

August/September 2024

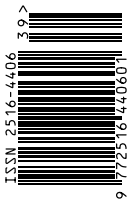
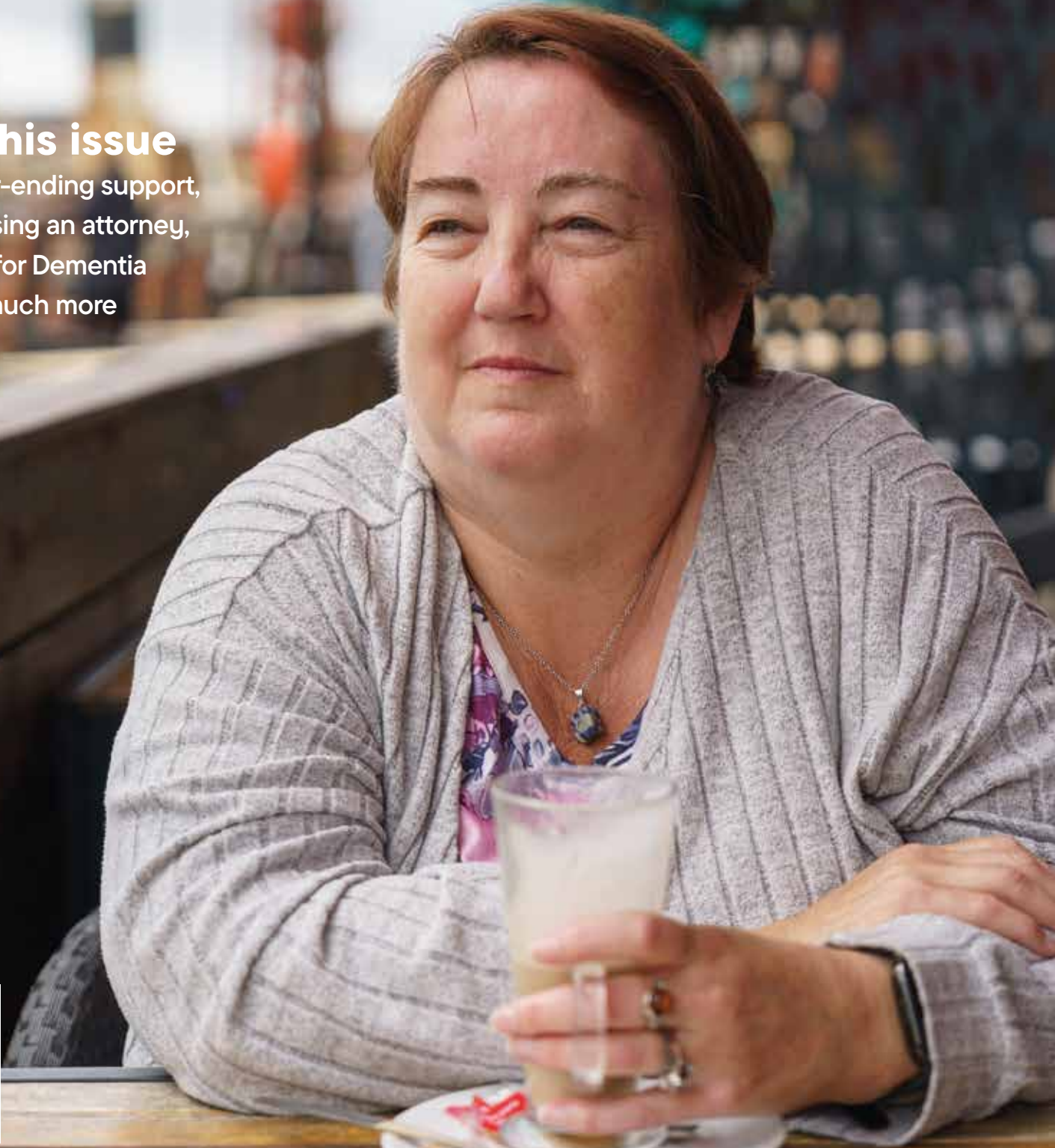
# Dementia together



Alzheimer's  
Society

## In this issue

Never-ending support,  
choosing an attorney,  
Time for Dementia  
and much more



# Welcome



I'm new to Alzheimer's Society and I've very quickly been struck by the passion and energy of our supporters.

Take our cover story about Dawn (see p8), who was initially floored by her diagnosis of young-onset dementia but now works to help other people. And there are many other inspiring people in this issue, including campaigner Edward (p16) and Memory Walk devotees Michelle (p17) and Suki (p30).

As well as their stories, we're sharing tips on choosing an attorney (p15), challenging a care home's notice to leave (p34) and dealing with hot weather (p35). Plus, we visit Sheffield's hub for African and Caribbean communities (p24) and our consumer panel tests dementia-friendly books and games (p20).

I hope you enjoy reading this issue as much as I did working on it. As always, we welcome your feedback and ideas, so get in touch if you have anything you'd like to share.

**Antonia Kanczula, Deputy Magazine Editor**



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

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## Directions

**I**t's amazing what we can achieve together. So many of you added your voice to our campaigning in the lead-up to the general election – you made dementia unignorable for a great number of candidates and newly-elected representatives.

We're keeping up the pressure on decision-makers so we can see much-needed changes in health and social care. We'll work with anyone at any level to make this happen.

Time for Dementia (see p22) is just one example of this, creating a new generation of professionals who better understand the impact that dementia has on people's lives. Of course, the key is connecting them with people who can share its day-to-day realities at a crucial point in their education.

We're also overjoyed to have our partnership with The FA extended, and you'll see even more high-profile sports initiatives in coming months. These are incredibly effective ways to bring dementia front and centre for absolutely everyone. We can't leave anyone in any doubt about the need to face the UK's biggest killer – and that Alzheimer's Society is here to help.

I'm looking forward to seeing many of you at this autumn's Memory Walk events. What better way for thousands of us to come together to celebrate, remember and be inspired?

**Kate Lee**  
**Chief Executive Officer**  
[@KateLeeCEO](#)

# News

## New government: unique opportunity

Thanks to your support in the lead-up to July's general election, 253 parliamentary candidates from all major political parties pledged to make dementia a priority. Of these, 22 were elected as MPs.

James White, Head of National Influencing at the Society, said, 'Dementia is the UK's biggest killer and our greatest health and social care challenge.'

'This new government has a unique opportunity to transform the lives of those living with dementia.'

Over 16,000 of you rallied behind our campaign calls – to achieve a more ambitious dementia diagnosis rate, to make dementia-specific training a central part of social care reform, and to ensure the NHS is prepared for new treatments.

We welcomed Labour's manifesto commitments to double the number of CT and MRI scanners in the NHS, and to improve access to research and clinical trials so we can lead the world in dementia treatment. We hope their long-term plans for a National Care Service will include provisions for dementia-specific training.

We'll be continuing our efforts to ensure the UK government fulfils its promises and delivers on our policy asks.

**Campaign with us – visit [alzheimers.org.uk/campaign](https://alzheimers.org.uk/campaign)**

## Memory Walk 2024

Come together with family, friends, four-legged companions and thousands of others at Memory Walk this autumn.

It's free to sign up and you're guaranteed an uplifting experience as you contribute to a future free from dementia.

**Find your nearest event or learn about hosting your own walk at [alzheimers.org.uk/memorywalk](https://alzheimers.org.uk/memorywalk) or call 0300 330 5452.**



# Trekking triumph

This has been a year of epic Trek26 events. Across 10 breathtaking locations, including Snowdonia, Lake District and Stonehenge, over 11,000 of you raised an incredible £4 million (and counting) to help transform dementia research and care.

We're already planning next year's Trek26, and you can save 20% if you register now with our code.

Sign up using the code **TOGETHER20** by 1 October for 20% off your registration fee – see [alzheimer.org.uk/trek26](https://alzheimer.org.uk/trek26)



## NI care pathway

We're working with others in Northern Ireland on the Regional Dementia Care Pathway Project Board to make the pathway a reality.

As the board plans next year's work, we're championing the voices of people living with dementia, with support from others including Dementia NI and DEEDS (Dementia Engaged & Empowered Derry & Strabane).

The pathway sets out the support a person with dementia should receive, and we aim to make sure our key calls to action are heard.

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## NCSS progress

We've been working hard to influence the Welsh Government's plans for a new National Care and Support Service (NCSS).

Fiona Carragher, our Director of Research and Influencing, has met with Dawn Bowden, Minister for Social Care to discuss a range of developments. This included the foundation of the National Care and Support Office and adoption of a National Framework for Commissioning Care.

We're calling for people living with dementia to be at the heart of designing, delivering and evaluating services provided by the NCSS.

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## Regional action

Local dementia strategies can ensure that people's needs are better met.

In Suffolk, we've worked with the local authority to develop its strategy. From prevention and early diagnosis to end-of-life care, it aims to tackle stigma and provide the right support at the right time.

We'll be working to make sure this strategy is implemented with meaningful participation from people living with dementia.

We plan to work with other local authorities and care systems to help deliver further regional strategies around England.

## New Lead Research Nurse

The Society has appointed a Lead Research Nurse for our new three-year programme to increase participation in clinical trials. Helping more people living with dementia to take part means we can speed up the development of life-changing treatments and care.

Laura Rooney takes up the post with lots of experience and a passion for getting more people involved.

'I know that when a person receives a diagnosis of a terminal disease, they can feel they have lost control over their own life,' says Laura.

'I have also been privileged to see how the opportunity to take part in a clinical research study can offer hope and how it can help people take some control back in the face of a frightening diagnosis.'

We're now recruiting up to 10 dedicated Research Nurses. Based around the UK, they'll work to reduce the barriers that can prevent people taking part in trials.

## Global unity on dementia

Each September, people around the world unite to raise awareness about dementia for World Alzheimer's Month.

This year's theme is 'Time to act on dementia, Time to act on Alzheimer's'. It will focus on attitudes towards dementia, and tackling the stigma and discrimination faced by many people living with the condition.

We'll be joining the global action with special activities during the month, including on World Alzheimer's Day, 21 September.

Find out how you can get involved at [alzheimers.org.uk/WAD](https://www.alzheimers.org.uk/WAD)

## CBRE bike ride success

The Great Property Bike Ride in June welcomed more than 600 cyclists, riding up to 122km while raising funds for the Society.

The event, at Sandown Park Racecourse in Surrey, was hosted by property company CBRE, who launched a charity partnership with us earlier in 2024. In its first six months, CBRE's UK Advisory business has raised over £325,000 – more than half of its two-year target.

By joining forces with CBRE, we want to reach thousands more families affected by dementia and their fundraising efforts allow us to achieve this.

## Society at Pride

This summer, we're at Pride events around the country to celebrate our commitment to supporting LGBTQ+ people affected by dementia.

Starting from Pride month in June, our staff and volunteers joined events in Blackpool, Belfast and many other locations to highlight the importance of inclusive and relevant dementia support.

We'll be at Pride events throughout the rest of August and September, including Leicester, Milton Keynes and Herts Pride in Watford, so come and say hello if you see us.

