

April/May 2024

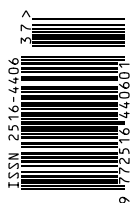
# Dementia together



Alzheimer's  
Society

## In this issue

A different world,  
telling people you have  
dementia, caring unfiltered  
and much more



# Welcome



**D**ealing with the realities of dementia while also remaining hopeful can be a hard thing to juggle.

There's no question that dementia involves a lot of loss. We can struggle with losing aspects of our own lives, aspects of relationships that we value and, ultimately, a life in itself.

We're not yet in a place where we can stop the loss completely. Although, with so much hopeful news about possible treatments and tests, we're closer than ever before to a time when we can lessen and delay the impact of dementia a lot more.

In the meantime, we do what we can by being here for each other.

Our magazine is here to help you. We hope the ideas and stories in this and other issues can inspire, inform and point you in useful directions.

We always want to hear your feedback and your ideas, so please use the magazine contacts below to let us know what you think.

**Danny Ratnaike, Magazine Editor**



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

Dementia together is the magazine for all Alzheimer's Society supporters and anyone affected by dementia. Contact us on **[magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk)**, **020 7264 2667** or **020 7423 3676**, or write to us at Magazine Editor, Alzheimer's Society, Suite 2, 1st Floor East Wing, Plumer House, Tailyour Road, Plymouth PL6 5FS.

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## Directions

**I**t's hard to believe I've been in my dream job for four years now! I'm incredibly proud of everyone here at Team Alzheimer's and thankful to you, our wonderful supporters.

How we pulled together in response to those awful pandemic years was nothing short of inspirational. Since then, we've been making sure everyone affected by dementia knows we're here for them, and that decision-makers understand they're never getting an easy pass from us when it comes to prioritising dementia.

Thanks to higher profile campaigns that don't shy away from the devastation caused by dementia, the number of people who know who we are, what we do and how they can help continues to grow.

Of course, there still hasn't been the massive reform that's needed for a health and social care system that works for people with dementia. But from the wins we've had, we know we're being heard more – we won't let up until everyone gets the diagnosis and support they need.

Dementia research – into care and technology as well as drugs and tests – is in a very exciting place. We'll be making sure that its results are used to make a real difference to people's lives.

It's your support that makes this possible – thank you!

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

## News

### Dementia Action Week 2024

This year's Dementia Action Week, 13–19 May, we're making sure everyone understands that one third of people living with dementia do not have a diagnosis. Thousands of people across the UK are living without the care and support they need to live their lives.

We'll be highlighting the benefits of receiving a diagnosis, the impact of delayed diagnosis and why this is such an urgent matter that needs fixing now.

As part of this, people living with dementia will share insights from their own experiences which show how receiving an early diagnosis can help to avoid moments of crisis.

Visit [alzheimers.org.uk/DAW](https://alzheimers.org.uk/DAW) to find out how you can get involved in Dementia Action Week.

### Memory Walk: bigger and better

You'll be able to join Memory Walk in two new cities this autumn – Norwich and Hull! That's a total of 26 locations where you can join thousands of others in cherishing memories and honouring loved ones, in Belfast, Cardiff and across England.

Visit [alzheimers.org.uk/memorywalk](https://alzheimers.org.uk/memorywalk) to find your nearest walk.



# Join our Forget Me Not Appeal

Last year, over 900 of you raised an incredible £125,000 for our Forget Me Not Appeal by volunteering for a supermarket collection. We're collecting at Morrisons stores across England and Wales during Dementia Action Week, 13–19 May. If you're in Northern Ireland, you'll be able to join a collection near you too.

Our Forget Me Not Appeal creates a special moment every year where we can stand together in solidarity while raising vital awareness and funds.

Visit [alzheimers.org.uk/forgetmenot](https://alzheimers.org.uk/forgetmenot) to sign up for a collection.



## First Minister's got mail

Wales's new First Minister will have mail from us as soon as they take up office. They're inheriting responsibility for a health and social care system that isn't meeting the needs of people with dementia.

Campaigners are signing an open letter. This is asking the new First Minister to meet with us during their first 100 days in office and to commit to a new Dementia Action Plan.

We want commitments to improve dementia diagnosis rates, invest in research and prepare NHS Wales for disease-modifying treatments once they're available. We also want to see a national care service that meets the needs of people living with dementia.

Visit [alzheimers.org.uk/100days](https://alzheimers.org.uk/100days) to sign our open letter.

## Stormont priorities

As soon as devolution returned to Northern Ireland earlier this year, we were back at Stormont to speak with newly re-appointed health minister Robin Swann and other MLAs (Members of the Legislative Assembly).

We continue to press the importance of them delivering on adult social care reform, and on promises made by the Regional Dementia Care Pathway. The pathway was launched six years ago but hasn't been fully funded or implemented yet.

## Spring Budget

Over 6,000 of you wrote to your MPs to call for a 10-year People Plan for the social care workforce to be included in the Spring Budget. Sadly, the Chancellor's budget in March continued to neglect a system facing staff shortages, high turnover and insufficient training. This needs to be a political priority – we won't stop raising it with the government and politicians from across the political divide.

Visit [alzheimers.org.uk/campaign](https://alzheimers.org.uk/campaign) to campaign for change with us.



## Understanding more about PCA

New research from one of our funded researchers and their colleagues is helping us to better understand posterior cortical atrophy (PCA).

Keir Yong at UCL in London is part of an international team that collected data from 1,092 people around the world who have PCA. This allowed them to see more about who the disease affects and what features develop in the brain.

PCA was identified in 1988 by a doctor in the US among people with dementia who had unusual symptoms. They had particular problems with their vision and understanding the things that they could see.

'Posterior cortical atrophy' means 'shrinkage in the back of the brain'. PCA gained wider attention when the late author Terry Pratchett announced he'd been diagnosed with it. However, there was still a lot that wasn't known about the specifics of the disease.

This recent research found that PCA typically affects people around the age of 60 and affects women slightly more often than men. They also showed that the way in which PCA damages areas of a person's brain has features in common with Alzheimer's disease.

More work is needed to understand why PCA starts by affecting the visual part of the brain and if things like genetics may play a role.

See [alzheimers.org.uk/research](https://alzheimers.org.uk/research) to find out more about Alzheimer's Society research.



Keir Yong

## Beacons of hope

Our current Accelerator Programme partners have been celebrating exciting news with the innovative products they've been developing with our support.

Simon Lord, our Head of Innovation, said, 'In collaboration with these entrepreneurs, we are transforming the dementia landscape and helping to pioneer solutions that are more than products. They are beacons of hope for people with dementia.'

Recreo VR launched its virtual reality headset over Christmas after testing it with 100 people living with dementia. Pobroll's waterproofed, comforting bed-bathing wrap became available in February, including from our online shop – visit [shop.alzheimers.org.uk](https://shop.alzheimers.org.uk) or call **0333 366 0035**.

The first book from Cognitive Books (see p13), specially designed for people with dementia, is also available for pre-order.

See [alzheimers.org.uk/accelerator](https://alzheimers.org.uk/accelerator) to find out more about the programme.

## Research trial sites network

A new network of sites for dementia trials is being established with nearly £50 million in government funding. The network will make it easier for more people to take part in dementia research, regardless of where they live in the UK.

We hope the Dementia Translational Research Collaboration Trials Network will accelerate the development of new treatments.

We now need clear UK and devolved government plans to ensure that our health and care systems are ready for future exciting breakthroughs. These plans must include investment to improve diagnosis rates and the involvement of people with lived experience.

## Our annual conference

Registration is open for the Alzheimer's Society Annual Conference 2024 in London on 14 May, during Dementia Action Week. Sponsored by Rothesay, the pensions insurance specialist, you can attend the event in person or online.

We're thrilled that this year's conference will be co-hosted by Society Ambassador Angela Rippon and Bill Wilson, whose wife had dementia.

The theme is 'making dementia a priority for all', and we're bringing together decision-makers and influencers who understand the urgent need to tackle dementia.

Visit [alzheimers.org.uk/conference](https://alzheimers.org.uk/conference) or call **0330 333 0804** to register today.

## Care home guides



Three new booklets offer practical and emotional advice at some of the most challenging times of our lives. They cover deciding whether a person needs to move into a care home, choosing the right home for them, and supporting them when they're living there.

For the booklets Care homes and other options: Making the decision (689), Choosing a care home for a person with dementia (690) and How to support a person with dementia in a care home (691), see [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call **0300 303 5933**.

## Time for Dementia turns 10

This year, we celebrate 10 years of Time for Dementia, the groundbreaking educational programme.

Time for Dementia involves people affected by dementia in healthcare students' education so that future professionals have a better understanding of the condition.

Developed in the south of England with healthcare students visiting families on a regular basis, people across the country can also take part over Zoom.

Over the last decade, the programme has involved more than 8,000 students and 2,200 families, including Daisy and Roy Timms (see p30).

**To find out more, please email [timefordementia@alzheimers.org.uk](mailto:timefordementia@alzheimers.org.uk) or call 07562 430204.**

## Our new partners

We're delighted to launch three new partnerships with businesses that have committed to supporting Alzheimer's Society for the next three years.

Between them, builders' merchant Travis Perkins, EDF Energy and commercial real estate company CBRE employ almost 50,000 people in the UK. All three will be raising vital funds and awareness, plus we'll work with each to help them offer the most dementia-friendly services possible.

## Download your fundraising packs

Our fundraising packs are full of tips and information for people supporting us in a range of fun and challenging ways. We introduced an option to download packs instead of getting them by post, making them more environmentally friendly.

Between April and December 2023, downloadable packs saved around two tonnes of carbon emissions – the amount of CO2 removed by 80 trees growing for a year!

**For great fundraising ideas and support, visit [alzheimers.org.uk/fundraise](https://alzheimers.org.uk/fundraise) or call 0330 333 0804.**

## Singing for the Brain works!

A recent evaluation has confirmed the amazing impact that Singing for the Brain has for so many people, and pointed to how we can make it even better.

Singing for the Brain lifts the spirits of people with dementia, with opportunities to make friends and to help memory and communication. Sessions also reduce stress and increase happiness for carers.

Pav Vryaparj, Evaluation Officer, said, 'Singing for the Brain is like a tonic for those living with and affected by dementia. It gives them choices and helps them feel confident and supported.'

Researchers interviewed, surveyed and observed hundreds of people attending Singing for the Brain groups, as well as those leading sessions.

They identified ways to better support people who run groups and a desire for more of them, including for online sessions.

**Visit [alzheimers.org.uk/singingforthebrain](https://alzheimers.org.uk/singingforthebrain) to find a group near you or to deliver your own.**

## Pedal power

Could you pedal towards a brighter future at this June's London to Brighton Bike Ride? Take on a cycling challenge for Alzheimer's Society and support the 900,000 people living with dementia in the UK.

