condition had improved.

Then there were riots in Hong Kong. 'I told him I'm not a selfish person who will leave injured people here suffering.'

Finally, she agreed to marry him and move to England to be with him.

She was 37 by this time, and women usually gave birth much younger in those days.

But at 41 she was thrilled to have her daughter, Rachel.

'I was so happy. My husband had a good job and he said I should give up work and become a full-time mother.

'I felt sorry for Rachel because I couldn't produce any more children, so I had an open house every Thursday afternoon, a tea party – any parent or child was welcome.'

## Loss and diagnosis

After 50 years of marriage, Annie's husband died before the Covid pandemic.

'I miss him very much,' she says. 'He loved classical music. I still listen and pretend he's by my side.'

She was facing other bad news too. After a bout of cancer, Annie had a brain scan to see if it had spread. It was then she found out, nine years ago, that she had Alzheimer's disease.

'I was shocked. I had been forgetting things, but I thought it was just old age.'

'I wondered how I would know how to look after myself. Then I thought, there's no need to be frightened. I started to research everything and try to understand it. I asked how I could help myself and use my knowledge to manage it.'

Annie was helped by Alzheimer's Society when her specialist introduced her to Singing for the Brain.

'It's so good. It means every week I have an activity and see people. I can't remember most of the words of the songs, but they give you the words on a sheet so I can sing along.'

'When we finish, we sit together and other people know I'm a nurse and ask me questions. I always tell them what I know.'

## Active as possible

Later Alzheimer's Society asked Annie if she could help student doctors and nurses learn about the realities of



living with dementia through the Time for Dementia programme.

'I talk about my experiences and how I deal with Alzheimer's myself.'

I tell them that I keep the brain as active as possible.

'I read every day, any book I like, especially if it's a storybook. With books, you try to imagine what the person is writing about. If you watch television your brain isn't forced to work in the same way.'

'I tell them I keep a diary by my side and write anything I want to remember. My short-term memory is bad. I live with my daughter, and she says where she's going, and the next minute I say, "Where are you going?"'

That's why I write everything down.'

Annie has found regular exercise to be important too.

'Before I get up and dressed, I lie flat and exercise. I use my hands to massage my scalp, head, neck, round my eyes, my shoulders, arms – my whole body. Then I sit up and do more exercises.'

## Fear and hope

Annie, who now lives with her daughter in Essex, worries about her mobility failing her, following a recent bad fall. She has other fears too.

'Deep down, I do worry that one day I won't recognise my dearest ones. I don't feel independent, but I still do as much as I can for myself,' she adds.

'I comb my hair and put my earrings in to make myself look nice, even if it takes me an hour.'

She also has advice for anyone communicating with a person who has dementia.

'I've noticed that if Rachel is talking to a friend, I can't follow the conversation. I need a clear voice talking to me, someone sitting down with me at the same level with eye-to-eye contact.'

Annie loves sharing her experiences and her knowledge.

'If I can help at any time, I always want to do that.'

'I have had an unusual life, and a long-living one,' she says. 'I'm still making the most of the time I'm here.'

'That's the best we can all do.'



“

I have had an unusual life, and a long-living one,  
I'm still making the most of the time I'm here.  
That's the best we can all do.

”



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](https://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 Annie to live as well as possible. **Donate online** or call **0330 333 0804**.

# Share and inspire

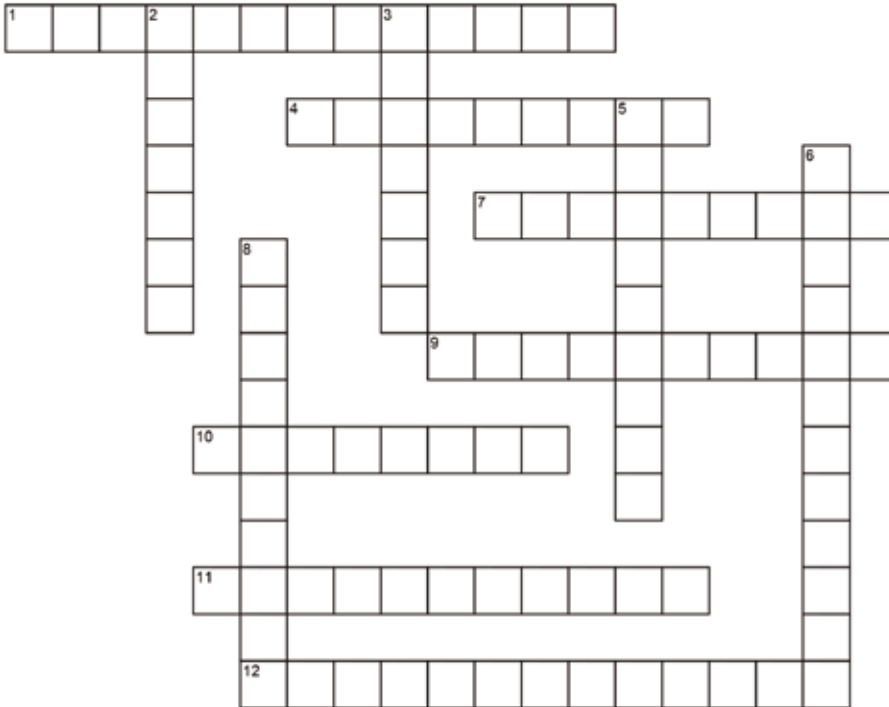
Views, updates and ideas – for and by you.

## Anagramword: Wellness

August is National Wellness Month, and Pete Middleton's latest puzzle features activities and habits that can help us to stay healthy, happy and well.

Each clue begins with words that are an anagram of the answer, along with a clue to its meaning. How many can you solve?

(see page 39 for the answers to this and last issue's puzzles)



### ACROSS

- 1 Daft crass rant that turns into a general term for creative pursuits (4,3,6)
- 4 A gay Choir will help keep you fit (5,4)
- 7 In hot yard, plenty of water will help with this (9)
- 9 Ruling Joan, only to discover a relaxing way to document your life journey (10)
- 10 Biro case repurposed as a form of exercise (8)
- 11 Sun ends film, but the result is personal enlightenment (11)
- 12 Wild king acorn becomes a method of hiking with poles (6,7)

### DOWN

- 2 Inns gig revolves around a fun vocal pursuit (7)
- 3 Raged in, but then engaged with this relaxing activity (7)
- 5 Ginger and made to engage in this rewarding hobby (9)
- 6 Grovel in tune to produce a useful, supportive activity that helps others (12)
- 8 Once trifle, but now a relaxing technique for examining oneself (10)



## Bright Times

People with dementia in east Kent are creating their own magazine called Bright Times, distributed locally and online.

The team of eight have been trained as journalists in a partnership between arts charity Bright Shadow and Kent and Medway Mental Health NHS Trust. By sharing their insights, interviews and pictures, they aim to shift how people living with dementia are viewed.

Reporter Gill Ashington said, 'Bright Times challenges so many of society's misconceptions about dementia.'

'It's different from anything else. It appreciates the value of peer support and the ability of people with dementia to learn new skills, giving us a voice. Instead of feeling finished or doomed, it offers hope and purpose.'

Fellow reporter Keith Oliver, also a Society Ambassador, adds, 'I and everyone involved are grateful to Bright Shadow for securing funding for this innovative project, and for providing us all with a platform to develop and showcase our creative skills as citizen journalists living with dementia.'

Introducing the latest issue, the team said, 'Bright Times is fuelled by the power of "yes".'

'But we have learned that life comes in "cans", and while a first encounter can seem daunting, it's always best to give things a go.'

Find out more about Bright Times and subscribe for free at [brightshadow.org.uk/bright-times](http://brightshadow.org.uk/bright-times)

# Never done before: Getting a degree

**S**ince his dementia and Parkinson's diagnoses, Ray Middleton, 69, in the West Midlands, has found a passion for learning:

I've got dyslexia but it wasn't diagnosed until 2010. When I was at school, back in the 60s, it wasn't even heard of. I was basically written off.

I left school with seven CSEs and off I went into the world of work.

I did various jobs, all sorts of things. I made cabinets, worked on a building site and at a supermarket before I became a lorry driver. Eventually, I set up my own haulage company.

It's the time-old thing – you want to provide for yourself and your family, so I just put my education to one side.

## Finding an outlet

The reason I started studying in the first place was that I had a bad accident in the 2010s, which meant I couldn't drive any more.

My wife Christine said, 'You can sit there moping as long as you want but it's not going to do you any good at all.'

I needed to find an outlet and decided to improve my computer skills, and my studying has gone from there!

I used to be a workaholic – all the energy that I used to put into work is going into learning now. I love it. My office wall is chock-full of certificates – everything from health and safety to leadership and logistics.

## Determined

I was diagnosed with dementia around five years ago. I noticed my memory



was going. I kept forgetting where I was going and what I was doing.