Find out more about living with dementia as an LGBTQ+ person at [alzheimers.org.uk/lgbtq](https://www.alzheimers.org.uk/lgbtq)



## New Easy Read resources



Dementia can be difficult to understand. But it's important that everyone can recognise dementia symptoms, know how to get a diagnosis and have access to care and support.

Our new Easy Read resources have been co-produced with people who have learning disabilities and health and care professionals. Five booklets and one poster feature simple words and images to help everyone understand dementia.

Download or order print copies of the new resources at [alzheimers.org.uk/easy-read](https://www.alzheimers.org.uk/easy-read) or call 0300 303 5933.

## Early career researchers

At this summer's Early Career Researcher Retreat, we once again brought dementia researchers together at a crucial early stage of their careers. We hope to support them to stay in dementia research for the long term, so they're able to transform future treatment and care.

The annual retreat provides an invaluable opportunity to meet fellow researchers, gain peer-to-peer advice and learn practical skills that will aid in their career progression.

This June's event in Solihull featured panels, talks and workshops. A 'soapbox science' competition gave participants the chance to present their research, while a mock grant board provided experience of grant review.

Researchers also met volunteers from our Research Network, who underlined the importance of participation from people with lived experience in all stages of the research process.

## Unforgettable success



Thank you to everyone who generously donated time, money and energy to make our 2024 Forget me not Appeal a huge success!

Over 50,000 of you wore pin badges to raise dementia awareness and vital funds to deliver support and research.

The appeal was seen by over 15 million people across the UK and raised over £1.5 million, with donations still coming in.

During Dementia Action Week (13–19 May), 1,100 volunteers raised over £100,000 at Morrisons stores in our biggest-ever national collection.

However you supported the appeal, you added to our call to end the devastation caused by dementia – and we can't wait for you to join us again in 2025!

## Accelerator Programme

We're thrilled to announce two new Accelerator Programme partners whose innovative ideas we'll be helping to develop.

Memory Lane Games creates interactive games on an easy-to-use app to trigger positive memories and conversations. These cover many topics including hobbies, music and sports.

The Tasty Spoon uses electrical stimulation to help people with dementia continue to enjoy food. By doing this, it reduces the need for additional salt or sugar.

To find out more about the Accelerator Programme, visit [alzheimers.org.uk/accelerator](https://alzheimers.org.uk/accelerator)

## Get together, get inspired

Organising your own fundraising event is a great chance to get loved ones together and create memories. From pizza parties to bake sales, gigs to sponsored bungee jumps, there are so many creative ways you can raise money.

Whether you're looking for a stand-out event idea or need help promoting your fundraising, we're here to help you.

Order your free fundraising guide at [alzheimers.org.uk/organiseyourown](https://alzheimers.org.uk/organiseyourown) or call 0330 333 0804.

## Common goals

The Football Association (FA) has extended its charity partnership with us until July 2025. This will be our fourth year of working together.

We've already achieved so much, using the power of football to raise over £870,000 and to spread awareness of dementia symptoms and the importance of getting a diagnosis. We can't wait to see where the partnership takes us next.

Kate Lee, our CEO, said, 'We are determined to use this unique platform to continue striving for a future where football is unforgettable.'

For more about our partnership with The FA, visit [alzheimers.org.uk/FA](https://alzheimers.org.uk/FA)



## Up for an Ultra Challenge?

Join an unforgettable 25km, 50km or 100km fundraising Ultra Challenge this autumn and winter.

Choose your distance and pace, and immerse yourself in amazing scenery among some of the UK's most iconic landscapes, such as the south coast and the Chilterns.

We're with you every step of the way whether you walk, jog or run – your entry includes food and drink at regular rest stops and support, including massage therapy.

If you're ready to challenge yourself, head to [alzheimers.org.uk/actionchallenge](https://alzheimers.org.uk/actionchallenge) or call 0330 333 0804.



## Don't miss...

Artwork, poetry, online workouts, webinars and more to inspire you. See p12.

Advice about deciding who to appoint as an attorney to make decisions on your behalf. See p15.

Brain stimulation technology being tested thanks to the participation of people with dementia. See p18.

People tell us what they think of Cognitive Books and the Matching Memories game. See p20.

Readers share advice about supporting a person with dementia during hot weather. See p35.

# Never-ending support

Dawn Davies' dementia diagnosis was a massive shock, but local support helped her turn things around. Margaret Rooke speaks to a woman now giving back to others.



## Quick read

Dawn Davies, in Swansea, has dementia and wants to stay active as much as she can.

Being diagnosed with young-onset Alzheimer's two years ago was a massive shock for Dawn.

She went through a very tough period, before getting invaluable support from the city's Dementia Hwb.

Dawn now works at the hwb, helping other people deal with life after a dementia diagnosis.



**W**hen Dawn Davies was diagnosed with dementia at just 62, she thought her life was over.

'I was in total shock, absolute total shock,' she remembers.

It's only two years since Dawn's partner Brian talked to her about her memory problems.

'When he asked me about something I'd forgotten, my answer was always, "I don't know, I've slept since then." Then he said to me in a jokey way, "You're losing your marbles, love."

### Massive shock

Dawn and Brian went to the GP for her to have a memory test. She was then sent for a CT scan, and the results changed her life forever.

'I was told there were changes in my brain,' says Dawn, who responded by shutting down from the world around her, including her daughter who was at her side.

'We went from the clinic to get a cup of coffee and I didn't realise my hand was shaking, until she told me to put the cup down.

'It was a massive, massive shock. I'd been to the clinic, was given a diagnosis and then I had been left to deal with it.'

Dawn went back home.

'I sat on the sofa and went, "Don't talk to me. Don't look at me. Just leave me alone,"' she says.

'I didn't want to shower, I didn't want to eat, I didn't want to go anywhere, I didn't want to deal with people.

'I was a bit of a living nightmare to my family. I told Brian to leave me and find someone else.'

Brian did his best to encourage Dawn to eat and to leave the house – just to set foot in the park on their doorstep. She wouldn't. The idea of

leaving the house and interacting with people terrified her.

'I was angry at the world, and I felt like a burden,' says Dawn. 'I had always been quite a bubbly person, chatty and friendly, and I sort of withdrew.

'I blamed myself for having this condition. The anger kicked in and I kept asking, "Why me?" which is quite selfish when other people are going through so much worse.

### Finding the hwb

One day Brian took control. He told Dawn they were going out for a walk, and he took her straight to the Dementia Hwb in Swansea's Quadrant Shopping Centre.

'I walked in here and spoke to a beautiful lady, and told her I had young-onset Alzheimer's,' Dawn remembers.

Dawn wondered whether the lady was being a bit patronising – until she said she'd had it herself for the past 10 years.

'I said, "You don't look like you have," and then I wanted to take the words back. I felt so stupid,' says Dawn.

'But she just laughed and said, "Well what am I supposed to look

“  
**I was angry at the world and felt like a burden. I had always been quite a bubbly person, chatty and friendly, and I sort of withdrew.**”

like?" and I thought, "Well yeah, you don't wear it as a badge; you don't have a neon sign on your head."

'I came in a few times, and each time they were wonderful. The support has been never-ending.'

### Listening ear

The Dementia Hwb is the place to go for a listening ear, a tissue or 10, a cup of tea and a biscuit, and a bucketload of understanding.

The knowledgeable hwb team is joined by experts from other organisations. They feed in information and services, on anything from respite care to help at home.

The range of those walking through the door – from across Wales and England, and even tourists from South Africa, America and Australia – shows how lucky Swansea is. The beauty of it is that it's there for anyone to spot on their way to Costa or New Look.

Often it's carers who walk in, looking for guidance and understanding. It can also be someone like Dawn with their own diagnosis, or professionals wanting information or someone getting leaflets for a friend in need.



## Giving back

As Dawn began to recover from the initial shock, she decided she wanted to start giving back to the charity. She started volunteering and learned so much from her new colleagues.

Then came the possibility of a job. Dawn had previously worked as a cleaner, and when she told her employers about her diagnosis, they immediately tried to get rid of her. She resigned.

‘The lack of support did it for me,’ she says. ‘I thought, if they can’t support me at the beginning, how are they going to support me when things progress?’

In her time, Dawn had worked in all sorts of places. She’d worked as a receptionist and bartender, as well as in silver service, residential care and at a car factory. After her last employer’s response, she thought no one would ever employ her again.

## New role

When the charity told her they were creating a new job, Buddy Project Coordinator, no one could be more suited for the job.

‘People who are first diagnosed come here and have a one-to-one appointment with me because I’ve gone through and I’m going through what they are.

‘It’s sometimes easier for them to talk to somebody who has the condition,’ says Dawn.

She treats everyone who comes to see her in the same way she was treated – ‘like a normal person, with feelings’.

‘If one person comes in a bit stressed, worried or scared and I can make them feel a little bit better by the time they leave, I’ve done my job.

‘People who come here sometimes feel they’ve been lost in the system. They feel alone. We show them they’re not.’

“

**When I look to the future I’m going to carry on as I am and enjoy life as much as I can. I’m going to enjoy my grandson, my sister, my children, my friends.**”

## ‘Wobble days’

Life isn’t all easy, Dawn admits.

‘I still have my wobble days. I still have the odd times when I think, “Do I want to be living with this?”

‘Sometimes I hear people making stupid comments about Alzheimer’s, and I think, “Unless you’re actually living with it, you haven’t got a clue.”





'I've had people cross the street to avoid me, and some so-called friends don't contact me any more.

'It's OK. People don't know how to deal with this sort of thing. They don't know how to talk to you. There's a stigma and that's what we need to remove.'

Generally, though, life is on the up.

'It seemed all I had to look forward to was a bleak future,' says Dawn, who now sounds inspired and full of ideas.

### **Intentionally busy**

Dawn runs her own business, making pictures, jewellery, bookmarks and glasses cases using diamond painting, and selling them on Etsy.

She walks with Brian along the seafront. She's planning a trip to Glastonbury – the town, not the festival – with her sister, and has a girlie weekend sorted with one of her closest friends.

With Brian, she's also co-director of a social enterprise called the Welsh Inclusion Sports Association. They make sure people with disabilities and health conditions aren't left 'sitting on the bench' at matches but can always be part of the game.

The busy schedule is intentional.

'I can be the world's most lazy person, but if I'm not doing something, I know I'll sit and overthink things,' Dawn says.

### **Carrying on**

Dawn remembers tough phone calls with her mum, who had vascular dementia in her 70s. She doesn't want her two children to experience the same thing.

Both have been wonderful, as has her grandson. He once happily suggested to Nanny Dawn that they could go and look for her 'lost marbles' together in the park.

They and others have all helped Dawn keep positive.

'You can still have an active life, a very normal life. You just have a health condition that you've got to take extra care with.'

Dawn is a tremendous role model.

'When I look to the future I'm going to carry on as I am and enjoy life as much as I can,' she says. 'I'm going to enjoy my grandson, my sister, my children, my friends.'

Then of course, there's her partner.

'He's my rock,' says Dawn of the former postman who fell in love instantly when he saw her.

There might be another rock on its way too, this one more sparkly – that's the final plan.