**Visit [alzheimers.org.uk/cycling](https://alzheimers.org.uk/cycling) for more information about this and other inspiring challenges.**



## Latest ads: The Long Goodbye



Our latest and most hard-hitting advertising campaign, The Long Goodbye, launched at the end of March.

Inspired by real-life experiences, it aims to raise awareness of both dementia and how we support people. It doesn't pull any punches, which is vital for us to make dementia the priority it deserves to be.

The ad highlights 'anticipatory grief', also known as 'the long goodbye' – the repeated feeling of loss that many people experience as dementia progresses. We want people to know that Alzheimer's Society will be there for them no matter what.

**For dementia support, call 0333 150 3456 or visit [alzheimers.org.uk/get-support](https://alzheimers.org.uk/get-support)**

## Don't miss...

**Telling people about your dementia diagnosis – tips from others who've been there. See p15.**

**Help make dementia a priority for local candidates and elected representatives. See p16.**

**Research into better diagnosis of dementia needs volunteers – people like you. See p18.**

**People try out a new day clock with easy-to-use reminders for daily tasks. See p22.**

**Readers share advice about coping with challenging personality changes. See p35.**





Photographs: Keith Freeburn



# A different world

**Teresa Davies was shocked by her young-onset Alzheimer's diagnosis and the lack of suitable support that followed. She tells Jessica Hubbard about finding a new purpose.**

## Quick read

**Teresa Davies, in north-east Wales, is living as well as she can with dementia.**

**Teresa's diagnosis of young-onset Alzheimer's, at age 59, came as a shock – 'like hitting a brick wall'.**

**She wasn't given the support she needed then, but Teresa now helps others dealing with a dementia diagnosis.**

**She says that, although living well with dementia is difficult, she has found a new purpose.**

**T**eresa Davies, now 70, has lived in north-east Wales all her life. She was born and brought up in Mold, Flintshire before starting her education at a nearby Catholic school.

'I had a happy childhood,' she says. 'I'm not academic at all, so I left school at 15 with no qualifications and worked in a cake shop.'

Teresa went on to marry and have two children.

'In those days, the mum stayed at home to look after the children, so I didn't work,' she says.

Once her children had started school, Teresa worked at a plant nursery.

'I loved it – I love being outside,' she says. She enjoyed the work so much that she became a landscape gardener.

### Getting through

When she was 45, Teresa was involved in a serious accident.

'I was enjoying my work but that all came to a stop when I got hit by a car,' she says.

'They were going 70 or 80 miles per hour, and I woke up with a broken neck and my leg shattered.

'My family were told I might not make the night. But I'm here now. I did survive. It took me three years to recover. But I did it. I walked every day during recovery, covered in plaster casts.

'I had hope and that's what got me through recovery.'

Teresa was forced to give up work, but she still had bills to pay.

'I tried for a job at a supermarket,' she says, 'but unfortunately, they couldn't take me on because of my neck and insurance reasons. That was a real knock to my confidence.

'But I'm not the type just to sit and give up.'

### Independent

Teresa has always been independent.

'I have lived alone for the last 20 years, though I do have my dog, Fudge,' she says. 'I get a lovely welcome when I come home.

'I'm not lonely – I think I prefer living alone because if I put something down, there's no one there to move it and I remember where it is!

'I can go out and come home when I like and watch what I want on the television.'

### Life-changing

When she was in her late 50s, something strange happened.

'One day, I was making myself coffee and the electric tripped on the kettle and it switched off,' Teresa says.

'I put my hand in the kettle to check if the water was hot. Well, obviously it was – it had just boiled!

'My daughter happened to call me that day and I told her what had happened. She said, "Actually Mum, I've been a bit worried about you."

At the time, Teresa was experiencing menopause and didn't suspect that anything else was wrong.

'I went to the doctor and they prescribed me antidepressants,' Teresa says.

But her daughter noticed her becoming more anxious, so they returned to the GP. They carried out a series of memory tests.

Teresa says, 'I must have failed these because they referred me to the memory clinic.'

Nobody had mentioned to Teresa that the tests were for dementia. So, when she was given a diagnosis of young-onset Alzheimer's, it came as a shock.

'I was 59 at this point. "Dementia" wasn't even a word in my vocabulary,' she says. 'I didn't know anybody with



dementia – I didn’t think anybody in their 50s got dementia.

‘It was like hitting a brick wall.’

### Dark place

Teresa was immediately told that her life expectancy would be five to eight years.

She wasn’t offered the support that she needed, instead getting help that was well-meaning but unwelcome.

‘After my diagnosis, we went home, and my daughter burst into tears,’ she said. ‘Being the mother, I was there supporting her. But when she left, I entered a dark place. I didn’t know how to cope with it.’

‘I was given a bundle of leaflets which I call the “Welcome Pack to Dementia” but it was too much,’ she says.

‘I had people coming round fitting whiteboards and special clocks, but I didn’t need them yet. It just made me feel that my life wasn’t my own anymore.’

‘I’ve got to carry on doing things for myself as much as I can.’

### Different life

Teresa feels the effects of dementia every day. She must be reminded when to eat and drink because she has lost her appetite and says her emails and calendar can get ‘muddled’.

‘My daughter Ellie set up an Alexa which reminds me when to eat and drink,’ she says. ‘If I’m out, I’ll get a notification on my phone.’

“

**I never thought I’d be up on stage speaking to people like Chris did, but since then I’ve spoken about dementia in front of hundreds of people at conferences.**”

‘I could do with a personal assistant! I’ve started to get very mixed up with my emails. That could be just because I’m getting so busy. Or it could be dementia – I don’t know.’

Despite being left in a ‘dark place’ following her diagnosis, a chance meeting helped to turn things around for Teresa.

She went to a Dementia Friends session at her friend’s workplace around a year after her diagnosis.

‘It was there that I met Chris Roberts,’ Teresa says.

‘It was the first time I’d seen someone with young-onset dementia – someone like me – up there speaking to a room of people. I was amazed.’

‘I put my hand up and said I had just been diagnosed with dementia, and his advice was to put myself out there and get involved with things.’

Teresa signed up to help facilitate Dementia Friends sessions and joined DEEP, the Dementia Engagement and Empowerment Project.

‘I never thought I’d be up on stage speaking to people like Chris did, but since then I’ve spoken about dementia in front of hundreds of people at conferences,’ she says.

### Purpose

Teresa says, ‘Dementia opened up a new world for me – a different world, yes. But in some ways better.’

She has since given talks about dementia, assessed venues to see how dementia friendly they are and set up support groups.

‘I run three groups for people affected by dementia, two of which I set up myself,’ Teresa says. ‘They’re for people with dementia, run by people with dementia – nobody tells anybody what to do!’

‘I always invite people who come along to do activities, but they say they just love coming, and the tea and biscuits.’

‘I share information leaflets too. They can be helpful (if the person is ready to read them).’

Teresa also set up a ‘friendly face’ scheme, sharing her phone number with people who have just received a dementia diagnosis.

‘We put fridge magnets with all the leaflets they give you at the doctors,’ she says.

‘When you’ve just been diagnosed, you might not want all the



“

**When you’ve just been diagnosed, you might not want all the medical information – sometimes you just want to speak to someone going through a similar thing. ”**

medical information – sometimes you just want to speak to someone going through a similar thing.

‘I did get a few calls and I was able to help people.’

Teresa’s average week is now packed with events and meetings.

‘I won’t stop as long as I’m able to carry on,’ she says, ‘though I have learnt to say “no” when I think it might be too much.’

‘I’ve been given a new purpose and I get something back from helping other people affected by dementia.’

### **Talk about it**

Teresa always encourages people with dementia to talk about it.

‘I’m trying to break the stigma,’

she says. ‘I’ve known people who are ashamed to tell other people about their dementia or even mention the word “dementia”.

‘If we don’t talk about it, people won’t know and won’t go to their GP. The earlier you get diagnosed, the sooner you can go on medication or get help.

‘Just keep going and keep laughing,’ she advises.

‘Get a power of attorney, a will and a future care plan set up – but only when you’re ready. Then you can just live for the day, you don’t have to worry about that again.

‘It’s difficult to live well with dementia, but people with dementia should live as well as we can.’



For The dementia guide: Living well after your diagnosis, visit [alzheimers.org.uk/dementiaguide](https://alzheimers.org.uk/dementiaguide) or call **0300 303 5933**.

Dementia Friends promotes understanding and action so people with dementia can live as well as possible – visit [dementiafriends.org.uk](https://dementiafriends.org.uk) to find out more.

## **Donate**

Donations like yours are vital to ensure that research into the effects of dementia on the brain can continue. [\*\*Donate online.\*\*](#)

# Share and inspire

Views, updates and ideas – for and by you.

## A life of art

A 93-year-old in East Sussex continues a lifetime of creativity and artistic expression with daily watercolours of flowers.

Audrey Beer, who now has Alzheimer's, went to Slade and Central art schools in London, moving in circles with luminaries such as Philip Sutton and Craigie Aitchison. Her work has ranged from calligraphy, map colouring and jewellery to delicate floral painting on harpsichords.

Jo, her daughter, says Audrey also inspired creativity among all five of her children.

'Despite her Alzheimer's, she is able to paint and focus for hours on end, and this creative pursuit definitely extends and enriches her life,' adds Jo.

We're pleased to share some of her watercolours, which her family hope to make available on gift cards.

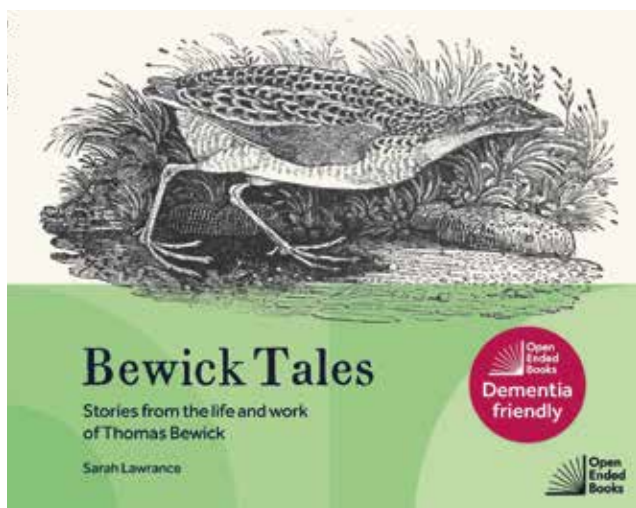
Visit [www.audreybeerart.com](http://www.audreybeerart.com) to find out more.



## Take on a puzzle (or two)

See p38 for a spring-themed 'anagramword' from Pete Middleton and 'Six mix' from March's Brain Workout puzzle pack.





## Bewick Tales

One of Northumberland's best-known artists has inspired a dementia-friendly book that focuses on creativity rather than reminiscence.