Later, I also received a diagnosis of Parkinson's.

It's not diminished my energy – I have a positive mental attitude and I'd like to think I'm pragmatic.

I started an online degree in business with Arden University before my diagnosis and finished it in 2025.

As well as studying, I've helped to set up a support group for people with young onset dementia in my area. My dementia adviser Elaine and I agreed there was nothing meaningful on offer and we needed to do something. It's thriving now.

I'm also part of a cancer support group called Let's Talk Hope in West Bromwich, as I survived a brain tumour over 20 years ago.

## Not stopping

I've got lots of plans for the future. What can I say? I like being busy. I'd like to increase help and support, especially for those with Parkinson's disease dementia.

I'm still studying – in fact, I'm about to start a master's degree in supply

“

**I started an online degree in business with Arden University before my diagnosis and finished it in 2025.**

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chain management and logistics with Arden University.

I always encourage people I meet with dementia to be brave and stay active.

It helps you feel useful and connected, which is really important.

You just need to find something that suits you!

# Onset, diagnosis and now

## Sue Noakes, 67, in West Sussex, shares thoughts about life before her dementia symptoms, before diagnosis and since.

Content warning: includes personal accounts of suicidal thoughts and suicide.

### Who were you before onset?

I'm the kind of person who doesn't wait around for things to happen – I get on and do them. I'm a go-getter.

I worked as a therapeutic counsellor, with all different types of people and all different issues. I absolutely loved my job.

I'm a musical person. I've played guitar since I was 12 and sung in choirs since school. My faith is important to me and I've always been active in the church. I'm creative too – I love all sorts of crafts including crochet, knitting and dressmaking.

Dementia affected my mum's side of the family. My uncle was the first to be diagnosed and sadly, he took his own life. It's a vile disease and doesn't discriminate. You can get it irrespective of who you are and what you do.

When Mum was diagnosed, I got to know about Alzheimer's Society and started working for the charity, managing a weekend respite club. To raise money, I once shaved my head at Mum's care home. My slogan was, 'Hair grows back brain cells don't!'

My dad, a former London cab driver, was also diagnosed with dementia. Balancing my parents' care and family life with my husband and two sons was hard.

### Who were you before diagnosis?

Because of my family experience and working with the Society, I recognised the signs of dementia. For around three years, I knew something was



happening. I constantly lost things, started to struggle with spelling and forgot the names of clients at work.

My brother, who is four years older than me, had also been diagnosed.

I eventually went to my GP but they couldn't really tell me anything. I made the decision to go private and I was diagnosed with Alzheimer's disease in 2023.

Getting the diagnosis was tough. It was also blunt – the letter detailed my condition in less than 10 words, with no mention of next steps, who to contact, what it meant for me.

### Who are you now?

I was in a very dark place after my diagnosis and the process of moving forward has been gradual.

I am thankful that I got a relatively quick diagnosis. This has enabled me to access medication, find support and get involved in research, something that makes me feel more hopeful about the future. I believe early diagnosis is really important.

I go to a young-onset dementia support group. It's a great group, so supportive and we have fun. I'm still playing guitar, being creative and active in church, though not as active as before. Getting my little dog Lily was the best thing ever. She gets me out and she helped me find a new friend, who I met on our walks.

I'm still able to drive but I know there will come a time that I won't be so independent. Sadly, my husband died last year and I'm in the process of moving house so I can be nearer to my sons and to amenities.

Dementia is very individual, but I would say to others, try to get out there. I love staying in watching telly as much as the next person, but staying active helps. Find a good group or activity that you enjoy. And if you can't find it, start something up.

I want the stigma around dementia to end. It feels like we get written off! I forget things, get muddled but there's lots of living left in me.

## Letter: Card reader confusion

Is it only me or do others have a similar problem?

You've just done your shopping and tap the debit card on the card reader, and nothing happens. Concerned but not quite in panic mode, you tap again then check for the 'insert card' message.

It's then that you spot a short message asking for a charity donation or if you had a good shopping experience or similar. You can't pay until you tap a button. Probably not a big deal for most people, but it floors me.

When I use that card reader the last thing I need is to be confused and embarrassed. I just want to check that the amount is correct and pay.

I know that, with fewer cash sales, charity boxes receive less small change at checkouts but is this really the way forward?

**Jane Buckels, South Wales**

We wouldn't want something positive – like a donation – to become a source of stress or embarrassment for anyone! But we're mindful that this kind of prompt on a card reader could be unexpected.

In many of our partnerships with supermarkets, donations are asked for on the large screen at self-checkouts, which may avoid the confusion you're talking about. However, we have also had partnerships that use prompts on card readers.

Key to our approach is helping in-store teams to feel confident about supporting customers when needed. We encourage all partners to ensure their staff understand how the prompts work so they can guide customers through the process clearly and calmly.

We also offer Dementia Friends sessions to all our corporate partners. The idea is for more of the people you come across in shops and elsewhere to have a better understanding of dementia and how they can help.

These kinds of partnerships help us to provide information, guidance, reassurance and practical help for people affected by dementia when it is most needed.

Each tap of 'yes' at the till to donate a few pennies might seem small, but together they go a long way!

## Stay safe, warm and supported

Rising household costs can be challenging, but there are simple ways to save energy, stay safe and access extra support.

Through Alzheimer's Society's partnership with Cadent, SGN and Wales & West Utilities, we are helping people affected by dementia access practical advice and support to stay safe and well.

### Reduce costs

Small changes around the home can make a difference to energy costs:

- Only boil the amount of water you need in the kettle.
- Use LED light bulbs.
- Only wash full loads of laundry.
- Air-dry clothes where possible.
- Keep your home draught-free.

### Carbon monoxide

Protect yourself from carbon monoxide (CO), which is a poisonous gas that you cannot see, smell or taste.

Make sure you have a working CO alarm, and regularly service appliances that use gas or other fuels.

Know the symptoms of CO poisoning – these include headaches, dizziness, nausea, confusion and tiredness.

If you suspect CO, open doors and windows, move into fresh air and call the Gas Emergency Service on **0800 111 999**.

### Priority Services Register

We can also help you maximise your income and sign up to the free Priority Services Register, which provides extra support during power, gas or water outages. For further support, call our Dementia Support Line **0333 150 3456** or visit **[alzheimers.org.uk/gdn-advice](http://alzheimers.org.uk/gdn-advice)**



# The right tech for you

## How can you choose and obtain technology and devices that help day-to-day life when you have dementia?

**I**f you have dementia, technology could help you to remain active and independent. Tech may also help others to support you later on.

It's generally better to start using devices earlier on, when it's easier to get used to them.

Decisions about tech and devices should be made by you, or with you. If you're unable to choose for yourself, other people ought to make decisions in your best interests.

### Choosing tech

What works for one person won't always work for someone else. Tech needs to suit your needs and routine.

Think about things you like doing – what could help you to carry on doing them? For example, if you enjoy going for walks, would you like to get used to using a GPS device?

Would you want support to learn or use the technology? Some devices are easier to set up with help, even if you use them by yourself after that.

If you already have a tablet or smartphone, could new settings or apps make it easier to use? Is there a simplified version of the device you'd like to get used to?

### Obtaining tech

People often need to buy devices themselves. But check whether you can get help with sourcing or paying for them.

This might be through your local authority or an occupational therapist. If you live in supported or sheltered housing, ask if they can help.

Some areas have independent living centres, where you can get advice and try out devices before buying them.

You can buy tech from many places, including from the Society's shop.

## Your tips

Jennifer Bute says, 'I use Alexa to remind me every day to take my medication, and "she" goes on and on until I tell her to stop (when I have taken my medication!)

'I also use it for listening to music from Amazon or Spotify – even if the request is vague, it almost always comes up with the right one. It reads me my Audible books too, usually when I go to bed.

'Alexa can be obtained free from Apple or Google for your phone or smart watch, but I chose to buy Echo Dot smart speakers for each room.'

'I bought a rainbow-coloured pill box organiser for my complicated medication, and I use a sensor night light to come on when get out of bed and until I get back in.

'Most days, I use computer dictation on my devices because I can't spell anymore.

'I use a smart watch to track me, so my son always knows where I am. If I get lost, it shows me the way. It reminds me about simple exercise – I can choose how much!

'If I fall, it alerts family who can contact an appropriate person as to where I am. When I fell unconscious once it alerted my son, who could immediately call for help.

'It also tells me the time and date, alerts me to family trying to make contact with me, and I can answer phone calls on it.

'In the background, I have a Nest camera in my lounge which can check on falls (or intruders!) or if I have not been in contact with my son.

'It was expensive but has been a life changer, as my son can monitor me when necessary – particularly useful in medical or situational emergencies.'

Our shop has dementia-friendly products designed to help with a wide range of needs – visit [alzheimers.org.uk/ShopTogether](https://alzheimers.org.uk/ShopTogether) or call **0333 366 0035**.