'One of these days,' says Dawn, 'I will finally get married to my beloved Brian.'

For more about Swansea's Dementia Hwb, see [www.dementiafriendlyswansea.org](http://www.dementiafriendlyswansea.org) or call **01792 304519**.

To find support near you, visit [alzheimers.org.uk/dementiadirctory](http://alzheimers.org.uk/dementiadirctory) or call **0333 150 3456** for personalised advice.

## **Donate**

**Donate today so we can continue to be there for Dawn and others like her after a dementia diagnosis. [Donate online.](#)**

# Share and inspire

Views, updates and ideas – for and by you.



## 3NDWG on YouTube

You can now watch webinars from 3NDWG (the 3 Nations Dementia Working Group) on its new YouTube channel.

Each month, a panel of people living with dementia, caregivers and professionals come together on the webinars to share valuable insights, personal stories, expert advice and updates.

Visit [www.youtube.com/@3NDWGwebinars](https://www.youtube.com/@3NDWGwebinars) and click 'subscribe'.

Find out more about joining 3NDWG at [alzheimers.org.uk/3ndwg](https://alzheimers.org.uk/3ndwg)

## Interested in research?

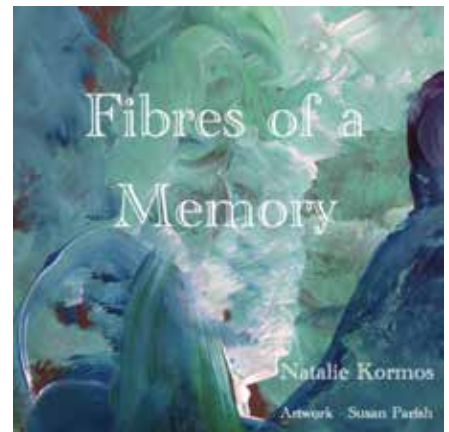
Volunteer with our Research Network to make sure the research funded by Alzheimer's Society continues to be informed by the realities of dementia.

Research Network volunteers draw on their lived experience to help develop and monitor dementia research. They do this in many different ways, so there are various ways you could get involved.

Find out more about becoming a Research Network volunteer – email [yoursay@alzheimers.org.uk](mailto:yoursay@alzheimers.org.uk)



Share your views, feedback and news – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on page 2. We can consider contributions received by 4 September for the October/November issue (wording may be edited).



## Fibres of a Memory

The artwork of a Canadian woman who had posterior cortical atrophy (PCA) features in a new book called *Fibres of a Memory*.

Paintings created by the late Susan Parish as art therapy are used throughout the book from writer Natalie Kormos.

The large print, lyrically rhyming story follows the perspective of a man living with Alzheimer's, his emotions, relationships and interactions.

Natalie says, 'I hope that this book can provide comfort and support to its readers, that it can encourage conversations between generations to discuss experiences, challenges and emotions, and that it can inspire creativity through its words and artwork.'

PCA is a rarer form of dementia that mainly affects the back of the brain at first, and a person's initial symptoms are often related to vision. *Fibres of a Memory* is available as a 38-page paperback for £9.59 from [Amazon.co.uk](https://www.amazon.co.uk)



## Home exhibition

A four-month art collaboration including people with dementia will culminate in an exhibition called Home at the Royal Hospital Chelsea in west London this September.

Chelsea Pensioners and members of Loveday, a residential care provider, are exploring their emotions, memories and perceptions of home at weekly art workshops. These are led by illustrator and creative educator Grace Holliday, in a programme developed with researchers with the University of West London's Geller Institute of Ageing and Memory.

Grace says, 'As cognitive decline progresses, memories associated with home, such as family gatherings, familiar surroundings and cherished moments, can become increasingly important and we want to honour this. We are all so excited to create "Home".'

The exhibition will be at the Soane Stable Yard, the Royal Hospital Chelsea from World Alzheimer's Day on 21 September.

Visit [www.lovedayandco.com](http://www.lovedayandco.com) or call **020 4530 4652** to find out more.

## Feel Good with Lavina



Join Society Ambassador Lavina Mehta MBE and her 76-year-old mother-in-law for free Friday workouts, streamed live online and designed for all ages and abilities.

You can also get moving to countless workouts on Lavina's YouTube channel, including a dementia-friendly Mind and Brain collection.

Lavina, whose slogan is 'exercise for sanity, not vanity', helped thousands of us stay well through the pandemic.

She says, 'My maternal grandmother, my Nani, had dementia. She lost her ability to communicate, but I used to sit with her and sing prayers to her and brush her hair.'

'Because of my Nani I'm passionate about raising awareness and understanding of dementia, particularly in the South Asian community, and about promoting the health benefits of exercise to treat, prevent and reduce the risks of dementia.'

Sign up to Lavina's free newsletter at [www.feelgoodwithlavina.com](http://www.feelgoodwithlavina.com) or visit [www.youtube.com/feelgoodwithlavina](https://www.youtube.com/feelgoodwithlavina) and hit 'subscribe'.

See Lavina's book *The Feel Good Fix* for fun and effective bite-size 'exercise snacks' for health in perimenopause, menopause and beyond, which includes a section on brain health and Alzheimer's.



## Dementia... Life Goes On

A group of people with dementia in Wakefield have created a video to help others adjusting to life after a diagnosis.

Voices Together, the local Dementia Voice group, worked with the Society and local dementia support services to share their experiences and inspire others.

People finding out about Wakefield's memory service will see group members talk about the challenges of life with dementia, but also the difference that coming together has made to them.

Group member Phil Burton says, 'With diagnosis your life changes completely, but it's not all doom and gloom.'

Watch *Dementia... Life Goes On* at [www.youtube.com/alzheimerssociety](https://www.youtube.com/alzheimerssociety)



## Give your brain a workout

See page 38 for a Memory Walk themed 'anagramword' from Pete Middleton, plus 'Codebreaker' from July's Brain Workout puzzle pack.

# Time in nature

**James Spinks, who lives with dementia in Surrey, shares how spending time in nature keeps his brain and body active.**



**A** while ago, I bought some woodland with hopes of developing something there when I retired from my work at Trading Standards.

But when I was about to retire, an unexpected opportunity arose. Work really took off when some of the smaller countries joined the European Union and I helped them to find the experts they needed.

I initially bought three acres of woodland with a six-acre field at the back. But by the time I'd finished work, nature had taken its course.

I visited one day and thought, 'What are those spikes coming out of the ground?' Of course, they were trees. So now I have nine acres of woodland!

## Keeping active

I was diagnosed with dementia around seven years ago. I sometimes have to be careful about what I say or do, and my memory is short.

Other than that, I've been able to manage very well, and the woodland helps.

I had to surrender my driving licence, so my wife Julia drops me off there around once a week – with lunch of course! This depends on the weather, but I do have a shed to protect me from the elements.

There's always something to do, like clearing up after storms, collecting logs for firewood or repairing the boundary fence.

I also make sure the deer can leap over, so they've always got access through the wood.

## Staying safe

I carry a mobile phone in case something happens when I'm alone.

I also have a GPS tracker on a necklace. Julia can access my location on her mobile phone and see exactly where I am.

This is handy as you can imagine trying to find me somewhere in nine acres of woodland would be quite difficult!

The woodland is also relatively close to home, about six or seven miles away.

## Stress free

The woodland is a good place to relax and be active, otherwise I'd sit around too much and get very down.

The woods are particularly wonderful at bluebell time, when they're carpeted in acres of blue flowers.

We've set up an automatic wildlife camera there. The deer use the woodland as a corridor, and occasionally we see badgers and rabbits on the film.

It's all been quite interesting to see what they get up to when I'm not there.

## Space for groups

We have also used the space for hosting members of the University of the Third Age and gardening groups.

They come along and we talk about all the nature and the woodland, with tea and cake provided by Julia of course.

Dementia is really not on my mind when I'm enjoying myself in the woods – except if I leave a wood saw or tools somewhere. Trying to find them again can take ages!

**Is there an aspect of living with dementia that you'd like to share? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2.**

# Choosing an attorney

Deciding who to appoint through a power of attorney, so they can make decisions on your behalf.

**W**ho would you trust to make important decisions on your behalf?

Who knows you well enough? Are they reliable? Do they have the skills to make the decisions you might need them to make?

How well do they manage their own finances or make decisions about care?

## Powers of attorney

In England and Wales, you can appoint someone to make decisions about your property and finances through a lasting power of attorney (LPA). You can set up a separate LPA for someone to make decisions about your care and medical treatment.

In Northern Ireland, you can appoint someone to make decisions about your property and finances with an enduring power of attorney.

Whichever legal tool you use, you might not need the person to act as your attorney until much later on. If you're appointing a relative or friend, will they still be in a position to do this then?

## Responsibility

Before you appoint someone as your attorney, make sure they're happy for you to do it. You can also tell them about things important to you that might affect future decisions.

If you appoint more than one attorney, they can share the responsibility between them. But make sure they get on!

If you don't know anyone you'd want to appoint for property and finance decisions, perhaps ask an accountant or solicitor about doing this instead.

## Your tips

'I chose friends I trust with my life. I know they will make good decisions for me. They know the care homes where I am happy to go when time comes and will sort it out.' **Sam50**

'Just the person you love and trust, simple as that.' **KevinI**

'You can't predict every eventuality that an attorney might face, or every decision they might need to make.

'You don't know how life's going to evolve, and there are only so many preferences and instructions you can write in the LPA form. You can't legislate for every single situation that they may encounter.

'So, you have to rely on their judgement – and how well they know you and how you might feel about something – in order to exercise your wishes. They're going to have to step into your shoes and know what you'd want. What would you say, what would you think if something came up?

'People are often quite surprised that an attorney doesn't have to be a family member. You can appoint more than one original attorney, but you can also appoint a replacement attorney who can step in if the original attorney can no longer act.' **Shiela Ajimal, LPA digital assistance volunteer**

Visit [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call **0300 303 5933** for our Lasting power of attorney (472) factsheet for England and Wales, and Enduring power of attorney and controllership (NI472) for Northern Ireland.

If you're unable to make an LPA online, the trained volunteers on our digital assistance service can't offer legal advice, but they can help by completing online forms. Call our support line on **0333 150 3456** to find out more.

# In the spotlight

Sharing your story with the media is an effective way to help create change. This doesn't have to be intimidating and we're here to help.



**P**eople like you are key to achieving positive change for everyone affected by dementia.

There are many different ways to campaign, but speaking to a local newspaper, magazine or radio station – or even to national media – can be extremely effective.

It might sound like an intimidating thing to do, but we support people who are doing it throughout.

Without hearing from people with direct experience of dementia, politicians and the public often don't understand its devastating impact.

## Advocating for people

Edward Wilson, who lives with young-onset Alzheimer's in Belfast, is using his voice to campaign for improved diagnosis.

Earlier this year, after helping to make a film shown to members of the Northern Ireland Assembly, Edward was interviewed by ITV.

'Throughout my career I've advocated for people,' Edward says. 'I once worked in a homeless hostel and became a social worker supporting people with mental health conditions.'