*Bewick Tales: Stories from the Life and Work of Thomas Bewick* follows the Georgian era artist and engraver from childhood to international recognition.

Gill Taylor, from East Durham, was one of the people with dementia who helped make sure the book was written and designed to be accessible.

'With dementia we lose our short-term memory,' says Gill, 'but you don't lose your intelligence and that is a big thing people don't realise, that desire to learn and stretch yourself doesn't go away.'

*Bewick Tales*, by Sarah Lawrance, is the first book from Open Ended Books, an Equal Arts initiative. It's available for £15.99 plus postage from [www.equalarts.org.uk/shop](http://www.equalarts.org.uk/shop) (52 pages, ISBN 9781738522903).



## Looking for books designed for people with dementia?

Win  
See p39

'Looking Back at... The Beatles' is the first title from Cognitive Books, supported by our Accelerator programme. It includes a free audiobook narrated by actor Bill Nighy, and you can pre-order it for £14.99 – see [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk) or call **0333 366 0035**.

## 3NDWG webinars are back

The 3 Nations Dementia Working Group (3NDWG) has restarted its popular webinars. With a different topic each month, the webinars are all designed and delivered by people living with dementia.

Supported by the Society, 3NDWG describes itself as 'a friendly group of people diagnosed with dementia who want to make a difference while we still can'.

Visit [alzheimers.org.uk/3NDWG](http://alzheimers.org.uk/3NDWG) to find out more.



## Sporting Memories online club

A weekly Sporting Memories Club that takes places over Zoom welcomes people living with dementia and anyone aged 50 plus.

Sporting Memories, the charity that helps older people to reminisce and reconnect through sport, hosts one-hour online sessions at 11.30am every Friday.

It runs many clubs in person, and the online sessions are a chance to enjoy their fun and friendly atmosphere from the comfort of home. Meet other sports fans while taking part in quizzes and other inclusive activities.

To find out more, email [rob.baker@sportingmemories.uk](mailto:rob.baker@sportingmemories.uk)



Share your views, feedback and news – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2. We can consider contributions received by 3 May for the June/July issue (wording may be edited).

# Photographic memories

**Jason Scott Tilley in Coventry, who has vascular dementia, tells us how he still draws on the skills of his photography career.**

**F**or a large part of my life, I was a press photographer.

My grandfather Bert worked as a photographer for the Times of India in the 1930s and 40s, capturing moments from the end of the British Empire. I grew up looking through his albums, which inspired me to take up photography too.

I started training and work from a young age – about 15 years old. Somebody introduced me to newspaper editor Barry Clark, and I went on to work for the Coventry Citizen and Coventry Evening Telegraph until I was about 23.

## Happy time

I worked for national magazines and newspapers. I was at the NEC in Birmingham a lot, so photographed all the famous faces including James Brown and Cliff Richard.

I remember photographing Elton John on his 50th birthday as well as Prince and Kylie Minogue. It was a happy point in my life.

## Different

In 2020, my partner noticed I was a bit different. She helped me to get to hospital where I had a brain scan. This was during Covid, so one of my memories of that day was constantly having test swabs up my nose.



Photograph: Marianne White

The scan showed that I'd had a transient ischaemic attack, or a mini stroke. I had a series of them. It was quite some news to receive – I was 55 and it was two or three days before Christmas.

## Difficult tasks

I then found out that I have dementia. The type of dementia I have is vascular dementia. My friends joke that is the one thing I can remember!

Dementia affects my short-term memory and I also stammer after the strokes. I started finding some of the easiest things to do the most difficult.

One day I was struggling to pay for something in a shop. I said to the lady behind the cash register, 'I'm sorry, I have dementia.' She said, 'No you haven't.' I said, 'Yes I have, I remember the MRI scan!' My dementia is an invisible disability.

## In the darkroom

I haven't been able to work since I was diagnosed with dementia, but what I really love doing is printing black and white photos in the darkroom. It's just the magic of seeing the photos come through and the memories they bring.

I've been working with an organisation to develop my archive of negatives. I was lucky to get some funding with help from my good friend Dr Ben Kyneswood and my prints are due to be in an exhibition next year.

## Future hopes

I want to sell some of my prints in the future. I look forward to getting back into the darkroom and I hope I might be able to teach printmaking to university students one day. I have decades of experience to share.



For our Keeping active and involved (1506) booklet, visit [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call 0300 303 5933.



# Telling people you have dementia

**Tips about deciding who to tell and how – from readers, Dementia Voice partners and Dementia Support Forum members.**

**S**ome people know straightaway who to tell first about having dementia. Others need time to decide how to approach it.

It's important to tell people when you're ready. This might be a few close people or everyone – whatever you're most comfortable with.

## Friends and family

People can respond very differently when told a friend or relative has dementia. When and how you tell someone depends on your relationship with them.

You can't control how a conversation will turn out, though there could be things that help. Some conversations go better if they're in private. Other times, hearing each other's ideas and feelings in a group could help.

Would more information about dementia help the person understand what you're telling them? If you're telling children, younger people or someone with a learning disability, you might also want to make sure they feel listened to and heard.

## Other people

Whether and how you tell people at work is up to you, but some people must tell their employer for safety reasons. Talking to your employer means you could also ask for help to continue working.

You may want people in shops and other public places to be more understanding. You could ask for patience rather than saying you have dementia – it depends on what feels safe and right for you. Using our Helpcards or a sunflower lanyard may help.

## Your tips

'Consider the pros and cons for each person you want to tell. People are different in terms of personality and where they are emotionally in their lives. Only tell those you want to tell, and only those you think can take it. It is, after all, bad news.' **David Joseph**

'I produced leaflets about my diagnosis. One for my family which was more detailed, another for friends, and a short, simple one for acquaintances. If anyone seemed to then avoid me, I followed it up and asked why in order to educate and reassure further.' **Jennifer Bute**

'Prevarication won't help. Tell them. Be prepared some will run into the sunset, others will ignore it and yet others helpful and supportive.' **vas**

'I know others who have lost friends following their diagnosis, but that hasn't been my experience. I've decided to be completely open about my brain disease. I reckon that the more people there are who are happy to tell their stories, the more we will break down any stigma.' **Willy Gilder**

'My other half wears a badge that says, "I have dementia, please be patient." He has a habit of talking to small children and used to show them his talking watch. I didn't want this misconstrued.' **maggie6445**

'I have a note on my phone which I show waiters, shopkeepers etc. It says in large writing: My husband has dementia so might behave "differently".

'Everyone I have shown this to is very grateful and incredibly accommodating and understanding.' **Mary Whitaker**

People with first-hand experience help shape our work through Dementia Voice – visit [alzheimers.org.uk/involvement](https://alzheimers.org.uk/involvement) to find out more.

Dementia Support Forum is free and open 24/7 – see [forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)

Visit [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call **0300 303 5933** for our:

- Your relationships booklet (1507).
- Supporting children and young people when a person has dementia factsheet (515).
- Employment booklet (1509).
- Helpcards that say 'I have memory problems', 'I have dementia' or 'I have Alzheimer's' (1561, 1562, 1563, 1564).

# Local influence

**You can help make dementia a priority for local decision-makers, whether you have local elections coming up or not.**

**W**e need to change how services are funded and delivered locally as well as nationally. This means working with local stakeholders like councillors, directors of adult social care and others.

Our campaigners – people like you – ensure local decision-makers understand why they need to prioritise better health and social care.

Local campaigning is always important, and this May's local elections in parts of England and Wales provide an opportunity to make dementia a priority for all candidates.

## Raising the profile

Emily Wilson, in North Belfast, wants better services, particularly for young-onset dementia.

Emily says, 'My husband had dementia with Lewy bodies. First, he struggled to get a diagnosis, and then he was misdiagnosed.

'Because he was in his early 50s, no one thought he could have dementia. I want to raise the profile of dementia when it comes to politics.'

## Big impact

Emily says that anyone can make a difference by speaking to their local candidates and elected representatives.

'We need to make them aware not only of the scale of the problem, but the scale of the problem to come.'

Emily recalls meeting her MP and him remembering the letter she'd written him using a template on the Society's website.

'Even though it might be something very simple, the impact we can have is amazing,' Emily says.

Here are some questions you can ask your local candidates and elected representatives:

- Dementia is the UK's leading cause of death and one in three of those living with dementia do not receive a diagnosis. Will dementia be a priority for you and your party?
- Dementia can affect every aspect of a person's life. How will you create a more inclusive, accessible community for people living with dementia?
- Carers face significant mental and financial strain, with many in the UK experiencing poor mental health. Is this something you will work to address?
- There is currently a postcode lottery for dementia care in the UK. How will you work with people living with dementia to make dementia a priority?
- Dementia diagnosis rates vary depending on where a person lives. Will you commit to working with people living with dementia to ensure fair access to diagnosis, support and treatments?
- Will you join the Alzheimer's Society Councillor Network?

Sharing your own experiences of dementia helps to get across its real-life impact.

Your local politicians are there to represent you. You can also ask them to take on an issue you've faced and to respond with information or a resolution.



Emily Wilson

## 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.

# Changing strings

**Ann MacCarthy in Derbyshire shares what it was like to play in a 24-hour guitar marathon in aid of the Society.**



**E**arlier this year, I joined the Wyvern Afinado Guitar Orchestra (WAGO) for a 24-hour guitar marathon. In total there were 17 of us, and we took turns sight-reading and playing music throughout the whole event.

The 'WAGOthon' took 12 months of planning, though I first heard about it last August. I live nowhere near North Somerset, where WAGO is based, but I attend a classical guitar summer school in Somerset every year.

Vince Smith, who runs WAGO, mentioned that he wanted to raise money for Alzheimer's Society, where I work. So I piped up and said I wanted to get involved!

## **Musical weekend**

The idea of a guitar marathon just grew and grew, and Vince found enough guitarists mad enough to play for 24 hours and have it live-streamed to the world.

Getting involved brought together everything I love doing. First and foremost, the event supported the

Society. But I also got to play classical guitar alongside other people and discovered new music.

We worked in three teams, taking it in turns to play for 20 minutes, with 40 minutes in between to get a snack or take a cat nap.

It was so encouraging to see supportive comments from people watching the live stream. I thought we'd get a few people logging on at the very beginning, and a few throughout the night to see if we were still going – but there were always people tuning in.

## **Friendly competition**

We also had a bit of friendly competition to see which of the three ensembles could fundraise the most. Every hour we'd update a whiteboard with our totals and members of the winning team received new guitar strings.

While this kept us going through the early hours – which were the hardest parts – it was really important to remember the reason why we were

doing it too, so we invited Society representatives along to the event.

For the last two hours we were joined by professional guitarists Craig Ogden and Francisco Correa. It was just a wonderful thing to be part of and we raised nearly £13,000.