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



People affected by dementia share ideas and advice on our Dementia Support Forum – visit [alzheimers.org.uk/ForumTogether](https://alzheimers.org.uk/ForumTogether)

# Opinion:

## Training is the tip of the iceberg

**Mary-Joy Albutt says dementia training for care staff is vital, but so much more is needed to provide good quality care.**



Mary-Joy is a nurse consultant for neurocognitive conditions at AIM to Get Better.

**T**here have been calls from across the health and social care sector to make dementia training mandatory for care staff. Without such direction from government, there are disparities in the amount and quality of training received.

It is inconceivable that some care staff receive no dementia training at all. Many organisations provide an hour's e-learning, usually lumped in with all the other modules staff complete as part of their induction.

Some organisations provide six hours of face-to-face dementia training, but its quality and benefits are rarely measured in ways that allow for comparison across organisations.

Even if mandatory dementia training is implemented, there would also need to be quality measures in place to ensure disparities do not continue.

### How do people learn?

Classroom training may provide knowledge about dementia and challenge myths and misunderstandings. It can give an understanding of why and how people express their unmet needs, and how to respond.

But evidence shows it does not teach the practical and relational skills staff need to care for people with dementia – these are learnt through role modelling.

As soon as staff demonstrate the skills required for high-quality, person-centred care, they get promoted. Then, their time is taken up with responsibilities that leave very few opportunities to work with new and less experienced care staff.

We need to create roles with status, recognition and higher pay, but which also keep people with highly developed care skills in a caring role.

There is an argument for care providers to have dementia champions or ambassadors. However, I have seen the inconsistency in training for such roles. One company offered eight days' training and an accredited dementia coach qualification, whilst another two provided the same dementia presentation used for all staff, with just two slides added on the end. Again, quality measures need to be in place for any such initiatives.

### Culture and conditions

Whatever training is provided, highly skilled care can only be delivered within an organisational culture that supports its implementation.

Staff cannot provide person-centred care if their own personhood is not recognised and nurtured. They cannot put what they have learnt into practice if senior managers make decisions that conflict with this.

In addition, there is no point in training staff in how to provide high-quality, responsive care if staffing levels do not allow them to provide it. If dementia training is made mandatory without addressing work

culture and conditions, staff may be scapegoated when it's not their fault – 'They've had the training, they just aren't putting what they've learnt into practice.'

If staff know the standards of care they should be providing, but are consistently unable to provide it, it creates inner conflict. This leads to high staff sickness and turnover, or to them 'switching off' and incapable of providing humanistic care.

### More than training

Dementia training should be mandatory. But it must be delivered within a work culture that supports humanisation, personhood and emotionally intelligent, relational care.

Classroom training needs to be backed up with structured role modelling, coaching, mentoring and supervision programmes that support the development of practical skills.

Most importantly, organisations need to enable staff to put their dementia training into practice. Without this, training – whether mandatory or not – will continue to be nothing more than a box-ticking exercise.

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

# Telling my story

**For Julie Kerr, in County Antrim, making a difference for other people with dementia is firmly rooted in staying connected and involved.**



**I want people to acknowledge that anyone can get dementia – not just old people, anyone – and we need help.**

If you can get an early diagnosis, your life's not over. There are actually groups out there, but when you get diagnosed they don't always tell you that you can still have a life.

I watched my mummy, who had dementia, she just sat in front of the TV all day, every day. It was a shock when I got diagnosed – I didn't want to be like that.

For six months after my diagnosis, I was completely lost. It was only by luck that our daughter was at the library and saw a notice for the Dementia NI Empowerment Group, otherwise it might have been longer.

## Being understood

When I went to the group, I just knew that they understood me. They turned my life around and helped me so much.

I remember commenting on the medication I was on and that I was getting bad dreams. One of them said, 'Go back to your doctor and you'll get put on another one,' and so I did. I wouldn't have known that, I would have just tried to live with it.

They are just like me, we don't get embarrassed, we don't think we're stupid, we just enjoy going out and doing things – you just feel normal.

We go on outings, wee walks and then go in for a cup of tea and a biscuit. We have people come from Age NI, Dementia NI, Alzheimer's Society – all different places – who talk with us and keep us up to date.

I'm still me. I tell my grandkids that part of Nanny's brain doesn't work right, so she's going to forget things.

But somewhere in there, there's still me. And while I can remember, I want to get out there and enjoy my life and what I have.

## Raising awareness

I love going out to do talks and to raise awareness. I tell my story at different groups – to the Bar association for Northern Ireland, the Food Standards Agency and events with politicians at Stormont.

Me and my husband David, we speak to healthcare students through Time for Dementia, with both Alzheimer's Society and Dementia NI. We'll have Zoom meetings with students so they can learn how to approach people, plus we have ones that come out to the house. It's been absolutely brilliant.

I was in a two-page story in the Belfast Telegraph a couple of years ago about working while you still have dementia, and there were wee clips on Facebook.

I would meet people I hadn't seen for years who would turn around and say to me, 'Oh, I didn't know you had it.' Then I'd get talking to them and it opens things up.

If someone in their family now gets diagnosed, they know something about it. They can turn around and say, 'I know a girl, Julie, she's still working in the council.'

Every wee bit of information you get out there is helping someone else. Being able to help others like me makes the journey I have been on feel more worthwhile.

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

Join us as a campaigner to create change for people living with dementia – visit [alzheimers.org.uk/campaign](https://alzheimers.org.uk/campaign)

# Beyond Broadway

**With family, friends and amazing community support, Linda Quinn in Somerset helps organise magical theatre nights to fundraise for dementia.**



**M**y mum Joyce passed away in 2021. She had heart issues, but she was also diagnosed with dementia about six years before she died. She was one of 14 siblings and 10 of them have had some form of dementia.

I cared for her at home during the pandemic. It was hard but it was also an important bonding time for us. I found a level of connection with her that I never expected, and the memories of this time help sustain me now.

## Drive change

As well as dementia impacting on my family, I have friends going through the experience of caring for parents with dementia. I'm also supporting my best friend who has frontotemporal dementia.

That's why it's become so important to fundraise and raise awareness about dementia. It shouldn't be a taboo.

I come from a family of musical theatre lovers – my nephew Ashley is a trained singer and performer, and runs a production company.

So it made sense to use our skills and contacts to start organising charity concerts. This year will be the third time we've staged an event to

fundraise for Alzheimer's Society and we've raised over £6,400 so far.

We have the drive to do something good – it's a cause that's close to our hearts.

We want to elevate awareness about dementia but also tell people that there is support available out there.

It's important to highlight what Alzheimer's Society does. When I was looking after my mum, I phoned the support line during particularly difficult times. We've also had wonderful support and encouragement from Siân, our regional fundraising contact at the Society.

## Community energy

With close friend Ken, we start planning the show months in advance – Ashley is the driving force and director.

The Bridgwater community gets right behind us. Local businesses, hotels, restaurants and shops generously provide raffle prizes and take adverts out in our programme.

Ken is very well-known in the town, which makes fundraising a little easier!

It happens at the McMillan Theatre, and it's a very slick and professional show. Ashley's wife, who works in the West End, stage-manages the whole night and his brother Aaron comperes.

Our performers, who all have roots in Somerset, return to do the show every year because it's such a special event. Jess, our talented musical director, arranges all the music and sends it out to the performers to practise at home. We rehearse everything over video call and meet up in person the night before the show.

## Pride and gratitude

This September, our show is called Beyond Broadway and we're featuring music from composers including Stephen Schwartz, who wrote Wicked.

There'll be some solos, duets and group songs. We've also invited a youth theatre group called MADE to perform – we're passionate about supporting young talent.

The night will be a mixture of emotions. There's an overwhelming sense of pride and of gratitude to the people who support us and those who perform every year. They're an amazing bunch of people.

My advice to other fundraisers is focus on something that you're interested in and fires your imagination, and get your community involved. You'll be amazed what you can achieve together!

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

# Better for all

**Through the CARE Network study, people from all communities are helping to build a more complete picture of dementia awareness and needs that will benefit everyone.**



**I**t's important that research reflects the experiences of people from all communities,' says Christina Israel.

'That's especially true in dementia research, where culture, lived experience and different perspectives all have an important part to play.'

Christina is Managing Director of 60 Up, a community interest company supporting older people in south London. She's also a public and patient involvement (PPI) volunteer with the CARE Network study.

This study is finding out how dementia awareness and support varies across ethnic and faith communities. PPI volunteers help the researchers keep their work relevant to people's real-life experiences.

Enduement Ruvon Adiohwo, another volunteer, says, 'Dementia affects individuals, families and communities in profound ways.'

Research is essential for improving understanding, enhancing care and strengthening support services.