'I'm using my experience to advocate for people with dementia – especially those who aren't able or confident enough to speak for themselves.'

## Diagnosis challenge

Edward wants healthcare professionals to be more aware of the signs of dementia, and to ask for advice or a referral when they're unsure.

'Getting my dementia diagnosis was very challenging,' he says.

'I first noticed issues with my memory when colleagues mentioned that I was repeating myself and forgetting things.'

'Like many people I was working at home during Covid, so I was able to mask the symptoms.'

Edward visited his GP three times and was eventually prescribed antidepressants.

'After three years of the antidepressants not working, I insisted that I be sent to a specialist and was eventually diagnosed with Alzheimer's.'

'I know GPs are busy, but I think it would be useful to encourage them to think differently or even pick up the phone to dementia experts if they're in doubt.'

## 'For as long as I can'

Since receiving his diagnosis and being prescribed medication, Edward says things have improved.

'I need well-established routines, but I can still cook, drive and do DIY,' he says. 'I've got a to-do list in the kitchen which my wife writes on, but I'm brilliant at forgetting to read it!'

'Alzheimer's is a progressive condition. As time goes on, I will lose more of my memory and other abilities.'

'I will campaign for as long as I can.'

## You're an expert

Edward's advice to anyone who wants to campaign would be to get in touch with an organisation like Alzheimer's Society.

'People affected by dementia are at the core of what they do, and they'll involve you in a way that suits you,' he says.

'You're an expert by experience and you're equally as essential and important as experts by profession.'

## Be a campaigner

Visit [alzheimers.org.uk/campaign](https://www.alzheimers.org.uk/campaign) to find out how you can make positive change for people affected by dementia and be the first to know about new campaigns.



# Walking together

**Michelle Spratt in Wokingham, Berkshire, is looking forward to Memory Walk this autumn – it's become a family tradition.**



**W**e started doing Memory Walks as a family in 2017 and have since been to lots of different ones, including Cobham, Guildford and Windsor. We even cut the ribbon to officially open the walk at Windsor in 2023.

Dementia is a topic that is very close to my heart because my dad, John, lived with the disease for 18 long years.

## **'Pops'**

Everybody loved Dad and wanted to be around him. He was a true gentleman and an exceptional parent.

He had a passion for country and western music and loved to teach people – whatever their age and ability – to line dance in his Stetson hat and western boots.

When I was growing up, my friends would love coming to our family home and they always enjoyed a natter with Pops, laughing at his jokes and silly sense of humour.

It was bewildering and heart-wrenching to witness my dad's dementia progress. Vascular dementia stole Dad from our family,

and I have struggled to find a way to remember the way he was before this.

## **Slow progression**

For a long while, Dad's dementia progressed slowly. But as time went by, the disease gained ground.

He would often say inappropriate things in public, which was difficult for my Mum. She was his sole caregiver and had very little support. She cared for him with endless patience and determination.

A lot of their friends – and they had many – slowly disappeared and the Christmas cards stopped coming, perhaps because people didn't know what to say and so decided to distance themselves from our family.

## **Day to remember**

Memory Walks have become a family tradition for us, much like going to the pantomime every Christmas is a tradition for some families.

It's a day to come together with like-minded people and it's a good way for our children to remember their grandad. They write little messages to put on the 'memory tree'.

When a person is diagnosed with dementia, it affects the whole family in different ways.

Memory Walks are a good opportunity to come and be with people who know exactly what you're going through.

It also allows time to reminisce and remember those people that are perhaps no longer here that were impacted by the disease.

## **Looking forward**

Our family looks forward to our Memory Walk every year and we will continue to go for years to come – even though Dad has been gone for five years.

The atmosphere on the day is incredible and it's heartwarming when you arrive to a sea of blue T-shirts.

It's important that we continue to unite against dementia, and that we fundraise and raise awareness as much as we can.

**Join thousands of others at Memory Walk this autumn – visit [alzheimers.org.uk/memorywalk](https://alzheimers.org.uk/memorywalk) or call 0300 330 5452.**

# Research: Stimulating change

**People living with Alzheimer's are helping researchers test a brain stimulation technique that could lead to future treatments.**



**Nir Grossman and Nigel Whiteley**

**Even the most exciting technological developments need the participation of people with lived experience if they're to succeed in the real world.**

Nir Grossman, a researcher at the UK Dementia Research Institute, is pushing the bounds of what's possible in treating the diseases that cause dementia. Yet he underlines how the impact of his team's work depends on insights they gain from people living with dementia.

'As well as people participating in the study, we've also had workshops to hear from patients, carers and families,' he says.

## Headset

Nir's team is developing a headset that can stimulate areas deep within the brain without using anything invasive, such as surgical implants.

'We need to know – if we're going to succeed in this – what people's concerns are, what their expectations are. Their input has been very, very helpful for us.'

The prize-winning innovation behind Nir's research is called temporal interference (TI) brain stimulation. This uses harmless electric fields, precisely targeted to affect what cells in specific parts of the brain are doing.

'The particular structure in the brain we are interested in is called the hippocampus,' says Nir. 'This area is pivotal for the operation of our memory and other functions.'

Having already proved the technique is safe to use, Nir's team is testing TI in people with either mild cognitive impairment or early stage Alzheimer's.

Memory loss is a common initial symptom of Alzheimer's because the disease usually affects the hippocampus and connected areas first. The idea is to use TI to regulate the activity of brain cells in ways that help them to function well for longer.

The study is seeing how TI could help people's dementia symptoms – reducing how much it affects their memory and thinking. However, in the longer term, Nir hopes it could eventually offer more than this.

'Our vision is to create a disease-modifying intervention that not just improves the symptoms, but really changes the course of the disease.'

## Opportunity to take part

Nigel Whiteley heard about the opportunity to take part in Nir's study through Join Dementia Research. Through this programme, you can register to hear about studies that are looking for people like you.

'Research work was something I myself had done in a London hospital decades ago,' says Nigel, who now has Alzheimer's. 'I know the importance of research.'

'I soon realised that I was just the right type of person these researchers were looking for.'

Taking part involves Nigel doing memory and thinking tests while his brain cells are stimulated.

'It's interesting to learn a bit about what the researchers can see on a screen,' he says, 'which indicates to

them what is going on in a part of my brain as I carry out various tests.'

## No reservations

Although it takes time and concentration – and occasionally feels repetitive – Nigel understands that it's the only way to make progress.

'Having done research work myself, I know that it is essential to repeat a test in the same way as before, except for changing just one thing each time.'

Nir's study is looking for more participants, and Nigel has no reservations about encouraging others to see how they could help.

'If you can set aside the time to be a "guinea pig" in research work on Alzheimer's disease, then do volunteer.'

'How else can we find a potential cure, unless we volunteer to give our time and efforts for research?'

**Find out how you can get involved in all kinds of dementia research. Call 0333 150 3456 and ask for the Join Dementia Research helpdesk, or email [joindementiaresearch@alzheimers.org.uk](mailto:joindementiaresearch@alzheimers.org.uk)**

# Understanding resilience

**By learning more about how the brain adapts to damage, we may be able to help people stay healthier for longer.**



**F**or Kamen Tsvetanov, at the University of Cambridge, dementia research is like solving a complex puzzle – it benefits from many different perspectives.

‘Dementia is complicated and needs experts from different fields to work together,’ he says. ‘I thought my expertise in engineering and brain science could be useful.’

‘Just like how everyone worked together to fight polio in the past, we need scientists, doctors, patients and families all working together.’

Kamen is a senior postdoctoral researcher in the cognitive neuroscience of ageing and dementia. His Alzheimer’s Society fellowship has provided more than funding.

‘It gives me what I need to complete my journey and make a significant contribution to the dementia field.’

‘This fellowship isn’t just about getting funds, it’s personal. It’s like having the voices of people affected by dementia and Society supporters alongside me on this research journey.’

## Reframing resilience

Kamen’s focus is on how people’s brains can adapt to damage caused by diseases such as Alzheimer’s. This means the damage may not affect their cognition – things like memory and thinking – as much or as quickly.

‘I try to understand how the brain stays resilient in the long period before any symptoms of dementia show up, and what leads to their eventual decline in cognition,’ he says.

‘I use new ways to examine brain scans at all ages. I assess when the brain starts to lose tissue and when different parts of the brain stop “talking” to each other.’

‘To understand this better, I use fancy maths to study brain information from lots of people who have dementia or might get it.’

‘I also look at where and when changes happen in the brain. Then I link this information to differences in people’s genes and how healthy the blood supply is to their brains.’

## Optimism about the future

Kamen is excited about his work inspiring people to make changes that help to protect their cognitive wellbeing.

‘If we can help people know what to do to keep their brains healthy, we might be able to stop dementia for lots of people and keep them mentally sharp for longer,’ he says.

‘People in their 40s, 50s and 60s might start thinking differently about their health. They could make better choices that could push back dementia.’

‘I hope we’ll soon have practical steps ready to go into clinical practice, allowing us to find out who might get dementia and help them avoid it.’

## Team effort

Kamen wants Alzheimer’s Society supporters to feel as hopeful as he does.

‘By supporting dementia research, you’re part of a team effort to create a future where we might stop dementia before it starts or treat it much better.’

‘Every bit of help, every shared experience, brings us closer to beating dementia and changing brain health for everyone.’

‘Hearing stories from people with dementia and their families really touches me, and I feel that by doing this research, I could make a big difference.’

## Donate

**Donating today will help us to fund more researchers like Kamen who can help determine the causes of dementia. [Donate online.](#)**

# Consumer panel: Read, play, chat

People living with dementia tell us what they think of products specially designed to prompt conversation and reminiscence.

**H**orsham Rusty Brains is a group of people with dementia who meet monthly to share news, views and ideas. It influences a range of work in the West Sussex town, and it's one of many Dementia Voice groups whose members have a say in what we and others do at a national level.

We took two Cognitive Books and the Matching Memories game – all available in our online shop – to the group to get their opinions.

## Cognitive Books

Matt Singleton first created Cognitive Books for his dad Brian, after his Alzheimer's made it difficult for him to follow complex plots. Matt developed the idea with support from our Accelerator Programme and many other people living with dementia.

Two titles are now available, each in hardback and with a free audio download. Alongside the clear illustrations, there's a large-print narrative to enjoy time and again.

The story works whether you read the whole book (which could take around 45 minutes to one hour, including exercises), just some of it, or only the simpler summaries on the left-hand pages.



The audio version of Looking back at... The Beatles is read by actor Bill Nighy, while that for Looking back at... The 1966 World Cup comes from commentator Clive Tyldesley.

After reading Looking back at... The 1966 World Cup with others, Martin said, 'That was an amazing 10 minutes that we had. The amount I dredged up from my memory was incredible!

'It was definitely well worth doing – just great.

Each book includes other events from the era it covers. So, although Paul, Sue and Nigel were reading the football-themed book, we also got an impromptu rendition of The Hills Are Alive from The Sound of Music.

We listened to the audio downloads, which come in full and simplified versions. The Beatles audio had feet and fingers around the table tapping within moments of starting.