## **Personal**

Several orchestra members have personal connections to dementia, so we're very familiar with how difficult it can be for people. My late mum had Alzheimer's and I saw how she changed as the disease progressed.

I want to do everything that I can to make that journey easier for those who've got to go through it, by supporting Alzheimer's Society to continue its research and provide support for those who need it.

**Get ideas about how you can raise funds for Alzheimer's Society – visit [alzheimers.org.uk/fundraise](https://alzheimers.org.uk/fundraise) or call 0300 222 5808.**



# Research: Detection and diagnosis

**Getting an early and accurate diagnosis will only become more important as new dementia treatments become available.**



**Monika, PhD researcher**

**T**hanks to people taking part in dementia research, there's been a lot of good news recently. Along with new drugs and hope for future blood tests, we're also learning more about reducing our risk of developing dementia.

'Many of the evolving drug treatments and lifestyle changes are most effective when used early on,' says Dr Dan Blackburn, Senior Lecturer and Honorary Consultant Neurologist at the University of Sheffield.

'It is vital that we detect dementia early, so we can link people early to appropriate information, treatment and support.'

Knowing what's causing a person's dementia – Alzheimer's, vascular or Lewy body disease, or something else – is also important. These need to be detected and dealt with in different ways.

'Even the same disease, such as Alzheimer's, can begin in different parts of the brain,' says Dan. 'We require the use of a range of detection methods to support accurate and timely diagnosis.'

'We also need tests that are low cost, non-invasive and scalable, saving more invasive investigations for later testing as necessary.'

## **Speech patterns**

University of Sheffield researchers are developing a new way to detect dementia called CognoSpeak. This is being supported by the National Institute for Health and Care Research and others.

With CognoSpeak, a computerised 'doctor' asks questions and analyses your responses. It uses artificial intelligence (AI) to look for changes in your speech patterns that could be early signs of dementia.

'Those who have some signs of memory and thinking problems will then be fast-tracked to specialist assessment,' says Dan, 'reducing waiting times and enabling earlier access to support.'

'So far, 900 people have tested the system, helping train the AI to recognise a wide range of speakers, and to differentiate those who are showing early signs of dementia.'

Testing CognoSpeak takes around 20 minutes per person, and they're looking for more people with all sorts of accents and from all backgrounds to take part.

You can get involved through Join Dementia Research, which may match you with other studies that might be of interest too.

## **Earlier detection**

Join Dementia Research is also helping people take part in an Anglia Ruskin University study into a new way of detecting mild cognitive impairment (MCI).

MCI is where a person starts to have problems with their memory or thinking but doesn't have dementia. It might be a sign they'll develop dementia later, but it can be caused by other problems too.

'We need tests that can screen for MCI well before dementia symptoms are noticeable for the individual and

for their family members,' says Monika McAtarsney-Kovacs, PhD researcher.

'These tests should be reliable, cheap, non-invasive and easy to run at GP practices and memory clinics.'

## **Visual memory**

Monika is part of the team at Anglia Ruskin's Vision and Eye Research Institute who are researching a computer-based test of visual short-term memory. This is an aspect of memory that isn't included in the most commonly used ways to assess memory and thinking skills

The team has been testing different groups of people so they can compare results between them. They're still looking for more volunteers aged 55 and over who have memory problems or an MCI diagnosis.

'The involvement of the volunteers from Join Dementia Research has been a tremendous help,' says Monika.

'In this type of research, the most challenging part is usually to reach participants who meet the criteria of the study and who are willing to participate.'

'Join Dementia Research makes this so much faster and easier.'

**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)**

# Whys and hows

**Understanding more about why some people are more likely to develop dementia points us to how we can reduce our risk.**

**D**orina Cadar's father was diagnosed with mixed dementia while she was doing her psychology degree in London.

'Suddenly, my entire world as I knew it was shattered,' she says. 'He was highly educated and was very much aware of his sudden cognitive changes.'

'My mum kept asking why this happened to him, as we were not aware of anyone else in his family having dementia. There were so many questions.'

All of Dorina's plans changed as she sought the answers to these.

'What makes some people prone to develop dementia in later life, while others are doing so well and preserve their memory?'

## Longitudinal studies

Dorina now leads the CEDAR (Cognitive Epidemiology, Dementia and Ageing Research) lab at Brighton and Sussex Medical School, where she's also Senior Lecturer in Cognitive Epidemiology and Dementia.

Several rounds of Alzheimer's Society funding have supported her career development in the intervening years.

'I work with a lot of longitudinal studies of ageing,' she says. 'These monitor many people for many, many years of their life.'

'Sometimes this is from birth, as in the British National Birth Cohort, and sometimes from middle life onwards.'

These studies provide information about people's lives you wouldn't get anywhere else – how their socioeconomic position, education and diet changed over time, the kind of work they did, and what other health conditions they developed. Some studies continue through the progression of dementia too, right to the end of people's lives.



'We are really lucky in this country to have a very good range of longitudinal studies of ageing. This allows us to investigate some of these questions which otherwise would not be possible.'

## Resilience and risk

Interesting as it is to learn what affects our risk of developing dementia, Dorina's sights are fixed firmly on what we can do with this knowledge.

'We're focusing more on cognitive reserve – the capacity of the brain to face the damage happening as its cells are dying.'

'What keeps some people masking the signs of disease and still doing better in cognitive tests? Why are others not able to still maintain some level of resilience?'

Even if our genes and earlier life put us at greater risk, there are still things we can do now to counter this. Dorina hopes her research will help us find ways to do this that are personalised to our own situations.

'By not benefiting from higher education or a high socioeconomic position from parents and so on, sometimes we come with a disadvantage in life.'

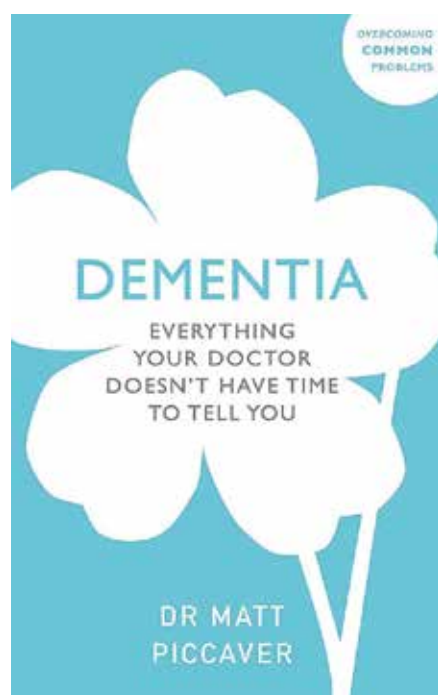
'But actually there are other aspects which you can build on, and still compensate for some of the disadvantage you might have inherited.'

**For our Dementia: Reducing your risk (35) booklet, visit [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call 0300 303 5933.**

# Book group:

## What the GP didn't have time to say

We read a guide for people dealing with a dementia diagnosis, written by a busy family GP.



**Dementia: Everything Your Doctor Doesn't Have Time to Tell You**, by Matt Piccaver (Sheldon 2020), 112 pages, £9.99 (prices vary), ISBN 9781847094827. Also available as an ebook.

**A**s a GP, Matt Piccaver knew there was so much to say to people dealing with a recent dementia diagnosis that routinely doesn't get said. So he wrote *Dementia: Everything Your Doctor Doesn't Have Time to Tell You*.

John Kemp in South Yorkshire, who has Alzheimer's, says, 'Dr Piccaver acknowledges the professional difficulties that dementia patients inherently give him – for a start, they need more than the standard 10-minute consultation that we, society, employs him for.'

'His obvious empathy has helped him write a book for a wide audience which is successful in all respects.'

Celia S says, 'One of my parents is very close to receiving a diagnosis of Alzheimer's. I don't know as much as I'd like to about the condition, but the amount of information online about it is overwhelming.'

'It's not always easy to judge which sources of information are reliable, and it can be especially upsetting going through forums and hearing about some people's experiences of the disease.'

'With the NHS under pressure, appointments are like a revolving door, and there is definitely not enough time to really go into the detail of explaining the condition like it does in this book'

'So, in that sense, the book really does what it says on the tin. I didn't know there were any treatments available, so I found that information valuable as I will know what to encourage my parents to ask their doctor about.'

### Easy to read

Michele P in Essex says, 'It's not too long with easy to read print, and the style of writing aims to make you feel at ease when reading about such a scary subject.'

'The author's tone is one that tries to make you feel comfortable with little quotes or sayings that everyone will relate to, not dissimilar to my own doctor.'

Ailsa in Cornwall agrees, 'I found the way Dr Matt Piccaver wrote this book made it very accessible, like talking to a friendly GP who wasn't on a time limit.'

'As I had researched my husband's condition, a lot of what was covered was not new to me, however, there was information that extended and consolidated my knowledge.'

The book is frank about dementia having no cure, and ultimately Celia was thankful for this even if it was hard to read.

'The only advice is to take all the help you can get and try to maintain the best quality of life you can,' she says.

'The book is quite blunt about this and it might be upsetting for some to see this written so plainly in writing (it was for me), but this is a message that cannot really be sugar coated.'

### What happens next

John found the 'What happens in clinic?' chapter too brief, and he suggests a follow-on chapter called 'What happens after the diagnosis?'

He says, 'The very first thing is that we might have a patient in shellshock. Perhaps delayed a bit. How do I know? It happened to me!'



Michele says, 'Some of the later chapters could be reordered, as I feel these are the things people are most concerned about initially.'

Despite recognising that the book couldn't cover everything, John would also have appreciated more about what people with dementia may still be able to do.

'He said nothing about whether it stops you from writing book reviews or playing the classical guitar (I'm still learning new pieces – the delightful 20th century minuet from Antonio José's Sonata).'

Michele adds, 'Some of the information is already out of date (my husband was diagnosed with the use of a PET scan, which I believe back in 2020 may not have been the case) and with new advances in medication on the horizon, this is something that will need to be updated.'

### **Solid starting point**

'Overall, the book has a lot of useful, easily digestible information, possibly aimed more at the later stages of the disease,' says Michele, 'but a good reference book to have at hand, without being overwhelming.'

Ailsa says, 'This book would be ideal for someone either newly diagnosed or who has a friend or relative with dementia.'

'It doesn't have all the answers, but it's a solid starting point to find out more,' notes Celia.

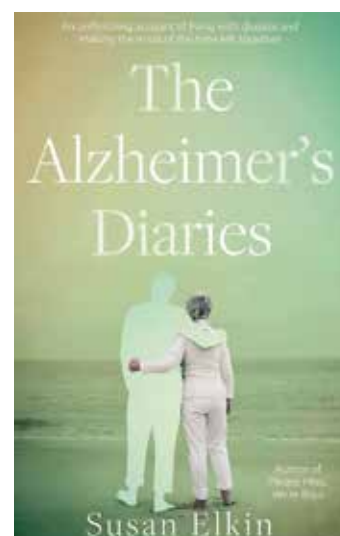
'The book is very well set out, and well written for a lay audience, but not patronising,' says John. 'It's stuffed with information and explanations that we can all learn from.'