'By contributing my perspective, I could help ensure that community voices are reflected in future policies, services and interventions.'

## Short surveys

The CARE Network study is looking for people aged 40 and over from all communities to take part. This includes people who don't have problems with their memory or thinking, as well as those who do.

Participants complete a short online survey every six months for 10 years. From their responses, researchers at King's College London will build the evidence and insight needed to improve dementia care and support for everyone.

Zunera Khan, who leads the study, says, 'Dementia does not affect all communities equally in terms of experience, access to services, or outcomes.'

'Without the voices of diverse communities, there is a risk that services and research will continue to reflect only a partial understanding of need.'

'The CARE Network is committed to changing this by ensuring that underrepresented communities are not only included but actively involved in shaping the future of dementia research and care.'

## Enlightening

Jakki Levene, another CARE Network PPI volunteer, got involved with research due to her experience of supporting both her parents.

She cared for her mother, who had dementia, as well as her father when he had cancer.

'I decided to get involved with as many things as I possibly could, to do whatever I can to help in research,' says Jakki.

'I find it very satisfying, very enlightening. I'm learning new things every time, sometimes from people with whom I wouldn't normally have contact.'

Taking part in a range of studies has also helped her acknowledge the emotional and psychological impact of caring.

'It helps to be aware of that,' she says. 'You can reconcile how you feel about it and deal with it in that way.'

## Genuine difference

Kamara McLeish Evoloko, CARE Network Study Co-ordinator, has no doubts about how vital volunteers are to dementia research.

'Participation makes a genuine difference,' she says. 'By sharing your experiences and perspectives, you help shape future research, services, and interventions so that they are more relevant and inclusive for all communities.'

Enduement says, 'It is an opportunity to have a positive impact on the lives of people affected by dementia.'

Christina agrees, 'I'd encourage anyone to give it a try. It's interesting, enjoyable and a chance to make a real difference.'

## Take part in dementia research

Find out what studies are looking for people like you, whether or not you have dementia – call **0333 150 3456** and ask for our Research Participation team, or email [joindementiaresearch@alzheimers.org.uk](mailto:joindementiaresearch@alzheimers.org.uk)

# From lab to finish line

**A passion to beat dementia that spans running to raise funds, alongside a career researching its prevention and treatment.**



**A**s well as researching how blood flow affects dementia, Harry Pritchard is getting his own blood pumping to help fight it.

He's part of our Dementia Run Club, formed earlier this year. The team of 10, all with a personal or professional connection to dementia, are taking on a half marathon to raise vital funds.

'I see the critical work of Alzheimer's Society firsthand,' says Harry, based at the University of Manchester's Geoffrey Jefferson Brain Research Centre.

'Now more than ever, hope is truly on the horizon for the breakthroughs we need in dementia research.

'It's why I am passionate about what I do – investigating the link between cardiovascular health and dementia. Understanding how one affects the other, and why, will bring us closer to a day where dementia no longer devastates lives.'

## **Dementia Research Leader**

Two years ago, Harry became a Society Dementia Research Leader – one of a select group of talented researchers who we support at a vital stage of their careers.

He established a research group to learn more about the impact of faulty blood vessels on how a person's brain works when they have Alzheimer's disease or vascular dementia.

Harry's previous research showed how blood flow can be reduced when a specific protein in blood vessels becomes inactive.

'By understanding what causes the reduced blood flow, and showing that restoring it improves symptoms, we could uncover a promising new target for dementia treatment,' he says.

## **Prevention and treatment**

A keen runner outside of the lab, Harry hopes his involvement with the Dementia Run Club will raise awareness of dementia prevention as well as research into its treatment.

'Being active doesn't just prevent dementia by lowering your blood pressure and helping you lose weight, it improves the health of your heart and blood vessels, directly benefiting the brain's blood supply.

'Research has shown that people who take regular exercise may be up to 20% less likely to develop dementia than those who don't.

'You don't need to run marathons! Physical exercise does not just mean playing a sport or running, it can also mean daily activities such as brisk walking, cleaning or gardening.'

## **Great North Run**

Dementia Run Club members are training for the 45th AJ Bell Great North Run on 13 September. They'll run this iconic event's 13.1 miles (over 21km) together from the heart of Newcastle upon Tyne to South Shields.

Harry's teammates include Jane Buckels from Abergavenny, who has young-onset dementia, and Paul Lindsay from Nottingham, who cares for his dad.

'Generous money raised by the Dementia Run Club will support Alzheimer's Society in developing the treatments of tomorrow, while ensuring people affected by dementia receive the support they need today,' says Harry.

## **Run or donate**

Alzheimer's Society is the official charity partner of the AJ Bell Great Run Series 2026/27.

As well as September's Great North Run, the series includes events from October to May in Portsmouth, Glasgow, Bristol, Birmingham and Manchester.

Sign up to run for us or donate to the Dementia Run Club at [alzheimers.org.uk/dementia-run-club](https://alzheimers.org.uk/dementia-run-club)

# Connection and support

**Dealing with dementia can be lonely, so our Companionship service offers comfort and company. Heather Stephen hears what it means to people with dementia and their families.**



## Quick read

**Our Companionship volunteers offer people affected by dementia emotional support and connection to other help.**

**Companionship phone calls began during the Covid pandemic, initially intended as a stopgap.**

**It was so successful that Companionship became a permanent service, which still runs today.**

**This year, the service expanded to include weekly online chats and connection to our online Dementia Support Forum.**

**L**oneliness eats away at you. You have to have someone,' says Jim at his weekly online group chat.

'It's friendship. That's what companionship is,' explains Norman, who keeps the group smiling with his cheeky humour and songs.

Norman admits that life after a dementia diagnosis can be 'a very difficult path to walk'.

The online meetup, launched in January, aims to make that walk a little easier by connecting people who share the same experiences.

It is part of the Society's Companionship service, which reduces isolation and provides reassurance for people with dementia and their carers.

### Good to talk

The Companionship service began during the pandemic with a volunteer-led telephone service.

Designed to be a temporary stopgap, it was such a hit that it's still offering the chance to talk about all kinds of things.

'People say it is nice to talk to someone outside the family about something other than dementia', says Sam Watson, a Companionship volunteer officer.

'And they appreciate that someone is checking in on them every week.'

Cam McNally, a team leader, explains, 'We decided to go online at the beginning of this year because people wanted that face-to-face contact, and to chat to people experiencing the same things.

'And we can direct them to the online forum where they can get information and support.'

### Giving back

Assunta Hammick began getting calls from the service two years ago after her husband John's diagnosis.

'The lady who called had cared for her mother and father-in-law,' says Assunta in Milton Keynes. 'So I felt I had someone who had been there too.'

Sadly, Assunta's husband died in March, but she plans to train as a volunteer caller.

'I want to give back. The NHS trains doctors and nurses in the medical stuff, but it is just as important to talk to people about the practical side of caring.'

Norman Blackmore started using the service after his wife Margaret was diagnosed with Alzheimer's seven years ago.

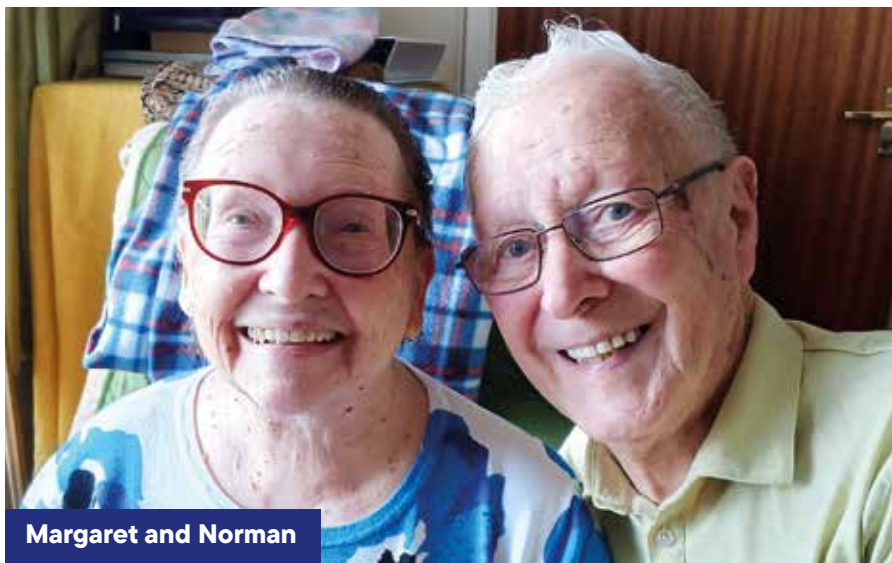
'The calls mean something to me because I no longer have chitchat with Margaret and they stop me feeling so isolated,' says Norman, from Cardiff.

'And the online group is brilliant. Everyone is so lovely, and it is great to see everyone. We talk about everything and I have even been known to give them a song or two!'