The group preferred the pace of Clive's narration, which was a bit faster than Bill's. There was recognition that some would appreciate a slower pace though.

Diana enjoyed the full list of songs at the back of the Beatles book. We also learned everyone's favourite band member – and a range of opinions about each of their careers following the group's break-up. While



Eddie thought the books were on the expensive side, Paul guessed they'd cost around £20, compared to their actual price of £14.99.

## Matching Memories

The Matching Memories game was developed by Matt and Emily Tyler, inspired by their family's own experience of dementia.

The game comes with two decks of cards – one blue, one yellow. They cover 33 topics such as 'my working life', 'DIY' or 'swimming'. Each card has two questions designed to get conversation and reminiscence going.

There are instructions for four different games you can play using the cards, with options for two or more players.

Group members took turns to pick a card and answer its questions, and Eddie couldn't believe his luck with the topic he got.

'I don't know anything about anything except rugby, and there was a rugby card!' he said.

From thinking he wouldn't have anything to talk about, Eddie went on to tell everyone about playing rugby as a wing three-quarter.

The cards' clear design and text was appreciated, with Jim noting, 'I'm reading this without my glasses.'

“

**I really like them. I can imagine taking them when I visit my daughter. I can play them with my grandchildren and adults – they’re really good questions.”**

There was a lot of laughter as cards prompted conversations to range from running to holidays, and one person observed, ‘Once you get going, the cards aren’t needed anymore.’

Given the topic of dancing, we heard about Jim’s ‘two left feet – both on the right-hand side!’

Nigel thought it could be confusing to have two decks when the particular game the group was playing didn’t need both. However, he joined in, sharing his choice of violinist André Rieu as his favourite live musician.

Ray appreciated how the cards opened up discussion.

‘We didn’t stick to answering the questions but enjoyed digressing,’ he said.

‘I really like them,’ said Diana. ‘I can imagine taking them when I visit my daughter. I can play them with my grandchildren and adults – they’re really good questions.’



Visit our online shop at [shop.alzheimers.org.uk](https://shop.alzheimers.org.uk) or call **0333 366 0035** for these and many other helpful products:

- Looking back at... The Beatles and Looking back at... The 1966 World Cup – £14.99 each (no VAT).
- Matching Memories game – £17.99 including VAT.



See our competitions on p39 for chances to win Cognitive Books and the Matching Memories game.

# Time for Dementia

A programme that's making future healthcare professionals more aware of dementia is 10 years old. **Heather Stephen** reports on Time for Dementia.

## Quick read

**Time for Dementia has been improving health care students' learning for 10 years.**

**Regular visits with people affected by dementia over two years mean students get a better understanding of its impact.**

**Dietetics student Naeema Austin-Quiry says it's helped her to see the whole person who's living with dementia.**

**Louise Oliver, who has vascular dementia, finds it rewarding to tell students about less obvious challenges.**

**Stephanie Daley, one of the programme's founders, says Time for Dementia offers people an opportunity to be heard.**



**P**eople living with dementia haven't always had the best experiences with healthcare professionals, but a groundbreaking scheme is changing that.

It's 10 years since Alzheimer's Society started working with Brighton and Sussex Medical School to improve learning for nursing, paramedic and medical students.

Since then, Time for Dementia has expanded to 11 universities in the south of England. It also involves a wider range of students, from fields including dietetics, occupational therapy, physiotherapy, radiography and speech and language therapy.

Under the scheme, a pair of students visits a family affected by dementia three times a year, in person or online. They do this for two years as a mandatory part of their course.

'We can't teach the students what these families can,' says one of the project founders, Stephanie Daley.

'When students build an authentic, meaningful relationship, they carry this with them into their working life and that is so powerful.'

### The whole person

Joe Tidswell, a second-year medical student at Brighton and Sussex

Medical School, has spent the last year visiting a woman with Alzheimer's and her husband.

'It has been a privilege to sit in someone's living room and talk to them about their life,' says Joe.

For the last four years, Joe has also worked as a health care assistant on a palliative care ward. He's used to seeing patients with advanced dementia.

However, he says, 'You are not seeing people as they were. This scheme has given me the chance to speak to someone at the beginning of their decline and to get to know what they need.'

Naeema Austin-Quiry, a second-year dietetics student at the University of Surrey, is at the end of two years of visits.

'I have learnt there are so many different types of dementia and everyone reacts differently,' she says. 'People are separate from their dementia, and it is important to see the whole person.'

'There shouldn't be a one-size-fits-all approach and this programme gives students a chance to look into the lives of people with dementia and their families, and how it affects the family dynamics.'

To find out more about Time for Dementia, visit [alzheimers.org.uk/timefordementia](https://alzheimers.org.uk/timefordementia) or call **07562 430204**.



### Lovely and keen

Eliza Kam, who has Alzheimer's, and her daughter Fiona moved to Bristol from Hong Kong two years ago. They've had visits from Chinese occupational therapy students for the last year.

Fiona says, 'The students are lovely and keen to learn about dementia.'

'They are from Hong Kong, so it has been great for Mum to chat with young people speaking the same language and to reminisce about the city where she spent 75 years of her life.'

Eliza says, 'I like the youngsters coming over,' she says. 'We do different activities and I really look forward to all the visits.'



### Family insight

Peter Chapman and his wife Louise Oliver, in Norwich, have met nursing and paramedic students online for the last 18 months.

Louise, who has a rare, inherited type of vascular dementia called CADASIL, has enjoyed interacting with the students.

Peter says it's been good to give the students an insight into how dementia affects a whole family.

'Some students have personal experience of dementia in their family,' he says, 'but for most, their only contact is with patients in the artificial environment of the ward.'

'People meet me and don't see what I go through,' says Louise.

'But things like planning, using public transport and using digital devices can be really difficult for me, so it has been good to tell the students about that.'

### Being heard

Although Time for Dementia has been growing in the south of England, people elsewhere have been able to meet students through online visits. There are also plans to expand to universities in other areas.

'When we started out 10 years ago, we never envisaged the programme would have expanded like it has,' says Stephanie.

'I think its success comes from the recognition that it offers a unique opportunity to complement healthcare training.'

'And it has given people who have had poor health care experiences the opportunity to be heard, so other people don't go through the same.'

## Donate

Your donations will help us continue to introduce future healthcare professionals to people living with dementia. [Donate online.](#)

# Singing the right songs

People with dementia need activities that resonate with their experiences. **Heather Stephen** visits a hub run by and for Sheffield's African and African Caribbean communities.

## Quick read

**Sheffield's Memory Hub offers culturally appropriate support for the city's African and African Caribbean communities.**

**A year after its launch, around 20 people a enjoy weekly activities from singing to reminiscing about their lives 'back in the day'.**

**Volunteer Carol says, 'Although not everyone has dementia, if we spot early signs we can signpost them to the right help and support.'**

**Carl, inspired by his mother-in-law's dementia, says, 'We are trying to increase awareness so people get help sooner.'**

**J**osh Evers takes great pride in getting dressed up in one of his many suits every Monday morning. That's when he and his wife, Del, head to Sheffield's Memory Hub.

'We go every week,' says Del, 'and only missed it once when it snowed. Someone at church told us about this group and we enjoyed it from the beginning.'

'Everyone is so friendly and gets on with each other and we are able to meet people in the same situation. Otherwise, we'd be stuck indoors.'

'It is nice to socialise,' agrees Josh, who was diagnosed with Alzheimer's a year ago.

'It's only the two of us at home and we can just walk here in 10 minutes and see our friends. It's the highlight of my week.'

The group, for people of African and African Caribbean heritage, attracts about 20 people each week.

### Culturally appropriate

When Carl Case's mother-in-law, Adella Johnson, was diagnosed with dementia, he found that groups often missed the mark in the activities they offered.

'It's all very well singing "Knees up Mother Brown" or "Roll out the Barrel", but if you're from Africa or

the Caribbean you won't necessarily know these songs,' says Carl, who runs a dementia training consultancy.

People of African and African Caribbean descent have a far higher risk of developing dementia than white people the UK, and they're more likely to die from the condition sooner. However, Carl says culturally appropriate support in Sheffield – as elsewhere – was lacking.

Partnering with SACMHA (Sheffield African Caribbean Mental Health Association), Carl worked hard to secure funding and the Memory Hub was born.

One year on, sessions are going strong. They feature everything from gospel and Caribbean folk songs, chair tennis and art, to cognitive exercises and reminiscence therapy. They've been so successful that they're looking for a bigger venue.

### Love for the hub

You don't need a diagnosis to take part – some people have problems with memory or thinking without necessarily having dementia. But what everyone has in common is love for the Memory Hub.

'Feedback has been excellent,' says Carl. 'And we have people coming back week after week.'

Organisers work hard to create a different theme each week.



Photographs: Paul David Drabble





On our visit, members from Jamaica, Guyana and St Kitts and Nevis enjoyed prayers, song and seated exercise. Images of buses from 'back home' and cedarwood pestles and mortars stimulated debate and memories.

Apart from being fun, Carl says the hub has an educational role in a community where lack of recognition of dementia often leads to delayed diagnosis.

'We are trying to increase awareness so people get help sooner.'

### Community support

The Memory Hub has been developed and run by the community it serves.

Carol Samuels got involved as a volunteer facilitator after losing her mum to dementia.

'I didn't find services to help Mum,' she says, 'so I really wanted to do something to help others.'

'The sessions stimulate the brain, as they remind people of how it

was growing up. And, although not everyone has dementia, if we spot early signs we can signpost them to the right help and support.'

Retired nurse Norma Goodison, who works for SACMHA and helps organise the weekly activities, also lost her mother to dementia.

'A lot of people affected by dementia suffer and worry about how they are going to cope,' says Norma.

'So, it is great to give people somewhere they can be signposted for help and to give them activities and the opportunity to make friendships.'

Carl says, 'Dementia can be frightening and challenging. No two journeys are identical, and no one can be certain about what lies ahead.'

'We are providing people the chance to do something together that is stimulating, interactive, fun and not solely about their condition.'

'If our parents hadn't been diagnosed with dementia the Memory Hub might never have happened, so this is their legacy.'

They would have been very proud.

For more about Sheffield's Memory Hub, visit [www.sheffieldmemoryhub.com](http://www.sheffieldmemoryhub.com) or call **07563 141682**.

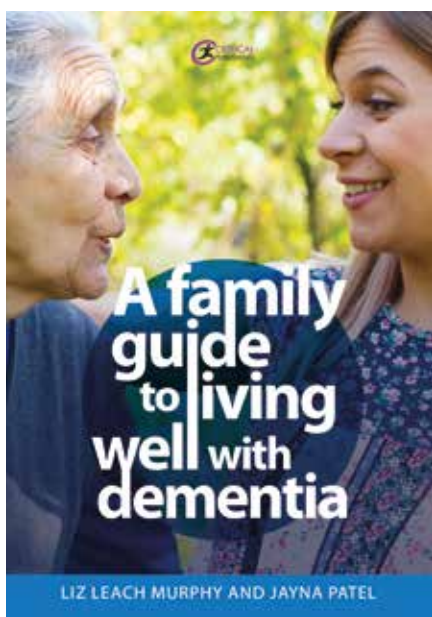
To find support near you, visit [alzheimers.org.uk/dementiadirectory](http://alzheimers.org.uk/dementiadirectory) or call **0333 150 3456** for personalised advice.