'The bottom line: Buy this book!'

“

**As I had researched my husband's condition, a lot of what was covered was not new to me, however, there was information that extended and consolidated my knowledge.**”

## **Your turn**



For our next book group, we invite you to read *The Alzheimer's Diaries*, by Susan Elkin (Book Guild 2022), 368 pages, £9.99 (prices vary), ISBN 9781915352293. Also available as an ebook.

Tell us what you think about this account by a journalist of her late husband's Alzheimer's, originally published as a blog.

Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by 3 May so we can share your comments in the June/July magazine.

## **Book giveaway**

We have three copies of *The Alzheimer's Diaries* to give away – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by the end of 14 April quoting 'Diaries' for a chance to win (see p39 for terms and conditions).

# Consumer panel: Routine help

**People living with dementia try out the Day Hub – a new day clock with easy-to-use reminders for daily tasks.**

**A** number of clocks are available that have large, clear displays. Some give additional information to help keep track of time, and a few let you set reminders too. But no reminder clocks give an easy view of what tasks have been completed and which haven't.

Relish developed the Day Hub day clock based on feedback and research over years. It helps with daily routines, so a person can remain independent for as long as possible.

The Day Hub has a list of daily tasks beside a clear display of the time and date. You set tasks depending on what you want to be reminded to do every day. When it's time to do a task, a flashing orange alert goes off with a sound, which you can select from a range of alert sounds.

You 'tick off' the task by pressing a button – this makes the task button turn green so you can see you've done it.

We asked people affected by dementia in Staffordshire to try out the Day Hub at home to see how useful they found it.

## Ticking things off

Julia lives on her own and was really pleased with her Day Hub.

'I look at it all the time,' she says. 'It's in the kitchen, so it's right there. I think I got used to it quite quickly!'

Rob, her son, said they'd set up reminders for mealtimes and things like morning snacks and cups of tea.

'We thought we'd keep it simple to start with, with just six things, and then we can always look at adding some things in later,' he said.

Julia said she'd previously been forgetting some meals, and they've since added reminders for her to take medications too.

'Now, with this here in the house, I know exactly what I should be doing as and when,' she says.

'It's a bit more peace of mind,' says Rob.

You can see if you've missed a task, since it will still be unticked on the list, but Julia says she always ticks things off.

Rob notes that, even before an alert goes off, you can see what tasks are coming up because the whole list is there.

'If I didn't have it, I don't know what I'd be doing!' says Julia.

## Help to set up

'The device was easy to set up in about 10 minutes,' says Julia, 'but this was done by my son.'

'We do not think that Mum would have been able to set it up on her own,' Rob adds.

Ann and her husband David were glad of help from Nicola at the Society when setting up the alerts on their Day Hub. Nicola managed to do this without looking at the instructions.

The 24-hour format confused Ann at first, but she got Nicola to change the time to a 12-hour clock.

To make it easier for more people to set the Day Hub up for themselves, Relish has been introducing step-by-step online videos along with frequently asked questions.

David and Ann both thought they'd find videos helpful.



## Daily focus

Although Tracy found the Day Hub relatively easy to set up for her mother, Vivian, its focus on daily tasks didn't suit them.

Tracy said it would be 'totally impractical' for either of them to keep reprogramming different or one-off tasks.

'It's easy enough to use on a daily basis if you wanted to be reminded of the same thing every day,' she says, 'but not if your daily needs change and you have to reset it again.'

Tracy also noted that you need to find a place for the Day Hub within reach of a power point, since it needs to be plugged in.

Rob agreed that it would be good to be able to program one-off tasks as well, especially if you could do this remotely using an app. Julia and he use other ways to keep on top of these.

## Lost without it

Ann used the Day Hub to alert her about mealtimes and medications she might miss otherwise.

'I think it's a good thing,' she says. 'It's got everything you want on it.'

'The Day Hub is in the living room. It's my main clock now, which is brilliant.'

'It has helped alleviate anxiety that I might forget to take my medication. The changing colour of the ticks help me know if I have taken it.'

'I think it is value for money – if I needed someone to come and prompt me, this would cost more.'

It's also made a difference for David. He needed to prompt Ann to do a lot of routine things before, which was frustrating for both of them.

'It's taken a lot of pressure off for me,' says David. 'It's definitely helped both of us. We'd be lost without it.'

The Day Hub day clock is £149.99 plus VAT in our online shop – visit [shop.alzheimers.org.uk](https://shop.alzheimers.org.uk) or call **0333 366 0035**.

There's also a Day Connect day clock (£83.33 plus VAT) with a smaller display, which you can pair with the Day Hub to get alerts in another room.



People living with dementia, and anyone purchasing on their behalf, can buy these and many other helpful products VAT free – saving 20%. Simply tick the box stating that you're eligible for VAT relief at checkout.





# Capital work

**A panel of people affected by dementia has been helping to make London dementia friendly. Jessica Hubbard joined the People's Panel as they looked back on their achievements.**

## Quick read

**A People's Panel has been influencing decision-makers to help create the world's first dementia-friendly capital.**

**Dementia Friendly London was launched in 2018, and we've made sure people with lived experience have been at its heart.**

**The People's Panel worked closely with the Greater London Authority, healthcare professionals, cultural venues and others.**

**Panel member Kate White says, 'The purpose of a group like us was to tell our stories, but also to hold feet to the fire.'**

**S**ince 2018, Alzheimer's Society has worked with the Mayor of London on Dementia Friendly London. The aim is to make London the world's first dementia-friendly capital city.

People with lived experience know the challenges and barriers posed by dementia, so we've made sure they've been central to this.

This includes through the People's Panel, which has met regularly to discuss everything from housing and health and social care, to transport and arts and culture.

The Mayor of London's Health Advisor, Dr Tom Coffey, says, 'I'm proud that, by working with the People's Panel, we've been able to make a real difference, empowering those with dementia and building a more inclusive London for everyone.'

### **Movement for change**

The People's Panel, a group of people affected by dementia, worked closely with the Greater London Authority, healthcare professionals, cultural venues and others to help build a movement for change.

The panel came together in February to celebrate its achievements and reflect on what still needs to be done.

Barbara Kirk said, 'Being on the panel has given me hope for the future.'

'It was helpful for sharing ideas and experiences and feeding these into local and national decision-making.'

'It took 18 months for my husband to get a diagnosis. Any networking this panel has done to stop people going through what we did is a good thing.'

Another panel member, Kate White, cared for her partner who had dementia.

'I was keen to be involved,' says Kate. 'There's a huge amount of time

and money wasted in fragmentation when it comes to health and social care for someone with dementia.

'The purpose of a group like us was to tell our stories, but also to hold feet to the fire. No more talking shops, it's time to put what we've learnt into practice!'

### **Joined-up care**

Helen Souris, from the London Dementia Clinical Network, spoke with panel members about improving joined-up care after a diagnosis.

'We provide leadership and advice to shape dementia services across London and we take any opportunity to hear from people with lived experience,' Helen says.

'The panel told us it takes too long to get a diagnosis and that care is fragmented after a diagnosis.'

'For example, we know that hearing loss is linked to dementia. But when we spoke to services, they weren't asking patients about hearing.'

'We brought audiologists and memory services together, creating a hearing checklist.'

Helen hopes that the hearing checklist and other examples of good practice can be rolled out across London. This includes the proposed Universal Care Plan, which makes a patient's notes accessible online across all the health services they use.

### **Diagnosis barriers**

Improving dementia diagnosis rates is crucial for a dementia-friendly London.

We worked with Humankind Research – an ethical research agency – to identify barriers faced by Black African, Caribbean, Black British and Arab communities when seeking a diagnosis.

This found that Black and Arab communities were less likely to seek healthcare for dementia concerns.

‘For some older Black women that we spoke to, their experiences in healthcare left them feeling very unwelcome,’ says Joanne Oguntimehin at Humankind Research.

‘It was difficult for them to look at their negative experiences and not link this back to their race and ethnicity directly.’

Belief that dementia symptoms were a natural part of aging – combined with stigma – meant these were not spoken about, reducing the urgency to seek a diagnosis.

This research can now be used to inform better dementia support for Black and Arab communities.

### **Dementia-friendly venues**

Making libraries, museums, theatres and other venues dementia friendly was another key goal.

The People’s Panel influenced an accreditation scheme created by cultural venues and the Greater London Authority.

Over 100 large and small venues across London have become more inclusive for people with dementia through the Dementia Friendly Venues Charter.

Inclusive performances, clear signage, quiet zones and staff training can all help make a venue dementia friendly.

### **Out and about**

Resonate Arts is a west London charity that offers free creative activities for people affected by dementia. In partnership with the People’s Panel, they invited people affected by dementia to be ‘mystery shoppers’ at various



London venues. This helped to shape recommendations for how they could improve.

Lal Kissoon visited one museum as a mystery shopper. ‘When I first went to the museum, it’s a huge building,’ he says.

‘I entered from the front which only had steps – people need to be told about the entrance with the elevator!’

‘Trying to find something there is very difficult, so I had to make enquiries with the staff.’

‘I was looking at ancient artefacts and it showed how life has improved. It’s important to preserve this for future generations so they can see too.’

## **Shape our work**

Visit [alzheimers.org.uk/involvement](https://alzheimers.org.uk/involvement) to help shape our work and use your experience to ensure everything we do reflects the needs of people affected by dementia.

## **Donate**

Your donations help us to continue working in partnerships such as Dementia Friendly London. [Donate online.](#)

# Diet and choice

**V for Life wants vegans and vegetarians' values to be respected throughout life, including in care settings. Jessica Hubbard finds out more.**

## Quick read

**As dementia affects a person's ability to communicate, it's important to respect their values and dietary choices.**

**V for Life is a charity that provides support and resources for older vegetarians and vegans.**

**It provides guidance for care providers, who can sign up to be included in its directory.**

**The charity also helps older vegetarians and vegans to share their wishes and connect with each other.**

**W**hen John visited his father, who had dementia, in hospital, he found him eating ham sandwiches. This was unusual because John's father had been a vegetarian for over 30 years – he'd simply forgotten.

This sparked a conversation between John and his mother, who was also vegetarian.

'Please don't ever let me eat meat,' she said. 'It's really important to me.'

She also developed dementia but, thanks to this conversation, John knew her wishes. He discussed these with her care provider, with support from a charity called V for Life.

### Supporting choice

V for Life provides support for older vegetarians and vegans.

'It's important for everybody to get a healthy, balanced diet,' says chief executive Amanda Woodvine.

'If you're in a care setting, you might be completely reliant upon the food that is provided for you. It's important that these meals

reflect your personal and ethical preferences.