“

**The calls mean something to me because I no longer have chitchat with Margaret and they stop me feeling so isolated.**

”



**Margaret and Norman**

### Reducing isolation

The service has 438 trained volunteers supporting 722 people in England, Wales and Northern Ireland.

The volunteers befriend rather than give advice, though they can refer to a dementia adviser.

Volunteer Zeinab Awadalla, from east London, was inspired to join by her grandparents who had dementia. And she gets as much from the calls as the users.

‘If you are an empathetic person, it feels good to help others. People tell me I’ve lightened their day and sometimes I’m the only person they’ve spoken to all week.’

### Inspiring action

Sharon Barnes in West Yorkshire, who has Alzheimer’s, is one of the people called by Zeinab every week. She says she doesn’t know what she’d do without her.

‘She’s absolutely gorgeous,’ says Sharon. ‘I don’t get out much now and I’m pretty lonely, but Zeinab puts my mind at ease and she’d make a great best friend!’

As well as relieving people’s loneliness, Zeinab is proud to have inspired her telephone companions to pick up hobbies again and go out more.

She explains, ‘When people say I have motivated them to go out, it makes me feel good.’

Cam says the service not only provides company but helps people stay independent longer by signposting support.

And Sam adds, ‘Even though the volunteers don’t give advice, just having that conversation with someone outside your family can help you feel lighter.’

Our Companionship service connects people affected by dementia with friendly Alzheimer’s Society volunteers for regular, supportive conversations.

You can sign yourself, or a loved one, up for Companionship at **[alzheimers.org.uk/companion-calls](https://alzheimers.org.uk/companion-calls)** or by calling the Dementia Support Line on **0333 150 3456**.

To find out about volunteering, please see **[alzheimers.org.uk/companion-calls](https://alzheimers.org.uk/companion-calls)**



People affected by dementia share ideas and advice on our Dementia Support Forum – visit **[alzheimers.org.uk/ForumTogether](https://alzheimers.org.uk/ForumTogether)**

# A new dementia guide

**People affected by dementia were instrumental in helping us update the Society's guide for people who are newly diagnosed.**



## Quick read

**The dementia guide is one of our key publications, offering support and information to people who are newly diagnosed.**

**A new version was recently produced – and people living with dementia and carers helped decide on its content, approach and look.**

**We worked with over 150 people affected by dementia around the UK to channel their perspectives into a refreshed guide.**

**Thanks to their contributions, we have a leaner and more focused guide, which is now available to order or download.**

“

**The guide is all about providing practical and emotional support, with guidance on living with dementia and planning for the future.**

”

**W**hen you're adjusting to life with a dementia diagnosis, access to clear and reassuring information is vital.

This principle shapes all our publications, and none more so than our flagship guide for people who are newly diagnosed.

The dementia guide has been produced by the Society for over a decade, described by one reader as a 'important road map'. It helps people take steps to understand their condition and move forwards, explains writer and editor Kathy De Mattia.

'The guide is all about providing practical and emotional support, with guidance on living with dementia and planning for the future,' she says.

'It is distributed through hospitals, memory clinics, GP surgeries and dementia advisers across the UK, so we reach as many people as possible.'

## Gone through it

'When it came to reviewing the dementia guide, we knew exactly who to ask to help us – those who have gone through the very difficult and emotional experience of a dementia diagnosis themselves,' says Kathy.

To gather these insights, we worked with national and local Dementia Voice groups, comprised mainly of people living with dementia and also carers.

Bindi Dhesi, Involvement Partner, says, 'We worked with Kathy to develop the questions to be asked of our group members and these were sent with the guide in advance of the meetings.'

One of the local groups was facilitated by Cherryll Hixon, Time for Dementia Officer in Kent.

'The group was excited to be asked to give their opinions. Its members had a real desire to improve things for people with dementia and raise awareness of the health inequalities experienced by people with a dementia diagnosis.'

“

**Discussing the guide prompted conversations that we would never have had without it.**

”

## Heartfelt

Over several months, 150 people affected by dementia shared their views, which Kathy says were candid and illuminating.

‘For example, when we asked people what they wanted to know immediately following a diagnosis, we received many different responses.

‘This made us realise that we needed to create a guide that was able to answer different questions, depending on people’s preferences, culture, living situations and life choices.’

Kathy says she was struck by the emotion in people’s responses, particularly their personal tips.

‘One of the first was, “Don’t be afraid to ask lots of questions. We all have different needs and worries. Getting answers early will help you feel supported and more in control.”’

Derek Wiley says being involved meant a lot to him and his wife Margaret, who has sadly since died.

‘I was able to raise a point from personal experience and, from what I had discussed with others, something I thought was missing,’ he says. ‘I was delighted at a later date to see it had been included.

‘It was good for us both, it awoke something in Margaret. All the things she got involved in, we found out about more services. If we hadn’t been involved, we would never have known about dementia crisis support, which we ended up needing to access 12 months later.’

Cherryll says sharing their perspectives was cathartic for her group.

‘Discussing the guide prompted conversations that we would never have had without it.

‘It was really inspirational to see how the group all gave advice and support to one group member who was fairly new, and finding it really difficult to accept their diagnosis.’

## What’s changed

When we had everyone’s comments, our knowledgeable in-house team worked with health and social care professionals, legal experts and others to create a guide that would give people what they most needed.

Kathy says, ‘Once our designers finished the first draft, we sent it back to groups to check if we’d met their brief and supported their needs.

‘We had, thanks to their incredibly thorough feedback!’

The result is a guide that Kathy says everyone involved can be proud of.

‘The content is more focused on individual needs and choices. It considers identity, personality, different emotions and responses to a diagnosis.

‘Throughout the guide are tips from other people with dementia, on things that helped them to cope better.’

The guide is now half the size and easier to navigate, with space to add notes.

‘It is designed to be picked up each time a person with dementia has an important question that they want an answer to,’ adds Kathy. ‘A guide they can keep to hand for whenever they need it.’

## Honesty and generosity

By opening up about their experiences, the people who helped create the new guide will help thousands of others feel less alone.

‘Their involvement means we are able to provide the best support and guidance for the many people who continue to receive a dementia diagnosis every year,’ says Kathy.

Derek adds, ‘It made us both feel part of a community, trying to do something good.

‘The more you do, the more you find and the more it makes you feel good.’



The dementia guide is for people who are newly diagnosed. Thank you to everyone who helped us make it even better than before!

To order or download the new dementia guide (872), see [alzheimers.org.uk/dementia-guide](https://alzheimers.org.uk/dementia-guide) or call **0300 303 5933**.

Find out how you can use your experiences of dementia to help shape our and others’ work – visit [alzheimers.org.uk/involvement](https://alzheimers.org.uk/involvement)

# Making products better

**Insights from consumer panels help people who are buying assistive products, as well as designers and sellers. We look at recent panel favourites and plans for future feedback.**

**I**n 2015, we took specially designed mealtime products to a day centre in Surrey for our very first consumer panel. This was followed by a group in Sussex looking at dementia-friendly clocks.

Since then, we've visited south Wales, south London, Stockport and many places between. People have tested all kinds of devices, from garden tools to robotic pets. Even during the pandemic, we continued to send out products for people to try at home, feeding back about them on video calls.

Consumer panels have only been possible with the support and enthusiasm of group members and facilitators – thank you to everyone who has taken part!

## Incredible benefit

It was Jon Wingrave, our Commercial Trading Manager, who thought of featuring consumer panels in the magazine. He says they've been of 'incredible benefit' for our online shop and assistive products catalogue.

'Meeting people who were happy to share their experience and expertise for the benefit of others, and hearing their insightful and honest opinions, has been a great joy and inspiration for me and my team,' says Jon.

'The feedback has helped us in our decision-making process and improved the range and quality of what we offer. The information and reviews have helped customers to decide which products will be of most benefit to them.'

## Never dull

Jon underlines how enjoyable and fulfilling it is to work with panel members.

'We've learned so much and had a lot of fun doing it! It has been, and will

continue to be, very important for us to be able to say that the assistive products we sell have been tested and evaluated by people living with dementia.'

Oli Story is Non-executive Director at one of our suppliers, Ravencourt. He says, 'It's one of the most rewarding parts of my job! There has honestly never been a dull moment.'

Jodi Sanders, Ravencourt's Managing Director, says, 'Feedback from panels has helped refine products like the Rosebud Reminder Clock and Safer Walking GPS Locator.'

'We get first-hand insight into how people interact with the products. Being a small agile business, we can make tangible changes very quickly that improve our products immeasurably, helping people to live more independent lives.'

Oli adds, 'We've also taken prototypes of new products to the panels, and the feedback has led to big user experience improvements.'

## People's insights

Jon's team is developing even more ways to benefit from people's insights.

'We intend to continue organising consumer panels with people affected by dementia but are also exploring other approaches.'