For The activities handbook (77AC), see [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call **0300 303 5933**.

# Book group: A family guide

We read a practical guide for families who are dealing with a dementia diagnosis.



**A Family Guide to Living Well with Dementia,** by Liz Leach Murphy and Jayna Patel (Critical 2023), 204 pages, £18.99 (prices vary), ISBN 9781915713063. Also available as an ebook.

**W**hen someone close to you is diagnosed with dementia, you might feel unsure about how best to support them. This book's name neatly sums up its aim.

A Family Guide to Living Well with Dementia focuses on giving you the information you need to enable a relative with dementia to live the life they want.

It's written by Liz Leach Murphy, who has a 25-year career in health and social care, with help from journalist and writer Jayna Patel.

### Front and centre

For reviewer Jo, empowerment is front and centre in the book.

'It's very respectful to the needs of the person with dementia, and a reminder that they are still a person with their own feelings and thoughts.'

'It focuses your mind to understand their perspective, preferences and choices, and for the person to remain empowered for as long as they can as opposed to making decisions on their behalf without consultation.'

'It highlights the complexities of dementia, but equally how different it can be for everyone.'

Another Jo, in Surrey, says this meant it was a comforting read.

'It was quite a revelation to discover that things I had instinctively been doing, such as setting up a supportive network for my father, were recognised by health and social care professionals as being important.'

A reader in Birmingham applauds the theme of personalised care and support that runs through the book.

'It frames each new topic, stressing the importance of giving people with dementia – and their carers – full choice and control over support and care.'

'Not only that, it goes into detail about what resources are available to facilitate personalised care.'

### Clear and accessible

Although it might look a bit like a textbook, A Family Guide to Living Well with Dementia is still warm and accessible, says our Birmingham reviewer.

'The book is extremely well written, with clear and easy-to-understand language that never feels overly technical, despite some of the more complicated topics covered.'

Jo in Surrey adds, 'Clear headings and well-spaced text make for easy reading. The glossary of abbreviations at the start is useful, and other terms and concepts are well defined and explained.'

Diagrams and illustrations are used to break things up, and they're very effective, adds our other Jo.

'There are some great suggestions which I hadn't thought about. The communication map of day-to-day activities with the drawings was an excellent idea.'

### Different perspectives

All our reviewers were struck by how comprehensive the book is, both in terms of topics covered and different perspectives included.

'It's a precise book and such a big undertaking by the authors,' says John Pops Hyde in North Somerset.

“

**Clear headings and well-spaced text make for easy reading. The glossary of abbreviations at the start is useful, and other terms and concepts are well defined and explained.** ”

‘It’s mainly aimed at people and families that already have a diagnosis, but I’m certain there will be huge numbers of people pre-diagnosis who would find its information truly invaluable and helpful before they properly start their journey.’

Jo in Surrey was also impressed by the scale of the book.

‘It’s not just focused on the person who has dementia and has a multitude of information about issues, such as the provision of care and support, ways to plan that care and support, and financial planning.’

### **Avoiding overload**

The downside of so much practical information, however, is that the book can feel overwhelming at times. Our reviewers recommend reading it in chunks and homing in on what’s most useful to you.

‘Initially I found it very helpful. However, after a few days it became a bit overwhelming and I had to take a break from reading, as there is so much content to absorb,’ says Jo in Surrey.

‘While family carers may be prepared to invest time in reading the book, friends or paid carers may be more reluctant.’

With so much information to absorb, the other Jo says the chapters on the stages of dementia were most interesting to her.

‘Chapters one to three are very informative and laid out well, but I felt the explanations of terminology could have been placed at the end of the book.

‘Chapter three starts off the journey of dementia, which was the right starting point for me.’

Our reader in Birmingham also found the information on the stages of dementia engaging.

‘Where the book really excels is in the practical advice it gives for each stage of the dementia journey.

‘Also worth mentioning is the chapter about ways to plan – it provides a whole range of different planning tools that can be used to map out how a person’s care will look, keeping them at the centre of the conversation throughout.’

Throughout this wealth of information, the book’s empathetic approach remains strong.

‘It details how to navigate each stage in a way that keeps the focus on the person with dementia and understanding their experiences from their perspective,’ adds our Birmingham reader.



## **Your turn**

For our next book group, we invite you to read *Travellers to Unimaginable Lands*, by Dasha Kiper (Profile 2024), 272 pages, £10.99 (prices vary), ISBN 9781800816206. Also available as an ebook or audiobook.

Tell us what you think about this book, in which a clinical psychologist explores the psychology of caregiving.

Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by the end of 5 September so we can share your comments in the October/ November magazine.

## **Book giveaway**

We have five copies of *Travellers to Unimaginable Lands* to give away – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by the end of 15 August quoting ‘Lands’ for a chance to win (see p39 for terms and conditions).

# Opinion: Need for equity

**Kiran Kaur Barn wants everyone to have the kind of dementia support that they need, including within her own Sikh community.**



**Kiran's Nani Ji holding her as a child.**

**M**y Nani Ji (my maternal grandmother) was such a wonderful being and instrumental in raising me. She expressed her love through delicious, authentic Punjabi food and kindness.

Before she was diagnosed with Alzheimer's and vascular dementia, this wasn't something we knew much about. Unlike my grandparents I was born and bred here in the UK, so you might think that I would have been more aware, but I really wasn't.

When we talked about dementia within the community, people often said things like, 'Oh it's just old age, these things happen'. There's a limited understanding about what dementia means and how it manifests in various ways, which can be quite tough.

My Nani Ji could have a conversation on the phone and say, 'I'm fine. How are you? How are the family?' However, we began to notice subtle changes – when you're closer to it, the reality is so different.

## Basic things

As a carer, you have to become aware of so many things, like the complexity of memory and how it is lost.

Simple things like eating and drinking had to be carefully monitored and encouraged, because my Nani Ji would say she had eaten or drunk water, but she had either forgotten or lost her appetite. Learning that she was seeing the world differently meant we had to adapt as she changed.

## Speaking up

At health appointments, if English isn't your first language, you're more likely to just accept advice without question – especially from medical professionals, held in high regard. I know that if we had not been with her

to speak up and ask questions on her behalf, she would not have received the best support available.

During the last year of her life, she often regressed and shared many happy memories, particularly when she was a young woman back in Punjab, India or the early days of coming to the UK.

Throughout her life, my Nani Ji always kept her hair neatly plaited or tied up in a bun. She understood that in this country that wasn't the norm. But during the latter part of her life, she became fixated on how hair should be kept.

When I came back after two weeks from travelling in Tanzania and summiting Mount Kilimanjaro, I was so excited to see her again. But she wasn't aware of the time that had passed. The first thing she said to me was, 'Why is your hair out? You should tie your hair up.' She was sharing her wisdom, as this core belief was very valid to her.

## Nuanced understanding

Health services should ensure staff have a better understanding of people from diverse backgrounds, and this needs to be nuanced.

I am from a Sikh background, however not baptised yet. The prominence of faith can be very important to an individual and needs should be catered to accordingly. It's important to ask questions to best support them.

For example, dietary requirements can vary, some may need a lacto-vegetarian or plant based diet. This is particularly important in a care or hospital setting, as my Nani Ji would never have eaten meat, fish or eggs.

Organisations need to involve people from local communities to gain understanding in an equitable way.

For our booklet **Caring for a person with dementia: A practical guide (600)**, visit [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications) or call **0300 303 5933**.

# Mind, body and wellbeing

**For Nick Stoleran in north London, family experience has led him to bring the power of yoga and meditation to help with dementia.**

**Y**oga and meditation always fascinated me. I used to work in marketing, then around seven years ago, I signed up for a yoga and meditation teacher training course. .

The minute I started to teach I thought, 'This feels wonderful.' I discovered a genuine love for it.

## Close understanding

I now run yoga, meditation and mindfulness classes full-time and in recent years, I have worked with a number of older people, some with conditions including dementia and Parkinson's.

My father had a stroke around 10 years ago and was diagnosed with Alzheimer's around five years ago.

He has always been an amazing guy, funny and mischievous, generous and caring.

He's a husband, father of three and a grandfather. He ran a business with his brothers with great integrity.

Over the last 10 years I've watched my lovely dad, who I'd grown up watching football and playing tennis with, just becoming less capable.

Mum cares for him round the clock. We've lost him bit by bit.

This has given me a close understanding of the challenges facing people with dementia, and their carers and families.

## For all ages

One of the meditations I regularly teach (Kirtan Kriya) is believed to improve memory, reduce anxiety and improve mood and sleep.

There are hundreds of different meditation and yoga exercises to choose from. They don't require participants to be particularly flexible or physically fit – there really is

something for everyone.

I teach people of all ages and stages of life.

It was by accident that I started working with people struggling with memory, anxiety, other aspects of illness and aging, and conditions like Parkinson's and dementia.

From my experience, meditation and yoga play a valuable role in supporting physical, mental and emotional wellbeing.

## Tailored sessions

I am now exploring how I can support people with dementia with tailored sessions, video classes and written instructions.

One client was diagnosed with dementia around eight months ago and said he'd wake up every morning with a feeling of dread. After coming to meditation sessions, he's now able to tackle those feelings before getting up every morning.

When I hear how meditation has helped people, I find it so gratifying.

## Have a go

As a teacher I know the benefits of yoga and meditation, and wonder why people don't do it all the time!

But of course, we tend to forget the things that really help us, such as breathing properly and moving our bodies.

However, these methods are free and once you've learned them, you can't unlearn them.

I hope to spread awareness and increase participation for people affected by dementia.



For tips, tools and activities to support mental health, see [www.nhs.uk/mental-health](http://www.nhs.uk/mental-health) and click 'Self-help'.

# No excuses, no hiding

**Suki, in Southampton, cared for her late father after his dementia diagnosis. She tells Jess Hubbard about the need for more openness, awareness and support.**

## Quick read

**Suki wants more openness about dementia so more people know how to get help.**

**Suki's family, in Southampton, weren't offered the support they needed after her father, Mehal, was diagnosed with dementia.**

**Suki and her sisters rallied around to care for him, but a crisis led to him being sectioned and moving into a care home.**

**Suki wishes more families, especially in Asian communities, felt able to speak more openly about dementia.**

**S**uki has lived in Southampton her whole life, growing up there with three sisters.

'At one point, Mum and Dad moved just down the road from me,' says Suki. 'It wasn't intentional, but ended up being essential later on so we could care for them.'

Years later, she often passes her parents' old home when out walking and the strong associations are still there. It's hard to see the house renovated when so much from such an important time in her life happened there.

### Methodical man

Suki always liked being around her dad, Mehal, when she was a child.

'I used to follow my dad around everywhere,' she says. 'If he was in the garden, I was in the garden. If he was doing something to his car, I was under the car passing him tools. When he went to the gurdwara, I went with him.'

Suki is still struck by the ways in which Mehal's personality changed as his dementia progressed.