'We are only aware of three fully vegetarian care homes currently in the UK. So, for older vegans and vegetarians, choosing a care home can be challenging.'

### 'Mixed bag'

A report for the All-Party Parliamentary Group on Vegetarianism and Veganism suggests that plant-based catering is lacking in some UK care homes.

'You can get a mixed bag when it comes to smaller operators, where catering for vegetarians and vegans isn't a main priority,' Amanda says.

'Menus for care homes aren't often publicised and don't necessarily have any symbols to show if something is plant-based or not.'

V for Life provides guidance for care providers, who can also sign up to be included in its directory of care homes. Listed providers have committed to training staff and providing nutritious, varied meals.





For more about V for Life, see [www.vforlife.org.uk](http://www.vforlife.org.uk) or call 0161 257 0887.

For our Eating and drinking (511) factsheet, visit [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call 0300 303 5933.



Amanda Woodvine

### Wishes respected

Being able to choose what you eat isn't only important for vegetarians and vegans. It applies to people with special diets due to their religion, health needs or simply personal preference.

'Those wishes can very much be lost if you're being cared for in the future and haven't made them clear,' says Amanda.

'If you're living in a care home, for example, you may have smells of meats and dairy wafting through, or plant-based options might not be advertised on the lunch or dinner menu.'

'In some cases, lifelong vegans and vegetarians are eating and asking for meat, even though this would not be their wish. They have forgotten that they don't eat meat or animal products.'

'This is why it's important to discuss wishes ahead of time.'

### Peace of mind

There are things we can do to help ensure that our wishes about diet are respected when we're less able to communicate them.

V for Life offers a self-advocacy pack, with a step-by-step guide as well as template letters for care providers and a statement of wishes. The pack costs £2 plus postage, and there's a different version for each UK nation.

'We encourage people to fill in the statement of wishes,' Amanda says. 'It helps to make it clear what you want for your future care, and you will have peace of mind that your values are being preserved.'

### Tools and community

V for Life has developed cards that can be used with Talking Mats – a way to help people communicate about feelings and views using picture cards on a surface.

'You could use a Talking Mat to ask why someone might suddenly want meat, even though they have been a vegetarian for years,' Amanda explains.

The charity has many other guides, including one to 'veganise' classic dishes like cottage pie, Eton mess and even fish and chips. Its pen- and phone-pal scheme also helps older vegetarians and vegans feel less isolated.

One pen pal says, 'There are a lot of younger vegans out there (which is brilliant) but I was feeling rather alone at 63. It's nice to be part of a community.'

'This is me' is a simple leaflet to share a person's preferences and more. Download This is me or order a free copy by post – visit [alzheimers.org.uk/thisisme](http://alzheimers.org.uk/thisisme) or call 0300 303 5933.

# Opinion:

## Carers need more understanding

**Cordelia Galgut wants people to stop minimising carers' experiences, especially when their partner lives in residential care.**



**M**y partner of 42 years and my wife has been in residential care for two years now.

As anyone in my position will know, it was an unspeakably hard decision to have to make, but I knew I couldn't cope any more on my own and that my wife needed round-the-clock care.

The huge negative emotional impact on me of making that decision and of coping with her in residential care continues to take a massive toll.

However, most people expect me to be used to it and to have moved on by now.

People still tell me with alarming regularity that I should get on with my life. Even a month or so after she moved into her home, people said similar things, as if the slate were wiped clean as soon as the move was done.

It's hard to describe what this did and still does to me emotionally. I want to use expletives!

### Discomfort and fear

The psychologist in me knows that it is very common for people to blank out other people's distress, no matter what it is a result of, because it triggers their own fears. I know dementia is a disease that it is incredibly hard not to be terrified of developing.

And of course, quite a lot of people have experience of (usually) a parent getting it. So, on one level, I understand the need for people to distance themselves.

But the honest thing for someone to do would surely be to own their discomfort and fear?

Perhaps that is me expecting too much – most people are probably not even aware of either how they are reacting or why. I wish they were, though!

### Still a lot to do

People just don't want to know how hard it is to have my beloved partner in a home. They often look at me incredulously when I try and explain the complex mixture of emotional responses I inevitably have.

People also don't seem to be able to compute that there is still a lot to do. I'd say it is overall harder emotionally to deal with my situation now than when my wife was at home, though obviously not as hard physically.

However, I have a lot of health problems and, amongst many other things, I hugely miss the practical support she gave me as I struggle on alone.

### A low bar

I'd say that, overall, the way that I am surviving currently is by setting the bar very low when it comes to others.

I'm protecting myself from those – the majority in my case – who watch, ears and eyes largely closed, from the sidelines. A sad state of affairs, I know, but I don't think I am alone in experiencing this version.

Even if people could manage to suspend their judgement about me and my situation a tiny bit, that would help enormously. I live in hope!

For our new How to support a person with dementia in a care home (691) booklet, see [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call 0300 303 5933.

# Caring unfiltered

**Hannah Cochrane, in West Yorkshire, shares why she posts about the realities of caring for her mum on social media.**



**I'm a senior support worker helping people with their wellbeing. I also care for my mum Gwendolyn who has Alzheimer's, though we call her Gwen.**

Mum went straight into nursing after school and did this for 50 years – it's what she always wanted to do. She had lots of different nursing roles, at one point becoming a midwife. Osteoarthritis forced her to leave, though she later became a practice nurse.

## **Bubbly**

To the people that she knew and loved, Mum was bubbly. She had a good sense of humour and would do anything for anyone.

Sometimes we were like chalk and cheese. We used to do amateur dramatics together and we'd often need separate dressing rooms due to our bickering!

## **Forgetting**

I remember we owed Mum some money after my wedding and we delivered it in person, as it was several hundred pounds. But a few days later she called me to ask when I would pay her back. It was as if it had been completely erased from her memory.

She started forgetting other things, like one day she forgot to let the dog out for us. It was lots of little things like that.

We went to a speech and language therapist because Mum would say 'cat' instead of 'dog' or 'fork' instead of 'table'. We were then referred to the memory clinic and told she has Alzheimer's.

## **Complex**

I've come to love Mum as she is now with dementia. Because I work full time I'm not her full-time carer, but sometimes it has felt like I am. We've finally found respite care because Mum was not safe at home.

It was complex. There was no stimulation and she started hoarding things, including food that was going off. Carer visits were inadequate.

## **Gwenventures**

Mum started to lose weight rapidly, so I started taking her out every week to ensure she was getting a good meal – fish and chips being her favourite. These became our Gwen adventures or 'Gwenventures'.

One of the reasons why I set up @OurGwenventures on Instagram is because friends wanted to know how

Mum was. They'd often ask after her and missed her presence – including at the drama group.

I already had a messaging group with my family to keep everyone updated but Instagram made it easier to update everybody.

## **Reality**

I will never not share both the good and bad bits, because people need to know how hard it can be. Lots of people who have been through similar situations say the posts help them feel less alone. I know Mum would want people to know how she is.

To me, there's absolutely no point if I can't share the dark as well as the light, because that's the reality of life with dementia.



# We need to talk

Daisy Timms, in Southampton, tells **Jessica Hubbard** how speaking openly and keeping in touch with people helps her in supporting her husband.

## Quick read

Daisy Timms had to get used to many changes after her husband's Alzheimer's diagnosis.

Daisy met Roy while working in Abu Dhabi, and they continued travelling for work before settling in Southampton in 2016.

After retirement, Roy found it increasingly difficult to work on his boat, and he started forgetting and losing things.

Daisy is keen to fight stigma about dementia, and the couple speak with healthcare students to raise awareness.



“

**He is such a gentle soul and never argues, even though sometimes I am not in the right mood.”**

**D**aisy Timms lives in Southampton with her husband Roy. They have settled in the city but used to travel a lot for work. Daisy moved a long way from home to be with Roy.

‘I’m from the Philippines originally,’ she says. ‘Traditionally we have very close-knit families, but my family are all back home.’

The couple met in 2013 while working for an oil and gas company in Abu Dhabi, one of the United Arab Emirates.

‘I worked there for seven years doing admin jobs,’ Daisy recalls.

‘Then I met Roy, who had been posted from Malaysia. His job was to look for new projects in the Middle East and I became his assistant.’

Daisy says Roy was a perfect gentleman and they got on really well.

‘I hadn’t met anyone as kind and supportive as Roy before,’ she says.

‘I refused him in the beginning, partly because of our age gap, but he was so sad after that. So, we decided to give it a go!’

### Life together

After Abu Dhabi, Roy went on to different job postings – including one in Eastern Europe – and Daisy joined him. The pair have been together ever since, and Daisy says they rarely argue.

‘He is such a gentle soul and never argues, even though sometimes I am not in the right mood.’

Roy is originally from Northampton and has three children in the UK, though he moved around a lot for work. The couple worked in Georgia for a year before settling in the UK in 2016. Roy retired shortly afterwards.

‘We went out together as much as we could and travelled a lot, never settling in one place,’ Daisy says.

‘We came to Southampton mostly because of Roy’s family and his boat. He had a yacht before and loved working on it. I also found a job as a receptionist here.’

### Changing plans

While working on his boat, Roy started to struggle with some tasks. This was unusual, as he has an engineering background and was always very capable at DIY projects. Then he started to forget things and lose his keys.

Daisy says, ‘He would get frustrated because he couldn’t coordinate what he wanted to do in his mind. One day he said, “Darling I think something is wrong.”’

‘We went to the GP and told them everything. We were referred and got a diagnosis almost straight away.’

Roy was diagnosed with Alzheimer’s disease in 2019.

‘Our long-term plan was to move to the Philippines,’ Daisy says, ‘but we had to change that.’

Travel plans and wishes for Roy’s retirement have been put on hold.

‘There’s so many things that he wants to do. Alzheimer’s has stolen a lot of time from us. We did go on one cruise to the Mediterranean which was lovely and travelled to Italy, where we met Roy’s old friends again.’

‘It’s difficult to travel now because Roy uses a wheelchair and other mobility equipment. This is not what we planned but this is what we’ve got to work with.’

### Missing signs

Looking back, Daisy realises that

some of the things Roy was doing could have been signs of Alzheimer’s, though she did not know this at the time. Things like forgetting his keys were put down to Roy’s age – he is now 84.

‘Now that I know what dementia is, I realise that forgetting things and struggling to find the words to describe what was wrong were signs,’ says Daisy.

‘He was having problems for quite some time after we met and in his last job.’

In 2020, around the start of the pandemic, Roy struggled with being alone and not being able to go out. Daisy quit her job, as balancing care and work became too much.

She sometimes worries she won’t be able to find employment later on due to taking time out.

‘I’m young and I worry I won’t be able to get back into work because the market is so competitive,’ she says.

‘I had to balance this from a financial perspective as well. Why go to work and pay for someone to care for him when I could do it myself? Sometimes you have to make that difficult choice.’