'We are looking into creating a Product Review Group of people living with dementia to test products at home and submit reviews that we could feature online. Michael Booth, who is living with young-onset dementia, is already testing products and writing reviews for our shop.'

## Recent favourites

So, which products most impressed panel members in the past 12 months?

A year ago, we took the latest mealtime products to Norwich's

Dementia Voice local group. As well as lightweight Rosa trays and mugs, group members loved Pashmina Style and Cross Scarf Clothes Protectors. 'You could take one to use at a restaurant,' said Jan – '... and not feel embarrassed,' added Carol.

Next, groups at Peterborough's Dementia Resource Centre tried the Idem smart clock. People with dementia appreciated the feeling of connection it gave, since nominated relatives or friends could access it through a mobile app. Carers felt reassured by being able to tell whether reminders and messages had been seen.

The New Ones on the Block, in Ferring on the south coast, liked many of our gift ideas but Cognitive Books were clear favourites. A third beautifully illustrated book on classic Coronation Street had just joined titles about The Beatles and 1966 World Cup, all with quizzes and audio versions.

The Dementia Voice local group in Hereford fed back about nighttime and morning devices. They most valued motion sensor lights – the Plug-in sensor light and 'Get up in the night' sensor light. In particular, they noted how all products need to be chosen with the individual's needs in mind.

Worthing Town Cryers looked at engaging and calming activity products. They most enjoyed the





Curiosity Box, with its intriguing collection of objects to explore and use. Along with the Fufuly calming breathing cushion and Fiddle book, Jean said, 'It's nice to know what's there for further down the line.'

Last issue, Solihull's Dementia Voice local group tested two simple mobile phones. They highlighted that all devices depend on a person's familiarity with how to use them – or ability to learn. However, the Chatsie smartphone and Doro Leva X10 mobile piqued the interest of many of the panel's members.



Pictured far left: Pashmina Style and Cross Scarf Clothes Protectors; left from top: Idem smart clock, Coronation Street Cognitive Book and Plug-in sensor light; above from top: Curiosity Box and Chatsie smartphone.



See page 39 for chances to win Cognitive Books and a Rosebud reminder clock (pictured above).



Visit [alzheimers.org.uk/ShopTogether](https://alzheimers.org.uk/ShopTogether) or call **0333 366 0035** for a range of helpful products and gifts.

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

**Win  
see  
page 39**

# Stark reality

**Helen Rimell turned her experiences of caring for her late mum, who had young-onset vascular dementia, into a valuable photographic legacy. She explains why to Heather Stephen.**

**T**he woman stares into the camera lens, fear and grief pouring out of her brilliant blue eyes. In another shot, she sits on the dining room floor, seemingly in a faraway world of her own.

These are two prints from a striking collection by award-winning photographer Helen Rimell. It records the daily existence of her late mother Sue, who had young-onset vascular dementia.

Helen took thousands of images for the No Longer Her(e) project. One of Sue sitting with her young granddaughter was selected to hang in the National Portrait Gallery, and Helen's next goal is to bring 200 of the photos together in a book.

## Quick read

**Photographer Helen Rimell gave up a busy life in London to care for her mother, who had vascular dementia.**

**Only intending to stay in Wales a few months, the experience lasted five years until Sue died this February.**

**While Sue still had capacity, she agreed Helen could take photos of her as she progressed through her illness.**

**Helen wants to publish the hard-hitting pictures in a book to show the reality of dementia.**

'Mum had a series of mini strokes in 2010, and when she was diagnosed with dementia five years later, I said I'd like to photograph her to show people what it's really like,' says Helen.

'She agreed straightaway because she thought it would help people, and that's what she's always done.'

### Funny and kind

Helen says her mum has always looked after other people. She cared for her elderly aunts at the same time when one had dementia and the other cancer.

'Mum was amazing,' says Helen. 'She was so funny and kind and was always doing things for other people.'

'She didn't have an easy life. She broke up with my dad when I was small, her second husband died and she was then a single parent to three children, but she was always glass-half-full and a ray of sunshine.'

Sue started forgetting things after the strokes but was told her memory shouldn't get worse if she kept up with her blood pressure medication.

'She'd always been a bit forgetful and scatty, so we didn't think much about it,' says Helen.

'I was living in London and she was in Wales, so I didn't see her every day. But my sister, who lived nearby, noticed she was getting worse and took her to the doctor.'

### Personal assistants

By 2019, Sue was being cared for by two personal assistants from 9am to 6pm, seven days a week.

'She had forgotten how to cook, so they were preparing her meals and giving her meds because she couldn't remember how to do that,' recalls Helen. Covid was particularly challenging.

'Because she hadn't been assessed for two years, her medication was wrong, so she got really aggressive.'

'She went into a respite home for a month but they didn't bath her for 10 days and threatened to section her unless we took her home. It was a nightmare.'

### Move to Wales

In 2021, Helen's sister said she felt Sue needed around-the-clock care, and she couldn't leave her own partner and two children.

'As a freelance photographer, I can work from anywhere,' says Helen.

'And I wanted to look after her. She had always been there for me and I was glad to be able to give back to her.'

Helen offered to move in for a couple of months, but she never left.

'I planned to shoot a documentary about Mum and then find her a nice home but we couldn't find anywhere right.'

'She was too manic for a "normal" home and wasn't bad enough for a nursing home because she could still walk by herself. There was nowhere for someone who was in between, so we decided to keep her at home.'

### Major adjustment

For Helen, uprooting her busy life in London to move in with her mother in a small town in Wales was a major adjustment.

'It was a massive shock to the system and I felt very much alone. I could take Mum to groups but there wasn't anything for carers and I struggled with my mental health.'

Helen is a photojournalist and wedding photographer. She says it was a challenge to balance work with her caring role.

“

**Now she's gone I feel like I've lost my purpose. My dad has Parkinson's so I don't know what the future holds for me.**

”

'I used to do 30 weddings a year but over the last five years this went down to 15, as caring was so time-consuming.

'I managed financially as I was able to keep my business going, but I don't know how people do it if they're not freelance. My sister stepped in with Mum when I was on a shoot, which helped keep my business afloat.

'In her last few years Mum couldn't do anything for herself. I would have to feed and dress her and give her a bath.

'It's hard physically and emotionally. Eventually she forgot who I was. It was horrific. She was my best friend my whole life. The only one who really understood me and who loved me most, and I don't know if she thought I was one of the carers.

'It's really hard to see your favourite person in the world like this.

'When she was lucid she would cry, saying she was a burden and that she wished she was dead.

'And one time she grabbed my

hand and said, "I'm scared because I don't know who you are."

### **Only human**

Helen had to learn a lot as she went along, and has regrets about things she wishes she understood more from the start.

'I wish I hadn't corrected her when she got things wrong or I hadn't yelled at her when things got hard.

'It only upset her and I have a lot of guilt, but I am only human.'



Helen wanted to document the stark reality of caring for someone with dementia, as she believes there is too little attention on this terrible condition.

She highlights how little funding there is to fight dementia compared to other conditions, like heart disease and cancer.

‘One in three of us will get dementia but it is shameful how little is being done to find a cure and how little people know about it.

‘Dementia is a horrible, evil disease where you lose the person you love over and over. You just have to watch and wait.’

### Emotional legacy

Sue died at home in February, surrounded by people she loved and listening to her beloved Elvis. But Helen is determined that her mum won’t be forgotten.

‘I hope my photography project will raise awareness and that my emotional journey will be a legacy for my mum,’ she says.

It’s important to her that the photographs are seen by as many carers as possible. Not out of vanity, but to help people feel less alone.

‘When the BBC ran a story about my collection I got some amazing comments on social media. Dementia happens behind closed doors and carers thanked me for showing what dementia is really like. Some people said, “I could see my own mum in your mum’s eyes.”

‘This personal story doesn’t shy away from raw emotion, but people should be prepared when they need to make important decisions for people they love.’

Before Sue’s dementia became too advanced she and Helen enjoyed a few holidays in the sun. One particularly memorable trip was to Florence.

Helen scattered some of her mum’s ashes there, so she will always be in her happy place.

‘Mum was full of fun so when I organised her funeral I asked everyone to wear bright clothes and

we hired two Elvis tribute acts – two young guys so they were hot Elvis!’

### Still not sunk in

After Sue died Helen threw herself back into work. A week later, she was in Costa Rica photographing a wedding.

When she came back, she was busy with wedding bookings and planning the funeral.

‘I don’t think it has sunk in yet,’ she admits. ‘It hit me in Florence because it made me think of her, but most of the time I just try to keep busy.

‘Now she’s gone I feel like I’ve lost my purpose. My dad has Parkinson’s so I don’t know what the future holds for me.

‘I could get hit by a bus tomorrow, so I’m going to carry on travelling and living my life the best I can.’