'He was 84 when he passed away in 2017,' she says. 'Normally, when I think about him, I think of dementia and how it changed him.'





**I will always remember that awful day. Even though I was trying to help, it felt like we were forcing him out of the house.**



‘But when we used to describe Dad to people, we’d say he was a methodical man, always living by the rules.

‘He worked on the railways, loved cars and religion was very important to him.

‘He was hardworking and generous and would do anything for anyone. I think this is where I get it from, as myself and my children do charity work and fundraising, including Memory Walk.

‘Dad was always smartly dressed – never a hair out of place – but dementia reversed all of that.’

### ‘Something’s wrong’

In around 2010, Suki noticed her dad behaving unusually.

‘I noticed he wasn’t doing the same things he used to do,’ she says. ‘I didn’t really know about dementia at the time, and we thought he was just getting older.’

A change in his writing was especially alarming for her to see.

‘Dad was known for his penmanship and people would ask him to sign certificates and write letters home to India,’ says Suki.

‘If he had a pen in his hand, he was always writing. He had a stylish signature and would draw flowers.

‘But one day I saw Dad scribbling and I knew this was not right.’

Initially, Suki put these things to the back of her mind. However, a few months later she went on maternity leave and was around the house more often.

‘Dad would leave the tap running and would walk out the house and then come back in, not knowing what he was doing,’ she says.

‘He put his shoes in a silly place.

He would always polish his shoes, so this was not like him.

‘I just thought, “OK, something’s wrong.”’

### Hard to accept

Suki spoke to a GP and her dad had some memory tests. He was diagnosed with dementia but had trouble accepting the diagnosis.

‘I was trying to help Dad, but he saw it as interfering and was angry at me for bringing healthcare professionals into his home to ask him questions,’ Suki says.

‘His personality completely changed. He went from being quite a strict person, not one for sharing his emotions, to like a grandad figure to us.

‘He also started worrying more about things – when I had health problems and looked ill, he would notice and bring it up, which was not like him.’

### No help

Suki says her family were told it was too late to give Mehal medication to manage his condition.

She also says they weren’t offered any help with his care or advice and had to push for assistance.

‘We needed all the help we could get,’ she says. ‘Someone should have told us what we were entitled to.

‘We were thinking, “Well what can we do?” Mum was also ill so couldn’t look after herself, let alone Dad.

‘But between us, we rallied around and we took care of him. I don’t know how we managed it.’

Suki and her sisters became ‘sandwich carers’ – caring for their children and parents at the same time.

### Crisis point

Suki says it was hard to find the right care to help her dad live at home.

‘We didn’t find out what was available until we really pushed. Even then, they kept changing the support at short notice – everything was so difficult,’ she says.

‘We had a carer overnight who slept there for a few weeks. It was really difficult, as Dad would throw things and nearly set the house on fire.’

Then things reached a point of no return.

‘He threw something at the carer and they walked out, leaving me with him. He was then sectioned.

‘When he was taken away and moved to a care home, we walked with him arm in arm along the driveway,’ she says. ‘Dad turned to me and said, “If you make me leave, I’m never coming back.”’

‘I will always remember that awful day. Even though I was trying to help, it felt like we were forcing him out of the house.’

### Difficult visits

Mehal’s condition deteriorated at the care home and visiting was a difficult experience.

‘We would go in every day to see him, even though we all had our careers, and young children to look after,’ she says.

‘It was really heartbreaking. This is what people don’t understand – people don’t realise how emotionally upsetting it is.’

Being alone had always been hard for Mehal, who became distressed when his family had to leave.

‘He liked being around people all the time,’ Suki says. ‘At the care home, we had to trick him that we weren’t

going home without him. I still feel guilty and upset about it.'

Suki believes having someone who spoke Punjabi at the care home could have made life more comfortable for her dad.

'I used to be a translator,' she says, 'so I know that when people are stressed or ill, they find it easier to talk in their mother tongue.'

### Mixed emotions

Despite doing everything she could for her parents, Suki says she has been left with feelings of guilt.

'It was my duty to care for my parents – my dad who had dementia and my mum who had many health conditions. But I'm left with the feeling I could have done more,' she says.

'My advice to other people who have a relative or friend with dementia would be to do everything you can and spend time with them.'

'I got really upset when my dad didn't know who I was. Every time I

visited, he gave me a new name. The last one before he died was "Shakira".

'They may have forgotten you, but you remember them! Talk to them and make new memories.'

'You can't make them better, but you can make them feel better.'

'Don't stop recalling their lives with them. Remember, you're their memory.'

### Need to be open

Suki was always open about her dad's dementia and wants others to be open too.

'We told everyone about Dad's dementia – we never made excuses or hid him,' she says.

'In the gurdwara, when he was having funeral prayers, we told everyone on the message board that he had had dementia.'

Suki thinks that families, especially in Asian communities, should share their experiences of dementia so others are more aware of it.

'More needs to be done so that dementia is seen as a condition, as people think it's just getting old,' she says.

'I wish we knew about Alzheimer's Society when Dad was alive.'

Since 2017, the whole family has taken part in Memory Walk.

'It's not all about raising funds, it's also about just being there and helping to raise awareness,' says Suki.

'There must be lots of families with a relative with dementia, yet they don't talk about it – it's like this secret thing, especially among Asian families.'

'I will never not talk about Dad and how dementia affected him and all of us.'





“

There must be lots of families with a relative with dementia, yet they don't talk about it – it's like this secret thing, especially among Asian families. ”

For our Changes in behaviour (525) factsheet, see [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call **0300 303 5933**.

Call our Dementia support line on **0333 150 3456** for personalised information and advice, or for Welsh speakers call **03300 947 400**.



## Memory Walk

Join people like Suki who have lost a loved one to dementia and sign up to a Memory Walk this September – sign up at [alzheimers.org.uk/memory-walk](https://alzheimers.org.uk/memory-walk) or call **0300 330 5452**.

# ? Ask an expert

**‘My mum’s care home has served notice for her to leave because they can’t deal with her behaviour. Can we challenge this?’**

## Notice to leave

**B**efore deciding whether you want to challenge the notice to leave, think about what you want to achieve.

Moving can be unsettling for a person with dementia. Equally, the notice to leave may indicate that this simply isn’t the right care home for your mum. It all depends on how things have been so far and what the alternatives are.

### What’s in the contract?

If you want to challenge the notice, start by checking the care home’s contract. What does it say the notice period should be?

When does it say the home can ask a resident to leave? This might be if the home can no longer meet their needs, or if the person’s behaviour is putting staff or other residents at risk.

The contract may also set out a process for you to appeal the home’s decision or have a mediation meeting.

### Need to be reasonable

Whatever its contract says, guidance from the Competition and Markets Authority (CMA) says the care home must operate in a reasonable way.

The home needs to explain why it’s asking the person to leave, and the reasons it gives must be valid. This could include that the home has tried making ‘reasonable adjustments’ but still can’t meet the person’s needs.

The CMA says examples of ‘reasonable adjustments’ could be getting help from the local community mental health team, other specialist services or social services. Has the home tried this?

### Other rights

CMA guidance says the care home should not ask a resident to leave

without first consulting the person, anyone assisting them and other relevant independent professionals.

The home must usually give at least 28 days’ notice, and the CMA also says it should be possible to review or appeal the decision.

Care homes should provide the quality of care they said they would. Could your mum’s behaviour be caused by poor care?

If your mum is settled in the home, then moving her might go against her human rights, as set down in law. Care homes must respect their residents’ rights. If you’re concerned about your mum’s human rights, make sure the home knows you’re worried about this.

### Talk to the manager

Try having a constructive discussion with the care home management. See if anything can be done to help keep your mum where she is.

If the home says it can no longer meet your mum’s needs, what is it that’s changed since your mum was accepted as a resident?

If you don’t think the home is being reasonable, you can make a complaint. Ask the home what its complaints process is – it must have one.

## Taking things further

If the care home does not deal properly with your complaint, you can take it to an independent ombudsman:

- In Wales, please see [www.ombudsman.wales](http://www.ombudsman.wales) or call **0300 790 0203**.
- In Northern Ireland, see [www.nipso.org.uk](http://www.nipso.org.uk) or call **0800 343 424**.
- In England, please see [www.lgo.org.uk](http://www.lgo.org.uk) or call **0300 061 0614**.

For our Supporting a person with dementia in a care home (691) factsheet, see [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call **0300 303 5933**.



## Your answers

Readers share tips about helping someone with dementia feel more comfortable during hot weather.

# Hot weather

'Try a cold water bottle. Refrigerate some water, then fill a hot water bottle with it. When it's wrapped in a towel or T-shirt, it creates a portable cool patch.' **Collywobbles**

'Keep the curtains closed to keep the heat out.' **canary**

'My husband has chronic obstructive pulmonary disease as well as dementia and finds it hard going in the heat because the air quality is not as good. He gets very tired and sluggish. So, I close the curtains for shade, put fans on and make sure he has plenty of fluids.' **jennifer1967**

'There are various things that help my dad. Ice lollies, ice creams and fruit with a high-water content, such as watermelon, melon, grapes and pineapple are good. Pre-prepared packs are very handy and the mix of fruits looks enticing.

'Tinned fruit works just as well, especially if it's cold and in juice or syrup. Or jelly pots, particularly ones with fruit pieces – you might need to add ice cream, custard or cream too.

'Try small juice cartons with a straw – sometimes drinking with a straw is easier. Dad likes beer and lager, especially in warm weather, so I buy alcohol-free versions – he never notices the difference.

'In general, try to make food and drink look as appealing and colourful as possible. A slice of lemon or lime in a drink, maybe a strawberry.

'Cold water bottles are great and can also be put in the bed. Wipe hands, arms, face and neck with cold, wet flannels, then leave skin to dry naturally. Put feet in a bowl of cool water.

'I've tried fans and open windows but it's not a cooling breeze to Dad,

it's a draught. Opening windows becomes a game of window whack-a-mole – I open them and he closes them. So, when Dad has gone to bed and the temperature has dropped, I open all the windows wide, get the temperature in the house down as much as possible.' **Graybiker**

'I've lived in Florida in a flat with no air con, so I have lots of tips. Using a fan can be irritating because they waft warm, not cold, air. So, put a bowl of cold water near a fan to cool down the breeze.

'Keep curtains closed all day. You can open windows and curtains on the shady side of your home, especially after sunset.

'It might seem counter intuitive but wear roomy cotton tops with short sleeves rather than straps, shirts, skirts and knee-length dresses. This will protect you from burning. Pale colours are also cooler.

'Wring out cotton tops or nightwear in cold water before you wear them – evaporation cools you down. Do the same with hand towels and facecloths to lay on hot skin.

'Run cold water to cover your hands, wrists and forearms and let it evaporate. When you're sitting down, keep your feet in a bowl of cold water. You can soak your sun hat in cold water and gently rub your hair with a wet cloth.