### Challenging

Daisy has taken on a lot of the daily tasks Roy used to do independently, which she says can be emotionally challenging.

‘It’s a real struggle,’ she says. ‘Roy is losing his abilities and is not able to make conversation anymore, which can be lonely.’

Finding residential care for Roy is a possibility, but Daisy says she would feel guilty about moving him away from his home.

“

**Sometimes I have to take myself out of the situation and have a cry. But I don't let Roy see it – it wouldn't help him or me. ”**

'I couldn't even consider it,' she says. 'He's a good man and he deserves to be looked after in his own home with undivided attention.'

'Sometimes I have to take myself out of the situation and have a cry. But I don't let Roy see it – it wouldn't help him or me.'

'If I didn't do this, we would both get frustrated and argue. I pick myself up again and carry on, but it's hard.'

Daisy says Roy's kind and calm personality 'still shines through'. Moving to a bungalow last year has also helped him to get around their home more easily.

## Speaking out

Speaking with others about the challenges of caring is important to Daisy.

She speaks to her family in the Philippines almost every day and has found a support network of fellow carers and church goers in Southampton. They often support each other by calling and visiting.

'It's a good feeling when people remember you,' she says. 'Before I had this, I was struggling a lot.'

'We used to go to a lot of groups for people with dementia and other community groups,' Daisy says.

'But quite a lot of them were in the morning so, by the time we had gotten ready, I was already exhausted. We do still go to one and it's great because we feel like one family there.'

## Stigma

Roy was reluctant to tell old colleagues and friends about his diagnosis due to the stigma that still surrounds dementia.

'I did my best to respect Roy's wishes,' Daisy says, 'but when his old friend saw him, they wished we had told them about his Alzheimer's.'

One particular incident knocked Roy's confidence. He was shopping alone and pushed into the queue without realising. Another shopper then shouted at Roy, who was confused. Since then, Roy doesn't go out on his own.

'He was really upset,' Daisy recalls. 'He was only trying to be independent.'

Following these experiences, Daisy wants everyone affected by dementia to talk about it more.

She says, 'When you're open with family and friends, you will be surprised how much support you can get.'

'I want everyone to try to talk. Don't stop trying even if you get rejected – there are a lot of understanding people out there.'

Roy and Daisy have since volunteered for the Society's Time for Dementia programme, which links people affected by dementia with healthcare students. Through a series of visits, the students learn about the realities of living with dementia so they can provide better care in the future.

Daisy hopes this will lead to a society more accepting of people with dementia, and recognition that dementia affects everybody differently.

'My goal is to help raise awareness – especially with the younger generation,' she says. 'People just don't know and that's why the stigma is still there.'

## Accepting help

Thanks to support from family members and other carers, Daisy has been able to take better care of herself and Roy.

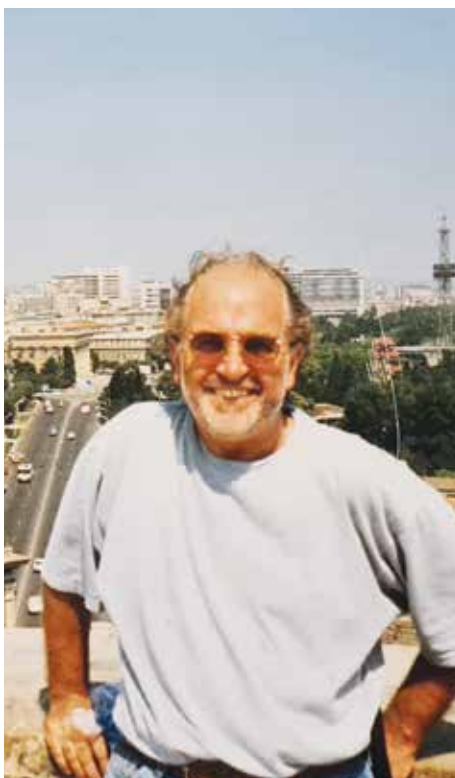
'Some people can be quick to judge because of the age gap between us,' she says. 'But once they get to know me, they say, "Hats off to you for what you do."'

'To me, it's my duty to my husband – we made a vow to each other when we got married.'

'But as a carer, you have to know when to accept help. Without that you just keep going, and there's a breaking point. I have very good support.'







For our Dementia symptoms checklist (78DDch), see [alzheimers.org.uk/symptoms-checklist](https://alzheimers.org.uk/symptoms-checklist) 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**.



## Donate

Your donation funds programmes like Time for Dementia, which links Daisy, Roy and others with professionals of the future. [Donate online.](#)

## ? Ask an expert

**‘My mother-in-law has dementia. I’m struggling to juggle my full-time job with being her carer. What rights do I have at work?’**

# Carers’ rights at work

Photograph: Freeimages.com/wagg66



**B**alancing work with caring responsibilities can be a challenge. You don’t have to tell your employer about your caring role, but it might help.

You have some rights at work, and some employers offer extra support too.

### Flexible working

Everyone has the right to ask their employer for flexible working arrangements. This includes carers!

Flexible working can include changes to what hours or days you work, or to where you do your job.

Your employer doesn’t have to give you the changes you ask them for. But they do have to consider your request carefully. If they refuse it, they need to give a good business reason.

From 6 April this year, a new law comes into effect in England and Wales. This means workers will have the right to ask for flexible working arrangements as soon as they start a job. In Northern Ireland, you’ll

still need to have worked for your employer for at least 26 weeks (half a year).

### Time off in emergencies

If your mother-in-law needs you to deal with an emergency, you can take a reasonable amount of time off work for it.

This right applies to emergencies involving a ‘dependant’ – someone who relies on you for help. It could include them being ill or injured, or usual care arrangements breaking down.

Your employer doesn’t have to pay you for this time off, but they can do.

### What about other times?

From 6 April in Wales and England (but not in Northern Ireland), carers will also have the right to take up to five days unpaid leave each year.

This must be to provide or arrange care for a dependant who has long-term care needs. You’ll have this right from day one of working for your employer.

### Check your contract

Some employers offer more than these basic legal rights. Check what your contract says and any policies that your workplace has.

For example, there might be a specific carer’s policy. Or parts of the leave policy or flexible working policy might help.

Your employer may be willing to agree something else that fits your specific needs.

### Equalities law

You have the right not to be discriminated against because of your caring responsibilities.

Discrimination might include passing you over for promotion or sacking you simply because you’re a carer.

## More help

- Carers UK has a lot of information about carers’ rights – see [www.carersuk.org](http://www.carersuk.org) or call 0808 808 7777.
- For support about employment issues in England or Wales, contact ACAS – [www.acas.org.uk](http://www.acas.org.uk) or 0300 123 1100.
- In Northern Ireland, contact the Labour Relations Agency – [www.lra.org.uk](http://www.lra.org.uk) or 0330 055 5300.



## Your answers

Readers share advice about coping with challenging personality changes as a person's dementia progresses.

# Personality changes

'I think the main thing is managing yourself. Recognising when you are tired or worn down and need a break. It's much easier to see things from the other person's point of view and remain calm when you are feeling OK yourself.'

'One of many personality changes I saw in my dad was that he went from being extremely generous to extremely tight and preoccupied with money. It was helpful to think about the childhood he had where his family was very poor to understand something about where that particular change had come from.'

'All much easier to reflect on when I'm not feeling frazzled myself.'

**Bettusboo**

'I would say don't take it personally. Sometimes my lovely, kind, gentle mother-in-law is grouchy with me. I'll have to try to remember some graceful exits from situations if feeling uncomfortable with shouting and lewdness etc.'

'I'm hoping that "I have to nip out to an appointment" will work if I need to escape a grumpy mother-in-law for a while till she forgets what she's cross about.'

**sheepfield**

'When my hubby gets angry or anxious, there's an underlying issue.'

'The other week, I sat him down and asked why he was getting angry about me driving our granddaughter home. It's a new route as they've moved home, he doesn't like this route as it's further and along a busy dual carriageway.'

'It turns out he's worried about me having an accident and what happens to him if I'm not there? I've therefore had to address this

concern and ask my son to become involved delivering and or picking her up to save my hubby becoming anxious.'

**clarinet**

'My partner has frontotemporal dementia, and it's as if he's separated mentally into two extremes of his pre-dementia personality.'

'Almost every day he gets up very late, refusing to eat, as his "bad" dementia self: angry, cruel, paranoid. Later in the day, he usually morphs into his "sweet" dementia self: affectionate, dependent, probably a bit frightened of what is happening to him, appreciative of everything I do.'

'I try to show his "sweet" self as much love and reassurance as I can, hoping some memory of that will carry over into the darker times. As for the other times, like everyone else I tell myself, "It's not him, it's the illness." If he's being verbally combative, I try not to engage with his arguments, but ask him not to talk to me like that.'

**masquereader**

'My mother was diagnosed with Lewy body dementia over 2.5 years ago – something she does not accept at all and gets quite angry about if the subject is broached.'

'No two days are the same and that can be very challenging and stressful, as you just don't know what you are going to face when she wakes up.'

'The only coping mechanism that works is not to try and defend our actions or try and correct what she is saying etc, even when she is clearly in the wrong – which frankly is easier said than done, especially, when you yourself are tired and frustrated.'

**hc10**

'Both parents have dementia now, and so their relationship (currently in the care home) is a tinderbox.'

'My only tip would be that I had to remove myself for a week or so every now and then, just to get a mental reset, and for me that worked.'

**Peachieperfect**

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

## Next time: Money conflict

Do you have any advice about family disagreements over a person's finances when they have dementia? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by 3 May.



# Noticeboard

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

## Support line – here for you



Last year was a busy year for the Dementia Support Line, which provides support and advice to anyone affected by dementia.

Our dementia advisers received just over 70,000 calls, 5,000 of which were from people looking for legal or financial help. Almost 4,500 were from people seeking advice about services available to them, and more than 3,500 from people needing emotional support.

You can call the Dementia Support Line on **0333 150 3456** or visit [alzheimers.org.uk/get-support](https://alzheimers.org.uk/get-support) for more options.

## Your recipes

### Blueberry cake

Chizz on the Dementia Support Forum gave us this treat, saying, 'As I'm not much of a baker, it means for me to make this, it must be simple!'



#### Ingredients

165g unsalted butter, plus to grease tin  
100g ground almonds  
110g plain flour  
1 teaspoon baking powder  
1½ teaspoon ground cinnamon  
¾ teaspoon salt  
115g soft brown sugar  
55g sugar, plus extra 3 tablespoons  
2 large eggs  
1 teaspoon natural vanilla extract  
300g blueberries.