It sounds like Sue would approve.





Follow **@helenrimell** on Instagram to see more of Helen's photographs and find out when her book comes out.



For our booklet *Caring for a person with dementia: A practical guide* (600) and factsheet *Carers – looking after yourself* (523) visit **[alzheimers.org.uk/](https://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 mum has dementia and lives with me in Wales. Can I access her UK bank account using the power of attorney she made in Australia while she lived there?’**

# Overseas power of attorney

This can be tricky. In England and Wales, the law allows banks (and others) to recognise an overseas power of attorney in many circumstances. But if a bank sees something it's not familiar with, it may reject it.

If you have assets in more than one country, it's usually best to create powers of attorney in each country.

‘Assets’ could include things like savings or property.

### What can my mum do now?

If your mum has assets in Wales or England, she could make a lasting power of attorney (LPA) for property and finance. It would have to be her decision to make the LPA. She'd also need to have mental capacity to make one.

When needed, this LPA could be used to manage her property and savings in England and Wales. You can use her Australian power of attorney to manage any property or savings she still has in Australia.

### What if she can't make an LPA?

Try asking her UK bank to accept her Australian power of attorney. Perhaps ask them to check with their legal team.

Explain that your mum used to live in Australia and she made the power of attorney under Australian law.

If the bank won't accept it, you could apply to the Court of Protection for one of two things.

You could apply for a declaration that your mum's Australian power of attorney can be used for assets in England and Wales. The bank would have to accept this.

Or you could apply for financial deputyship. This would give you similar powers as an LPA for property and finance.

Bear in mind that applying to the Court of Protection for either of these can take many months and you may need legal help.

### When to step in

Generally, you should only step in to manage your mum's property and finances if she lacks the mental capacity to do it herself. Even if she does not have capacity, try to involve her in making decisions as much as possible.

### What if you are in Northern Ireland?

When it comes to using an overseas power of attorney, Northern Ireland is much like England and Wales.

But options would include an enduring power of attorney (EPA) instead of an LPA and controllership rather than deputyship.

An EPA would be seen as ‘overseas’ in Wales or England, as would an LPA in Northern Ireland. But because many banks operate throughout the UK, they're more likely to accept them both.

For our Enduring power of attorney and controllership (NI472) factsheet, visit [alzheimers.org.uk/publicationsttogether](https://alzheimers.org.uk/publicationsttogether) or call **0300 303 5933**.

If you need legal help, it's a good idea to find a solicitor or legal executive who knows about dementia.

To find one, you could try [lifetimelawyers.org.uk](https://lifetimelawyers.org.uk) or call them on **020 8234 6186**. Make sure you get a clear idea of likely legal costs when you first speak to a lawyer.



See [alzheimers.org.uk/publicationsttogether](https://alzheimers.org.uk/publicationsttogether) or call **0300 303 5933** for our factsheets:

- Lasting power of attorney (472)
- Deputyship (530)

**Readers share advice for other carers about accepting and adapting to outside help when it is needed.**

## Adjusting to help



'The crucial step is admitting to yourself that you need the help. It feels like failure, but it isn't.

'What is happening is that the needs of your person with dementia are developing in such a way that it is impossible for one person to do all that's necessary.

'One of the most helpful things said to us was that, sooner or later, it gets to a point when the person with dementia needs a team to care for them.' **Veritas**

'We have started with a "befriender" for Mum as she refused to have anyone come in to help. Mum thinks she's a volunteer, though she's actually a paid carer.

'I hate not being truthful but she's really enjoyed the visits for company, and hopefully she'll accept carers later when needed.'

**julesinsuffolk**

'Introduce outside carers as friends. This worked for me when introducing them to Dad and I would leave them watching TV.

'The same thing worked for me when I introduced him to the care home manager.' **MaNaAk**

'My sister was very resistant to carers visiting the home, so we worked on companionship carers. The carers would visit and go for a walk with her and then make meals.

'She also had a habit of losing her hearing aid, glasses, meds, so I bought a security box with spares for all the above. I told her the code so she felt involved, but she didn't remember it so the items were safe.'

**Joanna hl**

'One thing I found to be helpful, was to colour code and label my husband's flannels (upper and lower body) and towel, so that a morning personal care visit, by a variety of different carers, didn't entail me supervising every step saying, "No, this one not that one."

'I also labelled the drawers in the bedroom to indicate where his clothing could be found, which meant I didn't need to lay out appropriate clothing for him each day.

'Only very small things, but they relieved a little of the pressure in adjusting to a huge change in our lives.' **SeaGirl**

'When care visits finally started I had online access to the visit notes, which I read to keep up with how it was going.

'The carers didn't do things the way I did and consequently weren't very successful at encouraging her to wash or eat, but I made a conscious effort to step back and not intervene.

'It wasn't easy but I think it was valuable. In time, they worked out what to do, what worked etc. I think if

I'd stuck my nose in all the time I would never have been free of the caring responsibilities, but now I feel I'm getting there.' **Tiddles123**

## Dementia Support Forum

Join our online community of people living with dementia at [alzheimers.org.uk/ForumTogether](http://alzheimers.org.uk/ForumTogether)

# Noticeboard

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

## Letter

### Conquering my worst fear



In 2021, I made a choice that completely changed the trajectory of my life. After 19 years in a secure, full-time job, I decided to take a leap of faith into the unknown. I left my career behind to start my own self-employed home support service as a caregiver, working closely with a small group of ladies.

When I started, I will admit I had very little real-world knowledge of dementia. Navigating it was one of the most profound, eye-opening challenges of my life.

Then, it hit even closer to home. A loved one who I am deeply close to was diagnosed with Alzheimer's. The impact was massive, and it left me wanting to do something major to get people's attention.

I am absolutely terrified of heights. So, I decided to conquer my ultimate fear: jumping 14,000 feet out of the sky with Skydive Langar.

I wanted to experience that raw fear of the unknown, the total loss of control and the overwhelming anxiety of stepping into blank space – the feelings families endure when navigating an Alzheimer's diagnosis.

Above all, I dedicated this jump to the memory of six incredible ladies who will always hold a place in my heart: Bren, Clarice, Mary, Monica, Gladys and Linda. I proudly carried their names, alongside Jenny, Celia and Trevor, printed onto my custom jersey.

When I was sitting in that plane looking out the open door, my heart was pounding. But when we jumped, I made a heart shape with my hands. That heart wasn't just for the camera, it was a tribute to their memory and a message of love to everyone fighting this disease.

Thanks to an overwhelming wave of support and love from friends, family and the community, we raised £1,870 for Alzheimer's Society.

To anyone wishing to do the same for a loved one or someone close to you: take the opportunity. It is a once-in-a-lifetime experience that changes who you are.

**Stacey Morley, Derbyshire**

**Feeling inspired by Stacey's jump?**  
Find out how you can raise funds with a skydive at [alzheimers.org.uk/skydive](https://alzheimers.org.uk/skydive) or call 0330 333 0804.



### Café volunteer completes Camino

A dementia café volunteer from Somerset has been raising funds for Alzheimer's Society while completing the Portuguese Camino pilgrimage.

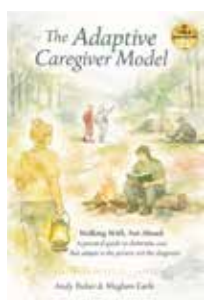
David Freestone walked the 260km route from Porto, Portugal to Santiago de Compostela in Spain in June. He took on the pilgrimage in memory of his late father-in-law Glyn Evans, who had Alzheimer's.

David explains, 'Myself and my wife, Megan, are active volunteers at the Memory Café in Bruton. With our firsthand experience of Alzheimer's, we provide support to local residents. The café brings joy to ourselves and those in need of support.'

'I completed the Camino Portugués, after 11 days, on Sunday 21 June and recorded my experience with daily updates, including photographs, on my JustGiving page.'

'Walking the Camino was an excellent way to experience local folk, nature and the pilgrim culture.'  
**Read David's journal and find out more at [justgiving.com/page/david-freestone-3](https://justgiving.com/page/david-freestone-3)**

## Books



### The Adaptive Carer Model

A new guide aims to support carers as the needs, abilities and relationships of a person with dementia change over time.

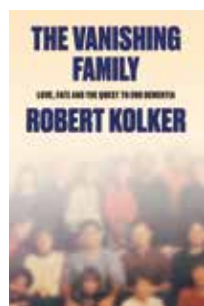
The Adaptive Caregiver Model offers a practical, compassionate framework that's built around the roles of guide, navigator, storyteller and companion. Subtitled 'Walking with, not ahead', it helps carers to adapt their support without losing connection, dignity or meaning.

The book is written by Andy Baker and Meghan Earle from Able Training.

It encourages readers to look beneath the surface of how a person is behaving, to find ways to respond that are more person centred and humane.

Andy, a behaviour specialist, also hosts the Able to Care podcast.