'Carry a cold drink everywhere! Make ice cubes with diluted squash, fruit juice or clear fruit flavoured water. Ice lollies made with jelly are a good idea as they're not so messy if they melt. Or liquidise some fruit and refrigerate. Buy a slushy maker cup to freeze your drinks – they work best with fizzy drinks.' **Alisongs**

Visit [forum.alzheimers.org.uk](https://forum.alzheimers.org.uk) to read more and join our Dementia Support Forum.

**Next time:**  
**Moving care homes**

Do you have any tips for when a person with dementia needs to move to a different care home? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by the end of 5 September.

# Noticeboard

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

## Music of our lives

Whether your tastes run to alternative rock, karaoke favourites or electronic sound collage, we have it covered...

### From Heroes to Rockstars



An East Yorkshire veterans group is donating all proceeds from its CD of cover versions, *From Heroes to Rockstars*, to the Society.

Amateur singers from Bridlington Veterans perform 24 favourites ranging from He Ain't Heavy, He's My Brother, made famous by The Hollies, and the 1940s classic Let There Be Love, to Spandau Ballet's Through the Barricades and Shania Twain's That Don't Impress Me Much.

Mike Rubery, group spokesperson, told local press, 'Eclectic is the word, as we cover everything from rock, pop, crooners, country and musicals.'

'The sales from the CD will be in aid of Alzheimer's Society and every penny raised will go to this great cause. Dementia has affected almost every family in the UK, and at present a few of our members are struggling with the condition.'

**From Heroes to Rockstars is available on CD for £10 – see [www.bridlingtonveterans.com](http://www.bridlingtonveterans.com) or email [bridveterans@gmail.com](mailto:bridveterans@gmail.com)**

### Times Like These

A choir in Beckenham, south London, is raising funds for Alzheimer's Society with their version of the Foo Fighters' 2003 hit Times Like These.

Members of Sing Like You Mean It were inspired by their own experiences of dementia, and choirmaster Andy Gilbert wrote additional verses that reflect these.

'Like much of the UK, many of our choir members have been directly affected by dementia, be it parents, grandparents or close friends,' says Andy.

'We also know that music is medicine. It reaches parts of the heart and the mind that little else can.'

**To hear the track and donate through the choir's JustGiving page, visit [li.sten.to/timeslikethese](https://li.sten.to/timeslikethese) or [www.youtube.com/@singlikeyoumeanit](https://www.youtube.com/@singlikeyoumeanit)**



### The Engineer



A collaborative project called Mortality Tables has created an extraordinary 14-minute sound collage, donating profits from its sale to the Society.

The Engineer draws on a short story written by the project's founder Mat Smith, loosely based on his father's working life. Jim, who had Alzheimer's, worked for years at a factory in Stratford-upon-Avon.

An incredible range of 29 artists were each given a 30-second extract of the story's narration and asked to provide a response in sound. Collected and recorded over two and a half years, these were then mixed back in with the story.

**Buy The Engineer for £2.50 to stream and download at [www.mortalitytables.bandcamp.com](http://www.mortalitytables.bandcamp.com)**

## Seen elsewhere

On social media, Dementia Friends welcomes many new groups who've attended sessions to learn more about dementia and how to turn that understanding into action.

On Instagram, this included new Dementia Friends at Newcastle Carers and at stairlift specialists TK Home Solutions.



Dementia Friends is [@DementiaFriends](#) on [X/Twitter](#) and [Facebook](#), and [@dementia\\_friends](#) on [Instagram](#).

Alzheimer's Society is [@alzheimerssocietyuk](#) on [Facebook](#), and [@alzheimerssoc](#) on [X/Twitter](#) and [Instagram](#).

## South Asian? Caring for a grandparent?

University of Portsmouth researchers would like to speak to people aged over 18 from South Asian communities who are supporting a grandparent with dementia.

Their study will draw on people's unique perspectives to explore the challenges and triumphs involved.

Contact PhD candidate Barialy Akbary to find out more – email [barialy.akbary@port.ac.uk](mailto:barialy.akbary@port.ac.uk) or call 07514 714709.

## Forgotten Fragments of Time

An independent poetry press in the Isle of Wight is donating profits from the sale of its latest anthology to Alzheimer's Society.

Forgotten Fragments of Time features contributions based on memories from 61 poets, many of whom have drawn on experiences of a family member's dementia.

adam Shove at Dark Thirty Poetry, who starts his name with a lower case 'a', edited the collection. He says, 'The idea started as a cathartic process to help deal with my grand mother dying of Alzheimer's.

'I wanted the theme of memories which are important in all aspects of life – how a smell, song, film, football jersey can take you back in your mind to a specific moment of time, something you may not normally think about.

'Once it went out into the universe, my inbox became flooded with emailed submissions.'

Forgotten Fragments of Time is available from bookstores as a 151-page paperback for £13 (ISBN 9781738412822).

## Dementia and continence advice

A new website offers information about managing continence at home when someone has dementia.

DemCon offers practical advice about continence and toilet-use problems for people who support a friend or relative with dementia. The information is broken down to help you find what you need, and it includes useful quotes from carers.

It also has a section for healthcare professionals, while sections for people with dementia and homecare workers are being developed.

The site was created by researchers at the University of Southampton and King's College London, with funding from the Society and the National Institute for Health and Care Research.

Visit [www.demcon.org.uk](http://www.demcon.org.uk)



Share your views, feedback and news – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on page 2. We can consider contributions received by 4 September for the October/November issue (wording may be edited).

# Puzzles and competitions

## Anagramword

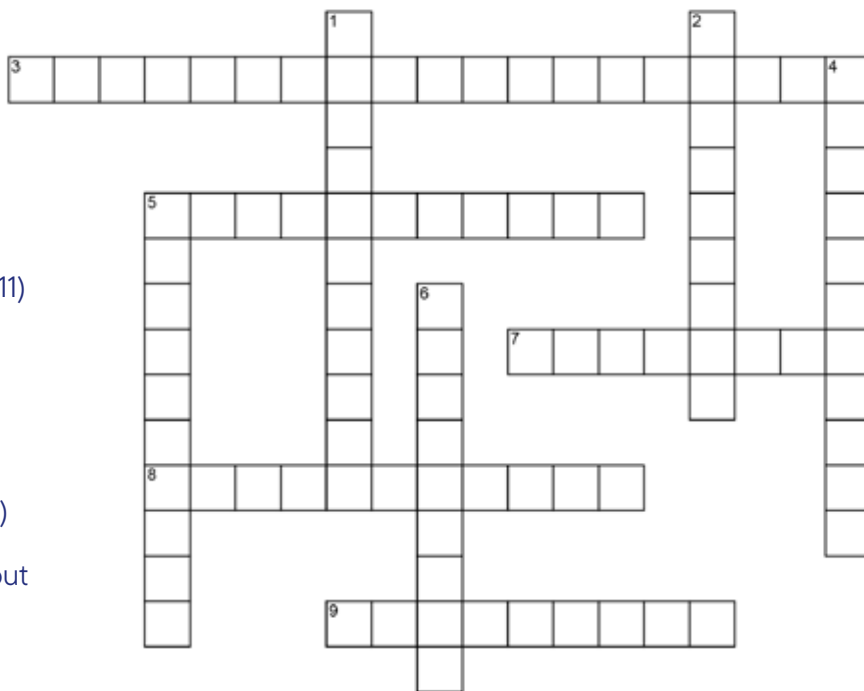
This time, Pete Middleton's puzzle celebrates our flagship autumn fundraising events (need a clue? Take a look at the back cover). Every clue contains the answer in an anagram – how many can you solve?

### ACROSS

- 3 Competent border base produces two months of fundraising. (9,3,7)
- 5 Is daring fun providing money to help the dementia community? (11)
- 7 I snog ear to make arrangements or put things in order. (8)
- 8 Prison shops – a way of raising funds. (11)
- 9 Dan's shout becomes a large number of memory walkers. (9)

### DOWN

- 1 Warmly smoke after these events? (6,5)
- 2 Sad notion help to raise money. (9)
- 4 Grim beer men taking time to think about dementia while walking. (11)
- 5 If hen drips, it can indicate a warm relationship. (10)
- 6 Poorville is one of many towns and cities of big-hearted supporters. (9)



See p39 for answers to last issue's puzzle.



## Alzheimer's Society BRAIN WORKOUT

From July's Brain Workout puzzle pack.

### Codebreaker

Each number represents one of the letters below. Can you create words and complete the grid?



If you enjoy word, number and logic puzzles, sign up to Brain Workout to receive a puzzle pack every month. These mind-stimulating puzzles – with a mix of difficulty levels – will keep you on your toes!

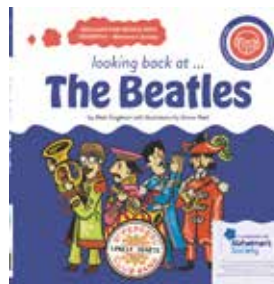
Visit [alzheimers.org.uk/brainworkout](http://alzheimers.org.uk/brainworkout) today and sign up with a monthly gift that helps provide vital support to people living with dementia.

## June/July winners and answers

Send us your competition answers with your name and address by end of 5 September – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2.

## Cognitive Books

We have a copy of Looking back at... The Beatles for one lucky winner drawn from correct entries and Looking back at... The 1966 World Cup for one other.



**Q: Cognitive Books include illustrations and narrative designed to be:**

- A. Enjoyed time and again.
- B. Difficult to read.
- C. Confusing to look at.

## Matching Memories

We have Matching Memories games for two lucky winners drawn from correct entries.



**Q: Matching Memories cards:**

- A. Tell you lots of information about 33 topics.
- B. Feature questions to prompt conversation.
- C. Include a jack of clubs.



## Book giveaway

See p27 for a chance to win a copy of Travellers to Unimaginable Lands, by Dasha Kiper.

## Lifelike pets

C Magson in North Yorkshire won a Berty the breathing dog from Ravencourt, and an anonymous reader won a Precious Petzzz. Answer: Berty the breathing dog has a heartbeat and gets warmer as you hold it.

## Trek26 goodies

D Lamerton in Cornwall won a pair of Trek socks and a Trek26 tote bag, while J Atkin in Lincolnshire, J Menzies in Lancashire and an anonymous reader each won a Trek26 tote bag. Answer: This year, Trek26 takes place in 10 breath-taking locations across the UK.

## Book giveaway

D Bebbington in Cheshire, S Clark in Greater London, H Ellis in Derbyshire, R Tyler in Surrey and H Greenway in Worcestershire each won a copy of A Family Guide to Living Well with Dementia, by Liz Leach Murphy and Jayna Patel.

## Anagramword

Across: guided tour, photographs, travel agent, cruise ship, reservations, itinerary, tourist trap, amusement park, museum. Down: suitcases, souvenir, train station, binoculars, foreigner.

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

Alzheimer's Society  
**Memory Walk**

Missing  
always  
Mum  
xx

Alzheimer's Society  
**Memory Walk**

I am doing  
this walk for  
my mum +  
Dad  
xx

**For those you love.  
For those you've lost.  
For everyone living  
with dementia.**

**Sign up to your local walk  
at [memorywalk.org.uk](http://memorywalk.org.uk) or  
search "Memory Walk".**

 Alzheimer's Society  
**Memory Walk**



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