- Preheat oven to moderately hot (190°C or 170°C fan) and grease a 23cm fluted tart tin or round cake tin.
- In a bowl, whisk together the ground almonds, flour, baking powder, cinnamon and salt.
- Using an electric mixer and separate bowl, beat the butter, brown sugar and 55g of sugar together on medium-high until super light and fluffy – three to four minutes.
- Scrape down sides of the bowl. With mixer on medium, add the eggs one at a time, beating until each is incorporated, then add vanilla. Increase speed to medium-high and beat until pale and nearly doubled in volume – four to five minutes.
- Fold in almond mixture until no dry spots remain, then gently add 225g blueberries by hand.
- Transfer batter to the tin and use a spatula or back of a spoon to smooth the top, then sprinkle remaining whole blueberries and 3 tablespoons of sugar on top.
- Bake until it's deeply golden brown and pulls away from the edges slightly – 30 to 35 minutes. It should start to crackle a bit on top. Remove from oven and allow to cool completely before slicing.

## Seen elsewhere

Nic Broome was one of many people moved by Jessica's memories of her late mum Polly, which we shared on Instagram on Mother's Day:

'This is a beautiful post, thank you for sharing, it helps me to appreciate the time I have with my Mom 💖 some days are harder than others but this helps to focus on all the amazing positives 💖 x wishing you and your family well x.'

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



Dementia Friends shared another inspiring picture on X/Twitter of people learning how they can make a difference, this time a group of Fire Cadets in Merseyside:

'Welcome to the Cadets from Merseyside Fire & Rescue Service who are now Dementia Friends! We are so happy you took the decision to help those living with dementia and taking the steps to make your community more dementia friendly 💖.'

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



Share your views, feedback and news – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2. We can consider contributions received by 3 May for the June/July issue (wording may be edited).

## Jointly app

Have you tried the Carers UK app that aims to make caring a little easier? You can log into the Jointly app from a range of devices and set up a 'circle of care' for the person you're supporting.

You can use a circle by yourself or invite others to join it, keeping track of tasks, events and key information. The app is free and setting up a circle of care has a one-off cost of £2.99. Visit [www.jointlyapp.com](http://www.jointlyapp.com) or find Jointly on your device's app store.

## NHS App: repeat prescriptions

People registered with a GP in England or the Isle of Man can now save delays by using the NHS app to order repeat prescriptions.

Vin Diwakar, National Director for Transformation at NHS England, said, 'The prescription service is the latest in a number of services we're adding to the NHS App to provide better care for patients. I'd encourage anyone who hasn't used the NHS App for a while, or who has never downloaded it, to "tap the app" and see what it has to offer.'

Find out more at [www.nhs.uk/nhs-app](http://www.nhs.uk/nhs-app) or find the NHS App on your device's app store.

## Online support

Dementia Support Forum is a helpful online community where people affected by dementia receive valuable support. It's free, open day or night and can be accessed online.

You can ask for advice, read other people's stories, offload your concerns and share helpful information.

Visit [forum.alzheimers.org.uk](http://forum.alzheimers.org.uk) to join the community.

# Puzzles and competitions

## Anagramword

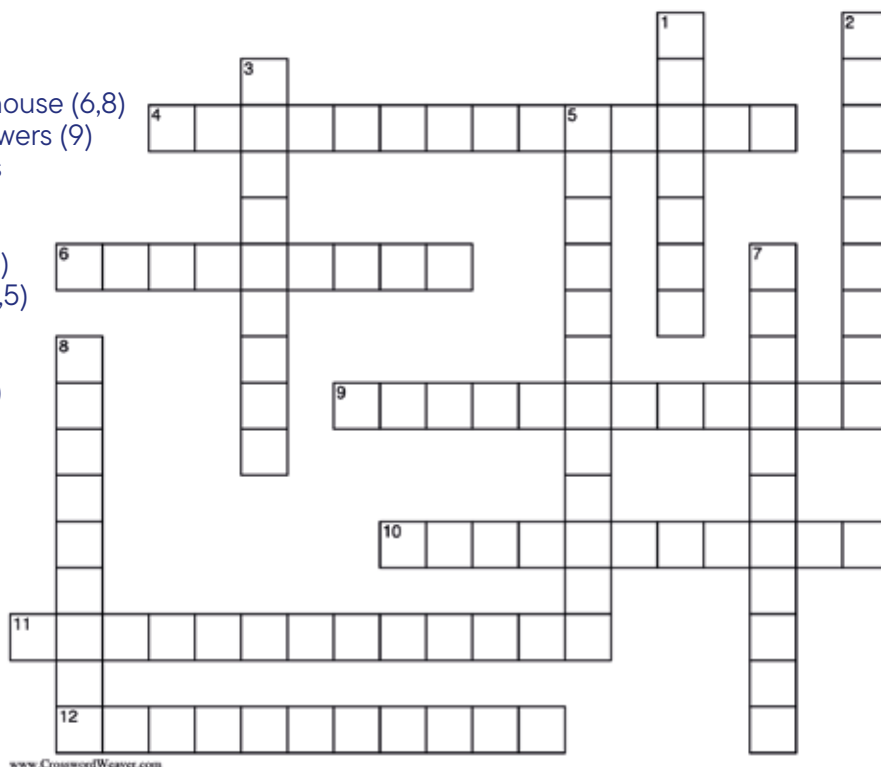
This spring-themed puzzle from Pete Middleton brings you animals, flowers and perhaps even a spot of rain. Every clue contains the answer in an anagram – how many can you solve?

### ACROSS

- 3 Nigel's prancing around tidying the house (6,8)
- 6 Doffs dial to reveal Welsh national flowers (9)
- 9 Perhaps gross, but these little insects hop around at springtime
- 10 Filter tubes that feed on nectar (10)
- 11 Slew blue blood in an idyllic spot (8,4)
- 12 PM Rings labs for wooly newborns (6,5)

### DOWN

- 1 Bar wino may lead to a pot of gold (7)
- 2 Kids clung to these fluffy baby water birds (9)
- 3 Dry log fan found flying around near a pond or river (9)
- 5 War-horse lips provide rainy interludes (5,7)
- 7 Trial parcel contains a creepy-crawly (11)
- 8 Rum labels may keep you dry in a shower (9)



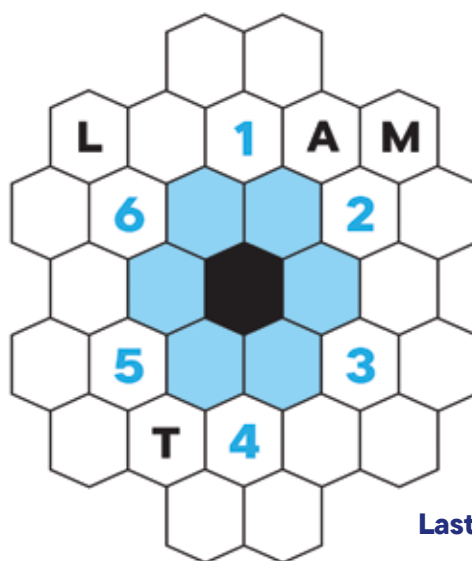
www.CrosswordWeaver.com

## Alzheimer's Society BRAIN WORKOUT

## Six mix

Write each answer in a clockwise direction around its clue number in the grid. We've included some letters to help you get started. When you've finished, the central blue hexagons will reveal a tree.

- 1 (Of time) pass or go by
- 2 Spoil, indulge
- 3 Fully-grown
- 4 Small piece of meat similar to a chop
- 5 Notice the presence of
- 6 Come to rest



From March's Brain Workout puzzle pack.

Last issue's answers on p39.

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.



Send us your competition answers with your name and address by end of 2 May – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2.

## Day Hub

We have a Day Hub from Relish for one lucky winner drawn from correct entries, plus a Day Connect for a second.

**Q: The Day Hub day clock gives you alerts:**

- A. For tasks that you do every day, so you can tick them off as you do them.
- B. If there's a big breaking story on BBC News.
- C. Whenever a tornado is predicted in Kansas.

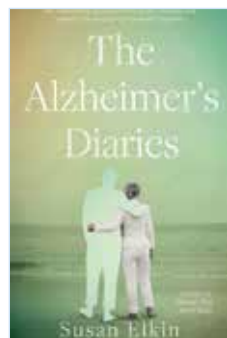
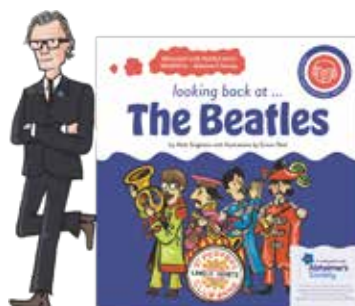


## Cognitive Books

We have a copy of 'Looking Back at... The Beatles', the first title from Cognitive Books, for three lucky winners drawn from correct entries.

**Q: The free audiobook that comes with this title is narrated by:**

- A. George Harrison.
- B. Yoko Ono.
- C. Bill Nighy.



## Book giveaway

See p21 for a chance to win a copy of **The Alzheimer's Diaries** by Susan Elkin.

**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.

## February/March winners and answers

### Safer Walking

I Dallow in Wiltshire won a Safer Walking GPS locator from Ravencourt, with six months' subscription to the Safer Walking 2 mobile app. Answer: If you press the SOS button on your Safer Walking GPS locator your nominated person gets a notification on their phone.

### Headgear

J Millar in Cheshire, D Marsh in Greater Manchester and an anonymous reader in Lincolnshire each won their choice of an Alzheimer's Society baseball cap or bucket hat. Answer: The headgear most associated with Sherlock Holmes is the deerstalker.

### Book giveaway

L Stewart in Buckinghamshire, S Allan in Lothian, A Tween in Cornwall, P Lee in Hertfordshire and M Perrett in Essex each won a copy of *Dementia: Everything Your Doctor Doesn't Have Time to Tell You*, by Matt Piccaver.

### Anagramword

Across: boyfriend, forget-me-nots, darling, admirer, romantic. Down: secret admirer, yearning, box of chocolates, bouquets, fourteenth, St Valentine, bow and arrow, girlfriend, heartthrob.

### Codebreaker

C	O	C	O	A
A		H		G
M	O	O	S	E
E		S		N
O	V	E	R	T

1	C	2	O	3	A	4	H	5	G	6	M
7	S	8	E	9	N	10	V	11	R	12	T

# Dementia Action Week

13 – 19 May 2024

One in three people living with dementia do not have a diagnosis. This is the UK's forgotten crisis.

Thousands of people are facing the realities of dementia alone, without access to the vital care and support that having a diagnosis can bring.

This Dementia Action Week we'll be shining a light upon the issues that delays in receiving a dementia diagnosis can bring, the benefits of receiving a dementia diagnosis, and why it's such an urgent matter that needs fixing now.



Find out more and get involved at  
[\*\*alzheimers.org.uk/daw\*\*](https://alzheimers.org.uk/daw)



Alzheimer's Society operates in England, Wales and Northern Ireland.  
Registered charity no. 296645

Together we are help & hope  
for everyone living with dementia