The Adaptive Caregiver Model is available from Amazon in hardback (£25), paperback (£14.97) and as an ebook (£4.97).



### The Vanishing Family

A book by a US journalist tells the moving story of a family affected by a type of frontotemporal dementia (FTD) called familial FTD.

The Vanishing Family, by Robert Kolker, explores the emotional journeys and relationships of the

family's members – those who have FTD and those who don't.

There are types of genes that can raise a person's risk of getting FTD. However, about 10 to 15 in every 100 people with FTD have familial FTD. This means they have a single faulty gene that will definitely cause FTD if it's passed down from a parent to a child.

Any child of a person with familial FTD has a 1 in 2 chance of getting this gene.

Members of the family featured in Robert's book face difficult decisions over whether to have genetic testing, and how to approach their lives either way. He also interviews clinicians, researchers and campaigners at the cutting edge of new discoveries.

**The Vanishing Family is out in hardback (£22) in bookshops from October, also available as an ebook and audiobook.**



### Poems by Dad & Me

A new anthology shares poems by a woman and her 94-year-old father, who was diagnosed with dementia two years ago.

Poems by Dad & Me features works written by Lisa and Paul Frederickson, in Norfolk, that range in tone from witty to poignant.

While Lisa is an award-winning author, this is Paul's literary debut.

They call poetry their 'family superglue: a quiet anchor, a secret handshake better than dad dancing and sweeter than homemade apple crumble'.

**Poems by Dad & Me is available from Amazon in hardback (£12.99), paperback (£9.99) and as an ebook (£4.98), and half of profits from its sale will be donated to Alzheimer's Society.**

## Compare+ Travel Insurance tool

A new online tool helps you to find travel insurance, including special guidance about cover for people aged over 65 or with pre-existing health conditions.

Compare+ Travel Insurance is available through MoneySavingExpert, the consumer website founded by financial journalist Martin Lewis.

The tool guides you through a set of questions, letting you know what kind of impact each response could have in the price of cover. If someone travelling has a health condition, it will also ask medical questions before giving you results that compare available insurance products.

Martin advises making sure you've got travel insurance as soon as you book a holiday – otherwise you may not be covered if something happens before your trip that means you can't go.

**Try the Compare+ Travel Insurance tool at [moneysavingexpert.com/travel](https://moneysavingexpert.com/travel)**



### The Mobiles: LockedIn

A band who reformed 44 years after their debut single are raising vital funds to beat dementia with their latest release.

The Mobiles are donating proceeds from downloads and streams of LockedIn to Alzheimer's Society.

David Blundell, who plays bass and keyboards, said, 'LockedIn is written from the very personal perspectives of how Alzheimer's has directly affected members of the Mobiles'.

**To find out more and to listen to LockedIn, see [themobiles.co.uk](https://themobiles.co.uk)**

# Here for you

**This is the last issue of Dementia together magazine, but you can still keep in touch with Alzheimer's Society and other people affected by dementia.**

## What is changing?

This is the final issue of Dementia together magazine.

If you currently receive your copy of Dementia together through the post, from January you'll get Society magazine twice a year instead. Find out more about Society magazine on page 38.

People who get the email version of Dementia together will get Alzheimer's Society's regular support email twice a month instead from October.

Those who receive Dementia together on audio CD, for blind and partially sighted people, will get Society magazine on CD instead.

If you want to change your details or have a query about Society magazine, please email [society@alzheimers.org.uk](mailto:society@alzheimers.org.uk) or call **0330 333 0804**.



## How else can I stay connected?

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 service (see pages 22–23) 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](https://www.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 and 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](https://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](http://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 advice, resources, real stories and more.

Visit [alzheimers.org.uk](http://alzheimers.org.uk) and scroll down towards the bottom of the page, where you can sign up by entering your email and name.

### What if I need advice about dementia?

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

For information about dementia and advice for people affected by the condition, see [alzheimers.org.uk](http://alzheimers.org.uk)

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

## All change

This final issue of Dementia together is the 150th since we first published our magazine back in September 2007.

Of course, all charity publications change over time.

The magazine was called Living with dementia until eight years ago. This originally merged two newsletters – Share, which was for carers, and Living with dementia, for people with a diagnosis. Readers had told us they'd prefer a single magazine for everyone affected by dementia, so that's what we created.

People's real-life experiences have always been at the heart of what we do.

We co-produced two special issues in 2023 and 2025. We created the first with a specially assembled panel of people with dementia and carers. To plan and create the second, we worked with the Young Dementia Thematic Group.

A big thank you to all our readers and contributors over the years!



# Society magazine

**Kelly Fisher, in Alzheimer's Society's supporter team, welcomes you to Society magazine.**



## Hello everyone!

I look forward to welcoming you to your first edition of Society magazine in January 2027.

We hope it will be something you look forward to receiving and reading too.

We publish two issues each year – a Spring/Summer edition and an Autumn/Winter edition.

Every issue is packed with inspiring stories from people affected by dementia, updates on the latest groundbreaking research, news from across Alzheimer's Society and the wider world of dementia, and information about the incredible impact your support helps make possible.

You'll also find features on projects and services such as Singing for the Brain, dementia-friendly communities and support groups, alongside personal stories from people finding their own way through life with dementia. These stories celebrate resilience, kindness, connection and hope, while honestly reflecting the realities and challenges of living with the condition. We believe that sharing lived experiences helps people feel less alone and reminds us all of the power of community.



Alongside these features, each issue includes:

- information about upcoming events and campaigns
- recipes and wellbeing ideas
- brain teasers and puzzles
- competitions
- Alzheimer's Society shop favourites
- how people deal with dementia in their lives
- and much more!

We also want Society to be shaped by the people who read it. You'll have opportunities to share your feedback through reader surveys, tell us about your own experiences of dementia, and offer tips or words

of encouragement that could help others. Whether you have a story to tell or simply want to let us know what you've enjoyed, we'd love to hear from you.

Each edition explores a different theme. Recent issues have focused on innovation, creativity, diversity and the importance of early diagnosis.

Our next issue explores the theme of community and the vital role it plays in supporting people affected by dementia.

You may have heard the phrase, 'It takes a village.' While this is often used in relation to raising children, we believe the same is true of living with dementia. Whether it's family, friends, neighbours, volunteers or local groups, no one should have to face dementia alone. Together, these connections can make a real difference to people's lives.

We hope you'll enjoy reading Society and that it helps you feel informed, inspired and connected to the wider Alzheimer's Society community. Thank you for everything you do.

If you'd like to read any of our previous editions before your first copy arrives in January 2027, or if you have any questions about the change, please don't hesitate to get in touch by emailing [society@alzheimers.org.uk](mailto:society@alzheimers.org.uk)



# Competitions



## Cognitive Books

We have a set of all three Cognitive Books for one lucky winner drawn from correct entries, while three runners-up will get their choice of one.

**Q: What subjects do each of the three Cognitive Books feature?**

- A. Geography, Biology and French.**
- B. The Beatles, the 1966 World Cup and classic Coronation Street.**
- C. Taylor Swift, the 2028 Summer Olympics and classic Gogglebox.**

Send us your competition answers with your name and address by end of 7 September – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or post to **Magazine Editor, Alzheimer's Society, Suite 2, 1st Floor East Wing, Plumer House, Tailyour Road, Plymouth PL6 5FS.**



## Rosebud reminder clock

We have a Rosebud reminder clock for one lucky winner drawn from correct entries.

**Q: How can the Rosebud reminder clock help a person with dementia?**

- A. It prompts the person to do daily tasks while clearly displaying the date and time.**
- B. It shows scenes from the movie Citizen Kane featuring the mysterious word 'Rosebud'.**
- C. It repeats clips of the Grateful Dead's Jerry Garcia playing his guitar, named Rosebud.**

## June/July winners and answers

### Chatsie smartphone

T Davidson in Bristol won a Chatsie smartphone. **Answer:** A trusted friend or family member can use the code you send them with your Chatsie smartphone to access your phone's settings through a website.

### Forget-me-not socks

L Appleby in Tyne and Wear, G Cook in Herefordshire and S Wann in Lancashire each won a pair of Forget-me-not socks. **Answer:** There are five petals on each forget-me-not flower used in Alzheimer's Society branded products.

### Anagramword

**Across:** Puffins, cormorants, seagulls, pelican, kittiwakes (though this should have been kittiwakes!), guillemot, fulmar.  
**Down:** Sea eagle, Manx shearwater, storm petrel, penguins, Arctic skua, shag, albatross.

## August/September answers

### Anagramword

**Across:** Arts and crafts, chair yoga, hydration, journaling, aerobics, mindfulness, Nordic walking.  
**Down:** Singing, reading, gardening, volunteering, reflection.

**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. 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](https://alzheimers.org.uk/MemoryWalkTogether)**

